PARLIAMENT OF NEW SOUTH WALES

LEGISLATIVE COUNCIL

STANDING COMMITTEE ON SOCIAL ISSUES

HEPATITIS C:

THE NEGLECTED EPIDEMIC

INQUIRY INTO
HEPATITIS C IN NEW SOUTH WALES

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CONTACT DETAILS

Members of the Standing Committee on Social Issues can be contacted through the Committee Secretariat. Written correspondence and telephone enquiries should be directed to:

The Director
Standing Committee on Social Issues
Legislative Council
Parliament House, Macquarie Street
Sydney New South Wales 2000
Australia

Email: sociss@parliament.nsw.gov.au

Telephone: 61-2-9230-3078

Facsimile: 61-2-9230-2981

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COMMITTEE MEMBERSHIP

The Hon. Jan Burnswoods, M.L.C., Australian Labor Party
Chair (from April 1998)

The Hon. Dr. Marlene Goldsmith, M.L.C., Liberal Party
Deputy Chairman

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(from June 1998)

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The Hon. Doug Moppett, M.L.C., National Party

The Hon. Peter Primrose, M.L.C., Australian Labor Party

The Hon. Carmel Tebbutt, M.L.C., Australian Labor Party
(from April 1998)

- Mrs Ann Symonds (Australian Labor Party) served as Committee Chair until her retirement from Parliament in April 1998
- The Hon. Dorothy Isaksen, M.L.C. (Australian Labor Party) served on the Committee until April 1998
- Miss Elisabeth Kirkby (Australian Democrats) served on the Committee until her retirement from Parliament in June 1998

COMMITTEE FUNCTIONS

The functions of the Standing Committee on Social Issues are to inquire into, consider, and report to the Legislative Council on:

- any proposal, matter or thing concerned with the social development of the people in all areas of New South Wales;
- the equality of access to the services and benefits including health, education, housing and disability services provided by the Government and non-Government sector to the people in all areas of New South Wales;
- recreation, gaming, racing and sporting matters; and
- the role of Government in promoting community services and the welfare of the people in all areas of New South Wales.

Matters for inquiry may be referred to the Committee by resolution of the Legislative Council, a Minister of the Crown, or by way of relevant annual reports and petitions. The Committee has the legislative power to:

- summons witnesses;
- make visits of inspection within Australia;
- call upon the services of Government organisations and their staff, with the consent of the appropriate Minister;
- accept written submissions concerning inquiries from any person or organisation; and
- conduct hearings.

TERMS OF REFERENCE

That the Standing Committee on Social Issues inquire into, and report on, the incidence and impact of Hepatitis C in New South Wales, and in particular:

a. the social and economic impact of Hepatitis C in New South Wales and the implications for future policy and funding of health and community services;

b. the extent of the disease and its aetiology and epidemiology;

c. the adequacy of policies, and diagnostic and treatment services with particular attention to strategies for prevention, given current health budget constraints;

d. the groups and individuals in the community at increased risk of infection;

e. the extent of the infection in specific population groups at risk, and the adequacy of education/prevention and care and treatment services available to them; and

f. the risks involved for health care workers and the adequacy of policies and procedures on occupational health and safety.

Hepatitis C people are in every part of our community. I've been a lecturer in tertiary education; a professional playwright and a freelance actor in theatre, television and film. I'm a grandfather; a devoted father of three adult children and one half of a long standing, loving partnership. I don't think I'm particularly different. I just happen to have Hepatitis C .

Help us beat it.

An extract from a personal submission received by the Inquiry

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CHAIR'S FOREWORD

Hepatitis C is a disease that, it is estimated, impacts upon the lives of up to 200,000 Australians with another 11,000 becoming infected each year. Yet it is a disease that is largely neglected by decision makers, health planners, the media, health care workers and the community in general.

Interest in the disease does, however, seem to be slowly increasing. The Committee noticed this during the course of our Inquiry. A number of significant events took place during the last few months of the Committee's deliberations. These events included: the long awaited publication of two important Australian based papers - Dr Ingrid van Beek's study of the rates of Hepatitis C amongst those attending the Kirketon Road Clinic and Brown and Crofts' analysis of the economic impact of Hepatitis C; the report of the Hepatitis C Virus Projections Working Group containing the most recent projections of incidence and prevalence; a feature on the television program '60 Minutes' on Hepatitis C; the review of the Hepatitis C National Action Plan; and the September issue of *Australian Family Physician* dedicated to Hepatitis C. The Committee hopes that these events, along with the release of this Report, will serve to increase the public profile of Hepatitis C.

The period over which this Inquiry was conducted saw considerable change take place in the Committee's membership. The Hon Ann Symonds, MLC, one of the Committee's original Members and Chair for the past three years, retired and I assumed the Chair. At the same time, the Hon Dorothy Isaksen, MLC was replaced by the Hon Carmel Tebbutt, MLC. The Hon Elisabeth Kirkby, MLC, another longstanding member of this Committee, also retired. Her place was taken by the Hon Dr Arthur Chesterfield-Evans, MLC. I would like to thank all Committee members, both past and present, for the commitment they demonstrated, a commitment to which the unanimity achieved in this report is strong testament. All of the recommendations contained in this Report have our unanimous support. Members have been united in seeking ways to control this epidemic and help to improve the lives of all people affected.

The Committee appreciated the assistance provided by the staff of the Hepatitis C Council of NSW throughout the duration of this Inquiry. The Committee Secretariat staff, in particular, appreciated the enthusiastic cooperation provided by the Council's Executive Officer, Mr Stuart Loveday and Project Officer, Mr Paul Harvey. Stuart and Paul were an invaluable source of the most up-to-date information on all facets of Hepatitis C, and their personal commitment to helping those with Hepatitis C is inspiring.

Most importantly, the Committee wishes to thank the 92 people with Hepatitis C who wrote to us telling what it is like to live with the disease. The Committee also thanks those with Hepatitis C who came and gave oral evidence to the Committee. For some, this task was particularly stressful, yet it provided the Committee with a very clear insight into the everyday realities of living with a chronic and debilitating disease. It was with profound sadness that, towards the end of the Inquiry, the Committee learned of the death of one of its witnesses - Rev Harold Smart. Rev Smart appeared before the Committee to give evidence, despite failing health. The Committee was particularly impressed with the way in which he spoke of the discrimination and stigmatisation he had experienced without a trace of animosity or bitterness. We were touched by his gentle nature and thankful for his contribution.

My thanks are also due to the Committee Secretariat and in particular, Dr Jenny Knight who was responsible for the research and writing of this Report. Dr Knight has presented complex medical and technical information in an extremely readable document. She always displayed compassion and empathy towards the witnesses and others affected by Hepatitis C throughout the course of the Inquiry.

I would also like to thank the Secretariat's Committee Officer, Ms Heather Crichton, for managing the administrative aspects of the Inquiry including processing submissions, arranging hearings and visits and assisting in preparing the final report for printing. As always, Ms Crichton's organisational skills ensured the Inquiry ran smoothly. Ms Beverly Duffy and Ms Julie Langsworth, Senior Project Officers, provided invaluable editorial assistance.

In addition, I would like to thank Ms Gro Frølund and Ms Alison Sherman, two student volunteers who were with the Committee Secretariat during the course of this Inquiry. Ms Frølund undertook a detailed analysis of the written submissions and prepared background notes on the social impact of Hepatitis C. Ms Sherman did a content analysis of the submissions and prepared an overview. The work undertaken by both these students has been of great assistance to the Committee and I thank them for the time they so freely gave.

I commend this report to the Government.

JAN BURNSWOODS, MLC
CHAIR

HEPATITIS C - AT A GLANCE

Clinical Features	Fatigue, nausea, jaundice, abdominal pain, loss of appetite, and vomiting.
Etiological Agent	Hepatitis C Virus (HCV).
Sequelae	40% of those infected will develop some liver damage. Over a 20 year period 20% will develop cirrhosis. After a further five to ten years, 10% will develop liver cancer or liver failure and require a transplant.
Incidence	8,000 - 11,000 new cases per year.
Transmission	Primarily blood borne Vertical and intrafamilial to a limited extent.
Risk groups	Injecting drug users Prisoners Health care workers Recipients of infected blood/blood products (prior to 1990) Household contacts of infected persons Recipients of tattoos and body piercing.
Trends	Transfusion-associated cases due to infected blood have virtually been eliminated. Most new infections occur amongst injecting drug users. Inmates in correctional centres are a particular ‘at risk’ group.
Prevention	Harm minimisation strategies Programs to encourage high-risk behaviour modification Screening of blood/organ/tissue donors.

GLOSSARY

Aetiology	The cause of the disease
Acute Hepatitis C	A clinical illness consistent with acute Hepatitis C virus infection together with serological evidence of recent exposure
AHMAC	Australian Health Ministers Advisory Council
ALT levels	Alanine Aminotransferase levels in the serum. An indicator of liver function
ANCARD	Australian National Council on AIDS and Related Diseases
Antibody	An immunoglobulin molecule that interacts only with the antigen that induced its synthesis
Anti-HCV+	A sample which is reactive to HCV-Ag in two different licensed enzyme immunoassays
Antigen	Any substance which is capable, under appropriate conditions, of inducing a specific immune response and of reacting with the products of that response
b-DNA	Branched-chain DNA amplification assay: a highly sensitive test to detect viral DNA or CDNA in blood
Chronic Hepatitis C	Patients who have been anti-HCV positive for six months or longer often, but not necessarily, with an accompanying elevation of ALT with or without histological evidence of chronic hepatitis
Cirrhosis	A chronic disease of the liver characterised by nodular regeneration of liver cells and diffuse fibrosis
Decompensated Cirrhosis	Patients with compromised liver function which any additional treatment may further aggravate the condition of the liver

EIA	Enzyme immunoassays: tests used to detect antibody to HCV proteins and used to diagnose HCV infection
Epidemiology	The study of the relationships of various factors determining the frequency and distribution of diseases
Fibrosis	Development of fibrous tissue in an organ
Genotype	The genetic constitution of an organism, as opposed to the phenotype or external appearance of the organism, or the type species of a genus
Haemodialysis	Removal of substances from the blood by virtue of the difference in the rates of their diffusion through a semipermeable membrane
HAV	Hepatitis A virus
HBV	Hepatitis B virus
HCV	Hepatitis C virus
Hepatitis C carrier	A person with HCV viraemia persisting for six months or longer
Horizontal Transmission	The spread of an infectious agent from one individual to another, usually through contact with bodily fluids or excreta
Incidence	The number of new cases of a specific disease in a defined population within a specified period of time
Interferon	A drug approved for the treatment of certain viral infections, including Hepatitis C
NHMRC	National Health and Medical Research Council
Needlestick Injury	Injury occurring accidentally due to needle prick from a syringe containing blood of a person infected with hepatitis or other blood borne disease
Non responders	Patients, who after 12 weeks of interferon therapy, fail to have normalised ALTs
NUAA	NSW Users and AIDS Association

Parenteral	Transmission of a disease not through the alimentary canal, eg. by subcutaneous, intramuscular, intrasternal or intravenous injection
PCR	Polymerase Chain Reaction: a test to detect genetic material (DNA or RNA) in serum or tissues - used here to detect HCV-RNA
Prevalence	The number of cases of a disease in a given population at one point in time
Relapsers	Patients who, after having responded to interferon treatment, subsequently have a recurrence of the disease
Ribavirin	A compound with similar chemical structure to the nucloside, used in combination with interferon for the treatment of Hepatitis C
S100	Section 100: a particular Pharmaceutical Benefits Scheme listing of certain restricted drugs. The Scheme also establishes the criteria under which patients qualify for interferon treatment
Seroconversion	The production in a host of specific antibodies as a result of infection or immunisation
Serotype	A term used to classify HCV according to the serological response to defined antigenic regions of the virus antigens
Sustained Response	Patients who maintain normal ALT levels and are anti-HCV negative following treatment
Vertical Transmission	Transmission from one generation to another
Viraemia	Presence of virus or viruses in the bloodstream
Viral Load	The level of circulating HCV RNA in a patient's plasma or serum

KEY CONCLUSIONS

- It is imperative that **policies and strategic plans are developed** to direct all facets of Hepatitis C including treatment, management and prevention. This commitment to sound Hepatitis C policies must be evident in upgrading the current Hepatitis Advisory Committee to a Ministerial Advisory Committee on Hepatitis C; designing, developing and implementing a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; providing adequate and ongoing dedicated funding for the implementation of the Policy Statement and Strategic Plan and appointing Area Hepatitis C Managers to the five Area Health Services with exceptionally high levels of Hepatitis C notifications;

- Strategies to **prevent the transmission of Hepatitis C** must be broad and multi-faceted. The Committee fully supports the concept of harm minimisation and considers it to be the most effective underlying principle for strategies to prevent the transmission of Hepatitis C amongst injecting drug users. It is the basis upon which the Committee framed all recommendations directed at injecting drug users (both in the general community and the state's corrections system);

- The Government must recognise that those in the **state's correctional system face an unacceptably high risk of contracting Hepatitis C** and, on release, these people pose a serious danger of dispersing the virus to the wider community. These circumstances warrant radical policies to reduce inmates' exposure to Hepatitis C. The Committee proposes a broad range of prevention strategies; the introduction of a Best Practice Model of treating Hepatitis C amongst inmates and the implementation of a strategic plan to manage Hepatitis C in the corrections system;

- There is an urgent need for **further research** to be undertaken in a number of areas, including: ascertaining the incidence and prevalence of Hepatitis C in the general community as well as in specific population groups such as injecting drug users and prisoners; developing an empirical understanding of the personal, social and economic impact of Hepatitis C; research into the causes of Hepatitis C-related discrimination; clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments; an understanding of the interaction between methadone and interferon and the impact of methadone on pregnancy; research into a range of injecting drug related issues; and studies into the effectiveness of complementary therapies to treat the symptoms of Hepatitis C;

- There appears to be **limited understanding in the community** about Hepatitis C, in particular, about the way in which it is transmitted. Many assume it has the same transmission routes as other blood borne viruses such as HIV/AIDS. Health care workers, including medical specialists, often have a poor understanding of the disease. This lack of understanding manifests itself in a number of ways including discrimination and stigmatisation towards those with Hepatitis C, frustration by those with the disease as they struggle to learn about the disease and sort through conflicting information, and a lack of compassion and tolerance in the general community. To redress this situation, Committee Members have called for the introduction of a number of strategies including education campaigns targeting all those working in the health care sector and public service, the production of an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination, support for the National Hepatitis C Education Program for General Practitioners which seeks to inform and educate general practitioners, and a **national community education Hepatitis C campaign**.

EXECUTIVE SUMMARY

Every hour of every day one person in Australia contracts the Hepatitis C virus. While some of these people will shake off the virus, over eighty per cent will go on to live with the disease and its chronic, debilitating effects. Some will require liver transplants, others will die of liver cancer.

The backgrounds of those with the virus are eclectic: current injecting drug users and past injecting drug users now far removed from the practices of their adolescence; infants and children who were infected at birth; prisoners; casualties of the health care system who received infected blood including those as young as eight years and as old as 80 years of age; and health care workers who became infected through their work.

In May 1997 the Legislative Council’s Standing Committee on Social Issues was asked to inquire into Hepatitis C (HCV) in New South Wales. This is the first time in Australia that a Parliamentary Committee has been asked to examine this disease and its implications which impact upon such a significant proportion of the community. The Committee was asked to comment on the social and economic impact of the disease; the extent and epidemiology of the virus; the adequacy of policies relating to diagnosis, treatment and prevention; and specific ‘at risk’ groups including health care workers.

During the course of the Inquiry, the Committee took evidence from 69 witnesses, including some of the nation's most eminent Hepatitis C specialists, in addition to experts in drug and alcohol, epidemiology, virology and public health. Evidence was also taken from agencies providing a range of services to those with Hepatitis C along with people who had the disease. Some of the most poignant and moving evidence came from those with HCV who recounted their first hand experience of dealing with Hepatitis C: the side effects of either the disease itself or the one available drug therapy; the difficulties in accessing information and understanding general practitioners; the overwhelming sense of helplessness as health deteriorates.

Submissions were received from 123 individuals and relevant agencies. A very wide range of people with Hepatitis C made submissions including injecting drug users, prisoners, and those who had contracted Hepatitis C through infected blood or blood products.

An aetiological and epidemiological context for the Report is provided in Chapters Two and Three, which identify and discuss the various features of the Hepatitis C virus along with a thorough analysis of the virus’ incidence and prevalence in Australia and, where possible, New South Wales. Evidence received highlighted difficulties in ascertaining, with any degree of accuracy, current rates of Hepatitis C. Recommendations call for regular and ongoing prevalence and incidence studies to be conducted at both the state and national level and amongst the general community as well injecting drug users and inmates of the state's correctional system.

The Committee was specifically asked to examine the social impact of Hepatitis C. Members came to appreciate that the disease impacts upon the lives of people in a myriad of ways. The debilitating fatigue, for example, limits relationships, work and interactions with children - even simple household tasks. Many recounted to Members the fear they have of neighbours, work colleagues, even family members finding out their Hepatitis C status and the prejudice and stigma that would come with that knowledge. Stories were shared of blatant discrimination and misunderstanding from community members, even health care workers, who fear a disease they know so little about.

The economic impact of the disease is also examined. Current research suggests that every one thousand new injecting drug users infected with Hepatitis C will generate, over their lifespan, $14.32 million worth of direct medical care costs to the Commonwealth. This potential bill does not take into account other economic costs such as lost production (paid and unpaid time off work), the cost of support services such as respite care and Meals on Wheels or the personal cost, in terms of pain and fatigue, to those with the disease.

Despite the current Hepatitis C epidemic, there are no policies at the state level giving overall direction to the control, treatment, management and prevention of this disease. To overcome the current inadequate situation, the Committee has forwarded a number of recommendations including the upgrade of the Hepatitis Advisory Committee to a Ministerial Advisory Committee on Hepatitis C; the design, development and implementation of a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; adequate and ongoing dedicated funding for the implementation of the Policy Statement and Strategic Plan and the appointment of Area Hepatitis C Managers to the five Area Health Services with exceptionally high levels of HCV notifications.

An important part of managing Hepatitis C is the provision of specialised diagnostic tests. Chapter Six reviews the current diagnostic tests available and the shortcomings in the delivery of diagnostic services. Many of those writing to the Committee spoke of the shock and distress they experienced when they first learned of their Hepatitis C status. The Committee considers it essential that pre- and post-test counselling be provided as a routine practice for all those undergoing HCV testing.

The current treatment regime for Hepatitis C is the drug interferon which is freely available for a twelve month period only to those who meet the strict S100 criteria: policies determine who will receive interferon, where interferon can be administered and how much interferon can be given. The Committee considered these policies, and others that limit pre-treatment assessment, restrict ongoing treatment assessment and monitoring and the availability of PCR testing for HCV+ women considering pregnancy. Recommendations addressing each of these issues are forwarded. The Report also identifies inadequacies in the current treatment regime and methods of delivering health care and examines models of best practice to address these shortcomings. The

Committee specifically recommends that the Minister for Health develop a model of best practice for the delivery of health services to those with Hepatitis C. This model is to be flexible and provide services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C.

The report identifies a number of difficulties currently being experienced in treating and managing Hepatitis C positive inmates of the state's correctional system. The Committee calls for the development of a best practice model for the delivery of health care in prisons and stipulates that the model address identified shortcomings of the current system including the limited number of available health care professionals, the limited number of inmates accessing interferon and identified difficulties currently associated with administering interferon to inmates. The Committee also recommends the development, implementation and funding of a strategic plan for the management of Hepatitis C in the state's correctional system.

Many of those with Hepatitis C need, or would appreciate, various forms of support ranging from information and advice to help with household tasks or child care. However a common theme running through the submissions and evidence from those with Hepatitis C was the lack of support available and difficulties accessing what limited support is available. A series of recommendations are forwarded to address the current inadequacies. These include enhanced funding to the Hepatitis C Council's Telephone Information and Support Service to enable it to increase its hours of operation and the trial of an Interagency Hepatitis C Support Project made up of the Departments of Health, Community Service, Housing and Transport and local government representatives. The aim of the Project would be to ensure government services are readily available and accessible to those in need.

The chapter addressing issues to limit the transmission of Hepatitis C is approximately 100 pages in length, which is indicative of the importance Committee Members attach to prevention. The emphasis of the chapter is on the two population groups considered to be at greatest risk of contracting Hepatitis C: injecting drug users and inmates of the state's correctional system.

The Committee considers it essential that the Government recognise that the major risk of infection with the Hepatitis C virus is borne by injecting drug users and that effective strategies to minimise this practice are essential to prevent transmission. The Committee wishes to see the Government review its harm minimisation strategies in the light of the known epidemiology of Hepatitis C. Proposed strategies to limit the spread of Hepatitis C amongst injecting drug users include an expansion of strategies already in place such as peer-based education, the needle and syringe program and the methadone maintenance therapy program. In addition new strategies targeting those who inject and measures to prevent or delay initial injecting should be urgently pursued.

The Committee also considers it imperative that the Government recognise that the prison population faces an unacceptably high risk of contracting Hepatitis C and, on release, these people pose a serious danger of transmitting the virus to the wider community. The Committee feels that these circumstances warrant radical policies to reduce inmates' exposure to Hepatitis C in correction establishments. Current preventative strategies are reviewed and recommendations to strengthen and expand them have been proposed.

Considerable support was given by witnesses and those making submissions to a national community education Hepatitis C campaign. It was anticipated that such a campaign would raise the awareness of the disease amongst the general community, which would, in turn, lessen discrimination and stigmatisation and raise tolerance and compassion towards those with the virus. Such a campaign would also alert those at risk of contracting Hepatitis C and those who may have engaged in 'at risk' behaviours in the past.

Throughout the Report a number of recommendations call for research to be conducted. While the Committee appreciates that some research is underway, there are a number of specific areas that require further research such as ascertaining the incidence and prevalence of Hepatitis C in the general community as well as specific population groups such as injecting drug users and prisoners; an empirical understanding of the personal, social and economic impact of Hepatitis C; and research into the effectiveness of complementary therapies to treat the symptoms of Hepatitis C.

Finally, the Committee recognised that, for a number of reasons, there is no single body that advocates for those with Hepatitis C. In response, and given the growing seriousness of the Hepatitis C epidemic facing New South Wales, the Committee has recommended the formation of a Hepatitis C NSW Parliamentary Liaison Group.

Throughout the course of this Inquiry, Committee Members have been overwhelmed with the enormity of the Hepatitis C issue. Not only is the disease one of epidemic proportions, but it is one that, given its chronic nature, touches every facet of the lives of those with the disease and the lives of their immediate families.

Committee Members have resolved to address current inadequacies and have unanimously proposed a framework for the state to respond appropriately and adequately to this disease which, to date, has been neglected. The Committee now seeks a similar resolve from the government: a resolve backed by political will and motivated by compassion. Hepatitis C is an epidemic that can no longer be neglected.

SUMMARY OF RECOMMENDATIONS

RECOMMENDATION 1:
That the Minister for Health urge his Federal counterpart to commission population **prevalence** studies of Hepatitis C at the national level to determine the prevalence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

RECOMMENDATION 2:
That the Minister for Health commission population **prevalence** studies of Hepatitis C at state level to determine the prevalence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

RECOMMENDATION 3:
That the Minister for Health urge his Federal counterpart to commission population **incidence** studies of Hepatitis C at the national level to determine the incidence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

RECOMMENDATION 4:
That the Minister for Health commission population **incidence** studies of Hepatitis C at state level to determine the incidence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

RECOMMENDATION 5:
That the Minister for Health urge his federal counterpart to establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma at the national level.

RECOMMENDATION 6:
That NSW Health establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma in New South Wales.

RECOMMENDATION 7:
That at the next Australian Health Ministers' Council the Minister for Health urge his federal, state and territory counterparts to establish clinical based morbidity registers to monitor Hepatitis C deaths.

RECOMMENDATION 8:
That NSW Health establish a clinically based morbidity register to monitor Hepatitis C related deaths in New South Wales.

RECOMMENDATION 9:
That the Minister for Health urge his Federal counterpart to institute standardised procedures for the notification of Hepatitis C across all states and territories of Australia.

RECOMMENDATION 10:
That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **prevalence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population prevalence studies proposed in Recommendation 2.

RECOMMENDATION 11:
That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **incidence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population incidence studies proposed in Recommendations 4.

RECOMMENDATION 12:
That the prospective, longitudinal cohort study to ascertain the incidence and prevalence of Hepatitis C amongst injecting drug users proposed in Recommendations 10 and 11 be based upon the Victorian Injecting Drug Study and, like the Victorian model, be conducted by an independent agency.

RECOMMENDATION 13:
That the Minister for Corrective Services and the Minister for Health ensure the prevalence of Hepatitis C in the state's corrections system is ascertained through ongoing monitoring and research.

RECOMMENDATION 14:
That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the prevalence of Hepatitis C in the state's corrections system.

RECOMMENDATION 15:
That the testing proposed in Recommendation 13 incorporate PCR testing to ascertain the viraemic status of HCV+ prison inmates.

RECOMMENDATION 16:
That the Minister for Corrective Services, in conjunction with the Minister for Health, commission an independent study of the incidence and modes of transmission of Hepatitis C in the state's corrections system. This study is to be in addition to the population incidence study proposed in Recommendation 4.

RECOMMENDATION 17:
That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the incidence and modes of transmission of Hepatitis C in the state's corrections system.

RECOMMENDATION 18:
That the independent study of Hepatitis C incidence proposed in Recommendation 16 be conducted on a regular basis to ensure information on the incidence and modes of transmission of Hepatitis C in the state's corrections system is gathered over time.

RECOMMENDATION 19:
That NSW Health design and implement an awareness campaign for all those working in the health care system addressing practices, values and attitudes that discriminate against those with Hepatitis C accessing the health care system.

RECOMMENDATION 20:
That the Minister for Health meet with representatives of the various professional colleges (including the Royal College of Surgeons, Royal College of General Practitioners, and Royal College of Nursing) and unions and urge them to support the awareness campaign addressing Hepatitis C related discrimination in the health care system proposed in Recommendation 19.

RECOMMENDATION 21:
That the Attorney-General instruct the Anti-Discrimination Board to conduct an inquiry into discrimination and Hepatitis C in New South Wales. The Committee further recommends that the resultant report of this inquiry be distributed widely to relevant employer and employee organisations, trade unions, education institutions, hospitals and relevant community organisations (such as the Hepatitis C Council of NSW) across the state.

RECOMMENDATION 22:
That the Premier direct an education campaign be designed and implemented across all sectors of the public service addressing practices, values and attitudes that discriminate against those with Hepatitis C and ensuring that those working for the government are aware of the illegality of discriminating against those with Hepatitis C.

RECOMMENDATION 23:
That the Anti-Discrimination Board of New South Wales design an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination. The Committee further recommends that the Hepatitis C Council of NSW be given responsibility (and adequate funding) to distribute this brochure.

RECOMMENDATION 24:
That the Attorney General provide adequate funding to the Anti-Discrimination Board of New South Wales for the design and development of the information brochure proposed in Recommendation 23.

RECOMMENDATION 25:
That the Minister for Health direct research be undertaken into the personal, social and economic costs of Hepatitis C infection to individuals, the state's health care system and to society.

RECOMMENDATION 26:
That the Attorney General request the NSW Anti-Discrimination Board conduct (or commission) social research into the causes of Hepatitis C-related discrimination.

The Committee further recommends that the findings of the proposed research be used in formulating programs to combat this form of discrimination including those programs proposed in Recommendations 19, 22 and 129.

RECOMMENDATION 27:
That the Minister for Health upgrade the Hepatitis Advisory Committee to become the Ministerial Advisory Committee on Hepatitis C. The Committee further recommends that the Terms of Reference of the Ministerial Advisory Committee on Hepatitis C include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;

2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;

3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and

4. to promote research and training in Hepatitis C.

RECOMMENDATION 28:
That the Minister for Health direct NSW Health to design and develop a NSW Hepatitis C Policy Statement to give overall direction to the control, treatment, management and prevention of Hepatitis C and the care and support of those with the disease.

The Committee further recommends that the proposed NSW Hepatitis C Policy Statement include, as a minimum, a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Policy Statement in January 2001 to assist in determining future responses and directions.

RECOMMENDATION 29:
That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 be the basis for all future planning and funding for Hepatitis C in the state.

RECOMMENDATION 30:
That the Minister for Health ensure adequate consultation with the major stakeholders during the process of designing and developing the NSW Hepatitis C Policy Statement proposed in Recommendation 28. Those consulted are to include, yet not be limited to, representatives of the Hepatitis C Council and relevant community groups such as NUAA, liver specialists, public health experts, epidemiologists, clinical nurse consultants.

The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C be actively involved in the design and development of the NSW Hepatitis C Policy Statement proposed in Recommendation 28.

RECOMMENDATION 31:
That the Minister for Health direct NSW Health to develop a NSW Hepatitis C Strategic Plan within the context of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and that the Strategic Plan clearly articulate how, when and where the state will address all facets of Hepatitis C control, treatment, management and prevention along with care and support for those with the disease.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Strategic Plan in January 2001 to assist in determining future responses and programs.

RECOMMENDATION 32:
That the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 identify goals, objectives and key strategies along with detailed implementation plans for each objective.

RECOMMENDATION 33:

That NSW Health ensure the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) are placed on the Department's website.

RECOMMENDATION 34:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 35:

That the Minister for Health urge his federal counterpart to provide funding allocations which reflect more accurately the rate of Hepatitis C in New South Wales and the state's need for support services and prevention strategies.

RECOMMENDATION 36:

That the Minister for Health ensure dedicated, adequate and appropriately graded full time and permanent staff are assigned within the AIDS and Infectious Diseases Branch of NSW Health to oversee the implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 37:

That the Minister for Health direct South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services develop and implement Regional Hepatitis C Strategic Plans in line with the NSW Hepatitis C Policy Statement (as proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (as proposed in Recommendation 31). This measure should be achieved through contract performance arrangements between NSW Health and the Area Health Services.

RECOMMENDATION 38:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the regional Hepatitis C Strategic Plans proposed in Recommendation 37.

RECOMMENDATION 39:
That the Minister for Health review all Area Health Services to determine the needs of each Area Health Services for Area Hepatitis C Managers.

RECOMMENDATION 40:
That the Minister for Health instruct that, as a matter of priority, the position of dedicated Area Hepatitis C Manager be established and filled in the following Area Health Services: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Norther Rivers. The Committee further recommends that the position of dedicated Area Hepatitis C Manager be in addition to existing positions of Area HIV/AIDS Managers which may currently exist in the identified Area Health Services.

RECOMMENDATION 41:
That the Minister for Health ensure dedicated funding is allocated to the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Norther Rivers Area Health Services for the establishment of Area Hepatitis C Manager positions.

RECOMMENDATION 42:
That the Minister for Health instruct that the positions of Area Hepatitis C Manager in the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services be incorporated in the review of Hepatitis C staffing needs proposed in Recommendation 39. The Committee further recommends that, following this review, and where necessary additional staff dedicated to Hepatitis C management at the local Area Health Service level be appointed.

RECOMMENDATION 43:
That the Minister for Health call tenders for the establishment of three major Hepatitis C reference laboratories in NSW. Selection of the laboratories should be based on the expertise and experience of the laboratories, the ability to interpret tests and develop new tests, and their capacity to participate in state-wide and national quality assurance programs. The reference laboratories should be able to conduct validation testing for private laboratories for a fee.

RECOMMENDATION 44:
That the Minister for Health ensure adequate funding is available to the Hepatitis C reference laboratories proposed in Recommendation 43 and that the funding allocation to the reference laboratories be made from NSW Health funds rather than the local area health services.

RECOMMENDATION 45:
That NSW Health recognise the provision of pre- and post-test information and counselling by health care professionals provides best practice patient management in relation to testing for Hepatitis C. The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C proposed in Recommendation 27 develop a set of policy guidelines for pre-and post-testing for Hepatitis C for health practitioners in NSW and that these guidelines ensure pre- and post test counselling are a routine practice for all people considering HCV testing.

RECOMMENDATION 46:
That the Minister for Health urge his federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to broaden the assessment criteria for interferon drug therapy under the S100 Highly Specialised Drugs Scheme to include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;
- patients with cirrhosis (dosage - 4.5MU daily);
- relapsers and non-responders; and
- patients with extrahepatic manifestations of Hepatitis C.

The Committee further recommends that the proposed new S100 assessment criteria for interferon be monitored for two years with patient response data continuing to be collected for the National Interferon Database.

RECOMMENDATION 47:
That the Minister for Health urge his federal counterpart to ensure funding continues to be provided to maintain operation of the National Interferon Database and that the intellectual property of the Database remain with the government so that optimum treatment regimes can be ascertained.

RECOMMENDATION 48:
That the NSW Hepatitis C Policy and the NSW Hepatitis C Strategic Plan (proposed in Recommendations 28 and 31) address the management needs of those who are HCV-positive and ineligible for interferon therapy. Issues to be considered are to include (although not be limited to) (i) information on the natural history of the disease, treatment options, health promotion and cross-infection and re-infection; (ii) counselling needs and psychosocial support of these patients and their families; and (iii) the role of primary health care providers in giving this support.

RECOMMENDATION 49:
That the Minister for Health seek the support of his Federal counterpart for a review of the criteria used to establish Interferon Prescribing Centres to enable the expansion of the limited number of hospitals allowed to dispense interferon without compromising clinical standards or cost controls.

RECOMMENDATION 50:
That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to determine genotyping and viral load in the pre-treatment assessment for patients considering interferon (and other drug) therapy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

RECOMMENDATION 51:
That the Minister for Health urge his Federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to introduce a degree of flexibility into the S100 Highly Specialised Drugs Scheme enabling the interferon dosage schedule to be increased where necessary and appropriate such as in the case of cirrhotic patients.

RECOMMENDATION 52:
That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to monitor interferon (and other drug) therapy and tailor therapy to ensure maximum efficacy of treatment and efficient utilisation of resources to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

RECOMMENDATION 53:
That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to predict the relative risk of vertical transmission during pregnancy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

RECOMMENDATION 54:
That the Minister for Health request his federal counterpart fund and support clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments. The Committee further recommends that the state government match federal funding for this research on a dollar for dollar basis.

RECOMMENDATION 55:
That the Strategic Plan proposed in Recommendation 31 consider the provision of adequate support mechanisms for people who do not respond to interferon therapy. The Committee further recommends that the Strategic Plan set targets for the establishment of support services in inner city, metropolitan and regional/rural locations.

RECOMMENDATION 56:
That NSW Health provide HCV specific training (both initial and ongoing) to existing providers of psychosocial support for people with chronic illness employed within the health care system, such as social workers, counsellors, chaplains, drug and alcohol workers enabling these professionals to provide support to those on interferon therapy.

RECOMMENDATION 57:
That the Minister for Health, through the forum of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to recognise Australia's low rate of organ donation and consider innovative and effective ways to increase the donations of organs in general and liver donations specifically.

RECOMMENDATION 58:
That the Minister for Health state his government's commitment to providing adequate and appropriate health care - from primary through to tertiary health care - to all those in NSW who are Hepatitis C positive.

RECOMMENDATION 59:
That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly enunciates the Minister's commitment to providing adequate and appropriate health care to all those in NSW who are Hepatitis C positive. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identifies the way in which the Minister's commitment will be realised along with appropriate time frames and funding allocations.

RECOMMENDATION 60:
That the NSW Hepatitis C Strategic Plan be the basis upon which NSW Health allocates funding to treat and manage Hepatitis C.

RECOMMENDATION 61:
That NSW Health conduct a comprehensive needs assessment and service planning exercise within six months of this Report being tabled. This exercise is to include the provision of services in all health areas and all public hospitals.

The Committee further recommends that the Department set minimum service levels based on a health outcomes approach.

RECOMMENDATION 62:
That NSW Health incorporate the implementation of the results of the needs assessment and the service planning exercise into the Strategic Plan proposed in Recommendation 61.

RECOMMENDATION 63:
That the Minister for Health allocate funding for the implementation of the results of the needs assessment and service planning exercise proposed in Recommendation 61.

RECOMMENDATION 64:
That the Minister for Health accept the principle of shared care as a viable and practical clinical management tool for Hepatitis C and ensure NSW Health takes all possible measures for shared care of Hepatitis C patients to be introduced into the New South Wales health care system.

RECOMMENDATION 65:
That the Minister for Health ensure all measures are taken for the full and unhindered implementation of the National Hepatitis C Education Program for General Practitioners in New South Wales.

RECOMMENDATION 66:
That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) address the issue of a Hepatitis C Education Strategy for Health Care Workers. The Education Strategy is to ensure that appropriate material, resources and training are available to health care workers throughout the state, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the Education Strategy be integrated with other education and training activities and initiatives. The Committee further recommends that the Minister for Health ensure the Hepatitis C Education Strategy for Health Care Workers is adequately funded.

RECOMMENDATION 67:
That NSW Health develop a Best Practice Model for the delivery of services to those with Hepatitis C in New South Wales. The Committee stipulates that the best practice model be flexible to provide delivery services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C. The Committee further recommends that NSW Health take into account the evaluations of the RACGP’s National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects, the HepCare trial and the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 in developing best practice models for the delivery of services to those with Hepatitis C.

RECOMMENDATION 68:
That the strategies to be implemented in establishing the model of best practice for the delivery of services to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 69:
That the Minister for Health ensure adequate funding is available for the implementation of the model of best practice for the delivery of services to those with Hepatitis C in NSW.

RECOMMENDATION 70:
That the Minister for Health urge his federal counterpart to encourage the NHMRC to support and fund research trials of complementary therapies designed to relieve the symptoms of Hepatitis C.

RECOMMENDATION 71:
That the Minister for Corrective Services ensure the program offered at the Lifestyle Unit be expanded (in both scope and size) to respond more adequately to the prevalence of Hepatitis C within the corrections system. The Committee further recommends that the program be extended to include female inmates who are Hepatitis C positive.

RECOMMENDATION 72:
That the Department of Corrective Services and Corrections Health Service recognise the extraordinarily high rates of Hepatitis C amongst inmates in the state's correctional system and develop a Best Practice Model for the delivery of Hepatitis C health care services to these inmates as a matter of priority. The Committee believes that the Best Practice Model must provide specific care to male and female HCV+ inmates located in both rural and metropolitan correctional centres. The Committee further recommends that the Best Practice Model must overcome shortcomings in the current provision of health care identified in this Inquiry, including the shortage of available health care professionals, the limited number of inmates able to access interferon therapy, and the difficulties currently experienced in administering interferon to inmates.

RECOMMENDATION 73:
That the strategies to be implemented in establishing the Best Practice Model for the delivery of health care to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 74:
That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system.

RECOMMENDATION 75:
That the Minister for Health and the Minister for Corrective Services form an Intersectorial Committee made up of representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses). This Committee should be required to develop a strategic plan to address issues including, though not be limited to:

- provision of low fat diets to HCV+ inmates;
- availability of light duties for those experiencing Hepatitis C and/or interferon side effects;
- the education of prison officers on Hepatitis C and/or interferon side effects;
- in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes;
- the design of post-release care plans for HCV+ inmates; and
- management difficulties experienced by those inmates on interferon therapy.

RECOMMENDATION 76:
That the implementation details of the strategic plan for the management of Hepatitis C in the state's correctional system proposed in Recommendation 75 be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 77:
That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of strategic plan for the management of Hepatitis C in the state's correctional system.

RECOMMENDATION 78:
That the Minister for Health and the Minister for Corrective Services take active steps to ensure officers from the Department of Corrective Services and Corrections Health Service/NSW Health (not only at the central agency level, but at the local correctional centre level) collaborate effectively.

RECOMMENDATION 79:
That the funding allocation by NSW Health to the Hepatitis C Council of NSW be increased to enable the Telephone Information and Support Service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

RECOMMENDATION 80:
That NSW Health commission an independent review and needs assessment of the services provided by the Hepatitis C Council of NSW, the Transfusion Related AIDS and Infectious Diseases Unit, the Haemophilia Foundation NSW, and New South Wales Users and AIDS Association to determine resource needs (including staffing needs for counselling, support, project and policy work and volunteer management) and demand for services. The Committee further recommends that the proposed review be conducted within six months of the tabling of this Report and that the results are with the Minister for Health no later than December 1999.

RECOMMENDATION 81:
That, upon receipt of the review proposed in Recommendation 80, NSW Health ensure sufficient and recurrent funding is made available to implement the recommendations of the review.

RECOMMENDATION 82:
That the Area Hepatitis C Managers proposed in Recommendation 40 be responsible for instigating Hepatitis C Support Groups in their local Health Areas and, while not necessarily involved in the day to day operation of the groups, provide expert input and information as required, act as a resource/referral person and ensure necessary resources are available.

RECOMMENDATION 83:
That the review proposed in Recommendation 39 take into consideration the need for support groups in each Health Area and the role played by Area Hepatitis C Managers in facilitating these groups.

RECOMMENDATION 84:
That, in developing a model of best practice for the delivery of services to those with Hepatitis C (as proposed in Recommendation 67), the accommodation needs of local Hepatitis C support groups be take into account.

RECOMMENDATION 85:
That NSW Health maintain a watching brief on the issue of changes to the Disability Support Pension. The Committee further recommends that, should changes be proposed in the future which would restrict those genuinely debilitated by Hepatitis C from accessing the Disability Support Pension, the Minister for Health, through the

forum of the Australian Health Minsters Council, advocate on behalf of those with Hepatitis C.

RECOMMENDATION 86:

That NSW Health trial an Interagency Hepatitis C Support Project to ensure government services required by those with Hepatitis C are readily available and accessible. The Committee further recommends that the government agencies involved include the Departments of Health, Community Services, Housing and Transport in addition to local government representation.

RECOMMENDATION 87:

That the Interagency Hepatitis C Support Project proposed in Recommendation 86 be trialed for a two year period in three Health Areas: Central Sydney Area Health Service (inner city), South Western Sydney Area Health Service (metropolitan) and Northern Rivers Area Health Service (rural). The Committee further recommends that the Area Hepatitis C Managers for each of these Health Areas proposed in Recommendation 40 act as project coordinator and chair of the Committee.

RECOMMENDATION 88:

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly state the Department's policy to prevent the transmission of Hepatitis C amongst target populations. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identify the direction to be taken to prevent the transmission of Hepatitis C amongst target populations. The Plan should identify existing preventative strategies, include a range of new preventative measures that are innovative and effective and be the basis for funding and evaluation.

RECOMMENDATION 89:

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) clearly identify the Department's policy to prevent the transmission of Hepatitis C in the injecting drug user population. The Committee further recommends that the NSW Strategic Plan (proposed in Recommendation 31) clearly identifies strategies that will be put in place to prevent the transmission of Hepatitis C amongst the state's drug injecting population.

RECOMMENDATION 90:
That NSW Health recognise and utilise more fully the role that the Methadone Maintenance Therapy Program plays in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that methadone therapy facilities be expanded and made available throughout the state. Resources should be made available to the Methadone Maintenance Therapy Program to provide initial education, counselling and support services for people who are Hepatitis C positive.

RECOMMENDATION 91:
That the Minister for Health, through the Australian Health Ministers' Council, urge the National Health and Medical Research Council to commission and fund research into the interaction between methadone and interferon and the impact of methadone on pregnancy.

RECOMMENDATION 92:
That, given the high content level of alcohol in methadone and the impact this has upon those on methadone maintenance therapy who are also undergoing interferon therapy, the Minister for Health conduct a rigorous scientific trial of all alternative therapies for this group of people. The Committee further recommends that an independent advisory committee be established to develop the trial protocol, oversee the trial and review the trial's subsequent evaluation.

RECOMMENDATION 93:
That the Minister for Police review the instructions concerning police patrols within the proximity of needle and syringe outlets and that the instructions clearly state that:

i) maximum and effective use of needle and syringe outlets is an effective preventative measure against the transmission of Hepatitis C and other blood borne diseases; and

ii) clients' access to needle and syringe outlets is to be unhindered and without fear of intimidation or arrest.

RECOMMENDATION 94:
That the Minister for Health recognise the role of the Needle and Syringe Program in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that the Program be further developed and extended in its reach and range of services so that outlets throughout the state provide:

- education and information (including available treatment options), counselling and support services to people who are Hepatitis C positive;
- increased after-hours service;
- access to sterile water, alcohol swabs and cotton wool filters; and
- for integrated services in conjunction with other community health programs.

RECOMMENDATION 95:
That the Minister for Health ensure the Needle and Syringe Program is adequately resourced to take on the additional functions proposed in Recommendation 94.

RECOMMENDATION 96:
That NSW Health design strategies targeting those who have just commenced injecting practices to warn them of the inherent dangers of contracting Hepatitis C from unhygienic equipment and to encourage them to utilise fully the services offered by needle and syringe outlets. The Committee further recommends that the Needle and Syringe Program be resourced to implement the proposed strategies.

RECOMMENDATION 97:
That NSW Health ensure workers at needle and syringe outlets are adequately skilled and trained to provide HCV specific information.

RECOMMENDATION 98:
That NSW Health provide funding for a state-wide peer based education campaign on the importance of blood awareness amongst injecting drug users. The Committee further recommends that representatives from the Hepatitis C community and other appropriate interest groups be involved in the development and implementation of the proposed education strategies to ensure the strategies are practical and effective and appropriate.

RECOMMENDATION 99:
That NSW Health and the Department of Education and Training ensure the basic message of all preventative strategies to prevent or delay initial injecting behaviour in adolescents is a very clear one that encourages young people not to take drugs.

RECOMMENDATION 100:

That the Minister for Health and the Minister for Education and Training meet and reach an agreement on the role to be played by the Department of Education and Training in providing Hepatitis C education to children and young people in the state's school system. The Committee further recommends that the two Ministers give consideration to the following aims for Hepatitis C education within the school system:

- to prevent infection with HCV by discouraging young people from engaging in risk behaviours; and
- to provide information on harm minimisation for young people who may have already become involved in drug use.

RECOMMENDATION 101:

That the Department of Education and Training develop school-based education programs to raise student awareness on issues including:

- the nature of Hepatitis C, including epidemiology, transmission and risk behaviours;
- a range of strategies to assist students to avoid injecting drug use;
- potential behavioural, social and environmental risk factors; and
- accessing appropriate sources of information, support and advice, including testing and treatment information and services.

RECOMMENDATION 102:

That NSW Health continue to urge the Commonwealth Department of Health and Family Services to provide funding under the Public Health Outcomes Funding Agreement Incentives Program for a pilot Hepatitis B vaccination program for methadone clients in New South Wales.

RECOMMENDATION 103:

That the Minister for Health ensure drug treatment services funded by NSW Health play a more direct and active role in providing information on the prevention of Hepatitis C to injecting drug users.

RECOMMENDATION 104:

That NSW Health increase the provision of drug treatment and rehabilitation programs as an effective Hepatitis C preventative strategy.

RECOMMENDATION 105:
That the Minister for Health establish a NSW Intersectoral Advisory Committee for Hepatitis C and invite the Ministers for Corrective Services and Police and the Attorney General to join him on that Committee.

RECOMMENDATION 106:
That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105:

- consider the role of drug policy and law reform as a pragmatic measure to limit the transmission of Hepatitis C;

- assess and examine how policies and legislation relating to prohibited drugs (such as the self administration and possession offences, s10 and s12 of the *Drugs Misuse and Trafficking Act, 1985*) can best be revised to serve as effective instruments of health policy and to support public health objectives designed to limit the spread of Hepatitis C;

- encourage public debate about the public health consequences of drug policy reform; and

- examine strategies to improve non-custodial sentencing options.

RECOMMENDATION 107:
That the Minister for Health urge his federal counterpart to fund research into issues including:

- reducing the number of injecting drug users;
- improving the effectiveness of treatment for persons using illicit drugs which can be injected;
- development of non-reusable injecting equipment;
- behavioural and ethnographic research into young injectors;
- the effectiveness of bleach and other agents used for decontamination of injecting equipment; and
- the danger of contracting Hepatitis C from the exchange of body fluids

and that the results of such research be used in devising strategies to target those at risk, particularly young injectors.

RECOMMENDATION 108:
That the Minister for Corrective Services commission a review of the HIV and Health Promotion Unit to ascertain the staffing needs of the Unit and to ensure the Unit is adequately resourced to meet the information and educational needs of Hepatitis C inmates in the state's correctional system.

RECOMMENDATION 109:
That the HIV and Health Promotion Unit ensure all educational strategies employed reflect current health promotion practices. The Committee further recommends that representatives from the Hepatitis C community are consulted along with experts in the field of health education and health promotion in the design of educational material produced by the HIV and Health Promotion Unit.

RECOMMENDATION 110:
That the Minister for Health ensure any shortcomings identified in the current review of the methadone maintenance program be considered and acted upon as a matter of priority as a pragmatic public health measure to limit the transmission of Hepatitis C within the state's corrections system and, consequently, the general community.

RECOMMENDATION 111:
That the Minister for Health ensure methadone maintenance therapy is available to new prison inmates with a history of injecting drug use to limit the transmission of Hepatitis C within the state's corrections system and, consequently, the general community.

RECOMMENDATION 112:
That, recognising the role of tattooing in the transmission of Hepatitis C, the Minister for Corrective Services enable tattoos to be available in hygienic conditions within the state's corrections system.

RECOMMENDATION 113:
That the Minister for Corrective Services ensure adequate bleach dispensing machines are available in all correction centres enabling inmates to access bleach freely and anonymously. This should be administered as a Hepatitis C control measure, and should not be linked to drug surveillance.

RECOMMENDATION 114:
That the HIV and Health Promotion Unit continue to encourage inmates not to share their razor blades and toothbrushes.

RECOMMENDATION 115:
That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 give urgent consideration to a range of non-custodial sentencing options such as:

- the use of diversionary sentencing;
- utilisation of drug courts; and
- the inappropriateness of mandatory sentences for minor offences

as a means of reducing the transmission of Hepatitis C in the corrections system.

RECOMMENDATION 116:
That the Ministers for Corrective Services and Health establish a medical records database throughout the state's corrections system to facilitate the successful follow-up of inmates and management of their Hepatitis C.

RECOMMENDATION 117:
That the Ministers for Corrective Services and Health collaborate to ensure that the Hepatitis B vaccination program operates effectively in every prison and where possible, every alternative community sentencing program.

RECOMMENDATION 118:
That the Minister for Health commission a cost effectiveness study of the Hepatitis B vaccination program currently conducted by Corrections Health Service and that the study examine a range of immunisation options including the use of accelerated vaccination schedules.

RECOMMENDATION 119:
That the Minister for Corrective Services instruct all correctional centres to purchase and supply only approved barber's shears with detachable heads that can be cleaned readily with bleach and water.

RECOMMENDATION 120:
That the Minister for Corrective Services direct that inmates required to clean up blood spills must be provided with adequate protective clothing and appropriate sterilisation solution to minimise their exposure to Hepatitis C.

RECOMMENDATION 121:
That the Minister for Corrective Services direct that appropriate educational strategies target non Hepatitis C positive inmates who are at risk of infection during their first few weeks in prison.

RECOMMENDATION 122:
That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 investigate and report on the appropriateness of introducing a needle and syringe program, modelled on the successful European trials, into the state's correctional system and, if necessary, develop guidelines for the program's implementation.

RECOMMENDATION 123:
That the Department of Corrective Services design, develop and implement an in-service training course for prison officers made up of education modules on harm minimisation and that adequate resources be made available to fund the implementation of the modules. The Committee further recommends that the Minister for Corrective Services direct all prison officers to undertake the proposed in-service training course on harm minimisation.

RECOMMENDATION 124:
That Corrections Health Service make available a range of drug withdrawal strategies to inmates seeking to give up their drug habit.

RECOMMENDATION 125:
That the Ministers for Health and Corrective Services direct that a policy addressing prevention of Hepatitis C within the state's correctional system and the role played by drugs in the transmission of Hepatitis C be collaboratively developed between the two departments and that the policy be included in the NSW Hepatitis C Policy Statement proposed in Recommendation 28. The Committee further recommends that the two departments also develop strategies to prevent Hepatitis C transmission in the state's

corrections system and incorporate these strategies into the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 126:

That the Minister for Health, through the forum of the Australian Health Ministers' Council, encourage the Australian Council on Health Care Standards to include the inspection of documentation verifying implementation of a Hepatitis B vaccination program for staff (excluding confidential staff records) in the hospital accreditation procedures.

RECOMMENDATION 127:

That the Minister for Health, through the forum of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to consider the adoption of national infection control standards. The Committee further recommends that the Minister for Health propose the NHMRC's guidelines for the prevention of transmission of infectious diseases entitled *Infection Control in the Health Care Setting* (1996) be considered as the basis for national infection control standards.

RECOMMENDATION 128:

That, within the context of the Australian Health Ministers' Council, the Minister for Health urge his federal, state and territory counterparts to consider the adoption of standard procedures for endoscopic units including sterilisation, staff training and use of disposable medical appliances as part of the hospital accreditation process.

RECOMMENDATION 129

That the Minister for Health encourage his federal counterpart to design and introduce a national community education Hepatitis C campaign. The Committee further recommends that NSW Health fully support the introduction of a community based Hepatitis C education campaign within NSW and provide whatever assistance may be required.

RECOMMENDATION 130:

That the national community education Hepatitis C campaign proposed in Recommendation 129 include a component about the role of preventative strategies such as the methadone maintenance therapy program and the needle and syringe program in limiting the transmission of Hepatitis C.

RECOMMENDATION 131:
That the Minister for Health urge his federal counterpart support and fund research into the social factors which increase the risk of contracting Hepatitis C. The Committee further recommends that the Minister for Health encourage his federal counterpart to utilise the results of sound social research in the design and introduction of the community based education Hepatitis C campaign proposed in Recommendation 129.

RECOMMENDATION 132:
That the Premier invite his Parliamentary colleagues, from both Houses and all political parties, to form a Hepatitis C Parliamentary Liaison Group. The role of the Liaison Group would be to advocate and support Hepatitis C related policies within the political domain with an overall objective to limit the spread of Hepatitis C in the general community and the corrections system.

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND TO THE REPORT

In May 1997 the Minister for Health, the Hon Dr Andrew Refshauge, asked the Standing Committee on Social Issues to inquire into, and report on, the incidence and impact of Hepatitis C (HCV) in New South Wales. The Terms of Reference sent to the Committee specifically asked it to examine:

- the social and economic impact of Hepatitis C in NSW and the implications for future policy and funding of health and community services;
- the extent of the disease and its aetiology and epidemiology;
- the adequacy of policies, and diagnostic and treatment services with particular attention to strategies for prevention, given current health budget constraints;
- the groups and individuals in the community at increased risk of infection;
- the extent of the infection in specific population groups at risk, and the adequacy of education/prevention and care and treatment services available to them; and
- the risks involved for health care workers and the adequacy of policies and procedures on occupational health and safety.

During the course of the Inquiry, the Committee took evidence from 69 witnesses including some of the nation's most eminent Hepatitis C specialists in addition to experts in drug and alcohol, epidemiology, virology and public health. Evidence was also taken from agencies providing a range of services to those with Hepatitis C along with people who have the disease. Some of the most poignant and moving evidence came from those with HCV as they recounted their first hand experience of dealing with Hepatitis C - the side effects of either the disease itself or the drug therapy, the difficulties in accessing information and understanding general practitioners, and the overwhelming sense of helplessness as their health deteriorated.

The Committee also undertook site visits to three organisations that are involved in managing or supporting those with Hepatitis C: the Kirketon Road Clinic at Kings Cross, the Albion Street Clinic located at Darlinghurst and the headquarters of the NSW Users and AIDS Association (NUAA) at Bondi. During the visit to NUAA the Committee took evidence from a number of people with Hepatitis C.

Submissions were received from 123 individuals and relevant agencies. A very wide range of people with Hepatitis C made submissions including injecting drug users, prisoners, and those who had contracted Hepatitis C through infected blood or blood products. Many of those making submissions asked that the material they provided be treated in confidence. To respect these requests submissions from people with Hepatitis C will be referred to by number rather than name throughout the Report.

As far as the Committee can ascertain, this is the first Parliamentary Committee in Australia to consider the issue of Hepatitis C. Throughout the Inquiry, the Committee received very strong support for its work and numerous witnesses commended the Standing Committee for considering the issue. The Chair of the Australian National Council of AIDS and Related Diseases (ANCARD), for example told the Committee that the Council was:

> *extraordinarily pleased with the establishment of this Committee and hopes that the Committee will have some positive recommendations to help us deal with the questions of Hepatitis C* (Puplick evidence, 7 November 1997).

1.2 PUTTING THIS INQUIRY INTO CONTEXT: PREVIOUS WORK

Throughout the past decade, the issue of Hepatitis C has been considered at both the federal and state level. The following discussion summarises the findings of various taskforces and committees that have attempted to come to terms with this disease and the impact it has both upon individual lives and the health system.

1.2.1 FEDERAL INQUIRIES

- **The Joint National Health and Medical Research Council and Australian Health Ministers' Advisory Council Taskforce: 1993**

In 1993 the Joint National Health and Medical Research Council (NHMRC) and Australian Health Ministers' Advisory Council (AHMAC) Taskforce established a joint Taskforce to report on the epidemiology and natural history of Hepatitis C, and the cost-effectiveness of proposed disease control and treatment protocols. The Taskforce was also requested to examine the use of interferon. At that time the Pharmaceutical Benefits Advisory Committee was in the process of considering an application for the listing of interferon as a pharmaceutical benefit for the treatment of Hepatitis C. It was therefore decided not to duplicate these deliberations and the Terms of Reference were revised accordingly.

The resultant report, *Hepatitis C Epidemiology, Natural History, Control and Treatment*, was endorsed by both the NHMRC and AHMAC the following year. The final report forwarded recommendations in the areas of diagnosis, screening, epidemiology, natural history, Hepatitis C control and management (NHMRC, 1994).

Following acceptance of the report by the NHMRC and the AHMAC, a Commonwealth/State and Territory Implementation Working Group was established by AHMAC to examine the implications of the implementation of the report. AHMAC also extended the sunset clause of the Taskforce to enable further review of the efficacy of interferon in the treatment of Hepatitis C, including clinical indications, dose and duration of therapy and appropriate limitations on prescribing. The second report of the Taskforce, *Treatment of Chronic Hepatitis C with Interferon*, was accepted by both NHMRC and AHMAC. The report was also considered by the Commonwealth's Pharmaceutical Benefits Advisory Committee (PBAC) which recommended interferon be made available as a pharmaceutical benefit along with a monitoring program for patients on interferon.

- **The National Hepatitis C Action Plan: 1994**

Following the acceptance of the NHMRC-AHMAC Taskforce's report AHMAC established a Commonwealth/State Working Group to examine the implications of the implementation of the report. The Implementation Working Group recognised the need for a nationally coordinated approach and initiated the development of the National Hepatitis C Action Plan. This Plan, which builds on the recommendations of the joint NHMRC/AHMAC report, was endorsed by AHMAC in October 1994.

The Plan has two aims:

- to minimise the transmission of Hepatitis C; and
- to minimise the personal and social impact for those already infected (AHMAC, 1994:i).

A series of recommendations were forwarded in each of four priority areas for action including: epidemiology and surveillance (three recommendations); testing (four recommendations); clinical management (three recommendations); and education and prevention (three recommendations).

In accordance with the National Hepatitis C Action Plan, the Commonwealth has been progressing a national package of measures to address the needs of people with Hepatitis C which includes:

- the development of a nationally coordinated approach to education and prevention working with affected communities to develop and implement a range of national education initiatives consistent with this approach (see Chapter Ten);
- the implementation of a package of education initiatives in identified areas of need including the following:
    - a national needs assessment on education needs of people with Hepatitis C conducted by the Hepatitis C Councils (National Hepatitis C Councils Education Reference Group, 1996);
    - a Hepatitis C program for people with haemophilia conducted by the Haemophilia Foundation of Australia (see Section 9.1.2);

  - a two year education program for general practitioners, to be implemented by the Royal Australian College of General Practitioners (taking into account the NHMRC Guidelines for General Practitioners) (see Section 8.4.1);
  - a national needs assessment for health care workers;
  - education material addressing infection control advice for the tattooing and skin penetration industry (see Section 10.5); and
  - a forum to address injecting drug use;

- incorporation of Hepatitis C messages into campaigns and education strategies under the National HIV/AIDS Strategy and the National Drug Strategy where appropriate;
- the introduction of more stringent requirements for pre-market evaluation and registration of Hepatitis C test kits under the *Therapeutic Goods Act, 1995*;
- a 12 month surveillance study with States and Territories on a pilot study to step up surveillance activities and commission research into the epidemiology of Hepatitis C in Australia - information from this study will inform future education programs for Hepatitis C;
- research into the epidemiology of Hepatitis C; and
- the development of these NHMRC guidelines on detection and management of Hepatitis C (NHMRC, 1997:iii).

The Hepatitis C Council suggested to the Committee that the extent to which strategies proposed in the National Action Plan have been addressed in NSW has been “limited” by a lack of Commonwealth funding for particular areas as well as a lack of agreement around responsibilities for education programs (Hepatitis C Council submission).

In early 1998 the Commonwealth Department of Health and Family Services commissioned a review of the *National Hepatitis C Action Plan* and an associated education document, the *Nationally Coordinated Hepatitis C Education and Prevention Approach* (produced in response to recommendation eleven of the Action Plan and reviewed in Chapter Ten).

The Review will:

1. Present a strategic overview of the HCV epidemic in Australia including:
   a. Estimates of HCV incidence and prevalence in Australia, projections of the long-term sequelae of HCV infection, estimates of present and future

economic cost of HCV to Australia, and a commentary on the social impact of HCV; and

b. Deficiencies in information collection and research capacity in achieving 1 (a); and

c. Priorities for future effort in remedying these deficiencies;

2. Assess the performance of the National HCV Action Plan and the Nationally Coordinated Hepatitis C Education and Prevention Approach in relation to their policies, principles and objectives across its major areas of activity:

   - epidemiology and surveillance;
   - education and prevention programs;
   - testing strategy; and
   - patient management counselling and treatment;

3. Identify the strengths and weaknesses of the current national and state level responses to HCV and the opportunities and threats facing these responses. This analysis should include consideration of the national coordination and liaison mechanisms linking Hepatitis C with HIV/AIDS, the National Drugs Strategy and other public health initiatives;

4. Consider and discuss the implications of the changing public health policy context since the National Hepatitis C Action Plan was first developed including:

   - the development of the National Public Health Partnership,
   - changes to Commonwealth-State relations including the broadbanding of Commonwealth public health program Specific Purpose Payments to State and Territory governments,
   - the development and implementation of the Third National HIV/AIDS and Related Diseases Strategy,
   - developments in national drugs policy, and
   - the development of the National Communicable Diseases Surveillance Strategy; and

5. Recommend strategic directions and priorities for national action on HCV including specification of the essential components of an organised response to HCV at the state and territory level (Commonwealth Department of Health and Family Services, 1998:2-3).

The Committee understands that various organisations are undertaking different components of the review including:

- epidemiological estimates: National Centre in HIV Epidemiology and Clinical Research;
- estimates of present and future economic costs: Alan Shiell, Department of

Public Health, University of Sydney;

- social impact, program history and review of the National Hepatitis C Action Plan implementation: Evaluation and Research Unit, Division of Public Health, Commonwealth Department of Health and Family Services;
- analysis of strengths and weaknesses and opportunities and threats in Australia's response to Hepatitis C: David Lowe Consulting and Mandala Consulting; and
- strategic directions and priorities for national action: David Lowe Consulting and Mandala Consulting.

According to the Review's tender document, it was anticipated the Review would be undertaken over a three month period commencing in March and finishing in June 1998. As of November 1998, the final report had not been released.

The Review's Background Briefing Paper used at the mid-review consultation meeting held in Sydney in July 1998 suggested that the final report would identify five key challenges that emerged from the Review's analysis of the strengths and weaknesses of the current national and state level response to HCV and the opportunities and threats facing these responses. The challenges identified include:

1. reducing transmission of Hepatitis C;
2. improving care and support for people living with Hepatitis C;
3. getting the research right;
4. extending partnerships; and
5. clarifying structures, roles and responsibilities (David Lowe Consulting and Mandala Consulting, 1998:15).

The Hepatitis C Council suggested to the Committee that the Review is:

> *expected to show some areas of need have begun to be met, [but] it will almost certainly show that the great bulk of prevention work and much needed improvements to care, support and treatment services remain to be done* (Loveday evidence, 30 March 1998).

The Committee understands that, following the finalisation of the review of the Action Plan, a list of recommendations for areas that need to be addressed will be developed and submissions will be sought to undertake this work (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:4). This work will be funded by a one-off supplement of $700,000 which will be made available in 1998-99 (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:4).

- **The NHMRC Strategy for the Detection and Management of Hepatitis C in Australia: 1997**

Realising that some significant aspects of Hepatitis C were not dealt with in the National Hepatitis C Action Plan, the NHMRC appointed a Working Party in 1994. Chaired by Professor Reed of the Department of Medicine, University of Western Australia, the Working Party's Terms of Reference were:

1. *To develop clinical protocols for the management of Hepatitis C;*

2. *To develop protocols for the laboratory diagnosis of Hepatitis C, including clinical and public health indications for testing, and the resolution of indeterminate test results;*

3. *To monitor data on treatment for Hepatitis C, including data to be obtained from the database set up as a result of the current NHMRC recommendations for the use of interferon in the management of chronic Hepatitis C;*

4. *To make recommendations on the place of interferon or other treatments in the management of Hepatitis C in children including if appropriate, dose, duration of treatment, and patient monitoring protocols;*

5. *To monitor data on the incidence, prevalence, epidemiology, and natural history of Hepatitis C, and make recommendations as appropriate to control the transmission of the disease, including a review of the surveillance pilot study approved by AHMAC;*

6. *To establish, where appropriate, smaller task groups to undertake specific work and to co-opt special members where necessary; and*

7. *To provide information direct to the AHMAC Education Reference Group, advise the AHMAC Implementation Working Group, and report to the Communicable Diseases Standing Committee of the NHMRC* (NHMRC, 1997:ix).

In dealing with management, the Working Party focused attention on treatment protocols in an endeavour to improve access to treatment, optimise treatment regimes and evaluate data now accumulating as a result of the Section 100 of the *National Health Act, 1953 (Commonwealth)* guidelines (NHMRC, 1997:iv). A cost-effectiveness analysis of interferon usage or care provision was considered outside the Terms of Reference of the Working Party and therefore not included.

The Working Party's final report, *A Strategy for the Detection and Management of Hepatitis C in Australia,* was released in March 1997 and is available on the Internet at http://www.health.gov.au:86/nhmrc/publicat/fullcopy.htm. The Report makes recommendations on:

- laboratory testing;
- treatment protocols and options;
- infrastructure for treatment and management (including expansion of shared-care management);
- funding for trials;
- counselling; and
- access and shared care (NHMRC, 1997:xiii - xiv).

In releasing the final report, the Working Party's Chair commented that the Working Party had:

> *focussed significant attention on treatment protocols in an endeavour to optimise treatment regimes, to improve access to treatment and evaluate data on natural history and response to therapy now accumulating in Australia* (NHMRC-ANCARD, 1997).

ANCARD Chair, Mr Chris Puplick saw the document as a "comprehensive review" of the management of Hepatitis C in Australia which will "act as a blue print for future directions" in dealing with Hepatitis C (NHMRC-ANCARD, 1997).

- **Australian National Council on AIDS and Related Diseases**

In 1996 the Commonwealth government released its third National HIV/AIDS Strategy, 1996-97 to 1998-98. At that time the Strategy was broadened to include blood borne viruses including Hepatitis C. As a result of that decision, the scope of the Australian National Council on AIDS (ANCA) was expanded and the Council became known as the Australian Council on AIDS and Related Diseases (ANCARD). ANCARD is the Commonwealth Government's key advisory body on HIV/AIDS and related communicable diseases that have clear and direct links to HIV/AIDS such as Hepatitis C.

ANCARD has convened a Specialist Sub-Committee on Hepatitis C to advise it on the measures necessary to achieve control of the Hepatitis C infection in Australia. The Committee's Terms of Reference are to advise ANCARD on:

1. the implementation of the National HIV/AIDS Strategy as it relates to Hepatitis C;

2. the evaluation and implementation of the National Hepatitis C Action Plan and the implementation and recommendations of the NHMRC Report: *A Strategy for the Detection and Management of Hepatitis C in Australia* to provide expert advice to ANCARD and all its subcommittees on issues relating to Hepatitis C;

3. activities addressing Hepatitis C being undertaken by Commonwealth, State and Territory Governments and non-government organisations; and

4. how to improve the monitoring of data on the epidemiology, transmission and natural history of Hepatitis C.

The Sub-Committee is made up of experts in a range of fields associated with Hepatitis C including gastroenterology, Hepatitis C viral research, epidemiology and surveillance in addition to the national peak organisation for Hepatitis C and the Australian Intravenous League. ANCARD Chair, Mr Chris Puplick considers the Committee would “play an important role in progressing Australia’s response to Hepatitis C” (NHMRC, 1997:2).

ANCARD’s 1997-99 Working Plan has been developed around the framework contained in the National HIV/AIDS Strategy. It identifies a number of priority projects specifically targeting Hepatitis C. Examples of Hepatitis C-oriented activities proposed in the Plan include:

- consider establishment and oversee a National Prisons Action Plan to deal with HIV and related diseases especially HCV;

- initiate and oversee development of a strategic plan for HCV transmission prevention;

- consider the recommendations of the review of the National Hepatitis C Action Plan in relation to care and treatment issues and respond in an appropriate manner (ANCARD, undated).

The move to broaden the HIV/AIDS Strategy to include Hepatitis C has not been without criticism or problems. The Hepatitis C Council, for example, has stated that:

> *Our belief is that . . . Hepatitis C policy has been tacked on to the Third HIV Strategy in particular, and HIV funding in general* (Hepatitis C Council supplementary submission).

In evidence before the Committee Dr Nick Crofts commented on a “major problem” with the policy:

> *at the Federal level Hepatitis C is not being accorded a status of its own and the terms of the National Strategy on AIDS and Related Diseases where Hepatitis C is to be addressed where there is significant overlap with issues related to HIV. The practical impact of that is that people are being asked to tackle two diseases of major public health and social significance on the one budget and the one budget being cut back. The social impact of that policy, more than anything else, promotes the sort of divisions that we fortunately have not seen a lot in AIDS, but the divisions between the differing camps, the differing interest groups; Hepatitis C versus HIV; injecting drug users versus the gay community* (Crofts evidence, 28 November 1997).

He elaborated further that:

> *the current policies of not addressing Hepatitis C related issues as specific issues in their own right are promoting that divisiveness, are leading to a lack of emphasis and importance being placed on Hepatitis C related issues* (Crofts evidence, 28 November 1997).

The Executive Officer of the Australian Hepatitis Council, Mr Jack Wallace, has expressed his concern that Hepatitis C is the "poor cousin" in the current AIDS and Related Diseases Strategy (Wallace correspondence, 2 September 1998). He is also concerned that:

> *the linking of Hepatitis C with sexually transmitted infections in national strategies perpetuates the confusion about whether Hepatitis C is sexually transmitted* (Wallace correspondence, 2 September 1998).

To overcome the concerns he has identified, Wallace has proposed the option of redefining ANCARD to the Australian National Council on AIDS and Hepatitis C (Wallace correspondence, 2 September 1998).

The Hepatitis C Council informed the Committee that they are "pleased" that:

> *at the national level, ANCARD under the chairmanship of Mr Chris Puplick, appears to be taking a proactive role in coordinating the national response to Hepatitis C, but there are too many aspects, particularly on the prevention front, where progress is far too slow and in some instances, non-existent* (Hepatitis C Council supplementary submission).

1.2.2 STATE INITIATED TASKFORCES

NSW Health established a Hepatitis C Taskforce in September 1994 to ensure a "consistent, planned approach" to all aspects of Hepatitis C (NSW Health tabled document, 3 October 1997). The Taskforce was made up of clinicians, epidemiologists and consumer group representatives. Its Terms of Reference were:

- *consideration of the epidemiology of Hepatitis C in NSW;*
- *advice on improvement in surveillance, education and prevention strategies;*
- *consideration of the cost effectiveness of proposed disease control and treatment protocols;*
- *advice on the implementation of the NHMRC Taskforce Report; and*
- *identification of gaps in existing policy and service provision* (NSW Health tabled document, 3 October 1997).

The Taskforce released its report in 1995. It described the known epidemiology of HCV and identified priorities for action in health and other non-health portfolio areas (such as Police, Corrective Services and the Attorney-General) required to address Hepatitis C (NSW Health submission). The Department advised that recommendations are being implemented progressively and they are "working towards full implementation as resources become available" (NSW Health submission). Details of the action being taken on each recommendation were contained in a document NSW Health tabled at its hearing which are reproduced in Appendix Three.

The cost of full implementation of the Taskforce recommendations relating to the Health portfolio has been estimated. NSW Health advised that a comprehensive program of appropriate activities under the health portfolio is estimated to require additional funding of approximately $3,240,000 annually with an additional $1,690,000 in 1998/99 to initiate appropriate actions, making a total of $4,930,000 in 1998/99 (NSW Health submission).

The Hepatitis C Council has described the Taskforce Report as a:

> *strategic document [that] made wide reaching and positive recommendations to address the HCV epidemic in this state. This report, however, has lacked sufficient and committed funding to undertake adequately many of the initiatives proposed* (Hepatitis C Council submission).

1.3 STRUCTURE OF THE REPORT

Chapter Two provides an introductory discussion of the Hepatitis C virus including its aetiology, modes of transmission, natural history, clinical features and genotypes. The discussion also compares and contrasts Hepatitis C with HIV/AIDS. The epidemiology of the Hepatitis C virus is considered, in particular its incidence and prevalence along with projected estimates of the long-term sequelae of the infection. National and state notification rates are also cited.

Chapter Three identifies the primary population groups at risk of contracting the Hepatitis C virus: injecting drug users, inmates in the state's corrections system, people born in certain countries overseas, recipients of infected blood or blood products, health care workers and their patients, people engaging in skin penetration activities (such as acupuncture and tattooing) and transmission from mother to child.

In Chapter Four the Committee examines the social and economic impact Hepatitis C has upon those with the disease. Many of those making submissions to the Committee wrote of the impact the virus has had upon all facets of their lives. The Committee has come to appreciate that HCV radically affects an infected person's personal life, social life, working life and, for many, their financial standing. In addition, many of those with Hepatitis C have experienced discrimination and stigmatisation as a result of a lack of understanding of the disease, and certain stereotypes. In terms of the economic impact of the disease, the chapter looks at two aspects: the impact of the disease upon individuals who are Hepatitis C positive and the broader impact upon the community as a whole.

The Committee was requested to examine current Hepatitis C policies. Chapter Five identifies the policies of NSW Health and reports comments made on the appropriateness of these policies by a range of experts appearing before the Committee. Strategies addressing current inadequacies are identified.

Diagnosing Hepatitis C is examined in Chapter Six. The Chapter looks at the various tests currently used to detect both the antibody and the antigen and the laboratory structure in place to perform these tests. The role of pre- and post-test counselling is discussed and proposals to formalise this process forwarded.

In Chapter Seven the current policies directing the treatment and management of Hepatitis C are identified. The discussion identifies current treatment regimes with particular reference to interferon, the only approved drug therapy. Three relevant medical procedures are also discussed: liver biopsies, liver transplants and treatment of hepatocellular carcinoma.

Chapter Eight builds upon the preceding chapter by identifying issues and concerns raised by witnesses that relate to the way Hepatitis C is currently treated and managed. In particular, the discussion looks at the adequacy of current policies regulating treatment, the adequacy of current treatment regimes and current clinical management practices. The issue of treating and managing prison inmates with Hepatitis C is also considered.

Chapter Nine reviews existing agencies that provide support to those with Hepatitis C. The Hepatitis C Council of New South Wales provides a very broad range of services to meet the needs of those who are Hepatitis C positive and their families. Throughout the report, the Council is referred to as the Hepatitis C Council. Other non-government agencies providing services are also reviewed. Many of these were primarily set up to provide support to those with HIV/AIDS and have had their scope increased to deal with the Hepatitis C epidemic.

In Chapter Ten a range of preventative strategies to limit the spread of the HCV virus is considered. Given the impact the disease has upon injecting drug users and those in the corrections system, the discussion primarily focuses of the needs of these two population groups. The Chapter also considers the need for a national education campaign to inform the general community on the disease, and minimise discrimination and stigmatisation.

In addition to drawing a number of key conclusions, Chapter Eleven notes that, unlike HIV, the Hepatitis C community is quite disparate and no one group advocates for those with the disease. To overcome this situation the formation of a NSW Parliamentary Liaison Group is proposed to provide a strong advocacy role and influence policy makers at the highest state level.

CHAPTER TWO

A PROFILE OF HEPATITIS C

The existence of a viral cause of hepatitis other than Hepatitis A and Hepatitis B was first recognised in the early 1970s following the development of diagnostic blood tests for Hepatitis A and Hepatitis B. Once these two forms of hepatitis could be identified, there still remained a form of hepatitis which became known as non-A and non-B hepatitis. This term lasted for approximately 20 years. It was not until the late 1980s that a test was developed to detect a particular kind of hepatitis which quickly became known as Hepatitis C.

Since that time, significant advances have been made in understanding the epidemiologic patterns of HCV transmission and its natural history and modes of transmission, but as MacDonald, Crofts and Kaldor observe, "much remains to be learned in all these areas" (1996:137).

The following discussion looks at the Hepatitis C virus: what it is, how it spreads, how it manifests itself and how prevalent it is in the community. The Chapter also compares and contrasts Hepatitis C with another blood borne virus: HIV.

2.1 THE HEPATITIS C VIRUS

The current Hepatitis C epidemic is unlike many other epidemics where the consequences are fairly immediately obvious. With Hepatitis C there is a considerable lag period between the epidemic of infection and the epidemic of consequences (Wodak evidence, 2 October 1997). As Wodak explained to the Committee:

> *in the 1990s we are now only just beginning to see the consequences of the epidemic of Hepatitis C that we think probably began in Australia in a big way in the late 1960s when drug injecting took off* (Wodak evidence, 2 October 1997).

2.1.1 AETIOLOGY

The aetiologic agent of this form of infection is the Hepatitis C virus. The virus is relatively robust and can live for an appreciable period of time outside the body. Research presented at the Australian Society for Microbiology National Conference in late September 1998 suggested that the virus can remain infectious in a bloody syringe for up to three weeks (Ferrari, 1998).

The virus was originally identified by Chiron Corporation, a Californian based company.

- **The Chiron Patent**

Having discovered the Hepatitis C virus, Chiron Corporation took out a patent on the virus effectively giving the company a monopoly on research use of the virus. The

Australian Patents Office has granted Chiron Corporation a patent which relates to, amongst other things, the identification of the causative agent of the virus.

The use and treatment of living matter in patentable form is not new. It is often the basis for genetic engineering of food plants and animals. However, in this case, the Committee understands some Australian medical researchers were “incensed” over the government’s decision to grant the patent (Mackenzie, 1994:9). The researchers believe such a patent makes HCV diagnostic tests more expensive and inhibits further research into vaccine and treatment development (Mackenzie, 1994:8). When the Committee questioned Professor Farrell on the impact the patent would have on Australian research he informed Members that:

> *it does place some impediments on research which could lead to a commercial outcome, particularly in the area of vaccines . . . and that has certainly been a concern to Australians because we have some really expert virologists in this country who would have been very interested* (Farrell evidence, 28 November 1997).

A representative from the Hepatitis C Council added that:

> *it has not been brought to our attention that there is a massive problem. Morally our belief is that it is a problem, but we have not come across practical difficulties which have prevented research* (Loveday evidence, 30 March 1998).

Court actions in the USA and the UK have involved litigation aimed at testing the legitimate extent of the Chiron patent. British courts ruled that the patent’s claims regarding vaccines and cell cultures were not valid due to insufficient legal justification. The British courts found, however, that the patent was valid in regard to the diagnostic kits. Australian courts are still undecided on the validity of the patent. The Committee understands that a case is currently before the Federal Court in which Chiron is claiming that Murex Diagnostic (a diagnostic testing company) has infringed its patent (Mackenzie, 1994:9).

2.1.2 TRANSMISSION OF THE HEPATITIS C VIRUS

Hepatitis C transmission is predominantly parenteral. The primary modes of transmission for this blood borne virus include shared drug injecting equipment, infected blood products (prior to the screening of blood products in February 1990), unsterile skin penetration practices such as tattooing, ear/skin piercing and acupuncture, needlestick and “sharps” injuries and shared personal items that may contain blood such as toothbrushes and razors. Patient-to-patient (via contaminated anaesthetic circuitry) and surgeon-to-patient transmission (via percutaneous injury) have been demonstrated. Sexual transmission without blood contact appears rare but the risk of blood exposure may be increased by sexual contact during menstruation and anal intercourse. Vertical transmission (mother-to-child) also appears to be rare. Each of these forms of transmission are discussed in further detail in Chapter Three. Arthropod vectors have not been identified (Sladden *et al*, 1997:290).

MacDonald, Crofts and Kaldor (1996:137) note that blood contact does not fully explain HCV transmission. They observe that there has been less certainty about the role of other routes of transmission and factors that modify the efficiency of transmission (MacDonald, Crofts, Kaldor, 1996:137).

Sladden and colleagues have conducted a population based, cross-sectional survey of notified HCV cases to determine the routes of Hepatitis C virus transmission (Sladden *et al*, 1997). The results of their survey, reproduced in Table One, show the routes of Hepatitis C transmission exposure. Non-parenteral transmission appeared to be minimal.

TABLE ONE
POTENTIAL HEPATITIS C TRANSMISSION EXPOSURE

	Number	Likely Primary Exposure	IDUs: Sharer	IDUs: Non-Sharer	Pre-'90 Transfusion	Dialysis	Needle Stick	Tattoos	Blood Splash	Post '90 Transfusion	Ear/Skin Piercing	Clinical Procedure
IDUs: **Sharer** **Non Sharer**	398 354 44	298 354 44										
Pre '90 Transfusion	70	30	30	10								
Dialysis	5	2	2	0	1							
Needlestick	67	6	51	8	9	0						
Tattoo	176	4	143	24	25	2	32					
Blood Splash	60	4	40	9	11	0	21	29				
O/S	13	3	8	0	4	0	2	4	0			
Post '89 Transfusion	14	2	10	0	0	1	3	5	2	0		
Ear/Skin Piercing	354	13	285	29	47	2	52	155	46	10	13	
Clinical Procedures	340	4	251	33	57	2	52	124	45	9	96	256
All Blood Exposures	1497	466										

Source: Sladden, Hickey, Dunn and Beard, 1997:291

The study identified injecting drug use as the mode of transmission for 85% of infections occurring in the Northern Rivers region. The second highest source of infection was blood transfusions prior to 1990. Sladden anticipates that the proportion of infections due to injecting drug use will increase now that the blood is screened for the Hepatitis C virus (Sladden evidence, 30 March 1998).

2.1.3 NATURAL HISTORY OF HEPATITIS C

The natural history of a disease refers to the way it evolves in individual persons and the way it affects their lives. An understanding of the disease's natural history is, therefore important. However, as Seeff has observed, the natural history of chronic Hepatitis C infection has not yet been fully defined (Seeff, 1997:26S). This could be because, as Hoffnagle notes, there is no single typical course or natural history of this specific disease, but rather a broad clinical spectrum of disease presentations and outcomes (Hoffnagle, 1997:15S).

The disease has been described as a "quiet" infection (Anlezark *et al*, 1997:81); a "silent" disease (Farrell evidence, 28 November 1997) which may have "a mixed picture from passivity to overt active behaviour" (Anlezark *et al*, 1997:81). As many as two-thirds of people with Hepatitis C do not know they have the infection even at fairly advanced stages of liver damage (Farrell evidence, 28 November 1997). The disease may manifest itself in either an acute or chronic form.

- **Acute Hepatitis C**

This form of the disease is commonly an asymptomatic and mild illness. Of 100 people exposed to the virus approximately 20 will clear it themselves within four to six weeks of infection. However, of this 100 approximately 80 - 85 will develop chronic Hepatitis C which for many will have long term health consequences.

- **Chronic Hepatitis C**

Chronic Hepatitis C is determined by persistently abnormal serum enzymes and/or viraemia (as measured by HCV RNA reactivity). Like the acute form of the illness, chronic Hepatitis C is also predominantly asymptomatic.

Once chronicity ensues, it is believed that the disease may range through incrementally advancing stages of histologically defined chronic hepatitis, progress to cirrhosis and other extrahepatic manifestations and culminate in the development of hepatocellular carcinoma (HCC) (Seeff, 1997:21S). Some authorities believe that these sequentially progressive changes are inevitable and will occur in most chronically infected persons provided they do not die first from another lethal illness. Others believe that only a proportion of infected persons will develop progressive disease. Attention should therefore focus on establishing as early as possible who is likely to show advancing disease and on attempting to define factors that might be responsible for such progression (Seeff, 1997:21S).

The Committee understands experts in Australia to support the theory that only a proportion of those infected will develop progressive disease. Educational material produced by the Hepatitis C Council, for example, suggests that out of 80 people with chronic Hepatitis C:

- approximately 20 people will not develop symptoms and will remain well;

- approximately 40 people may develop some liver damage and will eventually experience symptoms;

- over 20 years, approximately 20 people will develop cirrhosis. After a further 5-10 years, ten of these people will develop liver cancer or liver failure which may result in a liver transplant (Hepatitis C Council of NSW, 1996).

A number of factors have been identified as possibly promoting progression of HCV-related chronic liver disease. These factors may be viral related, host related or extraneous to either virus or host. They are recorded in Table Two.

TABLE TWO
POSSIBLE FACTORS IN PROMOTING PROGRESSION OF HCV-RELATED CHRONIC LIVER DISEASE

CATEGORY	FACTORS
Virus-Related	Viral Dose Viral Genotype Quasispecies
Host-Related	Age Sex Race
Extraneous	Geography Smoking Environmental Chronic Alcoholism Viral Co-Infection

Source: Seeff, 1997:25S

2.1.4 CLINICAL FEATURES OF THE DISEASE

Common features of chronic Hepatitis C tend to be nonspecific, mild and intermittent. The most frequent symptom is fatigue, variably described as lethargy, malaise, lack of energy or stamina and easy fatiguability (Hoofnagel, 1997:17S). In the study by Sladden *et al* 36% of respondents reported fatigue (1998:509). Wodak and Crofts have described the fatigue experienced as "distressingly common and often precludes employment or home duties" (Wodak and Crofts, 1996:181). One HCV positive person who wrote to the Committee described it as:

> *I always want to sleep. By midday I'm back in bed. I sleep two hours get up for two hours then I'm tired again* (Submission 7),

while another told the Committee in evidence that:

> *fatigue is a terrible thing. I get up, I walk about for a while extremely dizzy and tired. I go back to bed and I try to do something else. I am just not functioning well at all* (Smart evidence, 26 February 1998).

Wodak informed the Committee that perhaps 40% of people with chronic Hepatitis C develop severe fatigue "at some stage in their lives . . . which is a very troublesome fatigue" (Wodak evidence, 2 October 1997). As he elaborated:

> *it means that people are unable to stay at work, they are unable to look after the kids at home or cook meals and so forth. This troubles a lot of people. It is difficult for the medical profession to deal with because it is hard to disentangle who is well, who is malingering, perhaps for social security reasons, and who is fatigued because they are depressed about their illness and who is fatigued because of the illness in the first place. This is going to be a problem that we are going to have to get better at grappling with* (Wodak evidence, 2 October 1997).

Other less frequent symptoms include nausea, poor appetite, muscle aches, arthralgias, feverishness, weakness, and weight loss (Hoofnagle, 1997:17S). Symptoms experienced by participants in the study by Sladden et al include nausea (21%), abdominal pain (21%), loss of appetite (13%), vomiting (6%) and jaundice (3%).

Psychological symptoms may also be experienced. A study on the morbidity of Hepatitis C conducted by Lee *et al* (1997) identified, for example, a high rate of depressive symptoms reported by patients with chronic Hepatitis C. They conclude that

> *fatigue and depression are commonly observed in chronic Hepatitis C and are likely to be codependent variables . . . Appreciation that many patients suffer from depression is particularly relevant because of the low rate of response to interferon therapy and the capability the drug has to induce or worsen depression* (Lee *et al*, 1997:191).

The consequences of these complications are discussed in further detail in Section 4.1 which looks at the impact of Hepatitis C.

2.1.5 GENOTYPES OF THE HEPATITIS C VIRUS

Genotype refers to the genetic constitution of an organism as opposed to the external appearance (or phenotype) of the organism or, the type species of a genus. The NHMRC considers there to be at least six and probably more than nine genotypes of Hepatitis C based on partial or complete genomic sequencing (NHMRC, 1997:1). Rawlinson suggested to the Committee that there are six major genotypes, "many" subtypes, and at least four other types (7 - 11) which may be different to genotypes 1-6 or may be sub-types of genotypes 1-6 (Rawlinson submission).

Each particular genotype of Hepatitis C has the potential to form quasispecies which are variant genomes of the same genotype, arising within a single patient, derived from the original infecting virus. Quasispecies diversity may increase with time and may contribute to interferon resistance (Sherman, 1996:9).

Research is beginning to identify specific characteristics of the various genotypes. For example, the major genotypes show distinct geographic clustering. Farrell informed the Committee that genotype distribution of the virus correlates "very closely with the ethnic background of the patient" (Farrell evidence, 28 November 1997).

HCV types 1 and 2 and their subtypes are distributed virtually worldwide including Europe, North America, Japan and Australasia. HCV type 3 has been reported in Europe, the United States, Thailand, India and Australia, but not Japan (MacDonald *et al*, 1996:138). HCV type 4 appears to be a Pan-African type (the principal genotype in Zaire and Egypt for example [Purcell, 1997:12S]) and type 5 has been found to be the principal genotype in South Africa (MacDonald *et al*, 1997 and Purcell, 1997:12S). Genotype 6 and its many variants have been found principally in Asia (Purcell, 1997:12S), though MacDonald *et al* narrow this to Hong Kong only (MacDonald *et al*, 1996:138).

Studies of HCV genotype distribution in Australia show genotypes 1 (both a and b) and 3 to be predominant (one study, for example, reported 49.5% type 1 and 35% type 3 [Swanson *et al*, 1997:75]). Given Australia's multicultural population, there are small numbers of genotype 4, mainly from Egypt which is otherwise very rare in Australia (Farrell evidence, 28 November 1997), and genotype 6a and 6c, all from South East Asia (McCaw *et al*, 1997).

Patterns of genotype distribution are also being identified according to the means by which people acquired the infection. Genotype 1b has, for example, been found to be more prevalent in those who acquired Hepatitis C through blood transfusions than injecting drug use (Sherman, 1996:9).

As will be discussed in Chapters Seven and Eight genotype is also considered a predictor of response to interferon therapy. Research to date has established that genotypes 1a (Bell *et al*, 1997:234) and 4 (Farrell evidence, 28 November 1997) respond poorly to interferon therapy, whereas patients with the genotype 3 can expect to have a 40 - 50 per cent cure rate with interferon (Farrell evidence, 28 November 1997). In his submission Farrell notes that:

> *there are certain groups in the community, eg those from particular ethnic backgrounds, who are very likely to have genotypes which respond poorly to interferon treatment. At present such patients are denied knowledge of this and thus they may often embark on treatment with less than a ten per cent chance of success*.

Not surprisingly then, Farrell concludes "if I had Hepatitis C I would certainly want to know my genotype" (Farrell evidence, 28 November 1997). The NHMRC however suggested that:

> *the immunological and pathological implications of HCV genotypic differences are as yet only partly understood [as] are the effects of interferon therapy on infection with different genotypes* (NHMRC, 1997:1)

2.1.6 OTHER FORMS OF HEPATITIS

As the Committee heard, there is "an alphabet" of hepatitis now from A to G (Dwyer evidence, 10 October 1997). Table Three compares and contrasts hepatitis A through to E and the features of these various viruses such as modes of transmission, 'at risk' groups, symptoms and treatment.

	Hep A	**Hep B**	**Hep C**	**Hep D**	**Hep E**
What is it?	A virus that causes inflammation of the liver. Does not lead to chronic disease	A virus that causes inflammation of the liver. Can cause liver cell damage, leading to cirrhosis & cancer of the liver	A virus that causes inflammation of the liver. Can lead to cirrhosis and cancer of the liver	A virus that causes inflammation of the liver. Only infects those with HBV	A virus that causes inflammation of the liver. There is no chronic state.
Incubation period	15-50 days (30 day average)	4-26 weeks (8-12 weeks average)	2-26 weeks (7-9 weeks average)	4-26 weeks	2-9 weeks (40 days average)
How is it spread?	Faecal/oral routs through close person/person contact or ingestion of contaminated food or water	Contact with infected blood, seminal fluid, vaginal secretions. Sex contact, contaminated needles, tattoo/body piercing and other sharps instruments. Infected mother to newborn. Human bite	Contact with infected blood, contaminated needles, razors, tattoo/body piercing and other sharp instruments. Infected mother to new born.	Contact with infected blood and contaminated needles. Sexual contact with HDV infected person	Transmitted through oral/faecal route. Outbreaks associated with contaminated water supply
Symptoms	May have no symptoms. Adults may have light stools, dark urine, fatigue, fever and jaundice	May have no symptoms. Some people may have mild flu-like symptoms, dark urine, light stools, jaundice, fatigue and fever	Same as HBV	Same as HBV	Same as HBV
Treatment of Chronic Disease	Not applicable	Interferon is effective in up to 50% of those treated	Interferon is effective in 10-20% of those treated	Interferon with varying success	Not applicable
Vaccine	Two doses of vaccine to anyone over the age of 2 years	Three doses may be given to persons of any age	None available	None available	None available
Who is at risk?	Household or sexual contact with infected person or living in an area with HAV outbreak. Travellers to developing countries; homosexual men and IV drug users	Infant born to infected mother; those engaging in sexual activity with infected person or multiple partners; injecting drug users; emergency responders and health care workers; homosexual men and haemodialysis patients	Injecting drug users; blood transfusion recipients prior to 1990; health care workers; infants born to infected mothers; patients on haemodialysis.	Injecting drug users; homosexual men and those engaging in sexual activity with an HDV infected person	Travellers to developing countries
Prevention	Immune globulin or vaccination. Personal hygiene.	Vaccination and safe sex. Clean up blood spills; Do not share razors or toothbrushes	Clean up blood spills. Universal precautions. Wear gloves when touching blood. Do not share injecting equipment, razors or toothbrushes	Hep B vaccine to prevent HBV infection. Safe sex	Avoid drinking or using potentially contaminated water

Source: Hepatitis Foundation International website

2.1.7 HIV AND HCV: CONTRASTING EPIDEMICS

The causative link between HIV and AIDS was discovered in 1983, some five years before the discovery of HCV. The two diseases have many parallels and present similar challenge, but also differ in important ways. As Wodak suggested to the Committee in his submission it is "instructive" to compare Hepatitis C and HIV (Wodak submission).

Leeder succinctly identified the common features of these two diseases: both are infectious blood borne diseases; both went unrecognised for a period; both preferentially affect socially marginalised groups; the realisation of how they may impact upon society came slowly; both have been subject to much misinformation and "scaremongering"; both were spread through our collective blood supply and both have "demanded significant changes in social policy" (Leeder, 1997:15). Leeder cautions though that the similarities between diseases can be "beguiling" and "all too easily obscure the major differences" (Leeder, 1997:15). He considers it:

> *time to develop an awareness of Hepatitis C which recognises its uniqueness rather than seeing it as a shadow of AIDS. . . From the perspective of public health, Hepatitis C is a different beast to AIDS and we can't depend on identical strategies to defend it* (Leeder, 1997:15).

Mr Jack Wallace, Executive Officer of the Australian Hepatitis Council, on the other hand, has contrasted the two diseases in the following way:

> *Hepatitis C is not related to HIV, with the exception that they are both blood borne viruses and are transmitted through the sharing of injecting equipment. Hepatitis C generally affects people who inject or who have injected drugs, whose social environment and cohesion are completely different from gay men; Hepatitis C has not received the level or concentration of funding particularly for treatments and research that has been provided to HIV; the treatments and information for people infected with Hepatitis C are vastly different than for people with HIV. In short, the epidemiology, virology, short and long term physical effects, treatments, social environments and consequences of the diseases are different* (Wallace correspondence, 2 September 1998).

- **Modes of Transmission**

As has been discussed, the major mode of transmission of HCV in Australia is blood-to-blood contact, in particular sharing injecting equipment and paraphernalia. Unlike HIV, sexual transmission appears to be very uncommon (as will be discussed in Section 3.8.1) occurring only in conditions of viraemia.

By contrast, Australian HIV transmission occurs principally within the gay community with over 80% of new cases occurring among homosexually active men. The prevalence of HIV among injecting drug users is approximately 2% (Cregan, 1998:5).

The Committee understands Hepatitis C to be a more infectious virus (for blood-to-blood spread) than HIV by a factor of ten (Wodak evidence, 2 October 1997). Both Wodak and Kaldor informed the Committee that the risk of infection following an occupational needle stick injury for a health worker is 0.3% for HIV, 3% for Hepatitis C and 30% for Hepatitis B (depending on the immune response of the infected person) (Wodak submission, Kaldor evidence, 3 October 1997).

- **Natural History**

The natural history of HCV infection is less well defined than that of HIV. HCV seems to be a more slowly progressive disease than HIV with an estimate of 20-30% of people with chronic infection developing advanced liver disease within 20-25 years, and liver cancer developing in a small proportion of these people in the subsequent 5-10 years (Dore and Kaldor, 1996:32). Already chronic HCV is the most common underlying cause of liver disease in Australia for people needing liver transplants (Dore and Kaldor, 1996:32). Even if only one in ten people infected with HCV develop advanced liver disease, the cumulative number of cases will be several times higher than the cumulative number of AIDS cases in Australia.

Wodak informed the Committee that people with HIV get sick in a higher percentage of cases much more quickly than with Hepatitis C. Roughly 50% of people go from HIV to AIDS in about 12 years whereas only 20% of cases of Hepatitis C go on to develop cirrhosis within a 20 year period (Wodak evidence, 2 October 1997). However, as Wodak added:

> *if we multiply the far larger pool size by the small proportion that are getting sick, we nevertheless come to estimates of the number of people who are going to develop life-threatening complications of Hepatitis C which suggest that it is a problem of enormous public health magnitude* (Wodak evidence, 2 October 1997).

- **Population Groups**

Those most at risk of either HIV or HCV are young adults within two groups - homosexually active men and injecting drug users respectively. Both groups are often perceived to be outside mainstream Australian society yet the social positioning of these populations is different. By the early ‘80s the gay community movement had organisational structures and communication mechanisms in place that could (and did) take up the challenges that the HIV epidemic presented.

In contrast to the gay community, injecting drug users have not developed as a distinct community. In its submission to this inquiry, the National Centre for HIV Social Research noted this distinction:

> *the affected communities are very dissimilar. . . The gay community is relatively cohesive in comparison with those at major risk from HCV. Injecting drug users are more widely diffused, geographically and socially, and have so far been far less ready than gay men to form a coherent community* (National Centre for HIV Social Research submission).

In addition, many injecting drug users have also spent time in prison which could have contributed to the spread of HCV due to the difficulty in obtaining clean injecting equipment.

- **Incidence and Prevalence Rates**

As has been discussed, it is estimated that up to 150,000-200,000 Australians have Hepatitis C with the current rate of infection in the range of 8,000 - 10,000 new cases per year; about 10 to 20 times the respective estimates for the HIV epidemic (Dore and Kaldor, 1996:30). Wodak noted in his submission that

> *There are approximately ten times as many old (prevalent) and ten times as many new (incident) cases of Hepatitis C in Australia than HIV. However, a very high proportion of individuals with HIV infection develop life threatening complications after ten or twelve years . . . A smaller proportion of a far larger sized pool develop severe complications of Hepatitis C* (Wodak submission).

By the time the Hepatitis C epidemic was identified the baseline prevalence rate was 80% compared with a baseline prevalence for HIV of only 0.5% (Wodak evidence, 2 October 1997):

> *We went into this [HIV] epidemic with very low rates of HIV infection among our injecting drug users in this country. In other countries it was different. In the United States, for example, in some parts such as New York City, when we first became aware of AIDS . . . 50% of their drug injectors were already infected. It has taken them a long time to pare that back; in fact, they are still struggling. In this country HIV entered the drug injecting population much later. By then we already had tests available and baseline levels were very low* (Wodak evidence, 2 October 1997).

It is generally acknowledged that widespread access to clean injecting equipment introduced in the late ‘80s allowed Australia to keep HIV prevalence among injecting drug users to 1-2% (one of the lowest in the world). As long as the extent of HIV infection in this population has remained low, occasional needle sharing among users has not led to significant spread of HIV. This is attributed to the 1:50 to 1:100 chance of being exposed to an injecting drug user with HIV. This ratio increases to 1:2 with respect to HCV.

- **Community (and political) Response**

Australia's response to the HIV epidemic has been described as "prompt, innovative and courageous" (Wodak evidence, 2 October 1997). Wodak attributes that to the multi-party political support:

> *I cannot help but contrast the national and international reaction to Hepatitis C with the . . . reaction to HIV. In this country, we are very aware of the benefits of that tremendous response. Whenever I talk in public about Australia's reaction to HIV I always emphasis that one of the reasons why Australia is now in the fortunate position to have controlled that epidemic is really because in the early years of the epidemic Australia managed to have a bipartisan approach or a multi-party approach* (Wodak evidence, 2 October 1997).

Wodak elaborated further:

> *It was an approach in which the state and commonwealth boundaries, for once, did not trip us up and those complexities were contained. I cannot emphasise enough the importance of that . . . I do not think we will be able to develop a response commensurate with the magnitude of this epidemic unless we follow the same principles of developing and strengthening the multi-party political approach and also work out a way for the Commonwealth and the states to work together rather than in competition* (Wodak evidence, 2 October 1997).

Kaldor also compares the response to HIV to that of HCV from the perspective of planning at the national level and research. He noted that:

> *With HIV we still have a national strategy which has allocated to it a clear and significant component of research funding that is tied into the strategic objectives of the national strategy. With Hepatitis C we do not really have a national strategy. Hepatitis C has been attached to the National HIV Strategy under the framework of related diseases and it is still being discussed* (Kaldor evidence, 3 October 1997).

He went on further to comment that:

> *At this stage it is not quite clear what HIV strategic moneys are allowed to be allocated for Hepatitis C. That argument is unfortunate because it*

> *leads to what might be called 'turf battles' between different diseases. That is unfortunate when all that is required is a consolidated effort to address these very important health problems* (Kaldor evidence, 3 October 1997).

- **Conclusion**

In their comparison of the HIV and HCV epidemics, Dore and Kaldor summarise the two diseases in tabular form which has been reproduced in Table Four.

TABLE FOUR
SUMMARY OF HIV AND HCV

	HIV	HCV
Start of epidemic	early 1980s	early 1970s
Peak of new infections	1984-1985	unknown
Estimated cumulative infections	15,000-20,000	150,000 - 200,000
Prevalence infection	0.1%	1.0%
Male:female ratio	17.0:1.0	1.7:1.0
Estimated new infections/year	500	8,000 - 10,000
Cumulative attributable deaths	5000	unknown

Source: Dore and Kaldor, 1996:30

2.2 EPIDEMIOLOGY

In many respects, Hepatitis C is still a relatively new disease. This is reflected in a number of ways including the limited availability of accurate prevalence and incidence estimates on the number of people with the virus. Wodak, for example informed Members that estimates of the numbers of HCV+ people are still "fairly inexact" and that there is "still some imprecision" about the exact prevalence and incidence figures (Wodak evidence, 2 October 1997).

ANCARD's submission to review of the Highly Specialised Drugs Program considered surveillance of HCV infections in Australia to be by no means as advanced as that of HIV and in need of "greater attention". As the submission noted, "in estimates of incidence and prevalence, only a very broad-brush approach is possible" (ANCARD submission to the review of the Highly Specialised Drugs Program, attachment to their submission to this Inquiry).

In its submission to the Inquiry, NSW Health cited six reasons for the lack of accurate prevalence and incidence data. These reasons included:

1. no population prevalence surveys have been done;

2. only a minority of people become ill when they first acquire the virus so infection often goes unnoticed, untested and unnotified;

3. available antibody tests cannot discriminate between a person with a new infection and one with a longstanding disease;

4. many people are ignorant of being infected due to the long latent period before symptoms commence;

5. available incidence estimates come from surveys of high risk populations who have been serially tested (eg prisoners and clients of agencies such as the Kirketon Road Centre which targets Kings Cross sex workers and at-risk youth); and

6. blood donor data probably underestimates population prevalence because the risk behaviour declaration screens out those most likely to be infected (NSW Health submission).

In addition, routine diagnostic antibody tests for Hepatitis C have only been available since 1990. Successive generations of tests have resulted in improved sensitivity and specificity with the result that comparisons of prevalence estimates over time have to be made cautiously. In addition, not only do antibody tests not discriminate between new infections and long standing ones as NSW Health suggested in Point 3 above, but the tests do not provide information on infectiousness or viral load.

During the last few months of this Inquiry the Hepatitis C Virus Projections Working Party released its report, *Estimates and Projections of the Hepatitis C Virus Epidemic in Australia* (1998). The Hepatitis C Virus Projections Working Group was formed under the auspices of, and reports to, the Australian National Council on AIDS and Related Diseases (ANCARD) Hepatitis C Sub-committee. Membership of the Working Group included clinicians, epidemiologists, statisticians, mathematical modellers, health economists and representatives from the Commonwealth, State and Territory Health Departments and the Australian Hepatitis Council. The objectives of the Working Group were:

- to provide consensus estimates of HCV incidence and prevalence in Australia;

- to obtain projections of the long-term sequelae of HCV infection;

- to identify gaps in research and surveillance relevant to these projections;

- to recommend a mechanism for updating and improving estimates over time; and
- to recommend mechanisms for monitoring the incidence and prevalence of complications of chronic HCV infections (such as cirrhosis, hepatocellular carcinoma, death) (HCV Projections Working Group, 1998:2).

The estimates and projections proposed by the Working Group are included in the following discussion.

2.2.1 PREVALENCE OF HEPATITIS C

Prevalence refers to the total number of people in a population who have the disease at a given point in time, or as Kaldor informed Committee Members, it is the “pool of infection that already exists” (Kaldor evidence, 3 October 1997). Prevalence depends on two factors: the incidence and the duration of the disease.

Direct estimates of HCV prevalence for the Australian population as a whole are difficult to calculate because studies of HCV prevalence have been conducted in specific populations (such as injecting drug users or prisoners), none of which may be considered to be representative (Hepatitis C Virus Projections Working Group, 1998:5).

An estimated 1-2% of the world population is chronically infected with HCV (Schering-Plough submission).

- **Prevalence of Hepatitis C in Australia**

There appears to be general consensus that the prevalence of the disease is, as of 30 June 1996, 150,000 - 200,000. These figures were given in evidence by Professor Batey (evidence, 27 October 1997), and in submissions made by Professor Wodak and organisations such as the Hepatitis C Council, and NUAA. Prevalence has also been cited as being between 0.5-1.0% of the total Australian population which equates to one in every 100 Australians carrying the virus (Hepatitis C Council of NSW, 1996:5).

The Hepatitis C Virus Projections Working Group estimated the prevalence of Hepatitis C in 1995 to be 170,000 - 195,000 with a lower limit of 130,000 and an upper limit of 230,000 (1998:6). Using modelled patterns, the Group’s preferred estimate of the number of prevalent infections at the end of 1997 was 196,000 (with a lower limit of 149,000 and an upper limit of 234,000) (1998:8).

However, despite this apparent agreement on the disease’s prevalence, it is generally recognised that accurate statistics are not available. Professor Farrell, for example, has observed that:

> *We do not even have accurate statistics on the real prevalence of Hepatitis C in the general Australian community . . . No studies have been done into the prevalence of the virus in the wider community. The current estimate of 0.5 - 1.0% is probably an underestimate as it is based on the results of routine blood donors. Community prevalence studies in France and the USA have found infection rates two to five times higher than this* (Farrell, 1997).

Similarly, Dr Kaldor acknowledges that:

> *there has been virtually no prevalence survey done of a group that might be considered representative of the wider population. The only group that has been regularly surveyed is blood donors and they are by no means representative because a wide range of factors have to be excluded for one to be a blood donor. The prevalence among regular blood donors is now around one in 1,000 so it is well down below these levels . . . So we have no really good idea about the different demographic clustering or patterns of Hepatitis C* (Kaldor evidence, 3 October 1997).

Clearly there is a need for monitoring of the prevalence of Hepatitis C on an ongoing basis to, as it were, keep a finger on the pulse of the epidemic. While the Hepatitis C Virus Projections Working Group's study is an initial attempt to get a consensus on the magnitude of the Hepatitis C epidemic, it is not the definitive study. The Committee therefore firmly believes further prevalence studies are required at both the national and state level.

RECOMMENDATION 1:

That the Minister for Health urge his Federal counterpart to commission population **prevalence** studies of Hepatitis C at the national level to determine the prevalence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

The prevalence of Hepatitis C has been estimated among various specific population groups in Australia including injecting drug users, prisoners and recipients of blood. These studies will be reviewed in Sections 3.1, 3.2 and 3.3 respectively.

Despite the lack of prevalence surveys, certain characteristics are becoming evident. It was suggested to the Committee that the prevalence of Hepatitis C is, for example, specific in terms of age and ethnicity. Farrell, for example, identified Hepatitis C as being common in Arabic, Italian, and South-east Asian communities (Farrell evidence, 28 November 1997). In giving evidence to the Committee he cited research from Italy suggesting that the prevalence of Hepatitis C amongst younger people (30 years and below) is between 1 - 1.4 per cent while the prevalence for those aged 40 years and over ranges from 12 - 20 per cent (Farrell evidence, 28 November 1997). He considers Australian prevalence rates amongst Italian communities to reflect a similar trend. He concludes that:

> *something happened 40 or 50 years ago, or longer, that gave those people Hepatitis C and it is almost certainly inappropriate medical behaviours and particularly use of glass syringes and non-disposable needles* (Farrell evidence, 28 November 1997).

In both his submission and during the course of evidence, McCaughan also noted national differences. He observed that the epidemiology of the infection in Australia and the US is "totally different" to the epidemiology in Italy and Japan (McCaughan evidence, 23 March 1998). While many HCV cohorts in Australia are in their early forties (reflecting injecting drug use many years ago) in Italy and Japan the average of the infected cohort is 70 years. As McCaughan observed, that cohort comes from iatrogenic use of glass syringes and non-disposable needles 30 to 40 years ago (McCaughan evidence, 23 March 1998).

Kaldor, in evidence before the Committee, identified certain demographic clusterings of Hepatitis C based on anecdotal observations rather than empirical evidence. He spoke of high representations of people from some Middle Eastern and Vietnamese backgrounds with advanced stages of Hepatitis C as evidenced in those attending liver clinics with severe liver damage (Kaldor evidence, 3 October 1997).

• Prevalence of Hepatitis C in NSW

Given the lack of general population prevalence studies, the Committee did not receive any indication of prevalence estimates for the state. Information provided referred rather to notification rates which are reviewed in Section 2.2.4. The Committee considers it essential that NSW conduct ongoing population prevalence studies of the Hepatitis C epidemic at the state level. Such studies are to be in addition to the national prevalence studies proposed in Recommendation 1. The Committee considers it important that studies be conducted at both the national and state level to provide as accurate and complete a picture of Hepatitis C as is possible. It is not anticipated that the studies will duplicate each other, but rather provide different levels of detail all of which will be necessary to appreciate more fully the scope of the disease.

RECOMMENDATION 2:

That the Minister for Health commission population **prevalence** studies of Hepatitis C at state level to determine the prevalence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

2.2.2 INCIDENCE OF HEPATITIS C

Incidence refers to the number of **new** cases of a disease within a population over a period of time and reflects only the rate of disease occurrence. Incidence is expressed in terms of XX per 100 person years.

While prevalence studies indicate the cumulative impact of a disease, only incidence studies can identify where infection is currently occurring and allow the effectiveness of current prevention strategies to be assessed (van Beek *et al*, 1998). In appearing before the Committee, Kaldor stressed the importance of knowing incidence rates:

> *Incidence is crucial . . . if you are thinking about prevention. If you do not know what is going on with incidence you do not know what is happening about your prevention efforts* (Kaldor evidence, 3 October 1997).

- **Incidence of Hepatitis C in Australia**

Up until the release of the Hepatitis C Virus Projections Working Group's report in August 1998, there was general consensus amongst the research literature, evidence taken and submissions received that the incidence of Hepatitis C in Australia is 8,000 -10,000 new infections per year. It would appear that this estimate was originally proposed by Crofts, Hopper *et al* in a 1993 study drawing upon estimates from preliminary results of their longitudinal study of injecting drug use (the Victorian Injecting Drug Use Cohort Study, VICS).

While the Crofts, Hopper *et al* estimate referred to the incidence of Hepatitis C amongst injecting drug users it does seem to have become a generally recognised "benchmark" statistic and was cited by the NHMRC (1997:2). It was also suggested to the Committee in evidence given by representatives from NSW Health (Wilson evidence, 3 October 1997) and in the submission made by Hepatitis C Council.

The Hepatitis C Virus Projections Working Group estimated HCV incidence in 1997 to be 11,000 with a lower limit of 8,500 and an upper limit of 13,500 (1998:8). These different figures were appropriately described by Dwyer as "rubbery" (Dwyer evidence, 10 October 1997).

Batey, Crofts and Wodak all suggested to the Committee that there are 6,000 - 8,000 new cases per annum (Batey evidence, 27 October 1997; Crofts evidence, 28 November 1997; Wodak evidence, 2 October 1997). In his submission, Wodak explained the difference between the figures 6,000-8,000 and 8,000-10,000:

> *there are probably 8,000 to 10,000 cases of acute Hepatitis C infection each year and about 80% of these go on to develop chronic infection; hence the estimate of 6,000 to 8,000 new cases of chronic infection each* year (Wodak submission).

These current incidence estimates equate to approximately one new case of Hepatitis C in Australia per hour (Wodak evidence, 2 October 1997). Given such a statistic, ANCARD considers there to be "no sign that incidence is slowing" (ANCARD submission to Highly Specialised Drugs Program - attachment to submission). The NHMRC considers trends in Hepatitis C incidence to be "impossible" to discern (1997:2).

As with estimates of prevalence, the Committee considers there to be scope for incidence studies to be conducted at the national level and proposes the Minister for Health approach his federal counterpart urging such studies to be undertaken.

RECOMMENDATION 3:

That the Minister for Health urge his Federal counterpart to commission population **incidence** studies of Hepatitis C at the national level to determine the incidence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

- **Incidence of Hepatitis C in New South Wales**

Evidence presented to the Committee on New South Wales' share of the national rate of Hepatitis C was limited and varied. In evidence before the Committee, NSW Health suggested, for example, that:

> *the NSW share of this [national incidence rate] is a guesstimate but it could be as high as 40 per cent to 50 per cent annually, given the profile of the high-risk groups* (Wilson evidence, 3 October 1997).

Wodak estimated that at least one-third of all national cases reside in New South Wales (Wodak submission).

The only regional incidence estimates presented to the Committee came from the submission from the A.W. Morrow Gastroenterology and Liver Centre, based at Royal

Prince Alfred Hospital. That submission suggested there are at least 250 new HCV infections each year in the Central Sydney Area Health Service.

The fact that no expert could, with any degree of accuracy, inform the Committee of the incidence of this disease in the state is indicative of the limited data available on this disease. Such a situation has major implications for planning and funding of health and community services and, as Kaldor has identified, assessment of preventative strategies.

RECOMMENDATION 4:

That the Minister for Health commission population **incidence** studies of Hepatitis C at state level to determine the incidence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

2.2.3 ESTIMATES OF THE LONG-TERM SEQUELAE OF HEPATITIS C INFECTION

As was discussed in Section 2.1.3 approximately 80-85% of those who come in contact with the Hepatitis C virus and do not clear it within the first few months go on to develop chronic Hepatitis C which may manifest itself in a number of ways, the most extreme form being hepatocellular cancer and ultimately liver failure. It is therefore important to know not only the incidence and prevalence of HCV infection, but the prevalence and incidence of those people living with the disease.

Kaldor suggested to the Committee that it is important to think not just about the incidence and prevalence of the virus, but the incidence and prevalence of the Hepatitis C illness. As he noted:

> *up to now most of the activity and monitoring has gone to . . . try to see where the virus itself is, but what impacts on people is the illness that is caused by the virus . . . we have not concentrated much effort to really find out what Hepatitis C is doing in the population as far as death rates go* (Kaldor evidence, 3 October 1997).

He went on to tell Members that:

> *when one looks at the pattern of illness, this is where we have limited information . . . As far as I am aware, there has been no comprehensive effort so far to put together a picture of the incidence of Hepatitis C-related cirrhosis and Hepatitis C liver cancer, or indeed, the prevalence or these conditions in people living with Hepatitis C. They are the most severe manifestations and probably the easiest ones to monitor. It is*

> *even harder to monitor the broader symptoms such as fatigue and other less severe symptoms that are associated with the infection. There is still a great deal of work required, similarly with mortality. I do not think anyone has tried to sort through deaths to assess what proportion are really Hepatitis C related to come up with an estimate of what the mortality of this condition is in Australia* (Kaldor evidence, 3 October 1997).

Since Kaldor appeared before the Committee the Hepatitis C Virus Projections Working Group has released its report. The estimates and projections contained in this report go some way to addressing Kaldor's concerns regarding the incidence and prevalence of, for example, Hepatitis C related cirrhosis, liver cancer and deaths.

Building upon the prevalence figures for the Hepatitis C virus discussed in Section 2.2.2, the Working Party has calculated that, based on direct estimates of the prevalence of HCV antibody, there were probably 130,000 to 145,000 people living with chronic HCV in 1995 (lower limit 100,000; upper limit, 175,000) (Hepatitis C Virus Projections Working Group, 1998:9). Based on modelled estimates, the Group estimated that there were 147,000 people living with chronic HCV in 1997 (lower limit of 112,000; upper limit of 176,000) (Hepatitis C Virus Projections Working Group, 1998:9).

Taken together, the Working Group concludes that these estimates and projections suggest that in Australia in 1997 there were around 190,000 people living with antibody to HCV (140,000 to 240,000). Of these people it was estimated that:

- 47,000 (35,000 to 60,000) had cleared their HCV infection;
- 134,000 (101,000 to 176,000) were living with chronic HCV infection and therefore at risk of developing cirrhosis;
- 8,500 (4,000 to 13,000) were living with HCV-related cirrhosis, the majority probably asymptomatic and undiagnosed;
- 80 (40 to 130) people developed HCV-related hepatocellular carcinoma (HCC) during 1997; and
- to the end of 1997, 3,000 (1,450 to 4,550) had died prematurely as a result of their HCV infection (Hepatitis C Virus Projections Working Group, 1998:10).

The Working Group also made projections for estimated incidence of both cirrhosis and hepatocellular carcinoma due to HCV infection through to 2010. These data are presented in Figures One and Two below.

FIGURE ONE

ESTIMATED NUMBER OF PEOPLE LIVING WITH CIRRHOSIS DUE TO HCV INFECTION 1980 TO 2010

FIGURE TWO
ESTIMATED INCIDENCE OF HEPATOCELLULAR CARCINOMA DUE TO HCV INFECTION 1980 TO 2010

Brown and Crofts recognised the need for prospective data on the prevalence and incidence of HCV-related sequelae (Brown and Crofts, 1998:388). Until such data are available, they argue, a full appreciation of the impact Hepatitis C will have upon the community as a whole and specifically the economic impact of Hepatitis C cannot be made.

Fully aware of the limited data available on the incidence and prevalence of Hepatitis C related diseases (such as cirrhosis and HCC) and deaths, the ANCARD Hepatitis C Sub-committee has identified clinical based morbidity registers and studies and monitoring of hepatocellular carcinoma incidence and associations as research priorities (Hepatitis C Virus Projections Working Group, 1998:32). The Committee appreciates the value to be gained from introducing such measures and therefore fully supports these priorities. Such measures go some way to addressing the current shortfalls in data identified by Brown and Crofts.

RECOMMENDATION 5:

That the Minister for Health urge his federal counterpart to establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma at the national level.

RECOMMENDATION 6:

That NSW Health establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma in New South Wales.

RECOMMENDATION 7:

That at the next Australian Health Ministers' Council the Minister for Health urge his federal, state and territory counterparts to establish clinical based morbidity registers to monitor Hepatitis C deaths.

RECOMMENDATION 8:

That NSW Health establish a clinically based morbidity register to monitor Hepatitis C related deaths in New South Wales.

2.2.4 NOTIFICATION OF HEPATITIS C

In addition to the limited prevalence and incidence data that are available, Departments of Health at both the state/territory and federal levels collect data on the numbers of Hepatitis C cases reported. The Committee is reporting these data separate to incidence and prevalence data as it believes notification data are not, as yet, a complete and true reflection of Hepatitis C cases, merely the results of those tested.

Hepatitis C became a notifiable disease in all Australian states and territories in 1990. From that time, it rapidly emerged as the most frequently notified infectious disease in the nation.

During the course of giving evidence to the Committee, Kaldor informed Committee Members that a secondary way of assessing incidence is to look at acute infections as recorded in notification data. He noted that, if done systematically, notification data should give a national picture of incidence (Kaldor evidence, 3 October 1997). He identified two problems:

> *It is believed that only about five per cent of people who acquire Hepatitis C get that illness: there is nothing to pick up in 95 per cent of people so*

> *that has to be multiplied by a factor of 20. Even if they do get the illness, it is not necessarily picked up as Hepatitis C by doctors and does not necessarily get reported along the public health reporting chain to health departments* (Kaldor evidence, 3 October 1997).

Kaldor concluded that:

> *it is an ideal system in theory but in practice it does not produce the incidence figures we would like to see for retracking what is going on with incidence at a population level* . . . (Kaldor evidence, 3 October 1997).

In using notification data, Kaldor has further cautioned that:

> *national reporting of Hepatitis C diagnoses provides a somewhat incomplete picture of the occurrence of HCV infection in Australia. Because of variable patterns of testing for HCV antibody, it is not possible to estimate population prevalence of HCV exposure from the diagnosed cases. Similarly, although national case reporting now requires the separate reporting of newly acquired or acute Hepatitis C infections, it is likely that only a small proportion of such cases will actually be recognised and reported. Furthermore, national case reporting has only provided limited details on the modes of HCV transmission in Australia, and no indication at all of the extent of illness and mortality caused by HCV infection* (Kaldor, 1997:47).

Associate Professor McCaughan made similar comments in his submission to the Committee. In it he noted that:

> *unfortunately, current notification data does not allow differentiation between incident or prevalent cases. As this crucial information and other epidemiological information is currently unknown, estimates have to be made to identify the extent of Hepatitis C infection in the community* (McCaughan submission).

The Hepatitis C Council commented that there is “huge room for improvement” in the standardisation of notification data (Loveday evidence, 30 March 1998). As Mr Loveday explained to Members:

> *we had the situation of national reporting being unavoidably confused by the fact that the States and Territories report differently to the Commonwealth Health Department. All States and Territories other than NSW and South Australia report non-specific notifications. These are Hepatitis C diagnoses and the person who has been tested might have contracted Hepatitis C 10 or 25 years ago. Those are called non-specific*

> *notifications or unspecified notifications. South Australia and NSW report only incident cases, which are new cases* (Loveday evidence, 30 March 1998).

As a result of these different reporting practices the total number of known Hepatitis C cases in Australia is "underplayed" (Loveday evidence, 30 March 1998).

The NHMRC notes that, because of chronicity of HCV infection and the asymptomatic nature of most acute infections, the notification system reflects changing trends in testing patterns and distinguishes "poorly" between prevalence and incident cases (NHMRC, 1997:2).

- **Notification of Hepatitis C in Australia**

Each state and territory collects surveillance data on Hepatitis C. These data are collated nationally each fortnight by the National Notifiable Diseases Surveillance System (NNDSS) under the auspices of the Communicable Diseases Network of Australia and New Zealand (CDNANZ) and published in *Communicable Diseases Intelligence* (the notification publication of the Commonwealth Department of Health and Family Services).

Between 1991 and 1997 over 57,000 diagnoses of HCV infection from all states and territories (excluding New South Wales and South Australia) were reported to the NNDSS maintained by the Commonwealth Department of Health and Family Services (Hepatitis C Virus Projections Working Group, 1998:2). A further 46,900 HCV diagnoses were reported in NSW and 7,500 in South Australia making a total of over 110,000 HCV diagnoses in Australia to the end of 1997 (Hepatitis C Virus Projections Working Group, 1998:2). NSW and South Australia are the only two states that base the data they provide to the NNDSS on confirmed recent infections rather than all diagnosed cases (some of which may be infections contracted years ago).

Notification data obtained from the National Centre for Disease Control (a unit of the Commonwealth Department of Health and Family Services) and broken down by state/territory and year has been obtained by the Hepatitis C Council and are reproduced in Table Five. The data are for 1993 to 1996 only and therefore not as complete as the data reported by the Hepatitis C Virus Projections Working Group.

TABLE FIVE
HEPATITIS C NOTIFICATIONS IN AUSTRALIA, 1993-1996

STATE/TERRITORY	1993	1994	1995	1996	TOTAL	TOTAL %
NSW	6,722	9,357	8,393	9,294	33,766	44%
Victoria	2,659	3,523	4,506	4,597	15,285	20%
Queensland	3,049	3,177	2,920	2,884	12,030	16%
South Australia	1,912	2,281	1,215	1,201	6,609	9%
Western Australia	1,176	1,416	1,268	1,230	5,090	7%
ACT	285	428	330	270	1,313	2%
Northern Territory	212	301	309	217	1,039	1%
Tasmania	161	53	268	291	773	1%
TOTAL	16,176	20,536	19,209	19,984	75,905	100%

Source: Hepatitis C Council of NSW, 1997

The Council advised that the following qualifications apply to the data:

- some notifications will represent the second or third time someone has had an HCV antibody test; and

- some notifications may represent false positive test results, although most of these would have occurred prior to 1992 when the HCV antibody tests were less sensitive and specific.

The Council cautions these figures must be considered as approximates, but because the margin of error (estimated to be 5%) applies equally across all states, comparisons can be made.

Given the different reporting mechanisms of New South Wales and South Australia and the remainder of the country, the Committee is not convinced that the quality of available notification data is as high as it could be. The Hepatitis C Council commented on the current situation in its submission:

> *the current situation of inconsistent reporting is highly unsatisfactory. There would be a natural tendency on the part of a reader who is not fully informed of all the facts to take, at face value, total national figures as*

> *reported in national surveillance publications. Figures published in such reports thus exclude the state with the largest number of HCV notifications in Australia. National figures reporting is thus highly misleading* (Hepatitis C Council supplementary submission).

The Committee can see little benefit in the current mechanism and wishes to see it rectified.

The Committee understands that earlier this year NSW Health contacted the National Centre for Disease Control and, in the "interests of national uniformity", requested that data on all NSW Hepatitis C notifications be published in *Communicable Diseases Intelligence* (O'Donoughue correspondence, 2 April 1998). However, as of August 1998 the publication still has NSW and SA unspecified cases as being "not notifiable". The confusion continues despite attempts by NSW Health to rectify the situation.

The 1997 Hepatitis C NHMRC report recognised current problems in the surveillance of Hepatitis C due to, amongst other factors, variance in surveillance methodology between the different jurisdictions. The report called for uniform data collection for Hepatitis C to improve Hepatitis C surveillance and recommended that States and Territories address this issue "as a priority" (NHMRC, 1997:31). The Hepatitis C Council's submission called upon this Committee to make a strong recommendation for consistency in national reporting of notification statistics (Hepatitis C Council supplementary submission).

The Committee fully supports both the NHMRC recommendation and the Hepatitis C Council's request. It therefore wishes to see action be taken at the federal level to ensure all states and territories standardise their reporting of Hepatitis C notifications.

RECOMMENDATION 9:

That the Minister for Health urge his Federal counterpart to institute standardised procedures for the notification of Hepatitis C across all states and territories of Australia.

- **Notification of Hepatitis C in NSW**

As Table Five shows, NSW has almost one-half (44%) of the Hepatitis C cases reported nationally in the period 1993-96. Notification data from 1991 to 1997 are provided in Table Six according to Area Health Services.

TABLE SIX
HCV NOTIFICATIONS ACCORDING TO NSW AREA HEALTH SERVICE

AREA HEALTH SERVICE	HCV NOTIFICATIONS CUMULATIVE TO 1997[1]	
	Number	**% New South Wales**
South Eastern Sydney	8,190	18.0
Western Sydney	4,646	10.2
South West Sydney	5,349	11.7
Central Sydney	6,088	13.4
Northern Sydney	3,416	7.5
Central Coast	1,852	4.1
Hunter	3,044	6.7
Wentworth	1,458	3.2
Illawarra	2,226	4.9
Northern Rivers	3,314	7.3
Mid North Coast	1,410	3.1
Mid Western	1,259	2.8
Southern	1,113	2.4
New England	808	1.8
Greater Murray	963	2.1
Macquarie	328	0.7
Far West	105	0.2
New South Wales	**45,569**	**100.0**

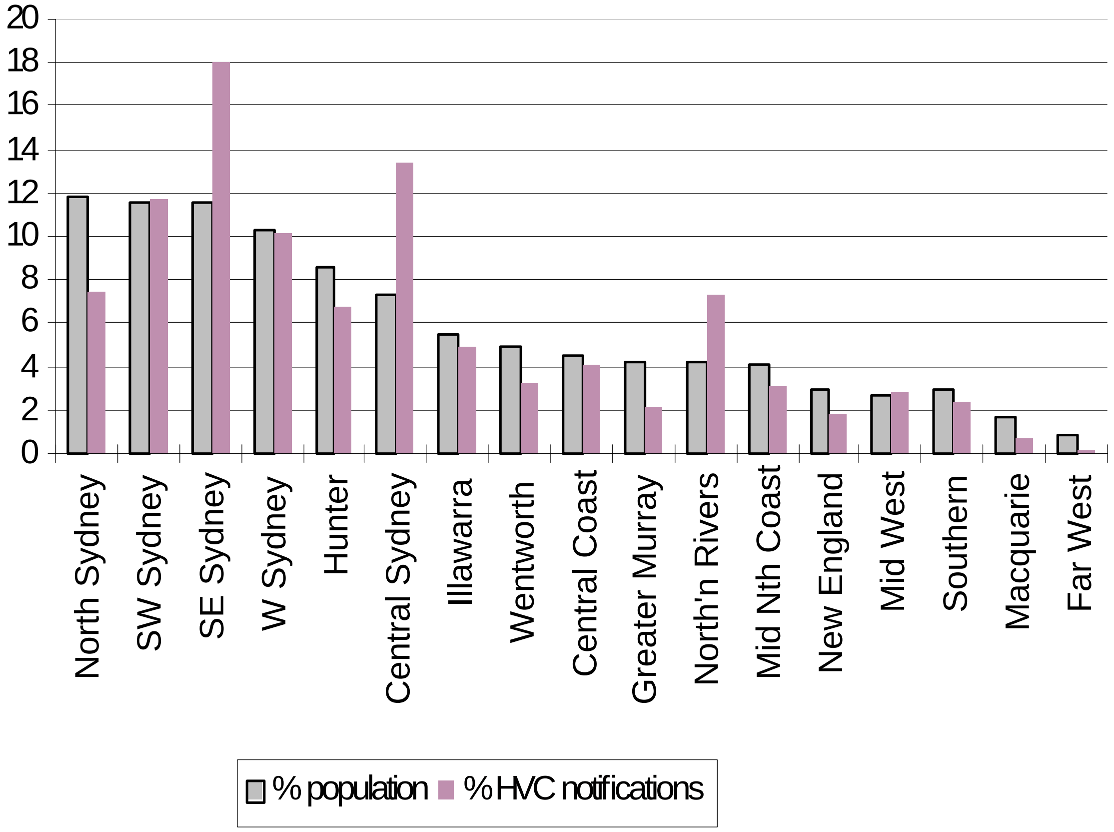
[1] Hepatitis C notifications is the cumulative number of positive Hepatitis C antibody tests notified to the Health Department since testing commenced in 1991

Source: NSW Parliament, 1998

As Table Six shows, the five Area Health Services with the highest notification rates are South Eastern Sydney (18%); Central Sydney (13.4%); South Western Sydney (11.7%); Western Sydney (10.2%); and Northern Sydney (7.5%).

In giving evidence before the Committee, the Hepatitis C Council reformatted the data presented in Table Six to demonstrate notifications as they relate to each Area Health Service's population. These data are reported in Figure Three below.

FIGURE THREE
AREA HEALTH SERVICE POPULATION (%) AND HCV ANTIBODY POSITIVE NOTIFICATIONS (%) 1991 - 1997



The Area Health Services where Hepatitis C notifications outstrip population are South Eastern Sydney, Central Sydney and Northern Rivers. While these data are based on notifications only, these regions clearly have specific service delivery needs that will be discussed later in the report.

In commenting on these data Mr Loveday noted that:

> *you would normally expect Hepatitis C being so widespread throughout the general community that it would be pretty much a 50-50 basis in proportion with the total population, but there are three areas where this is wildly out. The biggest is South Eastern Sydney, which has a much bigger share of notifications, Central Sydney and Northern Rivers and the converse of this is that Northern Sydney, which has a much higher general population as a pro rata basis to the total, has a smaller share. This is the first indication we have seen as a result of these figures . . . that could possibly guide the provision of resource allocation* (Loveday evidence, 30 March 1998).

Studies analysing the notification rates at the regional level are limited. As far as the Committee could ascertain, the only published work that teases out official notification data at the regional level appears to be that done by Sladden (based at the Northern Rivers Institute of Health and Research) and colleagues. Over the past five years, an average of approximately 550 cases have been reported in that region (Sladden evidence, 30 March 1998). Sladden *et al* (1997:290) have calculated the rate of Hepatitis C notification in the north coast to be 201 per 100,000 residents. They note that such a rate is double the state's rate of 103 per 100,000 and nearly three times the Australian average (74/100,000). In evidence Sladden informed the Committee that he has:

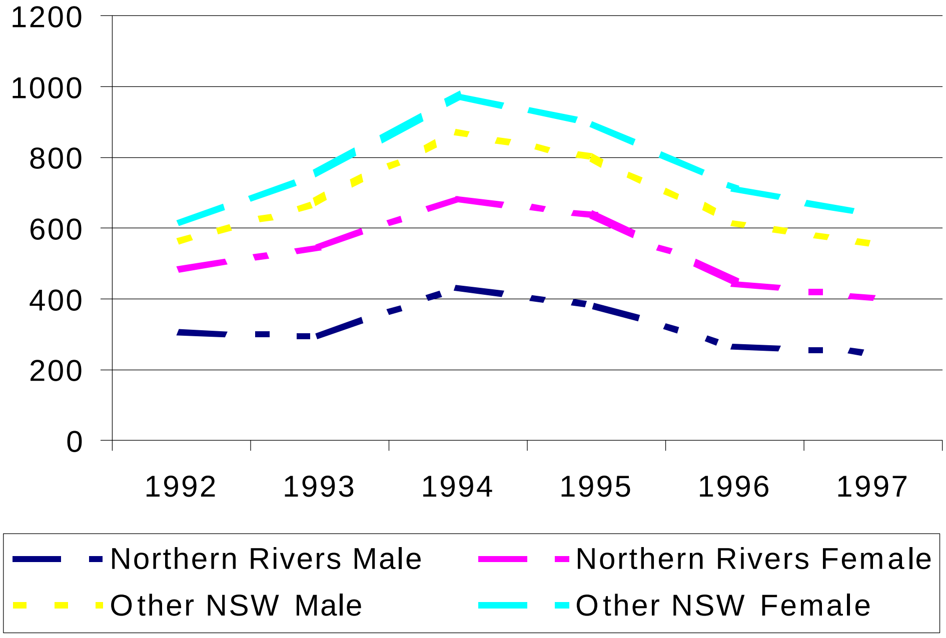
> *estimated that about 0.2 per cent of the population in the Northern Rivers area is infected. That is about one in 500 people, as opposed to about 0.1 per cent in the New South Wales population as a whole. So it is about double the state average* (Sladden evidence, 30 March 1998).

Data provided to the Committee by Sladden demonstrate the notification rates for males and females in the Northern Rivers area as compared to other NSW residents over time (1992-1997). In commenting on the data to the Committee, Sladden noted that:

> *the rates appear to be coming down over the last three years but they remain above the New South Wales average. Now they are about 50 per cent above. We do not have a long enough trend to say whether this is a fluctuation or a continued downward trend* (Sladden evidence, 30 March 1998).

With regard to the 1994 peak, Sladden considers it could be “just a testing artifact” due to a lot of people getting tested that year for the first time (Sladden evidence, 30 March 1998). These data are recorded in Figure Four.

FIGURE FOUR
HEPATITIS C STANDARDISED NOTIFICATION RATES PER 100,000
NORTHER RIVERS AND OTHER NSW RESIDENTS, 1992-1997



Source: tabled material, Sladden evidence, 30 March 1998

Sladden described the Hepatitis C situation in the Northern Rivers region as a “double whammy” in that:

> *a lot of previous injectors have retired and are no longer injecting, but they still have Hepatitis C. We also have a high rate of current injecting drug use, with the second highest provision of needles in any area of the state. So there is a lot of continued drug use and a lot of current infection going on* (Sladden evidence, 30 March 1998).

2.2.5 CONCLUSION

Given available data, what then can be said about the incidence and prevalence of Hepatitis C in Australia? The Committee feels it can say with a certain degree of confidence that:

- in Australia one person each hour of each day contracts the Hepatitis C virus which, in New South Wales equates to one person every three hours (Wodak evidence, 2 October 1997). This adds up to 8,000 - 10,000 new Hepatitis C cases each year. Of this number 6,000 - 8,000 will go on to develop chronic Hepatitis C;

- approximately one in every 100 Australians has the Hepatitis C virus with up to 200,000 cases of Hepatitis C in Australia;

- 90,000 of these cases have been tested (Batey evidence, 27 October 1997) of whom approximately 76,000 tested positive.

The discrepancy between the estimated 150,000 - 200,000 people with Hepatitis C and the actual number of reported cases (76,000) is of great concern. The discrepancy highlights the number of people who remain undiagnosed. As the Hepatitis C Council observed:

> *this may be because of a lack of public awareness about HCV and limited medical practitioner knowledge. It is also likely that a number of people have not yet developed symptoms and have not yet presented for medical assistance* (Hepatitis C Council submission).

The issues of limited public awareness and limited medical practitioner knowledge will be discussed further in Sections 10.6 and 8.3.3 respectively.

The second discrepancy of concern to the Committee relates to the figures proposed by the Hepatitis C Virus Projections Working Group. The concerns do not relate to the quality of work produced by the Working Group, but rather the large range given in upper and lower limits for both incidence and prevalence data. The Working Group, for example, suggested the incidence of Hepatitis C in 1997 to be 11,000 with lower and upper limits of 8,500 and 13,500 respectively. A range in the order of 100,000 was suggested for Hepatitis C prevalence with the lower range proposed as being 130,000 and an upper range of 230,000. Such a range is very broad and a fair reflection of the uncertainties in the point estimates (Law correspondence, 29 October 1998).

The discussion above has also demonstrated to Members current inadequacies in the appreciation of governments at both the federal and state/territory level to the epidemiology of Hepatitis C. As Farrell admitted to the Committee:

> *I regard the knowledge about epidemiology and the investment of government in understanding epidemiology to be totally inadequate* (Farrell evidence, 28 November 1997).

The Committee trusts that the recommendations it has forwarded will go some way to redressing the current inadequacies on the part of government to understand and appreciate the epidemiology of the Hepatitis C virus.

2.3 CONCLUSION

The discussion in this chapter has sought to provide an aetiological and epidemiology context for the rest of the report. Various features of the Hepatitis C virus have been identified and discussed along with a thorough analysis of the virus' incidence and prevalence in Australia, and where possible, New South Wales. Evidence received highlighted difficulties in ascertaining, with any degree of accuracy, current rates of Hepatitis C. The Committee sees a need for regular and ongoing prevalence and incidence studies to be conducted at both the state and national level and has recommended accordingly.

CHAPTER THREE

GROUPS AT RISK AND EXTENT OF INFECTION IN THESE GROUPS

Since the discovery of Hepatitis C virus and development of a diagnostic assay to detect antibodies against it, the major pathways of transmission have been reasonably well defined. Needle and equipment sharing among injecting drug users and transfusion of blood products before the introduction of screening for Hepatitis C have accounted for most infections in developed countries. Other modes of parenteral transmission (non-sterile medical and dental equipment, needlestick exposure in the healthcare setting, and skin penetration practices such as tattooing or acupuncture) and mother-to-child transmission occur, but their population impact has not been reliably estimated. Sexual and household contact have been the subject of conflicting reports as to their likelihood of transmission of the virus (Dore, Kaldor and McCaughan, 1997:333).

The Hepatitis C Virus Projections Working Group has estimated that, of all infections, 80% were due to injecting drugs, 7% due to receipt of infected blood and 13% due to other transmission routes. Of incidence HCV infections in 1997 the Working Group estimated that 91% were due to injecting drugs, 0% to receipt of infected blood and 9% due to other reasons (Hepatitis C Virus Projections Working Group, 1998:8). The following discussion reviews these “at risk” population groups and the extent of Hepatitis C amongst each group.

3.1 INJECTING DRUG USERS

Injecting drug use is the most commonly identified risk factor for Hepatitis C infection in Australia. It was initially thought that transmission of the Hepatitis C virus occurred with reusing or sharing needles and syringes. However, it is now generally accepted that transmissions can occur without actually sharing needles and syringes - any equipment used in the injecting process may be contaminated with minute traces of infected blood including spoons, filters, tourniquets and alcohol swabs. The situation where this is most likely to occur is when two or more people inject together. Wodak spoke on this form of transmission during the course of his evidence. He referred to,

> *a growing suspicion that there is more to the transmission of Hepatitis C than blood-to-blood transmission in the conventional sense. . . We now think that in the case of Hepatitis C often the transmission involves blood which is not apparent - microscopic dots of blood which cannot be seen. Evidence to support this is suggestive rather than conclusive and it involves videos of drug injectors who are injecting according to practices that we think satisfy the need to keep HIV under control* (Wodak evidence, 2 October 1997).

Wodak cited the following example taken from these videos: someone compressing a colleague’s vein with their finger or thumb and after the colleague has successfully injected, commencing work on their own veins without washing their hands. Wodak observed that such practices are not a problem in terms of HIV transmission, but they are “more than enough” to transmit the Hepatitis C virus (Wodak evidence, 2 October 1997).

The risk of Hepatitis C infection from injecting drug use begins in the first few years of an injecting career. Crofts, Louie, Rosenthal and Jolley (1996:1188) go so far as to suggest that the risk begins with the very first injection. The Royal College of Nursing, Australia's submission noted that the group at "most" risk of acquiring Hepatitis C infection are young people who are considering injecting drug use.

Because of this risk to new injecting drug users and because of continued recruitment to injecting, Crofts *et al* (1996:1188) suggest that the HCV epidemic amongst injecting drug users will not "mature out".

The strongest single predictor of risk among users is duration of injecting (MacDonald, Crofts and Kaldor, 1996:139). Advancing age is also associated with higher risk of HCV seropositivity but largely through its association with duration of injecting (NHMRC, 1997:5). Crofts et al's 1993 study documents the increase risk of HCV with duration of injecting and age (see Table Seven).

TABLE SEVEN
PERCENTAGE OF INJECTING DRUG USERS SEROPOSITIVE FOR HCV

DURATION OF INJECTING YEARS	PERCENTAGE OF INJECTING DRUG USERS				
MEN	**< 25 YEARS**	**25-29 YEARS**	**30-34 YEARS**	**35+ YEARS**	**TOTAL**
0 - 4	37%	25%	67%	0	37%
5 - 9	67%	63%	67%	100%	67%
10 - 14	-	100%	93%	100%	90%
15+	-	100%	100%	90%	93%
Total	**46%**	**64%**	**88%**	**90%**	**70%**
WOMEN	**< 25 YEARS**	**25-29 YEARS**	**30-34 YEARS**	**35+ YEARS**	**TOTAL**
1 - 4	35%	60%	0	100%	40%
5 - 9	75%	70%	100%	100%	77%
10 - 14	-	100%	83%	67%	90%
15+	-	100%	70%	100%	83%
Total	**46%**	**82%**	**73%**	**93%**	**65%**
TOTAL	**46%**	**71%**	**83%**	**91%**	**68%**

Source: Crofts and Hopper *et al*, 1993:238

Other factors associated with injecting drug use that have been shown to be associated with high HCV risk include opiate use (as opposed to stimulant use), prison history, and heterosexual orientation, but not a history of sex work (MacDonald, Crofts and Kaldor, 1996:139).

Established cases of Hepatitis C that are attributed to injecting drug use often refer to practices that occurred decades ago. As Wodak informed the Committee:

> *I commonly see patients in their late forties and early fifties who are now well-established in life and prosperous, working in the private sector, with family responsibilities and in every way they are conventional citizens. With a little bit of probing it emerges that there was a temporary period of three months adolescent rebellion thirty years ago when they lived in Kings Cross and injected drugs. Now they have presented with cirrhosis and they are Hepatitis C positive and there is no other cause for Hepatitis C* (Wodak evidence, 2 October 1997).

Wodak and Crofts put it a little more colourfully:

> *many a temporary injecting drug user of yesteryear has now metamorphosed into a middle-aged yuppie with liver disease of insidious onset* (Wodak and Crofts, 1996:181),

with the result that the connection of these cases with injecting drug use and needle sharing is “easily overlooked” (Wodak and Crofts, 1996:181).

These observations were reflected in submissions received by the Committee from HCV+ people who, at some time in their past, injected drugs:

> *I experimented with IV drugs a couple of times nearly 25 years ago like many of my generation in the sixties and early seventies. Drugs didn’t change my life I’m pleased to say, but I’m afraid Hepatitis C has. There’s the possibility that I’ll die prematurely in the next few years* (Submission 8).

3.1.1 PREVALENCE OF HEPATITIS C AMONGST INJECTING DRUG USERS

Cross-sectional surveys and cohort studies among injecting drug users in Europe have found seroprevalances of HCV of 60 - 80% (Wodak and Crofts, 1996:181). HCV rates amongst injecting drug users in the United States tend to be lower. Wodak suggested to the Committee that this could be due to the “very different moral and legislative climate” in the United States with people less prepared to identify that they are, or in the past have been, injecting drug users (Wodak evidence, 2 October 1997).

In Australia, estimates of Hepatitis C prevalence among injecting drug users also vary. MacDonald, Crofts and Kaldor for example cite a range of 50-90 percent (1996:139) while MacDonald and Kaldor cite 60-80 percent (undated:26). The NHMRC reported results of studies ranging from 30% to 85% (NHMRC, 1997:3). Farrell considers prevalence amongst injecting drug users to be "alarmingly high":

> *Seventy to ninety percent of actively injecting drug users are infected with Hepatitis C. However for every person currently injecting there may well be three or four others who have experimented with drugs at some time earlier in their lives* (cited in Schering-Plough submission).

In giving evidence before the Committee, Dr Wodak claimed that two-thirds of Australian injecting drug users were already infected with Hepatitis C before 1971 (Wodak evidence, 2 October 1997). In his estimation, between 80 and 90 per cent of newly diagnosed Hepatitis C cases and those with established Hepatitis C are injecting drug users (Wodak evidence, 2 October 1997).

Prevalence results from the Victorian Injecting Drug Users Cohort Study (VICS) study are reproduced in Table Eight. As the table shows, approximately two-thirds of subjects were found to have been infected with HCV. Prevalence did vary over time but there was no discernible (ie statistically significant) trend (Crofts and Aitken, 1997:18).

TABLE EIGHT
PREVALENCE OF HEPATITIS C IN A COHORT OF VICTORIAN INJECTING DRUG USERS 1990-1995

	POSITIVE AT FIRST TEST		**ANNUAL PREVALENCE (%)**					
	Number	**Prevalence (%)**	**1990**	**1991**	**1992**	**1993**	**1994**	**1995**
HCV	321	62.4	81.0	70.4	72.9	67.7	71.1	69.6

Source: Crofts and Aitken, 1997:18

HCV seroprevalence rates amongst people attending needle and syringe exchanges are available from the National Centre in HIV Epidemiology and Clinical Research. Data for 1995 and 1996 are recorded in Table Nine.

TABLE NINE
HCV SEROPREVALENCE AMONG PEOPLE ATTENDING NEEDLE AND SYRINGE PROGRAMS 1995 AND 1996

	NO OF IDUS SEEN		NO OF HCV+ %	
STATE	**1995**	**1996**	**1995**	**1996**
ACT	74	139	61	74
New South Wales	1,029	1,026	85	83
Queensland	555	710	40	46
Victoria	467	422	53	70
Other	248	395	58	60
TOTAL	**2,373**	**2,692**	**63**	**66**

Source: National Centre in HIV Epidemiology and Clinical Research, 1997:54

These data show the greatest increases in rates of HCV seroprevalence to come from the ACT and Victoria. The data source does not offer any suggestions for these increases, nor does it explain the 2% decrease in NSW statistics.

The prevalence of Hepatitis C amongst injecting drug users is so high that Crofts suggests that:

> *by the time injecting drug users have been injecting for several years, their chances of having been exposed to HCV approach 100%* (Crofts, 1994:235).

Kaldor supported the results of Crofts' study. As he stated in evidence before the Committee:

> *prevalence increases with the duration of injecting. With those who have been injecting for about seven to eight years, the prevalence approaches 80 per cent . . . Even people who have been injecting for three years or less the prevalence is of the order of 25 per cent. There is a steady and clear increase according to how long one has apparently been injecting according to the self-reporting injecting status. The two main conclusions . . . are that, first, people who have been injecting in the last three or four years, all have Hepatitis C. Second, of those who started injecting in the last three or four years, about 25 per cent already have Hepatitis C which is consistent with the high incidence* (Kaldor evidence, 3 October 1997).

Loxley's study provides similar findings. The 1994 Australian Study of HIV and Injecting Drug Use (ASHIDU), which is the largest Australian study of Hepatitis C in injecting drug users with 872 respondents equally distributed across Adelaide, Melbourne, Perth and Sydney, found that 15% of respondents were infected with Hepatitis C after injecting for up to two years; 25% up to four years; 40% up to eight years and 80% after more than eight years (Loxley, 1997:54). As Loxley notes:

> *figures like these have fuelled a research interest in people in the early stage of their injecting career, and the first transition to injecting* (Loxley, 1997:54).

3.1.2 PREVALENCE OF HEPATITIS C AMONGST NSW INJECTING DRUG USERS

In their submission to this Inquiry, NUAA suggested that at least 80,000 injecting drug users in NSW are Hepatitis C positive. They base their assessment on 200,000 Australians being Hepatitis C positive, 44% of whom live in NSW and the estimation that over 90% of positive people contract the virus by unsafe injecting practices (NUAA submission).

Given the limited data available on prevalence of Hepatitis C amongst injecting drug users, the Committee considers there to be a need for further research to establish accurate prevalence figures for this population group. ANCARD's Hepatitis C Sub-committee has identified cross-sectional studies of prevalence in priority populations including young recently initiated injecting drug users and needle exchange clients to be a research priority. The Committee agrees that it is important these groups be included in any prevalence studies conducted.

RECOMMENDATION 10:

That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **prevalence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population prevalence studies proposed in Recommendation 2.

3.1.3 INCIDENCE OF HEPATITIS C AMONGST INJECTING DRUG USERS

The annual incidence rate of Hepatitis C amongst injecting drug users from a number of developed countries has been assessed as ranging from 10-40% (Wodak and Crofts, 1996:181). The incidence of Hepatitis C in injecting drug users in Australia ranges from 15 - 20 per 100 person-years. Wodak (1997a:284) has suggested 15 per 100 person-years (Wodak, 1997a:284) and 20 per 100 person-years in evidence before the Committee (Wodak Evidence, 2 October 1997). As he explained in evidence:

> *if we start off on 2 October 1997 with 100 uninfected drug users who are starting to inject today, we can expect in a year's time that 20 of them will be infected. The next year 20% of the other 80 users will be infected and so on* (Wodak evidence, 2 October 1997).

This pattern of transmission is responsible for up to 10,000 new infections related to injecting drug use occurring each year (Wodak and Crofts, 1996:181). Not surprisingly Wodak and Crofts conclude that:

> *the importance of the epidemic of Hepatitis C among injecting drug users has to date been seriously underestimated* (Wodak and Crofts, 1996:183).

The Victorian Injecting Drug Users Cohort Study (VICS) is the first (and as of 1998, only) longitudinal cohort study of injecting drug users carried out in Australia which monitors the incidence and prevalence of blood borne viruses (including HCV) in a field recruited cohort of injecting drug users in both metropolitan and rural Victoria (including prison inmates as will be discussed). Preliminary results of the study were reported in 1993 (Crofts, Hopper, *et al*). More detailed, longitudinal results became available in 1997 (Crofts and Aitken).

In 1993 Crofts and colleagues reported HCV RNA being detected in 48% of subjects - 61% of whom were HCV seropositive and 5% seronegative (Croft and Hopper *et al,* 1993:239). Subsequent retesting of the seronegative subjects found that five had seroconverted to HCV. The crude incidence rate of HCV infection in this population group was calculated to be 19.6 infections per 100 person-years (Crofts and Hopper *et al*, 1993:239).

The 1997 study reported incidence of Hepatitis C from 1990-1995 with an overall rate of 10.7 per 100 person-years. As Table Ten shows, there was a downward trend in HCV incidence over the period, however the trend was not statistically significant (Crofts and Aitken, 1997:18).

TABLE TEN
BIENNIAL INCIDENCE OF HEPATITIS C IN A COHORT OF VICTORIAN INJECTING DRUG USERS 1990-1995

	1990-91	1992-93	1994-95	OVERALL
Seroconverters	5.0	8.0	6.0	19.0
Person-years at risk	30.1	73.4	74.1	117.6
Incidence (per 100 person-years)	16.6	10.9	8.1	10.7

Source: Crofts and Aitken, 1997:18

The Committee was impressed with the thoroughness of the `VICS study, in particular the longitudinal nature of the study and its attempt to ascertain both incidence and prevalence.

3.1.4 INCIDENCE OF HEPATITIS C AMONGST NSW INJECTING DRUG USERS

One of the largest studies on the incidence of Hepatitis C amongst injecting drug users in terms of the number of recorded seroconversions comes from New South Wales. The study was conducted at the Kirketon Road Clinic, Kings Cross from 1992 to 1995. Dr Ingrid van Beek, Director of the Kirketon Road Clinic and principal researcher for this study, gave evidence before the Committee and provided Members with data over a five year period, rather than the three year period as in the published study.

The retrospective cohort study found an incidence rate of Hepatitis C of 20.9 per 100 person-years (31 seroconversions) among 152 injecting drug users initially negative for Hepatitis C virus. An additional 14 injecting drug users have seroconverted to Hepatitis C subsequent to the formal study, bringing to 45 the number of people who were initially HCV-negative but who have subsequently become HCV-positive. The incidence rate is measured at 18 per cent which has not changed over the five year period (van Beek evidence, 6 November 1997).

Table Eleven reports the seroconversions among Sydney based injecting drug users broken down for risk factors. As the Table shows the two most at risk groups in this study were injecting drug users aged less than 20 years (with an incidence rate of 75.6 per 100 person-years) and those with a history of imprisonment (with an incidence rate of 60.8 per 100 person-years).

TABLE ELEVEN
RISK FACTORS FOR HEPATITIS C VIRUS SEROCONVERSION AMONG INJECTING DRUG USERS

VARIABLE	SEROCONVERSIONS	TOTAL	INCIDENCE PER 100 YEARS
Gender:			
Men	15	63	26.2
Women	14	85	15.9
Transsexual	2	4	70.3

VARIABLE	SEROCONVERSIONS	TOTAL	INCIDENCE PER 100 YEARS
Age at test:			
< 20 years	13	31	75.6
20-29 years	17	110	14.7
> 30 years	1	11	6.6
Shared equipment since last test:			
No	9	80	11.9
Yes	22	72	30.2
History of imprisonment:			
Yes	12	25	60.8
No	15	118	12.5
Overall Number	31	152	20.9

Source: van Beek *et al*, 1998

While the published study reported the incidence of Hepatitis C in the under 20 year old group to be 75.6 per cent, subsequent data reported to the Committee by van Beek suggest the rate to be 89 per cent (van Beek evidence, 6 November 1997). She considers this rate to be “staggering” and as she commented to Committee Members:

> *cause for great concern, particularly when it is considered that this was measured in a group of people attending a service which has a focus of HCV prevention and measured in a group of people who attended over time. For us to measure incidence, we can do that only if people have at least two tests for HCV, so it requires something of an on-going relationship. That we are seeing that sort of incidence in that group of people leads us to be particularly concerned about the people who are not accessing prevention programs* (van Beek evidence, 6 November 1997).

During the course of giving evidence, van Beek identified three reasons for the high rates amongst this age group:

i. the infection is being transmitted very early in people’s injecting drug use careers and that services such as ours by and large tend to have engaged such people a year or two into their drug using careers, by which stage it is often already too late;

ii. the very high prevalence of the disease means that even very low levels of needle sharing are likely to result in transmission of the infection compared with HIV where the pool of infection is still so small (van Beek evidence, 6 November 1997); and

iii. injecting drug users who know they are HIV positive tend to "remove" themselves from the risk-taking, drug-using population and take "additional" care that they do not share their injecting equipment with others. However van Beek considers that injecting drug users do not see Hepatitis C as a "serious thing" and they do not remove themselves from the sharing population (van Beek evidence, 6 November 1997). Further, as has been discussed, the long lead time of the disease to manifest itself means that people can have Hepatitis C and continue to share unwittingly exposing those they share with to the Hepatitis C virus.

As has been discussed, it is generally accepted that the risk of contracting Hepatitis C increases with time - the longer one injects, the greater the risk. For so many young people to have the disease so early on in their injecting career suggests that a prevalence rate of 100% amongst injecting drug users could be achieved amongst young injecting drug users earlier than experts had believed.

In identifying the limitations of the study, the authors suggested that the high incidence among subjects recruited in the study's particular clinical setting may not be representative of Hepatitis C incidence among injecting drug users more generally. As Kirketon Road Centre provides HIV and Hepatitis C virus prevention services, its clients may differ from injecting drug users who do not attend the Centre. On the other hand, the Centre's location in Kings Cross, may result in the recruitment of injecting drug users at higher risk (van Beek *et al*, 1998).

Kaldor commented upon the Kirketon Road study during the course of his evidence. He noted that:

> *the extent to which this represents injecting drug users in general is impossible to state because this is a group of injecting drug users and it may be that the ones we see in these studies are a particularly high risk group, or it may be that they are at a lower risk. I would say they would be at the higher end, given the way the population has been selected* (Kaldor evidence, 3 October 1997).

Table Eleven shows that those with a history of imprisonment are five times more likely to contract Hepatitis C than those who have not been in prison. As van Beek told the Committee, it is not possible on the basis of available data to determine whether the period of imprisonment was between the last negative and first positive test result (which is why these results are reported here rather than Section 3.2.4 which examines the incidence of Hepatitis C in the corrections system). As van Beek noted:

> *it is possible that those who are incarcerated are at a higher risk, more disorganised and chaotic, and that this is a correlate rather than a casual relationship. However, the fact that the magnitude is in the order of five times would suggest it is perhaps more than that, but that cannot be said for sure* (van Beek evidence, 6 November 1997).

However, as van Beek notes, the association deserves further investigation specifically to assess whether preventing the spread of Hepatitis C should be better dealt with in the prison setting. The issue of prevention of Hepatitis C in the correction system is discussed in detail in Section 10.2.

The study concludes that the extremely high incidence of Hepatitis C virus among subjects under 20 years of age is a "major public health concern". Van Beek *et al* refer to Crofts' study reviewed above (Crofts and Aitken, 1997) which shows a decline (albeit non significant) in the incidence of Hepatitis C virus. Van Beek proposes that the absence of a similar decline in this study among an inner city population of injecting drug users already attending an HIV prevention service "strongly suggests" that current efforts aimed at the prevention of blood borne viral transmission are "inadequate" to stem Hepatitis C virus infection (van Beek evidence, 6 November 1997). Van Beek assured the Committee however, that she is not suggesting existing strategies should be dropped:

> *it is particularly important to continue to send a message of safe injecting practices to those who are injecting . . . we should not be directing anything away from existing strategies; we should be adding to them and extending our focus* (van Beek evidence, 6 November 1997).

The issue of preventative strategies for injecting drug users will be pursued in full in Section 10.1.

RECOMMENDATION 11:

That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **incidence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population incidence studies proposed in Recommendations 4.

RECOMMENDATION 12:

That the prospective, longitudinal cohort study to ascertain the incidence and prevalence of Hepatitis C amongst injecting drug users proposed in Recommendations 10 and 11 be based upon the Victorian Injecting Drug Study and, like the Victorian model, be conducted by an independent agency.

3.2 PRISONERS

Many prison entrants have histories of drug use, including injecting. NUAA's submission suggested that up to 85% of inmates are in prison on drug-related offences. A proportion of these prisoners continue their drug taking behaviour while in prison (Crofts, Thompson, *et al*, 1996:20). Given the blood borne nature of Hepatitis C transmission, this practice puts those who inject drugs while in prison at risk of contracting Hepatitis C. In addition to injecting drug use, a second major risk behaviour for HCV transmission in prisons is tattooing. This practice is illegal within the corrections system and is therefore inevitably undertaken using unsterile equipment and techniques.

During the course of this Inquiry, a number of attributes, unique to prison life, were identified as facilitating the spread of Hepatitis C amongst this population group. Crofts, for example, has noted that:

> *prisons take people from diverse settings who would not otherwise meet, create the opportunity to spread blood borne viruses among them and then send them back to their original networks as potential sources of infection* (Crofts, 1997:116).

In addition, as Dolan notes, a very high level of mixing occurs in prisons. She documents that:

> *in NSW there are about 6,000 inmates on a daily basis. There are 14,000 people entering prison each year. They are transferred 20,000 times. The dynamic turnover will be conducive for the transmission of infections not only in prison but beyond to the general community* (Dolan, 1997:353).

ANCARD has suggested that:

> *it is naive to suggest that injecting drug use does not occur in the prison setting. The prison population is at a significantly higher risk for blood borne . . . diseases than the public and have few opportunities to avoid infections. Anecdotal evidence suggests that on returning to the community, prisoners may resume their injecting drug behaviours . . . with people who would normally be at low risk. It is therefore necessary to emphasise the fact that the transmission of Hepatitis C within the prison setting has a major impact on the transmission of Hepatitis C in the whole community* (ANCARD submission to the NSW Parliamentary Inquiry into Safe Injecting Rooms, attachment to their submission to this Inquiry).

The following discussion looks at the incidence and prevalence of Hepatitis C in the state's corrections setting with particular reference to rates of Hepatitis C amongst those who inject drugs and/or receive a tattoo while in prison.

3.2.1 PREVALENCE OF HEPATITIS C IN PRISONS

Overseas studies report prevalence rates of HCV among prison entrants to be high: 38% in a Maryland study and 46% in Norway (NHMRC, 1997:6). Within Australia, Crofts and colleagues have been responsible for some of the most thorough research of Hepatitis C amongst prisoners (see for example Crofts and Stewart, 1995; Crofts and Thompson *et al*, 1996; Crofts and Hooper, 1997).

In Crofts *et al's* 1995 study all entrants to the Victorian corrections system from October 1991 to September 1992 were offered Hepatitis C screening. Results suggested the overall prevalence of Hepatitis C to be 39.1%. The rate was higher in women (66.7%) and injecting drug users (65.3%) with the highest seroprevalence rate being amongst women with a history of injecting drug use (84.8%) (Crofts and Steward, et al, 1995:286).

A subsequent study by Crofts and colleagues (Crofts, Thompson *et al*, 1996) was based on an extension of the VICS study that has been discussed. It recruited and followed injecting drug users inside Melbourne's Pentridge Prison. Self-identified injecting drug users were tested for, amongst other factors, HCV antigen and by PCR for HCV RNA. The majority of subjects (88%) were positive for HCV antibody, of whom 75% were PCR positive. Two of six HCV antibody negatives were PCR positive. The overall prevalence of Hepatitis C was calculated to be 92% of participants (Crofts, Thompson *at al*, 1996:23).

3.2.2 PREVALENCE OF HEPATITIS C IN NSW PRISONS SYSTEM

In its submission to the Inquiry, the NSW Department of Corrective Services advised the Committee that studies of Hepatitis C in the correctional system show "alarming rates" of Hepatitis C amongst NSW correctional inmates (NSW Department of Corrective Services submission). The submission noted that these:

> *studies have confirmed Hepatitis C infection rates of between 40-60% for male inmates and 70-80% for female inmates (with female inmates accounting for approximately 5% of the overall inmate population)* (NSW Department of Corrective Services submission).

Two studies attempting to ascertain the prevalence of Hepatitis C in the state's corrections system were brought to the attention of Committee Members. The first study was conducted by Butler and colleagues amongst prison entrants in the second half of 1994. The study found 37% of inmates to be positive for HCV antibodies.

These results are in line with comparable Victorian studies already discussed. Extrapolating these results, Butler *et al* suggest there to be over 2,000 inmates in the NSW corrections system who are HCV+ (Butler *et al*, 1997:129). Such figures confirm a comment made in the NSW Department of Corrective Services' submission which suggested that the Department has to deal with "probably the greatest concentration of Hepatitis C positive people anywhere in NSW, possibly Australia" (NSW Department of Corrective Services submission).

A subsequent survey based on a cross-sectional, random sample of 800 prisoners from all NSW gaols was conducted in 1996. As Butler informed the Committee:

> *the main reason for doing the study was the total lack of baseline data on blood-borne communicable diseases on prisoners. So it was seen as essential to carry out the survey* (Butler evidence, 23 March 1998).

Overall, the prevalence of Hepatitis C was found to be 38% amongst prisoners tested (Butler evidence, 23 March 1998) with one-third of male participants and two-thirds of female inmates who participated in the survey testing positive for HCV antibodies (Butler, 1997:42). Butler suggested to the Committee that the discrepancy between males and females appears:

> *quite shocking when one first looks at it, but it probably indicates that females tend to be incarcerated for drug-related offences whereas males are incarcerated for drug-related offences and also for sex offences, violence, driving offences, etc. That explains the huge discrepancy. However it [the prevalence] is still pretty high amongst both groups* (Butler evidence, 23 March 1998).

Inmates testing positive for HCV antibodies were tested for the presence of Hepatitis C RNA using a PCR test. Over two-thirds of both males (76%) and females (65%) were found to be PCR+, indicating a high proportion of inmates with Hepatitis C antibodies are also viraemic (Butler, 1997:443). Such results have important implications for transmission as those testing PCR+ are at greater risk of transmitting the disease than those testing negative.

In evidence before the Committee, Butler observed that:

> *I think the prevalence has been a bit of a shock. I remember speaking to someone about this in 1994 . . . The estimate was about 11 per cent. Suddenly, the estimate is about 33 per cent. That is a bit of a shock and they have not geared up for that. The data we are collecting is a start in the process* (Butler evidence, 23 March 1998).

The Committee concurs with Butler: the rate of Hepatitis C in the state's corrections system is shocking, and his study is a start. The Committee considers it vital that this process of gathering data to ascertain the prevalence of Hepatitis C amongst prisoners continues on a regular basis. The Committee was particularly impressed with the PCR component of Butler's study as these results have provided information not able to be ascertained from antibody testing alone. The Committee would like to see all further studies incorporate PCR testing. In promoting the incorporation of PCR testing the Committee is aware of the possibility that some inmates may misunderstand their PCR status, particularly if it is negative. The Committee does not wish to see inmates lulled into a false sense of security that could arise if they considered themselves to not be at risk of infecting others and therefore engage in unsafe practices.

RECOMMENDATION 13:

That the Minister for Corrective Services and the Minister for Health ensure the prevalence of Hepatitis C in the state's corrections system is ascertained through ongoing monitoring and research.

RECOMMENDATION 14:

That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the prevalence of Hepatitis C in the state's corrections system.

RECOMMENDATION 15:

That the testing proposed in Recommendation 13 incorporate PCR testing to ascertain the viraemic status of HCV+ prison inmates.

3.2.3 INCIDENCE OF HEPATITIS C IN PRISONS

Crofts *et al's* 1995 study found the incidence rate of Hepatitis C in the Victorian corrections system to be 18.3 per 100 person-years. In men who injected drugs and were aged less than 30 years the rates were higher: 21 and 41 per 100 person-years respectively (Crofts and Stewart *et al*, 1995:287). Conversion to Hepatitis C was inversely associated with length of time in prison: in those whose length of stay was one month or less, the incidence was 65% a year compared with 26% a year in those whose stay was over one month (p=<0.01) (Crofts and Stewart *et al*, 1995:287).

3.2.4 INCIDENCE OF HEPATITIS C IN NSW PRISONS SYSTEM

Butler informed the Committee that, to date, there have not been any studies in New South Wales to determine the incidence of Hepatitis C in the state's corrections system

(Butler evidence, 23 March 1998). Ascertaining incidence rates would necessitate measures taken over a period of time or Hepatitis C status ascertained as prisoners entered and exited prison. To date, Hepatitis C exit levels amongst the general prison population are not known. Selvanera suggested to the Committee that:

> *the exit level for Hepatitis C is perhaps the area in which more research needs to be done so that we can gain a better understanding of the level of infection that takes place while in prison* (Selvanera evidence, 23 March 1998).

Professor Lloyd informed the Committee that he had undertaken preliminary (and as yet unpublished) research that substantiated Crofts's incidence rates of one in five per annum (Lloyd evidence, 30 March 1998). He considers his results demonstrate "a frighteningly high transmission incidence" (Lloyd evidence, 30 March 1998). During evidence, he also referred to another study (awaiting publication) he and gastroenterologist colleague Dr Paul Haber had undertaken. The study documents four individuals who, on entry to prison and on at least one other occasion months later, received Hepatitis C negative test results but who subsequently became infected during their time in prison (Lloyd evidence, 30 March 1998).

At the First Australasian Conference on Hepatitis C held in Sydney last year, it was observed that:

> *there still has not been one proven and published case of hepatitis transmission occurring in an Australian prison* (Dolan, 1997:353).

Lloyd's research suggests it to be only a matter of time before such a claim is outdated as such a comment is, in the Committee's opinion, more a reflection on limited research than the absence of Hepatitis C transmission in the country's corrections system.

In addition to Lloyd, other witnesses commented on the transmission of Hepatitis C within the corrections system. Harper, an Acting Clinical Nurse Consultant with Corrections Health Service, informed Members that:

> *I believe that there will clearly be some evidence to show that Hepatitis C has been contracted in gaol through people sharing needles and syringes. There is no question about that: it merely has to be substantiated* (Harper evidence, 23 March 1998).

Lloyd also observed that:

> *I feel very suspicious, although we do not have good data, that a lot of transmission is happening in the prisons. If that fact is put together with*

> *the fact that the average length of stay is six or seven moths, then prisons could generously be regarded as a hotbed of transmission back out into the community* (Lloyd evidence, 30 March 1998).

At the time of giving evidence, Lloyd informed the Committee that he had a proposal for a research study with the Ethics Committees of Corrections Health Service and the Department of Corrective Services. It is intended that the prospective cohort study would identify a large group of approximately 1,000 HCV- inmates and follow them for the period of their imprisonment. The study would attempt to ascertain how common Hepatitis C transmission is in the corrections system and identify factors associated with transmission. The results would provide "key information to sensible harm minimisation strategies" (Lloyd evidence, 30 March 1998). Lloyd told the Committee that:

> *we need to know if half of the transmissions are happening from barber's shears, or whatever else it may be. Deep down I am sure that the majority of it is related to drug use but even there we need to know if there are practical things that we can do to minimise transmission* (Lloyd evidence, 30 March 1998).

Lloyd was, however, experiencing difficulties in gaining approval for his study. He informed the Committee that:

> *perhaps predictably that application is meeting with controversy in the Department of Corrective Services Ethics Committee. We are yet to see whether we are to win out but, as yet, we do not have approval to do the study* (Lloyd evidence, 30 March 1998).

The week before tabling this Report, Lloyd advised that approval for the study had been obtained from the Corrections Health Ethics Committee (Lloyd correspondence, 1 November 1998). At that time, he was hoping to gain NHMRC funding to proceed with the project in 1999.

The Committee sees a very real need for the type of information Lloyd's research seeks to ascertain. While the Committee is not in a position to recommend his particular research project be approved and funded, the Committee is concerned that difficulties have been experienced in gaining approval. The fact that the research may be controversial is not grounds for procrastination.

The Committee recommends a study be undertaken to ascertain the incidence and modes of transmission of Hepatitis C in the state's corrections system.

RECOMMENDATION 16:

That the Minister for Corrective Services, in conjunction with the Minister for Health, commission an independent study of the incidence and modes of transmission of Hepatitis C in the state's corrections system. This study is to be in addition to the population incidence study proposed in Recommendation 4.

RECOMMENDATION 17:

That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the incidence and modes of transmission of Hepatitis C in the state's corrections system**.**

RECOMMENDATION 18:

That the independent study of Hepatitis C incidence proposed in Recommendation 16 be conducted on a regular basis to ensure information on the incidence and modes of transmission of Hepatitis C in the state's corrections system is gathered over time.

3.2.5 INJECTING DRUG USERS IN PRISON

Considerable research has documented the intricate relationship between prisoners, injecting drug use and Hepatitis C (see for example, Crofts 1997; Dolan, 1997; Cregan, 1998). In summary, available research suggests that:

- approximately one half of all injecting drug users have histories of imprisonment (Loxley et al, 1995; Crofts, 1997:116);
- approximately one half of all prisoners have histories of injecting drug use (Crofts, 1995; Crofts, 1997:116); and
- approximately one half of all imprisoned injecting drug users inject in prison (Crofts and Thompson *et al*, 1996; Crofts, 1997:116).

It is difficult to generalise on the impact of imprisonment upon drug use and practices as the Committee was informed that:

> *People's patterns of drug use change in prison; some people reduce their injecting and others will switch. It is often drugs of opportunity versus choice. Some people commence injecting while incarcerated; they may not have injected prior to prison. Others will reduce or increase their*

> *injecting. So it can change from outside patterns of drug use as well and through periods of incarceration drug use will often change* (Butler evidence, 23 March 1998).

It has been suggested to the Committee that prison policy may actually facilitate the transmission of blood borne viruses such as Hepatitis C in a number of ways including:

- sharing of injecting equipment is much more common in prison than outside where access to clean needles and syringes is relatively freely available through established and accessible Needle and Syringe Exchange Programs (Crofts, 1997:116). As a result:

  > *when [inmates] do inject they are likely to be forced into equipment sharing networks, among whom the majority of members are likely to be already HCV-positive* (Cregan, 1998:5);

- surveillance policies tend to induce a need for secrecy and speed to avoid detection and punishment (Cregan, 1998:5). As a result the cleaning that does occur may not be effective in preventing the transmission of blood borne viruses such as Hepatitis C. The Committee understands that bleach is not always readily available and there is some debate over the efficacy of bleach. Further, as Crofts has documented, some prisoners report that a request for bleach to disinfect injecting equipment is often followed the next day by a urine test (Crofts, 1997:116);

- prison drug policies can modify not only frequency and patterns of drug use but choice of drug. For many, the drugs used are dependent upon availability rather than preference. In terms of the transmission of blood borne viruses such as Hepatitis C, a drug such as cannabis, which is smoked, is relatively safer than a drug which is injected. For many prisoners however, cannabis is not a drug of choice for two reasons: i) the bulky nature of cannabis makes it more difficult to obtain in jail than powder drugs because trafficking is easier to detect and it is less profitable to import on a per unit volume; and ii) the speed with which drugs clear from the body's system differs. Cannabis, for example, does not clear quite so quickly as heroin. Efforts to detect drug use, such as urine testing, may result in prisoners choosing to inject heroin rather than smoke cannabis which, given the length of time taken to clear from the system, can be detected through urinalysis.

  The Committee was informed that, given these two factors, prisoners are more likely to make heroin the drug of choice because of the drawback associated with using relatively safer drugs such as cannabis. As Cregan observes, these factors:

> *Lead to the anomalous situation where cannabis, which is smoked and therefore safer in terms of viral transmission, is currently subject to heavier disincentives to its use than heroin and other injectable drugs which represent the highest of all risks for HCV transmission* (Cregan, 1998:5).

During the course of this Inquiry, the Committee gained an understanding of the prevalence of needles and syringes in the prisons system from both prisoners and medical practitioners along with viewing slides of confiscated equipment. The Committee received several submissions from prisoners in NSW Correctional Centres providing Committee Members with first hand insights into drug use in the state's corrections system. One described his experiences to the Committee in the following way:

> *one day I was shocked to witness three inmates of the Special Care Unit borrow and share a syringe from an inmate who was HIV positive . . . three months later . . I noticed the same men sharing needles with a different group of men. I then realised just how quickly blood borne viruses could spread at a rapid rate throughout the prison system* (Submission 63).

This prisoner went on to note that:

> *I've used needles that have to be sharpened on a match box prior to use they're that blunt. I've also seen syringes that are so old that the rubber on the plunger has gone hard or perished and had to be replaced by a piece of rubber thong - not what you'd call real sterile* (Submission 63).

As a practising clinician in the prison system, Professor Lloyd told Committee Members that:

> *in my clinic the other day I saw a man who was in a wing with several hundred other prisoners. In that wing, for two or three months prior, he knew of only one fit, only one needle and syringe. He estimated that it had been reused many hundreds of times, probably thousands. It is the perfect opportunity for viral transmission; you could not ask for it to be better. That is why I have little or no doubt that a huge amount of transmission goes on in prisons* (Lloyd evidence, 30 March 1998).

During the course of taking evidence, the Committee was shown a series of slides of syringes, needles and other injecting paraphernalia confiscated from inmates. The Committee saw, for example, slides of syringes hidden in transistor radios, pens and books (Butler evidence, 23 March 1998). As the Committee heard:

> *one hears stories of needles being separated and one person carrying one little bit around and another person carrying another bit, just in case they get busted* (Butler evidence, 23 March 1998).

The Committee also heard from a Clinical Nurse Specialist with Corrections Health that:

> *we have had problems when guys have got needles stuck in their veins, they have had abscesses and they do not rotate veins. It is dreadful. Their veins are scarred and they cannot be accessed. It is shocking* (Parsons evidence, 23 March 1998).

In his submission to the Committee, Wodak discussed the risk of Hepatitis C to prisoners who are injecting drug users. He noted that:

> *In prison, equipment is severely worn by extensive use and modified by attempts to conceal this equipment. All of these factors have the effect of increasing the likelihood of Hepatitis C transmission* (Wodak submission).

Further, as Wodak noted:

> *networks of injecting drug users who share in the community these days are small and fairly stable. That is, injecting drug users in the community usually only share with their sexual partner and one or two close friends. In prison, there is random sharing with large numbers of total strangers who change rapidly over time* (Wodak submission).

3.2.6 RATES OF HEPATITIS C AMONGST PRISONERS WHO INJECT DRUGS

In the available studies on Hepatitis C and prison inmates it is often difficult to tease out the results of Hepatitis C in prisoners from that of Hepatitis C amongst prisoners who inject drugs. The study by Crofts and Hopper *et al*, does, however, make such a distinction, the results of which are reported in Table Twelve.

TABLE TWELVE
HEPATITIS C IN PRISON ENTRANTS ACCORDING TO INJECTING STATUS
VICTORIA, OCTOBER 1991 - SEPTEMBER 1992

	USERS OF INJECTING DRUGS	NOT USER OF INJECTING DRUGS
Men HCV+	63.6%	16.0%
Women HCV+	84.8%	26.4%
All men and women HCV+	65.3%	16.3%

Source: Crofts and Hopper *et al*, 1997:186

As these data demonstrate, the prevalence of Hepatitis C amongst prison entrants is significantly higher in those with a history of injecting drug use than those who have not engaged in injecting drug use. For males, the prevalence of Hepatitis C amongst injecting drug users is approximately four times higher than the prevalence of the disease amongst non injecting drug users. For women, the rate is approximately three times higher for those who inject drugs.

Incidence data from another of Crofts' studies shows Hepatitis C incidence rates for injecting drug users (38.2 per 100 person-years) that are significantly higher than the incidence rates for non injecting drug users (5.9 per 100 person-years). These data are recorded in Table Thirteen.

TABLE THIRTEEN
INCIDENCE OF HEPATITIS C INFECTION AMONGST INMATES ACCORDING TO DRUG USE
OCTOBER 1991 - SEPT 1992

	NUMBER INITIALLY SERONEGATIVE	NUMBER OF SEROCONVERTERS	INCIDENCE RATE PER 100 PERSON-YEARS
Drug Users	47	8	38.2
Not Drug Users	72	2	5.9

Source: Crofts and Stewart *et al*, 1995:287

No comparable data are available for the NSW corrections system. The data that are available suggest that 90% of inmates who had injected for more than ten years are HCV+ (Butler evidence, 23 March 1998). Approximately 86% of female inmates testing HCV+ had a history of injecting drugs compared with 81% of male inmates (Butler, 1997:42). Butler's 1994 study found that 66% of those who reported a history of injecting drug use were HCV+ (Butler *et al*, 1997:129).

3.2.7 TATTOOING IN PRISONS

Within the NSW corrections system tattooing is an illegal activity. However, as the Committee heard:

> *Tattooing is very common in prison ... it occurs in prison under circumstances where there is no monitoring and there are no infection control guidelines and where Hepatitis C infection is guaranteed* (Wodak evidence, 2 October 1997).

The Committee also heard that:

> *the rate of tattooing is quite high in prisons due to boredom and other things. . . people having tattoos while inside is becoming a major Hepatitis C risk factor* (Vumbaca evidence, 23 March 1998).

Slides of tattooing guns shown to Committee members during the course of the inquiry showed a toothbrush frame attached to a cassette player with a needle inserted in the end (Butler evidence, 23 March 1998). Such a mechanism was described to the Committee as “brutal” (Butler evidence, 23 March 1998).

The Committee also heard that:

> *inside the prisons the tattoo guns are made from gutted tape-recorders and the like and cannot be cleaned properly. We have found that a lot of inmates are not aware that there is a risk of Hepatitis C with tattoos* (Vumbaca evidence, 23 March 1998).

The 1996 study by Crofts and Thompson *et al* discussed above, also examined skin piercing and tattooing practices of prison inmates. The study was, however, limited to those with a history of injecting drug use.

In Crofts’ study, approximately 94% of subjects had skin piercing in sites that included the ear, nipple, nose and foreskin (Crofts and Thompson *et al*, 1996:5). Six inmates (19%) had had their tattoo done by a professional while 46% used “other” means and 61% had done the skin piercing themselves. Instruments used for non-professional skin piercing included sewing needles, studs, safety pins, hot pins and copper wire. Some made no attempt to reduce infectious hazard while others heated the needle with a match or a lighter, washed the needle in disinfectant or simply wiped it (Crofts and Thompson *et al*, 1996:5).

Approximately 97% of the sample had been tattooed, most having at least one tattoo at an unregistered premise and at least one while in prison (61%) or a Juvenile Justice Centre (21%) (Crofts and Thompson *et al*, 1996:5). Almost one-half reported that their last tattoo had been while in prison. Multiple tattooing while incarcerated was common: three respondents reported more than 200 tattoos while in prison (Crofts and Thompson *et al*, 1996:5). The equipment used was always a sewing needle for skin penetration mostly with a gun using a motor derived from a walkman or cassette player. In five cases no gun was used and the tattooing had been done by hand.

Approximately 21% of respondents claimed that the person who had performed their last tattoo had some knowledge of infection control, on the basis that they had worked professionally as a tattooist, or they used disinfectant or heat on the needle. Two-thirds reported that the equipment had previously been used by someone else and two-thirds of respondents said that the same pot of dye would have been used for tattooing others

(Crofts and Thompson *et al*, 1996:5). Those who were last tattooed in prison "universally" reported boredom or "killing time" as a motivating factor (Crofts and Thompson *et al*, 1996:6).

In conclusion, Crofts and Thompson *et al* note that:

> *the majority of prisoners had been tattooed while in prison or a juvenile justice centre under very unsterile conditions, with the same tattooing equipment often being reused on multiple people with little or no effective attempt at sterilisation between. The potential for spread of blood-borne viruses in these populations is obviously therefore very high, especially a virus which is very infectious and at a very high prevalence, such as HCV* (Crofts and Thompson *et al*, 1996:25).

3.2.8 TATTOOING IN NSW PRISONS

The results of the Inmate Health Survey released by NSW's Corrections Health Service show that 51% of female respondents and 57% of male respondents were tattooed (Corrections Health Service, 1997:82). Table Fourteen shows the location where the tattooing occurred: most respondents obtained their tattoos whilst in the community. Males (20%) were more likely than females (6%) to report being tattooed in gaol (Corrections Health Service, 1997:82).

TABLE FOURTEEN
LOCATION OF TATTOOING

	MALES (%)	FEMALES (%)
Community	46	79
Prison	6	20
Both	15	35

Source: Corrections Health Services, 1997:82

3.2.9 CONCLUSION

The issue of Hepatitis C amongst inmates of the corrections system, particularly amongst those who also engage in injecting drug use or tattooing, is complex. Dolan has noted that the study of Hepatitis transmission in the prison setting is "a difficult but important task". (Dolan, 1997:347). She considers the difficulty to lie in:

> *gaining access to inmates, obtaining representative samples and reliable reports of risk behaviours and collecting conclusive evidence of Hepatitis transmission in prison* (Dolan, 1997:347),

while the issue is important:

> *because the high level of inmate turnover means that hepatitis transmission in prison threatens hepatitis control in the community when inmates are released* (Dolan, 1997:347).

Clearly, given the numbers of those already infected and the potential risk for infection, there is a need for decisive and prompt action. The Department of Corrective Services can no longer turn a blind eye to the injecting drug practices of its inmates when it is this specific behaviour that is responsible for so many inmates becoming infected or put at risk.

Crofts argues that sentencing prisoners to Hepatitis C infection as well as to the loss of liberty is a violation of human rights (Crofts, 1997:116). The Committee fully agrees with this statement and, as will be discussed in Chapter Ten, proposes a number of measures to address the transmission of Hepatitis C in the corrections system.

3.3 RECIPIENTS OF INFECTED BLOOD AND BLOOD PRODUCTS

Given the blood borne nature of Hepatitis C transmission, recipients of infected blood and blood products are potentially a primary ‘at risk’ group. The Committee received submissions from a number of people who had acquired Hepatitis C medically. As one person wrote to the Committee:

> *I have never used drugs, I do not have tattoos, I have had only one partner . . . I had surgery 11 years ago and something went wrong. I was given 10 units of blood* (Submission 20).

During the 1980s, the NSW Blood Bank (as it was then known) introduced a number of screening mechanisms as a public health response to the HIV/AIDS epidemic (these are described in Section 10.4). While it was not appreciated at the time, these actions were to have significance far greater than the possibility of transmitting HIV in that they assisted in limiting the spread of HCV through blood transfusion.

Serological testing for HCV became available in 1990 shortly after the discovery of the virus. Australia was the second country in the world to test blood transfusions and blood products for the Hepatitis C virus with the NSW Blood Bank introducing HCV antibody screening in February 1990 (Benjamin evidence, 10 October 1997). Such a response at both the national and state level was, according to Wodak “part of our commendably early response to this [HCV] epidemic” (Wodak evidence, 2 October 1997).

In Australia, the incidence of acquiring Hepatitis C through blood or blood products prior to screening was 1% (NHMRC, 1997:5). The incidence rate has reduced significantly as a result of the strict screening procedures. The current risk of HCV transmission through blood transfusion has been assessed by the NHMRC to be:

> *extremely low, and although still possible, clinical post-transfusional hepatitis has been virtually eliminated in Australia* (NHMRC, 1997:3).

The Blood Bank has established the Hepatitis Lookback Unit which seeks to identify those who, prior to 1990, may have received blood contaminated with the Hepatitis C virus. The NSW Red Cross Blood Bank informed the Committee that "lookback" is:

> *the process of tracing blood products released by a blood bank for normal use. The term is often associated with tracing components suspected to have been contaminated with an infectious agent* (NSW Red Cross Blood Bank submission).

The main functions of the Hepatitis Lookback Unit are to:

- trace components released for normal use when a donor is identified as HCV+ (referred to as case triggered lookback); or

- investigate the HCV status of donors where a recipient believes they have been infected following a blood transfusion (known as donor triggered lookback) (NSW Red Cross Blood Bank submission).

The Lookback program is a joint project with the NSW Health Department and the Red Cross. The project has the support of both State and Federal Health Ministers. As Dr Benjamin, then Head of the Unit, told the Committee:

> *it is important that there was both a state and a federal commitment to proceeding with such a large exercise and many countries around the world who were faced with the same problem have decided not to do Lookback because it is so expensive and extremely difficult* (Benjamin evidence, 10 October 1997).

At the time of making their submission to this Inquiry in October 1997, the Blood Bank advised that 365 people had been identified through the Hepatitis C Lookback Program. Of this number:

- 186 cases had been identified through case triggered lookback; and
- 179 cases have been identified through the Hepatitis Lookback Project (Blood Bank submission).

These figures do not, however, fully reflect all who may have received Hepatitis C. The process of conducting donor triggered lookback is ongoing. In addition, of those who received HCV+ infected blood:

> *approximately fifty per cent of people who receive transfusions will have died twelve months after the treatment and that is because the majority of transfusions are given to sick people. It is not the transfusion* (Benjamin evidence, 10 October 1997).

Those alive and subsequently diagnosed as being HCV+ range from those who are quite elderly to children as young as eight years of age. As Table Fifteen shows, these people are scattered throughout the state.

TABLE FIFTEEN
RESIDENTIAL LOCATION OF PEOPLE WITH TRANSFUSION TRANSMITTED HEPATITIS C

REGION	NUMBER OF CASES
Metropolitan Health Services:	
South Eastern Sydney	53
Central Sydney	51
Northern Sydney	69
Western Sydney	34
South Western Sydney	33
Central Coast	21
Hunter	17
Wentworth	14
Illawarra	16
Subtotal	**308**
Regional Health Services:	
New England	6
Northern Rivers	4
Mid North Coast	10
Far West	1
Macquarie	1
Mid Western	4
Greater Murray	4
Southern	6
Subtotal	**36**
Other:	
ACT	4
Interstate	17
TOTAL	**365**

Source: NSW Blood Bank submission

Dr Benjamin informed the Committee that some of those who acquired Hepatitis C through blood transfusion are proceeding with legal action. This issue will be discussed in further detail in Section 9.3.2.

3.4 PEOPLE BORN OVERSEAS

Professor Farrell considers the second largest group of HCV+ people in Australia to be immigrants, particularly those from southern European countries, the Middle East and parts of Asia (Farrell submission). In his opinion, the majority of these patients acquired HCV from inappropriate medical use of unsterile (nondisposable) needles and glass syringes in their childhood, usually between 40 to 60 years ago (Farrell submission).

Wodak noted before the Committee that, in some developing countries there is a “poorly understood” high prevalence of Hepatitis C which, in countries such as Egypt and Vietnam, can range from 5 - 8% (Wodak evidence, 2 October 1997). Like Farrell, Wodak suggested the high prevalence to be related to poor infection control practices in the health care system with many of these countries unable to afford sterile needles and syringes (Wodak evidence, 2 October 1997). As he illustrated:

> *at 10 o’clock in the morning the only electricity generator in town will break down and there is no way of sterilising needles and syringes. People have injections and vaccinations throughout the day and the equipment is not properly sterilised . . . In some of these countries also traditional ways of skin piercing, both tattooing and scarification, would be other ways that Hepatitis C would be transmitted* (Wodak evidence, 2 October 1997).

Further anecdotal evidence was given to the Committee by Ms Janice Pritchard-Jones who noted that:

> *quite often the Italian patients tell you they can remember standing out in the street as children and the army coming around and vaccinating all the kids, and they just used the same needle for all the kids until the needle was blunt. The Egyptian men tell you of being in the army and Nasser wanting to vaccinate the army at the time for schistosomiasis and the same needle was used* (Pritchard-Jones evidence, 2 October 1997).

The Committee was not able to ascertain the prevalence or incidence of Hepatitis C amongst various ethnic communities as these data are not available. While anecdotal evidence was presented during the course of evidence, the Committee is not aware of any empirical data.

3.5 HEALTH CARE WORKERS AND THEIR PATIENTS

Given the blood borne nature of Hepatitis C transmission, health care workers and their patients are at risk of exposure to the virus. Within the health care setting, transmission of HCV can occur in one of three ways:

- patient to health care worker;
- health care worker to patient; and
- patient to patient.

Cases of HCV transmission have been reported for each of these three modes of transmission (see MacDonald, Crofts and Kaldor, 1996 for an extensive literature review). As the Committee heard from the Chairman, Infection Control Advisory Committee, Royal Australian College of Surgeons (RACS), Dr Richard West:

> *it has been established there is a risk of transmission of Hepatitis C in a hospital setting from patients to health care workers, from health care workers to patients and from patients to patients and that has now been established and substantiated by a number of documented papers* (West evidence, 28 November 1997).

3.5.1 TRANSMISSION FROM PATIENT TO HEALTH CARE WORKER

The submission from the RACS reported seroprevalence studies showing that health care workers are at “increased risk” of acquiring HCV infection. Early studies that used a first generation anti-hepatitis C virus without confirmatory testing found a two to three fold increase in the prevalence of HCV infection in health care workers (RACS submission). As the submission explained though, when more sensitive testing became available and was used 2% of 861 clinical health care workers were shown to be positive for anti-HCV, a rate four times higher than that seen in volunteer blood donors. The submission reviewed available literature on the issue which can be summarised as follows:

- a case control study of dentists found a four fold excess risk resulting from occupational exposure;

- the risk of HCV transmission to health care workers from needle stick injury from source patients with HCV antibodies ranges from 2-10%. As West stated in evidence:

  > *the problem with Hepatitis C is that . . . if you get a needle stick injury the sero-conversion rate is about two to ten percent, probably around about six percent which we think is high and concerning* (West evidence, 28 November 1997);

- there has been one case reported of HCV transmission from a blood splash to the conjunctiva (RACS submission).

The submission also reported that there are a number of Resident Medical Officers in the state's health care system who have seroconverted following needle stick injuries (RACS submission).

An extensive multicentric national survey of more than 15,000 surgical procedures has suggested there to be a 34.8% lifetime risk to surgeons of contracting HCV infection in the operating room, given the current level of application of universal precautions (Pietrabissa, 1997). As will be discussed in Section 10:3, this risk could be reduced to 16.6% with the adoption of preventative strategies. While West considers the risk proposed by Pietrabissa to be "very high" he does acknowledge that the article was published in the very reputable *World Journal of Surgery* (West evidence, 28 November 1997) and therefore must be given credibility.

Dr West informed the Committee it is estimated that approximately 1400 health care workers in the United States develop Hepatitis B and Hepatitis C each year and of these approximately 400 die (West evidence, 28 November 1997). As he informed the Committee:

> *we do not know the figures in Australia at the moment. We have not got enough research and we have not got accurate figures* (West evidence, 28 November 1997).

However, it is estimated that one percent of surgeons may be HCV+ which, given that there are 4000 surgeons in Australia would equate to 40 to 50 surgeons being Hepatitis C positive (West evidence, 28 November 1997).

3.5.2 TRANSMISSION FROM HEALTH CARE WORKER TO PATIENT

Dr West expressed the following concerns of the RACS to the Committee:

> *as surgeons, as clinicians, we are concerned that patients are getting infected with Hepatitis C. We are concerned with how they are getting infected. We are a little concerned that there is the possibility they may be getting infected during hospital procedures . . . We are concerned with the patients . . . some action needs to be taken to do something about the problem* (West evidence, 28 November 1997).

The RACS submission summarised a number of relevant cases including:

- a reported case of a cardiac patient in the UK who developed HCV infection following surgery, the probable source of infection being a HCV+ health care worker;

- a cardiac surgeon in the UK with chronic Hepatitis C who transmitted the virus to five of his patients during open heart surgery between 1988 and 1993; and
- a Barcelona cardiac surgeon who transmitted the virus to patients during surgery. Of the 220 patients surveyed, five are confirmed HCV+ (RACS submission).

In evidence, Crofts referred to “multiple reports” in the scientific literature of outbreaks of Hepatitis C in patients in haemodialysis units. He cited a case study from Japan where Hepatitis C outbreaks were occurring despite investigations which revealed no overt breaches of infection control procedures. It was found, however, that the nurses were taking pathology specimens from haemodialysis patients straight to the hospital’s pathology labs on the next floor. Having used a swab to stop the bleeding after taking the blood, the nurses’ gloves were contaminated. The nurses would then press the lift button, effectively contaminating the lift button and those who subsequently pressed the button (Crofts evidence, 28 November 1997). Such is the virulency of the Hepatitis C virus.

West noted during the course of his evidence that:

> *the problem with many of these [health care worker to patient] studies is that it is a very difficult disease to pick up because the patients do not often get terribly sick. They actually picked up the one in Barcelona because they were doing a survey of post-operative infections* (West evidence, 28 November 1997).

In commenting upon the transmission of Hepatitis C from health care workers to patients, Wodak commented to the Committee that:

> *We do not conduct much surveillance in that area and this is an area of great concern, the spread from health professionals to patients . . . it is an area of great complexity and concern* (Wodak evidence, 2 October 1997).

3.5.3 TRANSMISSION FROM PATIENT TO PATIENT

In its submission to this Inquiry, the Royal College of Nursing, Australia noted the high incidence of Hepatitis C amongst patients on haemodialysis. The submission suggests that:

> *Haemodialysis patients have a higher incidence of Hepatitis C than their peritoneal dialysis counterparts and the incidence of infection increases with the length of time on dialysis* (Royal College of Nursing, Australia submission).

Supporting data provided to the Committee is reproduced in Table Sixteen. The submission suggests blood transfusion and cross infection to be the probable causes for the higher incidence of Hepatitis C amongst this population group.

TABLE SIXTEEN
HEPATITIS C STATUS OF PATIENTS ON MODES OF DIALYSIS IN NSW, MARCH 1997

	HCV ANTIBODY STATUS: +VE	HCV ANTIBODY STATUS: -VE	STATUS NOT DETERMINED
Continuous Ambulatory Peritoneal Dialysis	13	559	35
Home Haemodialysis	21	378	8
Home Intermittent Peritoneal Dialysis	n/a	39	3
Hospital Haemodialysis	22	452	4
Hospital Intermittent Peritoneal Dialysis	n/a	3	n/a
Satellite Haemodialysis	25	356	2

Source: Australia and New Zealand Dialysis and Transplant Registry. Data provided in Royal College of Nursing, Australia submission.

The submission also included information, although no analysis, on the Hepatitis C status of dialysis and functional (successful) transplantation patients. This information has been reproduced in Table Seventeen.

TABLE SEVENTEEN
HEPATITIS C STATUS OF AUSTRALIAN DIALYSIS AND TRANSPLANT PATIENTS, MARCH 1997

	HCV ANTIBODY STATUS: +VE	HCV ANTIBODY STATUS: -VE	STATUS NOT DETERMINED
Dialysis	185 (3.8%)	4,599 (93.9%)	111 (2.3%)
Functional Transplant	155 (3.4%)	3,112 (69.2%)	1232 (27.4%)

Source: Australia and New Zealand Dialysis and Transplant Registry. Data provided in Royal College of Nursing, Australia submission.

The RACS submission reported an episode of HCV nosocomial infection involving five patients who had undergone surgery in western Sydney, New South Wales (RACS submission). This case is also reviewed by (for example) MacDonald, Crofts and Kaldor (1996) and MacDonald and Kaldor (undated). The patients were detected following routine notification of two patients who presented with acute Hepatitis C infection after undergoing minor surgical procedures in the same operating session. Genotyping showed that the five patients with HCV antibodies were infected with HCV genotype 1a. Only one patient, the first in the surgical session, reported a history related to potential prior exposure to HCV. It was proposed that transmission had occurred through blood in respiratory secretions via anaesthetic circuitry (MacDonald, Crofts and Kaldor, 1996: 140) although as MacDonald and Kaldor note, the mechanism of transmission was not "clearly identified" (undated:27). They conclude that this cluster of possible patient to patient transmission of HCV "highlights uncertainties" surrounding HCV transmission (MacDonald and Kaldor, undated:27).

3.6 MOTHER-TO-CHILD TRANSMISSION

Several studies have documented mother-to-child (or vertical) transmission of the Hepatitis C virus with rates varying from 0 - 9% (see MacDonald, Crofts and Kaldor, 1996 and MacDonald and Kaldor, undated for comprehensive literature reviews). The US based Centers for Disease Control however, have estimated the likelihood of perinatal transmission to be "low", in the order of 5-6% (Dienstag, 1997:69S). MacDonald, Crofts and Kaldor (1996:144) suggest that the rate of transmission from HCV from mother-to-child appears to be lower than the rate of transmission of HIV and Hepatitis B.

The NHMRC study noted that the reported studies of mother-to-child HCV transmissions have been carried out on relatively small cohorts. The Council concluded that it is not possible to draw firm conclusions from the available studies (NHMRC, 1997:10). The report identified a need for large, long-term prospective studies to examine the effect of viral load and genotype, maternal health, mode of delivery, breastfeeding and other associated factors, on transmission (NHMRC, 1997:10, 13). Given the current uncertainty, Sladden *et al* propose that:

> *people with Hepatitis C who are contemplating having children would be advised to seek medical advice regarding their HCV-RNA PCR status, hepatic enzyme function and clinical symptoms as markers of viral activity* (Sladden *et al*, 1997:293).

This issue is pursued more fully in Section 8.1.6.

While limited, the following remarks have been made about mother-to-child Hepatitis C transmission:

- in utero: having reviewed the available data, Dienstag concludes that:

> *currently data are considered insufficient to warrant any special treatment or unusual precautions for pregnant women with chronic Hepatitis C and their children* (Dienstag, 1997:69S);

- labour and delivery: MacDonald, Crofts and Kaldor (1996:144) note there is "limited information" about the effect of mode of delivery on HCV transmission; and

- breastfeeding: while noting that individual cases of breast fed infants contracting HCV have been documented, MacDonald and Kaldor observe that:

  > *there is little information about the role of breast feeding in modifying transmission of HCV from mother to child because of the small numbers of infants in individual studies and the low rate of HCV transmission in these studies* (undated:28).

  Dienstag concludes that breast feeding is not to be discouraged amongst mothers which chronic Hepatitis C (Dienstag, 1997:69S).

In summary, Dienstag suggests that:

> *data are insufficient to support the interdiction of pregnancy in women with chronic Hepatitis C, screening of pregnant women for HCV infection is not recommended and breast feeding is permitted* (Dienstag, 1997:69S).

3.7 SKIN PENETRATION: TATTOOS AND ACUPUNCTURE

There are a number of skin penetration activities that potentially pose a risk of Hepatitis C transmission including tattooing, skin piercing, electrolysis, beauticians, folk medicine and acupuncture.

The presence of tattoos has been independently associated with an increased risk of HCV infection (MacDonald, Crofts and Kaldor, 1996:139). A number of studies have demonstrated higher prevalence of HCV among persons who have had a tattoo but who have never injected drugs. The NHMRC 1997 report cites Kaldor's study which found a 27-fold increase in HCV prevalence among blood donors with tattoos (NHMRC, 1997:6). The risk of HCV infection increases with the number of tattooed sites and tattooing done by a non-professional, rather than a professional, tattooist. The NHMRC report suggests that a similar risk exists for other body piercing activities if the equipment was not sterile (1997:6).

3.8 OTHER MODES OF HEPATITIS C TRANSMISSION

In addition to the modes of transmission discussed above, three other modes of transmission have been identified: sexual and household transmission and unapparent inoculation. These three are discussed below.

3.8.1 SEXUAL TRANSMISSION OF HCV

Given the blood borne nature of Hepatitis C transmission, it is generally recognised that HCV is not a sexually transmitted disease. However, the evidence is not conclusive. On one hand, several studies support a role for sexual transmission of Hepatitis C. Approximately 10% of persons with reported cases of acute Hepatitis C in the United States report a history of potential sexual exposure. Anecdotal cases of sexual transmission have been reported, and HCV nucleotide sequence homology has been observed in viral isolates from sexual partners (Dienstag, 1997:66S).

However, other observations weigh against sexual transmission of HCV infection. Sexual transmission is negligible in sex-partner studies; alternative risk factors account for many cases of apparent sexual transmission between sexual partners; the prevalence of HCV infection in high-risk groups is much lower than that of other sexually transmitted infections; and the risk of apparently sexually transmitted HCV infection does not always correlate with intensity and duration of sexual exposure (Dienstag, 1997:66S).

Comprehensive reviews of available research are found in (for example) MacDonald, Crofts and Kaldor (1996), MacDonald and Kaldor (undated) and NHMRC (1997). MacDonald and Kaldor (undated:27) conclude that:

> *From all available evidence, the rate of sexual transmission appears to be low, particularly in comparison with blood borne transmission, and the rate of sexual transmission for HIV and HBV.*

Wodak made a similar observation when giving evidence to the Committee:

> *Sexual transmission is of very low prevalence. A very low proportion of new cases. There is argument about whether it is very, very low or just very low, but it certainly would not be more than one per cent of all new transmissions* (Wodak evidence, 2 October 1997).

Dienstag, in presenting at the US National Institutes of Health Consensus Development Conference on the management of Hepatitis C, concluded that "a consensus is difficult to draw among the many studies reported to date of sexual transmission of Hepatitis C" (Dienstag, 1997:67S). In view of the inconclusive evidence, the NHMRC called for further studies on the role of sexual contact in the transmission of HCV (NHMRC, 1997:12).

3.8.2 HOUSEHOLD OR INTRAFAMILIAL TRANSMISSION OF HCV

Transmission of HCV to household contacts of people with HCV infection has been investigated in cross-sectional prevalence studies. MacDonald, Crofts and Kaldor note that the prevalence of HCV in this group is “low”, however, they conclude that it is “difficult” to rule out blood borne transmission through items such as razors and toothbrushes as the route of transmission (MacDonald, Crofts and Kaldor, 1996:142). Dienstag noted that studies, particularly those from the United States, have failed to demonstrate any serologic or virologic evidence of HCV transmission to nonsexual partners within households (Dienstag, 1997:69S).

The NHMRC report stated that it seems “reasonable” to conclude that household contact, that does not involve blood or sexual exchange, is epidemiologically “insignificant” (NHMRC, 1997:9). Similarly Dienstag concludes that current data “do not support” household exposure as a risk factor for HCV infection (Dienstag, 1997:69S). MacDonald and Kaldor (undated:28) are more cautions stating that “it is not yet possible to make a conclusive statement about household transmission”.

3.8.3 UNAPPARENT INOCULATION

The Committee was advised that there is a small percentage of people who have Hepatitis C but who do not have any of the known risk factors - they have, for example, never lived overseas, had a blood transfusion, medical procedure or tattoo, or injected drugs (Wodak evidence, 2 October 1997). In such cases, transmission is usually attributed to what is called unapparent inoculation.

3.8.4 CONCLUSION

While injecting drug use is by far the major transmission route for HCV the Committee is aware that sexual and vertical transmission have yet to be conclusively proven. Clearly, as the NHMRC has suggested (1997:12-13) there is a need for further research in at least these two areas to determine exactly how HCV infection is transmitted between sexual partners and from mother to child. The importance of understanding the role these routes may play in transmission has been noted by Dienstag:

> *once risk factors for sexual and perinatal transmission, rare as they are, are delineated more accurately, public health officials may be in a better position to make recommendations about limiting transmission of HCV infection in these epidemiologic settings* (Dienstag, 1997:69S).

3.9 CONCLUSION

This chapter’s discussion has clearly identified injecting drug users, both past and current and those in prison, as the primary population group at risk of contracting Hepatitis C. As Kaldor noted in evidence, there are ”probably not other striking patterns or pockets of higher risk in other parts of the population” (Kaldor evidence, 3 October 1997).

The significance of injecting drug users as the primary ‘at risk’ population group has been succinctly summarised by Crofts who has noted that:

> *The major risk group, injecting drug users, is unpopular and finds public advocacy more difficult, often for compelling legal reasons . . . The apparently very low rate of sexual transmission means that the general community does not feel as threatened by Hepatitis C. Hepatitis C lacks the drama and novelty that the HIV epidemic had in abundance, thus making the task of capturing the attention of the public and policy makers much more difficult. The challenge of bringing Hepatitis C under control faces formidable epidemiological, microbiological and political obstacles* (Crofts, 1996:231).

CHAPTER FOUR

THE SOCIAL AND ECONOMIC IMPACT OF HEPATITIS C

The Committee was specifically asked to inquire into the social and economic impacts of Hepatitis C. The following discussion attempts to identify the major impacts faced by Hepatitis C infected persons and their families. In doing so the discussion draws heavily upon submissions received during the course of the Inquiry.

Of the 123 submissions received by the Committee 91 (or over two-thirds) were private submissions from Hepatitis C infected persons many of which described the impact the disease has had on their lives and often the lives of their partners and children. Some of these people contracted Hepatitis C through infected blood, others through health care related work or by sharing infected injection equipment while others do not know the source of their infection. What they all have in common, however, is a chronic virus for which there is at present no cure, little public awareness and rarely adequate and available information.

The majority of those contacting the Committee requested that their submissions be treated as 'Private and Confidential' thus protecting them from public knowledge of their condition. The Committee also noted that many of the submissions were written by spouses or close relatives, rather than by the Hepatitis C infected person, suggesting that the task of preparing a written account of the disease and its impact may simply have been too physically and/or psychologically taxing. It was also noted that, while it has been estimated that less than 15% of infected persons contracted the virus in ways unrelated to intravenous drug use (see Chapter Three), almost one third of the private submissions the Committee received identified infected blood or blood products as the cause of their infection.

The following discussion looks at the social impact of Hepatitis C with particular reference to the impact of the disease on those with medically acquired HCV, those who live in rural areas and parents. Experiences of discrimination and stigmatisation are also recounted. The economic impact on both those who have HCV and the community in general is also discussed.

4.1 THE SOCIAL IMPACT OF HCV

The Committee has heard that Hepatitis C affects all aspects of an infected person's life. As one infected person noted:

> *My illness has limited my capacity to work, seriously questioned my ability to be an effective parent, partner or friend, and prevented me from participating in my community. I feel isolated and often through that isolation robbed of the necessary tools to combat negativity and hopelessness* (Submission 67).

Another person wrote:

> *My life has changed. I was once full of energy, now I have none . . . My house work never gets done. I have lost interest in the world. I would*

> *really love to get the spark back in my life, but it all seems so hard. Depression takes over. This is a result of not having the energy to do anything or go anywhere* (Submission 7).

With dwindling energy levels everything, from close relationships with family members to social activities with friends, becomes increasingly overwhelming for the infected person. As a result, many become isolated at a time when strong networks of support from family and friends are needed the most.

In terms of relationships with family members, the Committee heard that:

> *My partner has been aware of my health situation since I first became aware of the specific nature of the illness in 1990. Whilst he has been very supportive, my illness has placed a significant burden on his life and upon our relationship* (Submission 31),

and

> *I got involved with someone who found out from my ex about the Hep C. He ran a mile. . . . As soon as someone finds out you have Hep C they treat you like some kind of leper* (Submission 40).

For some the pressure is just too much and the family breaks down:

> *My second marriage broke up as a result of my Hep C with the last words being "You're nothing but a diseased _______ "* (Submission 40),

and

> *my de facto relationship of 11 years, the result of which is a nine year old daughter, now seems doomed as my partner can't handle it anymore* (Submission 50).

In appearing before the Committee Crofts referred to the "increasing number" of divorce cases where Hepatitis C has become a factor (Crofts evidence, 28 November 1997).

Others recounted incidents experienced with friends:

> *I have had friends tell me to stay away until I am better as they fear I may infect their children*;

and

> *I have seen the questions in the eyes of the few close and trusted friends I have disclosed [it] to and feel a strong urge to reassure them that I'm not a "druggy" but an "innocent" victim - this then also appals me as no one*

> *deserves this disease or the stigma associated with it. No one is innocent or guilty - HCV does not discriminate, people do!!!* (Submission 81).

Even if the infected person has strong support from a partner and friends, the practical aspects of socialising, such as visiting or being visited by friends and family, can prove too much:

> *My social life is almost non-existent, as I am so fatigued that I cannot go out at night and I find that often I cannot get up (not because I don't want to), but through fatigue. I am at my best around lunchtime, but after that I need to rest again... We go visiting friends rarely, as I am too fatigued, nauseous or have bowel upsets and our plans fall apart* (Submission 22).

Not only are difficulties commonly experienced with family and friends, but most feel unable to reveal their status to the general community:

> *this is a very isolating illness as there is a stigma involved and you can't talk about it openly - in fact you mustn't tell* (Submission 1).

4.1.1 THE IMPACT OF THE VIRUS' PHYSICAL AND PSYCHOLOGICAL SYMPTOMS

As noted in Chapter Two, the most common symptom of Hepatitis C is fatigue while symptoms such as nausea, poor appetite, muscle aches, arthralgia, feverishness, weakness, and weight loss are also experienced. One HCV+ person told the Committee that:

> *I experience pain all the time in some part of my body. My abdomen is always very tender and painful to touch. I have extreme pain at night in the right upper quadrant (like a heart attack, heart checked thoroughly several times - normal). Other symptoms are: itchiness, rashes, headaches, bowel upsets, eye problems, stiff neck, feeling the cold much more, shivering spells, dry mouth, bleeding, nausea/extreme fatigue* (Submission 22).

Participants asked to comment on their condition in a North Coast Hepatitis C study confirmed the range of physical symptoms along with a number of psychological symptoms. In evidence Sladden, of the Northern Rivers Institute of Health and Research, noted that:

> *...the fatigue and inability to continue with the usual lifestyle is the most commonly reported problem that people experienced in the study that we conducted . . . They suffered from poor sleep, stress and depression, which compounded the problem . . . people obviously have a lot of psychological impacts from this disease* (Sladden evidence, 30 March 1998).

For many, the physical symptoms lead to depression, anxiety over the future, social isolation, depression and mood swings, loss of self esteem, the development of mild paranoia, acute stress regarding the decline of control over one's life, even a sense of "identity crisis" due to an inability to remain active socially, personally and professionally. The Committee heard from one HCV positive woman that living with the virus had had, and continues to have, a major impact on her. The virus and its symptoms has led to:

> *a loss of self-confidence..., loss of self-esteem, loss of energy, a loss of income, because I could not work full-time any more, difficulty with weight gain and self-image, difficulty with word finding when I am tired and not well and, above all, loss of self esteem that I can no longer count on myself to be dependable or reliable* (Lamb evidence, 30 March 1998).

Another wrote that:

> *It is so hard to try and lead any sort of normal life because of other people's ignorance towards the condition. You try to explain but they don't want to know. You get that way that you can't trust anybody. With me, paranoia has set in in a big way* (Submission 40).

Yet another HCV positive person had to give up a promising career as an artist when the symptoms started to dominate her life. Even a less physically demanding post-graduate degree could not be coped with:

> *I had to discontinue my studies for a year due to illness, which was difficult for me as I have been academically a high achiever all my life, and I am used to being energetic, involved and active. I have liver pain, fatigue, and chronic depression, and often feel like I don't have a future anymore* (Submission 85).

For many, one of the most difficult aspects of the diagnosis of HCV was the lack of information available and the fact that they have battled with symptoms for many years before an accurate diagnosis was made. The stress and anxiety of not knowing, the Committee acknowledges, adversely affects a person's ability to cope with the disease. As one infected person writes:

> *[I] was undiagnosed for many years, and even after diagnosis in 1991 found that there was extreme ignorance on the part of even high level professionals as to the cause and effects of Hep C. It is only now that I have fortunately managed to overcome most of the distressing difficulties of the disease (thanks largely to Interferon and much hard work on my part) that I have ceased to feel like a leper and an outcast from society* (Submission 42).

Debilitating symptoms are not confined to the disease itself. Interferon, the only approved and available form of drug therapy, often brings with it its own set of physical and psychological side effects (as will be discussed in detail in Section 7.2.1). The Committee heard from one infected person that:

> *Undergoing the interferon treatment was a very difficult period of my life. I experienced with it severe depression, terrible hives, which nothing would get rid of, increased weight some five stone and difficulty in losing it, lethargy and arthritis* (Lamb evidence, 30 March 1998).

The dwindling energy levels and bouts of pain, depression, sleep disturbance and irritability affect all aspects of an infected person's life. Depending on the severity of the symptoms, Hepatitis C can radically affect an infected person's working life, family life, sex life and social life, often resulting in a loss of most aspects of a dignified life.

4.1.2 THE IMPACT OF THE DISEASE ON THOSE WITH MEDICALLY ACQUIRED HCV

- **Recipients of Infected Blood or Blood Products**

Those who contracted the Hepatitis C virus through infected blood or blood products often expressed a combination of frustration, anger, disbelief and bitterness at their diagnosis. As public perception of the virus is still, erroneously, often linked to the issue of "hygiene", several submissions stressed that the disease left them feeling "dirty". One person noted, "... you cannot imagine the shock and feelings of uncleanliness that I experienced and still do when I think about it all" (Submission 29), while another recalled that "for a long time I felt dirty" (Submission 1).

The link between Hepatitis C and injecting drug use results in some respondents worrying that they will be stigmatised as users by those to whom they reveal their status. One person commented that she no longer reveals her status to anyone except health care workers because "they straight away think that you have been a drug addict. I don't think that I should have to keep explaining" (Submission 47). Another states that she feels "violated":

> *These feelings have calmed somewhat but I now find myself in great company. I have something in common with most NSW prisoners, most drug users and unfortunately I am now lumped into this group so I dare not tell anyone that I have HCV* (Submission 20).

Others recognised that the issue is not how the disease was transmitted but "how to treat it" (Submission 29). As one person notes:

> *In my case, no one can blame me for what happened yet I still have the distinct feeling I am a social pariah and have been treated like shit. What hope, then, has some poor bod who experimented with intravenous drugs years ago got?* (Submission 69).

- **Health Care Workers**

While Hepatitis C impacts upon the ability of most to work, the Committee has come to appreciate that HCV+ health care workers face additional questions. A positive diagnosis forced one health care worker who wrote to the Committee to ask:

> *Could I go on working as a registered nurse? Was I a risk to others? Had I already [prior to diagnosis] spread it unknowingly? Should I disclose [my status] socially and/or professionally?* (Submission 81).

4.1.3 THE IMPACT ON THOSE LIVING IN RURAL AREAS

Infected persons living in rural NSW are another group who face difficulties in addition to those already discussed. Long distances, few resources, self employment (often as farmers) and small communities are just some of the aspects of rural life which have the potential to intensify the already existing problems for an infected person.

While some respondents describe their family support as good, the lack of resources – including support groups – and the fear of being rejected by the local community can, and often does, lead to isolation and alienation for infected people. As one submission noted “telling anyone other than immediate family about Hepatitis C is not an option in a country town” (Submission 45).

Furthermore, being situated far from tertiary medical centres often affects the infected person’s ability to find information confidentially. One person wrote that:

> *There are very limited support services down here [south coast], and because of the very nature of a small country town and the gossip grapevine, I feel even more isolated – nobody here wants to put their hand up and admit to this disease – our children may well be persecuted* (Submission 38).

Another person added:

> *In the area I live in there is no support for Hep C people at all. My local doctor admits he knows very little about the virus; the Community Health Centre has no support group or even person; most of the time I feel alone, isolated and sick. Sick of being sick; sick of people’s ignorance, prejudice and paranoia* (Submission 73).

The lack of information, confidentiality and support services are, according to the submissions received, the most common problems in rural areas. In addition, the travel to and from tertiary hospitals situated in major regional centres (mainly along the coastline) for tests and treatment is both exhausting and expensive. As a spouse of an infected person, currently living in rural NSW, wrote:

> *We had to travel to Sydney every two months (very difficult when one is on a pension with no back up finance). It was necessary for me to travel with him due to his condition. It was done for 12 months* (Submission 36).

4.1.4 THE IMPACT OF HCV ON PARENTING

Numerous submission written by parents or grandparents highlighted a particular set of issues. For many the possibility of passing the Hepatitis C virus onto their loved ones has imposed enormous strain on their lives and the relationships they have with their partners and children. Lack of energy impacts upon the way they relate to their children and dealings with the wider, extended family can become complicated. These issues are examined in the following discussion.

- **Transmission**

The Committee received a number of submissions that expressed concern over the possible transmission of the Hepatitis C virus from parent (particularly mother) to child. As has been discussed in Section 3.6 research suggests the risk to be low, however, submissions from HCV positive parents and parents to-be still expressed much anxiety and concern.

Submissions referred to contradictory advice being given by medical specialists which only adds to the concern of parents. One woman recounted that the fertility clinic she was attending would not allow her to continue once they learnt of her Hepatitis C positive status despite her gastroenterologist advising the risk of transmission to her baby to be low (Submission 81). A worker with NUAA told the Committee that:

> *I have had a lot of contact with women . . . there are so many concerns, uncertainty, misinformation, fears, guilt factors . . . I have spoken to a lot of women who have terminated pregnancies on advice that they are Hepatitis C positive and therefore should not have children . . . This is advice from general practitioners, from friends and from people who they would think had the correct information . . .* (Poeder evidence, 7 November 1997).

Ms Madden, also from NUAA, added:

> *there are reports of women being put last on lists for procedures during the day and of women having to fight to get caesarean sections rather than natural births because they might be worried about the amount of blood, tearing and so on, associated with natural birth. It is a real struggle* (Madden evidence, 7 November 1997).

Many parents appeared to be overwhelmed by the possibility of having infected their children unwittingly. As one woman writes:

> *The horrible [fact] that I could have given it to my husband and children began to sink in... I cannot describe the guilt and sheer utter despair I felt in the next week waiting for their results to come back* (Submission 21).

- **Family Issues**

In addition to the risk of transmission, the Committee heard that parenting and other family issues present a number of practical difficulties. The combination of pain, exhaustion and general unwellness which the HCV positive person typically experiences severely inhibits their ability to interact with their children. One parent describes it as follows:

> *I wake up every morning with permanent "morning sickness". Some days just getting out of bed is impossible. My little boys ask me "When will you be better again mummy", "Why can't you play mummy", " You're always too tired, it's not fair". And they're right - it is not fair - not for my children or my husband who has a wife who cannot do her home duties let alone her wife 'duties'* (Submission 73).

Another parent adds:

> *The worst impact is on my family. My...children don't really understand except that Mum is tired and cranky and money is tighter because Mum can't even do as much part time work as before. My husband (an incredible support) is working longer hours to make ends meet as well as often coming home and making dinner or other jobs traditionally mine* (Submission 12).

Mothers wrote that:

> *I see the change in my family. My husband had to stop work when he's a good hard worker. My 15 year old daughter feels she had to step in mum's shoes and had to grow up too fast. My nine year old can't understand why mum can't work in her canteen as I've been told everyone would have to know. I have also lost some family and friends due to not understanding* (Submission 55)

and

> *there isn't a day in my life when I don't think about my prognosis, whether I will live to see my children [aged one and three years] become adults . . . I don't cope very well a lot of the time - emotionally* (Submission 1).

These comments are characteristic of the general problems families face according to the submissions presented to the Committee. With smaller incomes, higher medical expenses, less ability to work and additional duties to be undertaken by the partner, there is a great concern among parents that there is simply not enough time and energy left for their children.

Needless to say, the problems facing single parents with advanced symptoms are even more severe - particularly if the parent in question has had, or still has a drug dependency. During evidence given by a clinical psychologist, the Committee heard of one of such case:

> *I came across a young woman... who has hepatitis C. She was a drug user. She is now on methadone. She has to attend the methadone clinic six days a week because she has one free day when she is allowed to take a dose home. She has a child who is four and another child who is two. She has to travel seven kilometres each day by three buses, dragging those little kids with her, to get her methadone . . . The location of services is often so poor. Here is this woman with no support and two little kids... That is just one of the many examples around* (Lamb evidence, 30 March 1998).

In evidence, Mr Harvey from the Hepatitis C Council told Members of a single mother who was faced with fostering out her children because she was so ill that she could not care for them:

> *I guess she did not have enough support from family and the community, so she was faced with a shocking decision* (Harvey evidence, 3 October 1997).

Problems also arise when the family unit breaks down. Crofts told the Committee of a case he was familiar with in which one partner is refusing custody or access to the other partner on the grounds that the other partner is Hepatitis C positive (Crofts evidence, 28 November 1997).

The medical, economic and social impact of HCV on the family is extensive, particularly in already stressed family situations such as the above. The symptoms of the virus and their fluctuating behaviour radically undermine the energy necessary to hold together even families without special needs and thus put a serious pressure on children/parent relations as well as relations between the parents themselves.

- **The Extended Family**

The epidemiology of HCV in Australia suggests that a large proportion of those infected are 40 years and over reflecting injecting drug use practices engaged in during the 1970s. Consequently, many of these people have families and extended families who are also affected by the diagnosis, making the issue of extended families one of considerable importance. Again, the question of transmission is at the forefront of concerns for infected people. As one person writes:

> *My main concerns were 1) did I give it to my wife? 2) Did I pass it on to my grandchildren? 3) Should I tell the rest of my family? ... 4) Where do I get good information on what to do – how not to pass Hep C on to others?* (Submission 48).

Another person adds:

> *My relationship with my family has changed from the time I was diagnosed as they are living in fear that my grandchildren or themselves may be infected. Overnight stays for my grandchildren place everyone on alert as the kids may accidentally use my tooth or hairbrushes,* (Submission 43).

While the issues are similar to those faced by the immediate family, the issue of Hepatitis C and the extended family is complicated by the fact that larger numbers of family members are involved and need to modify their behaviour without overreacting through fear. Furthermore, older people may experience great difficulties in admitting to the virus, partly out of fear of rejection from the family, as suggested in some submissions, and partly out of fear of accusations regarding its source. All these issues add to the complication of dealing with HCV in the extended family.

4.1.5 CONCLUSION

Hepatitis C is a condition which affects those infected in a number of ways. The numerous private submissions the Committee received highlighted the day to day reality of the disease and the impact it has had, and continues to have, in a number of contexts on people's lives and on those of their families and loved ones.

Sladden et al have attempted to quantify the impact of HCV on personal circumstances. Their findings are reported in Table Eighteen below.

TABLE EIGHTEEN
IMPACT OF HCV ON PERSONAL CIRCUMSTANCES (%)

CIRCUMSTANCES	NO CHANGE	CHANGE: WORSENED	CHANGE: IMPROVED	OTHERS/ NOT STATED
Relationship:				
• with partner	69.4	16.1	4.3	10.3
• with household	76.7	11.1	3.9	8.4
Financial situation	69.8	22.7	1.9	5.6
Ability to perform daily tasks	54.4	39.0	1.5	5.1

CIRCUMSTANCES	NO CHANGE	CHANGE: WORSENED	CHANGE: IMPROVED	OTHERS/ NOT STATED
Fatigue	45.4	45.4	3.4	5.8
Diet	48.2	20.3	25.1	6.4

Source: Sladden *et al*, 1998:510

Part of the social impact of Hepatitis C is generated from the lack of general recognition of the problematic extent of the condition. The fact that few infected people knew anything about the virus before they became infected, combined with the widely reported lack of information available from general practitioners upon diagnosis, were described in many cases as contributing to long periods of extreme anxiety and a feeling of being ‘in limbo’. One woman who has suffered from numerous serious conditions all her life, some life threatening, describes her reaction to her HCV diagnosis as follows:

> *I am a fighter, I should have died many times through my life and I have survived, I have an outrageously strong will, and can keep walking when most people would faint from lack of oxygen, from lack of blood. I have felt discomfort every day of my life, and accept that it is possibly true for the rest of it, but during this period [before diagnosis but after the symptoms set in], I was overwhelmed and wanted to die because I couldn’t stand having so little control over my body and my life, and not knowing what was wrong with me... I sometimes thought of suicide, which was strange for I had spent so much of my life winning over death. It nearly sent me insane* (Submission 88).

She concludes by stating that “feeling ill is unbearable when you are frightened about what and why” (Submission 88). Similar sentiments were expressed in numerous submissions. As these people point out, until an infected person knows what is at stake and what the condition involves and until adequate support is in place for coming to terms with this information, an infected person cannot start to relate to it in a way which may secure progress. Stress and anxiety are not unrelated to the physical aspects of the disease and are likely to undermine a person’s ability to cope. It is precisely because HCV affects a person in so many facets of their lives that the well-being of the whole person must be secured in order to create the possibility of living a dignified life with HCV. Rejection and stigmatisation by health professionals, the general public or loved ones is extremely hurtful and only adds to the struggle to cope with the disease.

4.2 DISCRIMINATION AND STIGMATISATION EXPERIENCED BY THOSE WITH HEPATITIS C

The Committee is aware of two studies documenting discriminatory incidents experienced by those with Hepatitis C. The 1997 study by Crofts, Louie and Luff draws upon 37 case histories detailing 41 problematic incidents gathered as a result of information collected by members of Hepatitis C support groups, foundations and councils during the last half of 1994. The study made no attempt to quantify the frequency of discriminatory practices nor the resulting problems. Rather, the aim of the study was to highlight the existence of the problems and to gain some idea of the situations in which they occur (Crofts, Louie and Luff, 1997:89).

The issue of discrimination was also considered in the National Hepatitis C Councils' Education Reference Group's Report into the needs of people living with Hepatitis C (1996). This study records respondents' experiences of discrimination from health care workers, employers, family and friends, the local government, the local community, and government departments (1996:32-38). Many of the examples given are similar to those reported to this Committee by those making submissions and for this reason are not included in the following discussion.

In speaking at the First Australasian Conference on Hepatitis C President of the NSW Anti-Discrimination Board, and Chair of ANCARD, Mr Chris Puplick, referred to the discrimination experienced by people with Hepatitis C as "a secondary or underlying epidemic" which he considered to be "just as prevalent, just as virulent and just as threatening" as Hepatitis C itself (1997:224). In making their submission to the Committee, the Hepatitis C Council noted that the discrimination experienced by those who are HCV+ may be:

> *institutionalised through insurance and superannuation policies, employment programs, or through the practices of professionals such as doctors, dentists or funeral industry workers* (Hepatitis C Council submission).

During the course of this Inquiry, the Committee heard considerable evidence concerning the extent of discrimination and stigmatisation against HCV positive people. Incidents reported included discrimination by health care workers (including nurses, general practitioners, medical specialists and dentists), friends of the infected person, and the general community. These distressing circumstances often result in the infected person opting for anonymity in all aspects of life. One HCV positive person wrote:

> *I have had a lot of bad treatment towards me by both friends and health professionals. I no longer disclose to friends, dentist, etc, my condition through fear of rejection and stigmatisation. This could be potentially dangerous to an unhygienic practitioner who does not thoroughly sterilise* (Submission 54).

Another HCV positive person from a rural area added:

> *I constantly live in fear of 'someone' discovering my 'secret' and being automatically pre-judged and stereotyped. The guilt I carry is soul destroying! It creates an added stressful burden that intensifies my illness and interrupts what could be a reasonably 'normal' life* (Submission 41).

Drawing upon their considerable experience, representatives from the Hepatitis C Council cited several examples of discrimination to Committee Members:

> *there was the case of one family whose son died of Hepatitis C and the funeral company refused to handle the body, refused to allow a viewing and even refused to carry the casket, . . . we have another case of a TAFE campus here in Sydney where a student's Hepatitis C status was made known to management. It was then made known to tutors and teachers, and those teachers refused to teach a class when that student was present* (Harvey evidence, 3 October 1997).

4.2.1 DISCRIMINATION BY HEALTH CARE WORKERS

Before diagnosis, an infected person typically experiences a large number of fatigue related symptoms which may not necessarily be assumed to be of the one cause. Prolonged periods of being unwell and an inability to cope despite the fact that no tests provide any explanation (in cases where Hepatitis C screening is not performed) has, according to many submissions, lead to implicit or explicit accusations of "malingering" or hypochondria. The Committee received numerous descriptions of such accusations:

> *I knew that I was ill with something, because I would wake at night and vomit, wake in the morning and have continual bad headaches and nausea. The GP clinic I attended was hopeless, I believe because I confided to them that the only thing that stopped the nausea was cannabis. They told me that it was purely mental, not physical. I had no support, my husband did not know how to respond, he wanted me to be as I was before. If there was nothing wrong I should get better, or behave better. If the doctor was right it was mental and I should stop it, it was selfish and unattractive. It was a dreadful time for me as I knew that I was sick but couldn't get help* (Submission 88).

Another person added:

> *...when I became ill I was a postgraduate student with a bright future. I have had to face the possibility of never working again and this has been very difficult to accept, particularly when other have disparaged me as "hypochondriac" and I myself have felt that my illness was psychosomatic*

> *or mere "laziness". Many people (myself included) find it difficult to accept the existence of "invisible" illnesses such as Hepatitis C* (Submission 67).

If liver damage is detected before correct diagnosis of the virus, excessive alcohol consumption is often assumed. Once the virus has been properly diagnosed, the assumption of injecting drug use is reported by many HCV positive people as a major obstructing factor in good relations with their doctors. These are concerns expressed both by those who contracted the virus through injecting drug use and those who received the virus through other means.

A number of submissions cited specific incidents of discrimination by their general practitioner or medical specialists. One woman wrote that her gynaecologist of six years no longer wanted to treat her once her HCV status became known (Submission 54). Another recounted that:

> *From the beginning every doctor I saw was hopeless; most were disdainful - I was just another junkie slag. I had a routine check for a congenital heart defect and remember the cardiologist doing the routine flirt then backing away when learning I was positive, telling me with disgust how skinny I was* (Submission 15).

Loveday told Committee Members of an incident recounted to him by a gentleman who contacted the Hepatitis C Council's telephone service. The gentleman had visited his general practitioner "of longstanding" to have a full range of tests as he and his partner were considering starting a family:

> *He got all the test results and when his doctor got to the HCV result section, which was positive, his doctor said "now that you know that, I don't want anything more to do with you"* (Loveday evidence, 7 November 1997).

Others recounted incidents experienced in hospitals where they felt "branded". Mr Loveday, from the Hepatitis C Council spoke of those who, upon disclosing their status within the health care setting, were "marked as having Hepatitis C through yellow armbands or through their new-born babies' bassinets being marked with a particular sticker" (Loveday evidence, 3 October 1997). In responding to these practices, NSW Health advised the Committee that:

> *the Department is aware of, but does not support, the routine use of coloured tags, sign posting or marking of patient records to indicate the presence of known infectious disease. The Department has advised Area Health Services of its position on this issue. The routes of diseases transmission and the unknown levels of infectivity in the general patient population make the use of armbands or prompts artificial protective measures. In addition, the use of surrogate markers potentially breaches*

> *patient confidentiality as those persons who understand the code indicated by the marker immediately know the patient's condition, regardless of whether or not they require the information for the purpose of providing health care* (NSW Health supplementary submission).

Other stories presented to the Committee include:

> *I was locked away in a little room somewhere [in the hospital], food was poked through a door and hospital staff would gown up and swathe themselves and come and talk to me* (Smart evidence, 26 February, 1998).

One person wrote:

> *I remember in hospital once seeing my notes which were marked "drug addict". I never told anybody that. It just came from being Hep C positive* (Submission 66).

Other incidents include:

> *When I was a patient in our local private hospital after the birth of our second son. The nursing staff had written on my bed notes and the baby feeding chart "Mother is HCV +ve" and had a large yellow contaminated waste bin at the door of my single room. This caused a lot of unnecessary stress and anxiety . . . had any of my visitors or nursing colleagues seen this?* (Submission 81).

and

> *I recently went to hospital and was given a yellow toxic bag for my rubbish - nobody else on the ward had this. This told the other people on the ward that something was wrong with me . . . This was very upsetting* (Submission 47).

Of the case studies reported to Crofts, Louie and Luff in their 1997 study, approximately one-half (46%) of the cases occurred in health care settings. In speaking on the results of his study during his appearance before the Committee Crofts referred to "many instances" of discrimination, some of which were "devastating":

> *stories of doctors advising women to have terminations of pregnancy because they are Hepatitis C positive, a lot of it around pregnancy and birth* (Crofts evidence, 28 November 1997).

In commenting on the role of health care workers in addressing the issue of discrimination against those with Hepatitis C Puplick has stated that:

> *I stress the responsibility of people in the health care system itself to take a lead in the elimination of discrimination against people with Hepatitis C.*

> *It is a sad fact that many people do not present for treatment, or receive inadequate treatment because they are intimidated by the attitude of the medical profession towards them. It is not the role of that or any other profession to be judgemental, but rather to act in accordance with the best standards and principles of their profession, treating people as human beings with the need for medical attention and rendering it accordingly* (Puplick, 1997:228).

In appearing before the Committee Puplick spoke of the "extraordinary" amount of discrimination against those who are HCV+ and that "regrettably" a "large amount" of that is from health care workers and providers of health care services (Puplick evidence, 7 November 1997). In his opinion:

> *that is something which Area Health Services, the Department of Health, the professional colleges and unions need to address because it is a very serious problem* (Puplick evidence, 7 November 1997).

The ANCARD Hepatitis C Sub-committee has recommended research into the knowledge and attitudes of health care professionals towards HCV (Hepatitis C Virus Projections Working Group, 1998:33). The Hepatitis C Council recommended the statewide implementation of general practitioner and health care worker education to address discrimination (Hepatitis C Council submission). It proposed that these programs cover values and attitudinal change and that they be both initial and ongoing (Hepatitis C Council submission). The Committee feels that the National Hepatitis C Education Program for General Practitioners currently being implemented (see Section 8.4.1 for discussion) may go some way to addressing the values and attitudes of general practitioners. However it does acknowledge that this program will only target medical practitioners and not other health care workers in hospitals. In the Committee's opinion, there is a need for all those working in the health care sector to be aware of Hepatitis C related discriminatory practices, values and attitudes.

RECOMMENDATION 19:

That NSW Health design and implement an awareness campaign for all those working in the health care system addressing practices, values and attitudes that discriminate against those with Hepatitis C accessing the health care system.

In proposing this awareness campaign, the Committee saw merit in Puplick's comment cited earlier in which he referred to the importance of the relevant professional colleges and unions addressing Hepatitis C related discrimination.

RECOMMENDATION 20:

That the Minister for Health meet with representatives of the various professional colleges (including the Royal College of Surgeons, Royal College of General Practitioners, and Royal College of Nursing) and unions and urge them to support the awareness campaign addressing Hepatitis C related discrimination in the health care system proposed in Recommendation 19.

- **Privacy Related Issues**

During the course of giving evidence the Committee heard of instances where breaches of confidentiality had occurred and people's Hepatitis C status made public. One witness told the Committee that:

> *my recent experience is in a large public hospital where I had been accessing treatment for Hepatitis C . . . An appointment for a biopsy was re-scheduled. A call was made to my home. To some degree there was a breach of confidentiality. The staff member from the hospital identified from which department he was calling, which pertained to liver biopsy. The caller pressed my flatmates for a further contact number, and my flatmates furnished the caller with a contact number at work. I work in public health. The call went to the front desk [of my work], then administration staff, where there was another breach of confidentiality, pertaining to which department, pertaining to a scheduled biopsy and my full name . . . the call then went to the nurse practitioners. More information was given to them. By that stage a staff member from the hospital became aware that I was not a client of the hospital, but a staff member. The call then went to my clinical supervisor who discussed the situation and became fully aware of my status. My clinical supervisor re-scheduled the biopsy for me.*

In discussing the consequences of this incident with Members, the witness stated:

> *I did not give permission to anyone to disclose this information. Suddenly I am informing [my flatmates] of what Hepatitis C is about, and I feel I have to justify myself, defend myself and explain myself. As a part of the breach of confidentiality with administration at work, staff members have become aware of some of my injecting drug use history, my past history. Being from the nurse practitioner unit, they have also expressed concern and shock at the degree of disclosure that came from the staff member at the hospital at which I was accessing treatment. Furthermore, my clinical supervisor is aware of the situation and I have felt it necessary to discuss with him the pros and cons and the specifics of my drug use . . . My history is open to some discussion and hearsay, and I am at the*

> *point at which my continued employment in that organisation is questioned. The director cannot give me assurances as to what will occur*.

Mr Puplick raised the issue of privacy legislation during his evidence. He felt it was urgently needed to address many of the problems experienced by those who are HCV+. He noted that:

> *for 12 years the Privacy Committee of New South Wales has been pleading with this Parliament to enact privacy legislation, which has been promised ad nauseam. Attorney General Hannaford had a bill before the Legislative Council prior to the last election . . . This Government was elected promising the enactment of privacy legislation. Attorney General Shaw on four separate occasions has announced the imminence of the legislation. There is still no legislation and as a result the health status privacy issue remains one of the most sensitive. People whose health status is revealed improperly have absolutely no means of redress within New South Wales* (Puplick evidence, 7 November 1997).

Mr Puplick added that:

> *if proper privacy laws were in place there would be at least some regime, some protocol, some redress. It remains extraordinarily unfortunate that the New South Wales Parliament just will not address this as an issue, and until the Parliament does address it, the providers of health care cannot be expected to do anything other than behave in the way they have traditionally done* (Puplick evidence, 7 November 1997).

The Committee notes that the *Privacy and Personal Information Protection Bill* was introduced into the Legislative Council on 17 September 1998. During the Bill's second reading speech, Attorney General, the Hon J Shaw, MLC, noted that the purpose of the Bill is:

> *to promote the protection of privacy and the rights of the individual by the recognition, dissemination and enforcement of data protection principles consistent with international best practice standards* (Shaw, 1998:7598).

He proceeded to identify the objects of the Bill:

> *to promote the protection of the privacy of individuals; to specify information protection principles that relate to the collection, use and disclosure of personal information held by public sector agencies; to require public sector agencies to comply with these principles; to provide for the making of privacy codes of practice for the purpose of protecting the privacy of individuals; to provide for the making of complaints about*

> *privacy-related matters, and for review of conduct that involves the contravention of the information protection principles or privacy codes of practices; and to establish an office of Privacy Commissioner and to confer on the Privacy Commissioner functions relating to privacy and the protection of personal information* (Shaw, 1998:7599).

The Bill was read a third time in the Upper House on 28 October 1998 and then referred to the Legislative Assembly. At the time of tabling this Report, the Bill was scheduled for debate in the Lower House.

4.2.2 DISCRIMINATION BY THE GENERAL COMMUNITY

Stories such as the following are typical of submissions received by the Committee:

> *I told one of my friends I have Hep C with only limited knowledge myself. I could not properly explain what it was all about. She assumed it was like AIDS and has had nothing to do with me, she won't have her kids play here either. I think she assumed I was a junkie, I don't really know. Her reaction stopped me telling anyone else* (Submission 7).

Such an experience with a friend or acquaintance often stops HCV positive people telling others of their condition. Further, the realisation that one's children might be affected by local community perceptions only adds to their distress. As one person from a rural area commented, combatting the disease and the discrimination simultaneously and with so little public information at hand makes the condition almost unbearable (Submission 47).

One of the very severe cases of discrimination of which the Committee was informed involved a church-going couple from a metropolitan area:

> *[My wife and] I were forced to leave the ... church we started to attend, when the members learnt that I had HCV. They had some quite erroneous notions about HCV, such as "It leads to full blown HIV/AIDS"; or, I might suddenly have an accident and cut myself and they would all be infected by me. Disturbingly the opposition [to us] was fanned by one member, a GP! This really hurt us* (Submission 22).

The Committee also heard of discrimination impacting upon work. During the course of evidence, the Committee heard from a young HCV+ woman:

> *I have had problems with work in a way. I was doing hospitality, and when they learnt that I was Hepatitis C positive they did not want me to work in the kitchen. If you put down that you are Hepatitis C positive you do not get the job. Then I changed and wanted to do child care, but I am not having much luck with that. So there is not really much I can do. If you put it down, you will not get the job; if you do not put it down, you are lying to them* (Howell evidence, 7 November 1997).

Puplick has noted that discrimination against people with Hepatitis C is against the law (1997:227). In areas covered by legislation (such as employment, the provisions of goods and services, state education, the operations of registered clubs and in relation to accommodation) discrimination is contrary to the disability provisions of the NSW *Anti-Discrimination Act, 1997* and (in a slightly wider context) the provisions of the Federal *Disability Discrimination Act, 1992.* He also informed conference participants that the Anti-Discrimination Board of NSW has issued formal guidelines explaining the provisions of the state's legislation and making clear that discrimination on the basis of Hepatitis C constitutes an offence and provides a legitimate basis for people to make formal complaints (Puplick, 1997:227).

In their discussion on anti-discrimination legislation in Australia, Crofts, Louie and Luff also identified the *Disability Discrimination Act* along with the *Human Rights and Equal Opportunity Commission [HREOC] Act, 1986.* The HREOC Act gives the Commission power to investigate breaches of the Declaration of the Rights of Disabled Persons. Infringements of the Declaration are not of themselves necessarily unlawful. The Commission can therefore only hold inquiries into complaints of discrimination or violation of human rights. It has no power to conduct formal hearings or complaints (Crofts, Louie and Luff, 1997:94).

While the Hepatitis C Council suggested discrimination to be “relatively widespread” (Hepatitis C Council submission), the extent of discrimination against HCV positive people in the general community is almost impossible to estimate. During the course of this Inquiry, the Committee has come to appreciate the problem to be extensive.

Due to the present levels of ignorance and stigma surrounding the disease, those who choose to disclose their status are often treated with disrespect, hysteria, coldness or rejection. While most infected persons who contacted the Committee choose to inform medical practitioners of the virus, few inform more than very close loved ones. Many even express deep regret about having told friends, only to be abandoned and ostracised. HCV positive people have an important contribution to make to the promotion of public understanding of the disease, its transmission and prevention, but are often unable to make this contribution because of the public's response to them as infected people.

4.2.3 DISCRIMINATION EXPERIENCED BY INJECTING DRUG USERS WITH HEPATITIS C

> *For many people with Hepatitis C, discrimination relating to Hepatitis C is actually the least of their problems. Because of the discrimination relating to their injecting drug use status, Hepatitis C is just the icing on the cake - double stigmatisation* (Crofts evidence, 28 November 1997).

The Hepatitis C Council noted that a “large part” of discrimination and stigmatisation is associated with injecting drug use and attitudes towards those who inject (Hepatitis C Council submission). As the submission notes, many people with HCV are assumed to be current injecting drug users regardless of their mode of infection, or whether they had used some time ago. The labelling of drug user, or the more negative term "junkie", can become barriers to people seeking assistance as they fear that they will encounter these reactions from health care providers.

The Council's submission also notes that current injecting drug users in particular may experience an additional layer of stigmatisation associated with criminality, arising both from the criminal nature of drug use itself, and also the fact that a substantial amount of property crime is committed by people needing to finance their drug use (Hepatitis C Council submission).

Puplick also noted the impact of the illegal nature of injecting drug use during the course of his evidence:

> *the discrimination which has taken place against people who are Hepatitis C positive undoubtedly stems in a large part from the fact that they are perceived as part of a group of people who have engaged in illegal behaviour at some stage in their life although . . . that may have been a single incidence 20-odd years ago in an experimental situation, not since repeated. The attached stigma persists and very often has negative consequences in encouraging people to come forward to be tested and subsequently receive treatment* (Puplick evidence, 7 November 1997).

Injecting drug users utilising the health care system also appear to experience difficulties. Puplick told the Committee that:

> *it frequently occurs in clinical situations that people who are HCV positive are those who are always attended to last, on the basis that junkies do not really matter in the provision of health care services* (Puplick evidence, 7 November 1997).

Speaking more generally Puplick informed Members that:

> *there is also a considerable amount of complaint, arising from breaches of privacy, that people's employment has been threatened or indeed terminated because they are HCV positive, on the assumption that they are a high risk because they are all current injecting drug users; which of course is not the case* (Puplick evidence, 7 November 1997).

4.2.4 CONCLUSION

The Committee has come to appreciate that, particularly in relation to the issue of discrimination, Hepatitis C is a medical condition, not a political issue or a moral question of right or wrong. As such, the dissemination in the community and among the broader medical services of thorough and inclusive information about the condition will be of help both as a ground for appropriate preventative strategies and as a step towards eliminating the kind of discrimination currently encountered on a regular basis by HCV positive people. The issue of education is considered in detail in Section 10.6.

Crofts, Louie and Luff note that the National Action Plan on HCV does not mention the issue of discrimination or examine strategies for its prevention, reduction or redress (1997:96). The Committee considers this to be most unfortunate. Members trust that any revision to the Plan resulting from the evaluation currently underway will take the issue of discrimination into consideration.

While the National Action Plan did not consider the issue or propose strategies to address the issue, a number of organisations have considered the issue and forwarded recommendations. The ANCARD Hepatitis C Sub-committee has, for example, recommended the systematic documentation of discrimination against HCV-infected people with investigation of underlying factors (Hepatitis C Virus Projections Working Group, 1998:33). Along similar lines, the National Hepatitis C Councils' Education Reference Group noted the impact of the NSW Anti-Discrimination Board's inquiry into discrimination and HIV/AIDS and its resultant report, *Discrimination: the other epidemic* (1992). This report recommended legal and administrative changes across a wide range of activities. The Reference Group proposed that similar inquiries need to be held in all states and territories to raise awareness about discrimination against people with Hepatitis C (1996:40). The Committee fully supports this recommendation.

RECOMMENDATION 21:

That the Attorney-General instruct the Anti-Discrimination Board to conduct an inquiry into discrimination and Hepatitis C in New South Wales. The Committee further recommends that the resultant report of this inquiry be distributed widely to relevant employer and employee organisations, trade unions, education institutions, hospitals and relevant community organisations (such as the Hepatitis C Council of NSW) across the state.

The Hepatitis C Council has proposed the development and implementation of public awareness campaigns to inform and educate people about HCV. This latter proposal is taken up in Section 10.6 which looks at a national education/information campaign. The Hepatitis C Council also recommended the design and implementation of private and public workplace education programs, both initial and ongoing, particularly in areas which impact directly on people with HCV such as social security, day care centres, funeral and prison settings (Hepatitis C Council submission). A similar recommendation was made by the National Hepatitis C Councils' Education Reference Group which called for education for employers, service providers and the general community (National Hepatitis C Councils' Education Reference Group, 1996:40).

RECOMMENDATION 22:

That the Premier direct an education campaign be designed and implemented across all sectors of the public service addressing practices, values and attitudes that discriminate against those with Hepatitis C and ensuring that those working for the government are aware of the illegality of discriminating against those with Hepatitis C.

It has also been proposed that people with Hepatitis C need information to ensure they are aware of their legal rights and of ways to address discrimination (National Hepatitis C Councils' Education Reference Group, 1996:40). A brochure addressing these issues entitled *Discriminating Against People Living with Hepatitis C* has been developed by the Equal Opportunity Commission Victoria (1996). The Committee is aware that the Anti-Discrimination Board of New South Wales has produced a factsheet entitled *Discrimination Against People with Hepatitis and Other Infectious Diseases* (undated). The Committee understands that the Board does not have the financial resources to produce factsheets aimed at people with specific infectious diseases and as a result, a factsheet specifically designed for those with Hepatitis C has not been available in the past.

The Committee also understands that when the factsheet was reprinted in 1997 all references to hepatitis were deleted and the generic term "infectious diseases" used instead. As the Board informed the Hepatitis C Council "hopefully this will encourage people to contact the Public Health Unit to find out about individual infectious diseases" (Dustmann correspondence, 21 July 1997). While fully appreciating the financial constraints of the Anti-Discrimination Board, the Committee does not consider it satisfactory that the only brochure addressing discrimination for Hepatitis C people now has no mention of the disease. The Committee wishes to see information specifically targeting those with Hepatitis C made available to ensure they are fully informed of their rights when experiencing discrimination.

RECOMMENDATION 23:

That the Anti-Discrimination Board of New South Wales design an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination. The Committee further recommends that the Hepatitis C Council of NSW be given responsibility (and adequate funding) to distribute this brochure.

RECOMMENDATION 24:

That the Attorney General provide adequate funding to the Anti-Discrimination Board of New South Wales for the design and development of the information brochure proposed in Recommendation 23.

In forwarding these recommendations addressing the issue of discrimination against those with Hepatitis C, the Committee is aware of the range of resources and services addressing the issue of discrimination that are available to those with HIV/AIDS such as the HIV/AIDS Legal Centre (HALC) run in conjunction with Community Legal Centres, the *HIV Legal Link* magazine, HIV-specific resources developed by the NSW Anti-Discrimination Board and specifically funded legal positions at ACON.

4.3 THE ECONOMIC IMPACT OF HCV

In considering the economic impact of Hepatitis C the Committee has looked at two aspects: the impact of the disease upon those who are HCV positive and the broader impact upon the community as a whole. Both of these issues are considered in the following discussion.

4.3.1 THE ECONOMIC IMPACT OF THOSE WITH HCV

Given the chronic nature of the Hepatitis C infection and the commonly experienced fatigue related symptoms, the disease has an economic impact upon many of those with Hepatitis C. The submissions received by the Committee suggest that many HCV positive people with serious symptoms are unable to continue working in their ordinary capacity. One gentleman who retired early as a result of his Hepatitis C wrote openly of the economic impact Hepatitis C has had upon his life:

> *My income dropped from around $40,000 in 1995 to a Beneficiary Fund amount per annum of $10,884. My wife worked at Hospital X but her worry about me caused her to seek a position closer to home. She was fortunate to find a position at Hospital Y but this meant a drop of $3,000 in salary too. I require constant medication for the many complaints I have and this is quite a drain on resources. We keep up our MBF cover as this means less wait for tests to be done . . . and this is much too expensive. I do not qualify for any pension or benefits, but the Pharmaceutical Safety Net is no some help as I pay reduced amounts for prescriptions* (Submission 22).

Another wrote that:

> *[T]o be honest, when I feel OK . . . there is no happier person, because I know that that day I will be able to work and to be active at home as well. This is a day for celebration, and I always do so, because I value every hour of being OK, having in mind that . . . the next day I won't be able to move from my bed for the rest of the week . . .*
>
> *. . . out there in the job market there is no tolerance for such a fluctuated behaviour, no one will tolerate that their worker is OK one day, not OK for two days and [only] so-so for the rest of the week. No company will tolerate this kind of worker* (Submission 51).

During the course of evidence the Committee heard that:

> *I have started working with handicapped people in a part-time job. That is all I could handle. I could not handle full-time work, because after a full-on day at work I need a day to recuperate. It is just that I am in a job in which I do some night shifts . . . or sleep-overs, and I do them when I have got time to recuperate. I could not work full-time*.

The effect of chronic tiredness limits many from working full-time:

> *I do not think I can work a full day's work. It is just fatigue . . . I just get too tired . . . I cannot be up for eight hours*.

HCV positive people in rural areas are also adversely affected by the fact that they are often self-employed on family run farming properties. Although this may initially provide some flexibility, the inability to work frequently puts already financially vulnerable businesses at risk:

> *living on a property some 200 kms from a major centre hindered by search for information. The thought of not working is an anxious one. We own a cattle property. Our sons are away at boarding school. Our economic situation would change* (Submission 19).

Tim Sladden of the Northern Rivers Institute of Health and Research noted that:

> *people found it difficult to work and obviously their financial situation was affected by that* (Sladden evidence, 30 March 1998).

Of all professions, the economic impact is possibly greatest upon those HCV+ people who are health care workers. As will be discussed in Section 10.3 surgeons who test positive are not able to perform exposure prone procedures. For many surgeons this eliminates many procedures they routinely perform forcing them to either retrain or retire from surgery. Other health care professionals such as dentists and nurses are often put in a similar situation. The Committee heard from one nurse that:

> *Because [among other things] the incredible stress associated with managing infected clients, I found I was unable to continue at work. The consequences for me are:*
>
> - *loss of employment*
>
> - *my [very long term] relationship failed. Consequently my home and assets are now at risk due to a pending property settlement . . . The drain on my assets makes any potential future expensive treatment unlikely;*

- *stress and depression has resulted in the need to seek support from a psychiatrist on a regular basis* (Submission 82).

4.3.2 THE ECONOMIC IMPACT OF HCV ON THE COMMUNITY AS A WHOLE

The economic impact of HCV will, of course, depend on the number of people infected, the course of the disease and the cost of providing treatment, care and support. As will be discussed, various estimates were provided to the Committee but, as NSW Health pointed out, data on which such estimates are made are constantly changing (NSW Health tabled document, 3 October 1997).

> *the combination of a larger pool size of infected individuals and more protracted complications leads to the perhaps unexpected conclusion that the net health and economic cost of Hepatitis C may even be roughly comparable with HIV* (Wodak and Crofts, 1996:182).

The cost of chronic Hepatitis C in the USA in terms of medical care and lost working days has been calculated to be approximately US$600 million per year (cited in Schering-Plough submission).

The Committee is aware of three studies that examine the economic impact of Hepatitis C in Australia. Shiell, Briggs and Farrell (1994) model the costs of interferon therapy in the treatment of chronic, active Hepatitis C. Briggs and Shiell's 1996 study also looks at interferon in terms of its costs and benefits. Both of these studies are reviewed in Section 7.2.1. The third, and most pertinent to the question of economic impact of the disease (rather than the medication) has been prepared by Brown and Crofts (1998).

Applying a Markov cohort approach, Brown and Crofts estimated the health care costs of the Hepatitis C epidemic amongst injecting drug users in Australia. According to their calculations, **for every 1,000 injecting drug users newly infected with Hepatitis C in a given year, there is an implied $14.32 million in health care spending over the years as the disease's sequelae become manifest** (Brown and Crofts, 1998:386; Crofts evidence, 28 November 1997).

They also calculate the exponential growth in the projected cumulative total costs to Medicare associated with the management and treatment of successive cohorts of 1,000 chronically HCV infected persons. According to their calculations, **after approximately 60 years, the cumulative total cost will be approximately $0.5 billion (1994 dollars)** (Brown and Crofts, 1998:387).

As was discussed in Section 3.1, the current 8,000 - 10,000 new HCV infections each year give rise to approximately 6,500 - 8,000 chronic carriers of HCV. If such estimates are accurate, Brown and Crofts calculate that **HCV among injecting drug users is costing $90-115 million per year (1994 dollars) in direct health care costs alone**

(Brown and Crofts, 1998:388). Such an amount equates to approximately 0.5% of the total 1994 health budget (Brown and Crofts, 1998:388).

Over the next 60 years, with an estimated 10,000 new HCV infections in Australia each year the total direct healthcare costs will be approximately $4 billion over that period (Brown and Crofts, 1998).

Building upon Brown and Crofts findings, NSW Health's submission calculated that the implied health service spending for those currently infected in NSW would be $601.44 million (expressed in 1994 dollars) over their lifetimes after infection (NSW Health submission). In terms of new HCV infections, the Department's submission proposed that 2,000 of the estimated 4,000 new infections estimated to occur in NSW each year will remain chronic carriers (a conservative estimate assuming 50% of those infected will remain chronic carriers), adding $28.64 million to the state's long term health care bill for each year's cohort (NSW Health submission).

Brown and Crofts' estimate is considered to be conservative for a number of reasons including:

- their projections are based on numbers of injecting drug users only and do not take into account those who already have the infection from other sources;

- the costings are for direct medical costs only such as ambulatory visits associated with ongoing monitoring and in-patient admissions to hospital for treatment over the course of the disease (Brown and Crofts, 1998:385);

- direct and indirect costs incurred by patients and their families and the way in which the disease may impinge on the ability of individuals to participate in the paid workforce or the costs of premature mortality are not factored in; and

- public funds for disability pensions for those whose Hepatitis C precludes them from working is not factored into the model (NSW Health submission).

Brown and Crofts note that these limitations:

> *reflect both the limited epidemiologic data available for the purpose of assessing the impact of Hepatitis C infection and the need for further research in this area* (Brown and Crofts, 1998:385).

4.4 THE IMPLICATIONS OF HEPATITIS C UPON FUTURE HEALTH FUNDING, PLANNING AND POLICY

Given the estimates proposed by Crofts and Brown and discussed above, the implications of Hepatitis C on future health funding are profound. If $4 billion is to be spent on Hepatitis C this money will not be available for services. Wodak noted this impact in his submission and commented that:

> *At the very least, the epidemic of Hepatitis C will have an impact on the general population of non-drug users by consuming large quantities of scarce health resources* (Wodak submission)*.*

If such significant resources are having to be spent on treating the Hepatitis C virus, there are profound consequences for health planning and, in turn health policy. Given the implications of Hepatitis C it is essential that governments at both state/territory and federal level get health policy right and get it right promptly. The Committee's proposals to assist in that process are outlined in Section 5.4.2. The Committee is not convinced that governments - at both the federal and state level - have as yet, fully grasped the enormity of Hepatitis C, its impact, particularly economic, and the implications it will have upon health funding, planning and policy. As will be discussed in the next chapter current policies addressing Hepatitis C in New South Wales are less than adequate and there is an urgent need for action.

4.5 NEED FOR FURTHER RESEARCH INTO THE SOCIAL AND ECONOMIC IMPACT OF HEPATITIS C

The Committee is aware of difficulties a number of researchers have experienced in attempting to conduct research into the economic impact of Hepatitis C. Shiell, based at the Department of Public Health and Community Medicine, University of Sydney, sought research funding from the NHMRC to evaluate the personal, social and economic impact of Hepatitis C. Although his grant proposal was "deemed fundable" he did not receive any funding (personal communication, 10 December 1997).

Dr Crofts told the Committee of two submissions for research that went before the NHMRC in 1997 and both failed (Crofts evidence, 28 November 1997). He also informed Members that the Commonwealth had tendered for groups to do work on the social and economic impact of Hepatitis C and then withdrew the tender (Crofts evidence, 28 November 1997). He concluded that "I think the money for that disappeared and I think the process has disappeared too". As a result there is "virtually nothing to go on" (Crofts evidence, 28 November 1997).

In appearing before the Committee, Crofts recounted the difficulties he experienced in getting his economic analysis study published. He informed Members that the paper had been sent to the *Medical Journal of Australia* but, despite receiving good referees' reports, was turned down on the basis that "it was not of sufficient general interest" (Crofts evidence, 28 November 1997). The Committee is somewhat amazed that a disease that will cost the health system an estimated $4 billion was not considered to be of sufficient general interest.

In appearing before the Committee the Executive Officer of the NSW Hepatitis C Council, Mr Stuart Loveday, was specifically asked if the difficulties experienced by Crofts and Brown and Shiell were indicative of a general reluctance to quantify the economic impact of Hepatitis C. Mr Loveday indicated that he believed that to be the case, adding that:

> *one gets the feeling that if one delays the knowledge of the size of the problem then the problem does not seem as bad, but we know from past evidence that it is a major problem* (Loveday evidence, 30 March 1998).

Numerous calls have been made for research to be undertaken into the social and economic impact of Hepatitis C. Loxley, for example, has observed that:

> *There are social costs and consequences to those who live with Hepatitis C and too little is known about these. Discrimination and public attitudes are a part of this, but beyond that there are relationships, employment, accommodation, parenting and a range of other issues to consider. All of these are amenable to, and deserve to be researched* (Loxley, 1997:58).

Crofts commented during the course of his evidence that:

> *currently we are in that position where we are just not looking for the impact of Hepatitis C. It would be quite easy to do, but it would make very clear that there is a need for a lot more action, a lot more expenditure* (Crofts evidence, 28 November 1997).

In March this year the Federal Minister for Health announced $1 million would be made available for Hepatitis C research (Wooldridge, 1998). The Committee understands that a set of guidelines for grants have been developed by the NHMRC. The guidelines that will be used are:

> *The Australian National Council on AIDS and Related Diseases and the National Health and Medical Research Council, through its Strategic Research and Development Committee, are seeking research proposals that are rigorous and innovative and will result in making a difference in reducing the spread of Hepatitis C or improving the quality of life for people living with Hepatitis C.*
>
> *Applications are called for in social and behavioural research which meet the following objectives:*

- *research will be funded that is an intervention, or that will lead to an intervention, to reduce the spread of Hepatitis C in Australia;*

- *research will be funded that investigates ways to minimise the personal and social effect of Hepatitis C;*

- *epidemiological research will only be funded where it meets the first objective. Counting exercises will not be considered; and*

- *drug trials will not be considered for funding* (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:3).

ANCARD's Hepatitis C Sub-committee has called for investigations into the personal, social and economic costs of HCV infection to individuals, the health care system and to society (Hepatitis C Virus Projections Working Group, 1998:32). In its submission to this Inquiry, the Hepatitis C Council also recommended that studies into the social and economic costs of Hepatitis C infection be supported and funded (Hepatitis C Council submission). The Committee fully supports these recommendations which, Members feel, are broader than the research that will be funded by ANCARD and the NHMRC.

RECOMMENDATION 25:

That the Minister for Health direct research be undertaken into the personal, social and economic costs of Hepatitis C infection to individuals, the state's health care system and to society.

Given the extent of discrimination experienced by those living with Hepatitis C the National Hepatitis C Councils' Education Reference Group (1996:40) has specifically called for social research into the causes of Hepatitis C related discrimination to assist in formulating programmes to combat it. The Committee considers this proposal to have considerable merit and fully supports the recommendation.

RECOMMENDATION 26:

That the Attorney General request the NSW Anti-Discrimination Board conduct (or commission) social research into the causes of Hepatitis C-related discrimination.

The Committee further recommends that the findings of the proposed research be used in formulating programs to combat this form of discrimination including those programs proposed in Recommendations 19, 22 and 129.

4.6 CONCLUSION

From a number of perspectives, the impact of Hepatitis C is enormous. The social impact of the disease is, as has been documented, profound and touches every facet of life - social, sexual, economic, physical and emotional. The impact is not only felt by the person with Hepatitis C but their immediate and extended families, friends, work colleagues and neighbours. Many not only have to deal with the disease and its debilitating side effects but also discrimination and stigmatisation from a range of sources including (and often surprisingly) health care workers.

The economic impact upon the wider community is considerable. As Batey concluded:

> *we are looking at a cost of some billions of dollars into the new millennium when patients have had their disease for twenty, thirty or forty years* (Batey evidence, 27 October 1997).

The Committee is not convinced that governments - be they federal or state - have as yet, fully grasped the enormity of Hepatitis C, its impact and the implications it will have upon future health funding, planning and policy. As will be discussed in the next chapter current state policies addressing Hepatitis C are not considered to be adequate and there is an urgent need for decisive measures to be taken to redress the current situation.

CHAPTER FIVE

HEPATITIS C POLICIES

The Terms of Reference for this Inquiry called upon the Committee to inquire into the adequacy of current Hepatitis C policies. The following discussion examines current policies, identifies their inadequacies and proposes a range of strategies to address these shortcomings.

5.1 CURRENT HEPATITIS C POLICIES

When the Committee asked NSW Health to identify its Hepatitis C policies, Departmental officers nominated a number of Departmental circulars that outline policy and procedures for publicly funded health services. These policies, according to the Department, also serve as "quasi-regulations" for the private health care sector. Policies identified to the Committee included:

90/11	Hepatitis C antibody screening of blood and blood products for transfusion;
95/13	Infection Control Policy (currently under review and expected to be published in December 1998);
96/36	Low Temperature Sterilisation;
98/11	Blood Borne Infections - Management of Health Care Workers Potentially Exposed to HIV, Hepatitis B and Hepatitis C; and
97/5	Section 100 Highly Specialised Drugs.

Two information bulletins and guidelines were also identified:

- Skin Penetration Guidelines (currently under review and expected to be released in December 1998) which are administered by Environmental Health and apply to skin penetration in non-medical settings; and

- IB 93/5 - Antenatal and Neonatal Infant Screening for Hepatitis C (which will be upgraded to a policy circular although as of mid August 1998 this work had not commenced).

At no time during the Inquiry process was the Committee directed to specific documents that clearly articulate the Department's policies on managing, controlling, and/or preventing Hepatitis C. While the Committee fully appreciates the importance of policies such as those identified which outline certain procedures in detail they would, given the framework outlined above, be considered administrative policies. None of these policies take a broad, macro view of the disease and give overall direction to the control, management, prevention of Hepatitis C and the care and support of those with the disease.

The only document identified by the Committee as coming anywhere near providing general direction is the Hepatitis C Taskforce Report summarised in Chapter One. However, at no time during the course of evidence, nor in their submission to the Committee did the Department identify this document as a policy statement. The only comment the Department made was in their submission where they noted that the report has "guided policy direction in NSW" .

Clearly it has not been assigned that status. This was confirmed by a representative of the Hepatitis C Council who informed the Committee that:

> *. . . the NSW Taskforce Report is a very good list of recommendations. But as a policy on its own, it is not really a policy because it does not have applied funding tied to it. It is a list of recommendations, some of which have been implemented, but from our point of view it seems that it is too little too late; it seems to be scratching at the surface* (Loveday evidence, 3 October 1997).

5.2 THE ADEQUACY OF THESE POLICIES: THE EXPERTS' OPINION

During the course of the Inquiry, the Committee met with and took evidence from some of the nation's most eminent Hepatitis C experts, including clinicians, epidemiologists and public health specialists. Amongst other issues, they were asked to comment on the adequacy of current policies. Without exception, these experts condemned current Hepatitis C policies at both the state and national level. Their comments are recorded in the following discussion.

Professor Geoff Farrell is the Robert W Storr Professor of Hepatic Medicine at Westmead Hospital's Storr Liver Clinic. In March 1997 he participated in the United States National Institutes of Health Consensus Meeting on Hepatitis C. When asked to comment on current Hepatitis C policies during the course of his evidence, Professor Farrell stated that:

> *I think [Hepatitis C policies] are inadequate in terms of, first of all, an appreciation of the general impact of Hepatitis C in the community at large, including such fundamental facts as its incidence and its distribution through various subsections of the community* (Farrell evidence, 28 November 1997).

His comments supported observations he made in his submission to the Committee where he wrote that:

> *despite the high prevalence of Hepatitis C in NSW recognised since 1989, NSW Health polices have not adequately addressed the need for improved funding of health and community services* (Farrell submission).

He urged the Committee to peruse reports presented to the Department by successive Hepatitis C Committees making detailed recommendations to "ascertain why political and administrative actions resulting from them have been so minimal" (Farrell submission).

Expert witness Professor Robert Batey is Director of the Gastroenterology Department at Newcastle's John Hunter Hospital and Clinical Coordinator of the National Data Base of patients treated with interferon. In addition, he was the Deputy Chair of the NHMRC Working Party on Hepatitis C, is a member of ANCARD and ANCARD's Hepatitis C Subcommittee, amongst other positions. In his opinion, current policies are:

> *probably not adequate for the extent of the problem . . . I think they are not adequate because we have 150,000 people with a disease that probably does demand a little more active intervention than we are currently providing. It is interesting that after three years of the S100 scheme there are only 2800 people who have received interferon for the disease* (Batey evidence, 27 October 1997).

Professor Alex Wodak, Director of St Vincent's Hospital's Drug and Alcohol Services commented to the Committee that:

> *I do not consider that current policies are adequate and I do not know how anyone could consider our policies adequate when we are currently experiencing roughly one new infection of Hepatitis C through injecting drug use every hour in Australia . . . I do not think our policies are adequate and if you try to find national or state polices aimed at controlling this epidemic I think you will have great difficulty. There are no policies to try to control this epidemic* (Wodak evidence, 2 October 1997).

Wodak acknowledged that some policies have been developed in relation to specific stages of the epidemic. As he observed, there are, for example, "well-developed" policies in the areas of diagnosis (as will be discussed in Section 6.2) and treatment (to be discussed in Section 7.2) (Wodak evidence, 2 October 1997). However he noted that:

> *the closer you get to the public health and epidemiological side of this epidemic, the more apparent it is - or least to me - that we do not have any policies at all* (Wodak evidence, 2 October 1997).

Further, he considered it:

> *scandalous that an epidemic has been allowed to continue for this length of time without this community responding to it* (Wodak evidence, 2 October 1997).

In addressing the adequacy of policies in his submission to the Committee, Wodak commented that

> *in contrast to the dynamic and innovative response to HIV, Australia's response to Hepatitis C has been lacklustre at best . . . There have been a few national efforts to develop a response to Hepatitis C. These focused on diagnostic and treatment aspects and at best provided cursory attention to prevention. In my view, this state of affairs is very inadequate* (Wodak submission).

Dr Nick Crofts also appeared before the Committee in his position of Head of the Epidemiology and Social Research Unit at the Macfarlane Burnet Centre for Medical Research in Melbourne. He informed the Committee that he considers current policies to be:

> *inadequate at the moment. I think that the major issues around Hepatitis C at the moment are prevention of continuing transmission of Hepatitis C, provision of adequate care and treatment and support for those people who have got Hepatitis C . . . and amelioration of discrimination against people who have Hepatitis C. I do not consider that our current policies address any of those three areas nearly adequately enough. I think the fourth area is the area of research . . . and again I do not think our policies are adequately coping with the need for research or the need for funding for research* (Crofts evidence, 28 November 1997).

Appearing before the Committee as Chair of ANCARD and Chair, Central Sydney Area Health Services, Mr Chris Puplick commented that:

> *I do not think we yet have a really comprehensive understanding of statewide policies in relation to Hepatitis C but the steps that have been taken by NSW Health have been very positive and very encouraging* (Puplick evidence, 7 November 1997).

Further, he felt that:

> *there is certainly no incentive provided for Area Health Services, or anybody else for that matter, to try to address some of these matters in the absence of what is seen as coherent public policy which can then be translated through the Department of Health and the Area Health Services into services on the ground* (Puplick evidence, 7 November 1997).

Finally, the submission from the Hepatitis C Council of NSW offered the following comment on policy:

> *Both in NSW and nationally, a vacuum has existed in regard to leadership that would guide HCV prevention programs and initiatives. Despite awareness since the early 1990s of the alarming rate of ongoing new infections, no programs are yet in place that are having any impact whatsoever on reducing the spread of HCV. Treatment, care and support initiatives exist on the back of already overburdened and under-resourced general clinical services, with precious little psychosocial support for those diagnosed with HCV* (Hepatitis C Council submission).

The Council's publication, *The Hep C Review* also notes that:

> *In 1995, NSW Health released a report on HCV, but we are yet to see a clear and funded strategic plan for the state . . . Both in NSW and nationally a vacuum has existed in regard to leadership that would guide HCV prevention programs and initiatives . . . no programs are yet in place that are having any impact whatsoever on reducing the spread of HCV . . . the biggest hurdle to a better response is State and Federal commitment to funding* (Editorial, 1997:1, 3).

5.3 WHAT IS POLICY?

Such a resounding condemnation of polices relating to Hepatitis C prompted the Committee to ask "What is policy?" There are a myriad of definitions of policy - what it is; what it is purported to do; what its function is. The term is used in a variety of ways to cover many, and often quite different types of statements, intentions and actions. Policy may refer to any or all of the following:

- a very general statement of intentions and objectives;
- a past set of actions of government in a specific area;
- a specific statement of future intentions; or
- a set of standing rules that are intended as a guide to action (or inaction).

Equally there are a range of ways to classify policy. The OECD, for example, has identified four categories of policy including:

- normative - policies at this level indicate overall orientation and direction. Tend to be set with a long-term time frame and are typically made by political authorities at the highest decision-making level. As Jones has observed, policies at this level may be made by apparently powerful individuals, they may serve largely symbolic purposes rather than act as sufficient and concrete guides for development of programs and projects (Jones, 1985:3978-3979);

- strategic - policies at this level give direction and emphasis to future action and they are statements of the means or strategies to be used to translate the ideals found in the normative policies into action. As any one normative policy can be achieved in a number of ways, this level establishes the orientation and direction to be followed by subsequent programs;

- operational - policies at this level are statements of activities or projects undertaken within the context of programmes specified in the higher-order, strategic policies. They identify the way strategies are to be put into operation and as such tend to be short- to medium-term in their orientation; and

- administrative - statements at this level describe actions in response to daily demands so that the projects at the operational level can be implemented. By their nature administrative policies must be relatively unequivocal and narrow in focus.

These four dimensions represent four different levels of policy. Each is related to the other in a highly interdependent manner, ie normative policies are used as guidelines for strategic policies. Strategic policies, in turn, direct operational policies which influence the policies made at the administrative level. The administrative, or “routine” policies clarify the operational policies (OECD, 1977:7). The four levels range from the most general, normative policies to the most specific administrative policies (Soumelis, 1983:37).

Generally speaking, normative policies have to do with what should be done; strategic policies with what could (when and how) be done; operational policies with what will (when and how) be done; and administrative policies with what is being done (Soumelis, 1983:38). In this way, the framework resolves a common tension between what “ought” to be done and what “is” done for a workable translation of goals into action.

The Committee fully appreciates that such a framework is not the only way to design and formulate policy nor does it expect NSW Health to adopt this framework. However the example does demonstrate the inter-related nature of policies and the importance of different policies being developed for different purposes.

5.4 RECTIFYING CURRENT POLICY INADEQUACIES

As has been discussed, Hepatitis C is an epidemic impacting upon an estimated 90,000 people and their families in New South Wales alone (Loveday evidence, 30 March 1998). The response of NSW Health from a policy perspective has been limited. The Hepatitis C Taskforce report makes a number of recommendations for government action but there are no policies at the state level giving overall direction to the control, treatment, management or prevention of Hepatitis C. The Committee regards this situation to be totally inadequate.

The Committee considers a range of strategies are called for as a matter of priority to redress the current situation. In the Committee's opinion these strategies must be instigated and implemented at the three tiers of the state's health system that have responsibility for health policy and planning in this state: the Office of the Minister for Health, NSW Health - central agency, and the various Area Health Services across the state.

5.4.1 ACTION AT THE MINISTERIAL LEVEL: THE OFFICE OF THE MINISTER FOR HEALTH

For some time there has been a Hepatitis Advisory Committee which is responsible for making recommendations on aspects of HCV prevention, care, treatment and support. The Terms of Reference of the Committee are:

1. to advise the Chief Health Officer on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of the hepatides;

2. to liaise with other Departmental committees relevant to hepatitis;

3. to liaise with the Public Health Network on hepatitis issues; and

4. to review NSW Health documents that have relevance to any of the hepatides.

The Committee's membership has been described as "similar but more comprehensive" than the Hepatitis C Taskforce membership (NSW Health submission). In addition to Departmental officers acting as Chair and Secretariat, the Committee's membership includes:

•	Professor Bob Batey	John Hunter Hospital
•	Dr Ingrid van Beek	Kirketon Road Centre
•	Professor Yvonne Cossart	Dept of Infectious Diseases, Sydney University
•	Professor Geoff McCaughan	Royal Prince Alfred Hospital
•	Mr Paul Harvey	Hepatitis C Council of NSW
•	Dr Michael Douglas	Western NSW Public Health Unit
•	Dr Alex Wodak	St Vincents Hospital
•	Dr Brenton Wylie	NSW Blood Transfusion Service

The Committee meets four times a year in addition to *ad hoc* issue dependent meetings.

The Hepatitis C Council considered the current Advisory Committee to be a "useful avenue" for giving advice (Harvey evidence, 3 October 1997). However, in the Council's opinion:

> *it could take on a much more effective role by taking on more of a planning and development role, more of a proactive role. At the moment it just responds to issues and questions* (Harvey evidence, 3 October 1997).

The Committee does not have the status of a Ministerial Advisory Committee and as such does not report to or directly advise the Health Minister. The Council is concerned with the status of the Committee as they "do not believe it is being given the right level of profile within NSW Health" (Loveday evidence, 3 October 1997).

During the course of this Inquiry, it was suggested to the Committee that there would be advantages in upgrading the status of the Hepatitis Advisory Committee to that of a Ministerial Advisory Committee. The Hepatitis C Council, for example, fully supported such a move along with Puplick who noted that:

> *I would have no difficulty at all with the [Hepatitis C] Committee having ministerial status in line with the Ministerial Advisory Committee on HIV which currently exists* (Puplick evidence, 7 November 1997).

The Ministerial Advisory Committee on HIV referred to by Puplick reports directly to the Minister for Health. Its Terms of Reference include:

1. advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic direction for HIV services;

2. liaise with other Committees and professional groups of relevance to HIV; and

3. promote research and training in HIV.

The Committee, which includes 12 experts and three ex officio Departmental officers, meets every six weeks, with two full day meetings each year.

In terms of giving Hepatitis C a higher profile and involving the Minister for Health more directly, the Committee wishes to see the Hepatitis Advisory Committee upgraded and given the same status as the Ministerial Advisory Committee on HIV. The Terms of Reference for the Ministerial Advisory Committee on Hepatitis C would include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;

2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;

3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and

4. to promote research and training in Hepatitis C.

RECOMMENDATION 27:

That the Minister for Health upgrade the Hepatitis Advisory Committee to become the Ministerial Advisory Committee on Hepatitis C. The Committee further recommends that the Terms of Reference of the Ministerial Advisory Committee on Hepatitis C include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;
2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;
3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and
4. to promote research and training in Hepatitis C.

As the Terms of Reference suggest, the Committee anticipates that the Ministerial Committee would be involved in driving policy at the macro level and having direct and substantial input into the design and development of the Hepatitis C Policy Statement as will be proposed in Recommendation 28.

5.4.2 ACTION AT THE DEPARTMENTAL LEVEL:CENTRAL AGENCY - NSW HEALTH

- **Development of a NSW Hepatitis C Policy Statement**

The Committee considers the first step in addressing the current Hepatitis C epidemic must be the development of a set of sound policies giving overall direction to the control, management and prevention of Hepatitis C along with the care and support of those with the virus. At present no such document is available.

The Committee is aware of the Department's experience in preparing the type of statement it considers to be essential. *The NSW Aboriginal Mental Health Policy* (1997), for example, goes some way in meeting the Committee's expectations. That document contains a broad vision statement, and explicitly states the guiding principles and aims of the policy. The second section of the policy statement deals with strategy and enunciates the policy's four strategic directions and an implementation timetable for each of these strategies.

While the Committee fully appreciates the development of a Hepatitis C policy statement may take on a different form to the Aboriginal mental health policy or any other policy statement of the department, it does call upon the Department to produce such a statement and to use it as the basis of all future Hepatitis C action and allocation of funding. It also considers it essential that, as a minimum, the proposed policy statement include a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

RECOMMENDATION 28:

That the Minister for Health direct NSW Health to design and develop a NSW Hepatitis C Policy Statement to give overall direction to the control, treatment, management and prevention of Hepatitis C and the care and support of those with the disease.

The Committee further recommends that the proposed NSW Hepatitis C Policy Statement include, as a minimum, a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Policy Statement in January 2001 to assist in determining future responses and directions.

RECOMMENDATION 29:

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 be the basis for all future planning and funding for Hepatitis C in the state.

To ensure the policy statement proposed in Recommendation 28 is relevant, adequate and appropriate the Committee considers it vital that the major stakeholders be involved in the policy development process. The Committee anticipates this would include, though not be limited to, representatives of the Hepatitis C Council, and relevant community groups such as NUAA, and appropriate medical specialists (for example liver/hepatic specialists, epidemiologists, public health experts, and clinical nurse consultants). The Committee also considers there to be value in involving the Ministerial Advisory Committee on Hepatitis C in designing and developing the proposed Policy Statement.

RECOMMENDATION 30:

That the Minister for Health ensure adequate consultation with the major stakeholders during the process of designing and developing the NSW Hepatitis C Policy Statement proposed in Recommendation 28. Those consulted are to include, yet not be limited to, representatives of the Hepatitis C Council and relevant community groups such as NUAA, liver specialists, public health experts, epidemiologists, clinical nurse consultants.

The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C be actively involved in the design and development of the NSW Hepatitis C Policy Statement proposed in Recommendation 28.

- **Development of a NSW Hepatitis C Strategic Plan**

As has been discussed, broad policy is usually formed to give direction to future action which may be spelt out in detail in subsequent documents such as departmental strategic plans. In the latter stages of this Inquiry, it was brought to the Committee's attention that the Department had commenced developing a Hepatitis C Strategic Plan.

While the Committee welcomes this long overdue initiative, it finds it curious that a strategic plan can and is being developed in the absence of a broad policy statement. The Committee questions the basic premises upon which such a plan is based as these have never been publicly enunciated or made available. Until the Department identifies and articulates **what** it wants to achieve in terms of Hepatitis C control, treatment, management, prevention, care and support, it is difficult to identify appropriate strategies to address the practicalities of **how, when** and **where**. Once the policy statement called for in Recommendation 28 has been developed, it is then important that a strategic plan be devised to spell out in detail the approaches to be used to meet the policy's vision and aims. It would be erroneous and extremely shortsighted to develop a statewide strategic plan in a policy vacuum.

RECOMMENDATION 31:

That the Minister for Health direct NSW Health to develop a NSW Hepatitis C Strategic Plan within the context of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and that the Strategic Plan clearly articulate how, when and where the state will address all facets of Hepatitis C control, treatment, management and prevention along with care and support for those with the disease.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Strategic Plan in January 2001 to assist in determining future responses and programs.

The Committee's call for the development of a Hepatitis C Strategic Plan brings New South Wales into line with most other Australian states and territories that have already developed and are in the process of implementing such plans. The Committee considers this to be the absolute minimum the Department can do to address the Hepatitis C epidemic in this state.

The Committee is aware that strategic plans have been developed by Queensland (Queensland Health, 1998), Victoria (Victorian Department of Health and Community Services, 1995), the ACT (ACT Department of Health and Community Care, 1998) and South Australia (South Australia Health, 1996). Each of these plans have various strengths and weaknesses and the Committee feels that there is much NSW Health can gain from reviewing these documents. Several features of the Victorian strategy particularly appealed to Committee Members. Each issue covered in the strategy contained stated goals, key strategies, and in some cases, guiding principles. The ACT strategy similarly spelt out its goals, objectives, strategies and actions and included a detailed three year implementation plan for each objective.

These attributes of the Victorian and ACT plans are routine features of a strategic plan. The Committee however wishes to ensure that they are features included in the Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 32:

That the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 identify goals, objectives and key strategies along with detailed implementation plans for each objective.

The Victorian strategic plan is available on the Internet (http://hna.ffh.vic.gov.au). The Committee considered this to be a very appropriate approach and wishes to see NSW Health adopt a similar practice.

RECOMMENDATION 33:

That NSW Health ensure the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) are placed on the Department's website.

- **Adequate and Dedicated Hepatitis C Funding**

Policy is mere rhetoric if it is not backed up with adequate and recurrent funding. During the course of the Inquiry, a number of specific comments on current funding levels were made to the Committee. The Hepatitis C Council, for example, noted that:

> *It is clear that the response to Hepatitis C has been slow and that funding levels are inadequate to manage the growing numbers of people with HCV . . . this area lacks clear strategies, coordination, adequate funding . . . given the large numbers of infected people in NSW* (Hepatitis C Council submission).

The Council's submission also noted that:

> *The biggest hurdle . . . is state and federal commitment to funding. In comparison to best standard models . . . the amount of money allocated to meet Hepatitis C needs is grossly inadequate* (Hepatitis C Council submission).

In evidence Mr Loveday stated that:

> *national and state funding has been one of too little too late. Various Federal and State policies have recommended that action be taken in specific areas, but these recommendations have not to date been translated into strategic plans of action with dedicated funding allocated to them. . . Overall budget allocations to date have been very ad hoc and grossly insufficient. Often they are year-end underspends relating to other areas of the budget where, because of time pressures, their allocations cannot be properly planned and consultation is certainly made all the more harder. To their credit, NSW Health has sought support from the Commonwealth and other States for matched funding arrangements similar to HIV, but with the coming of the public health agreements between the states and the Federal Government, this was really unlikely to succeed and, of course, did not get up* (Loveday evidence, 30 March 1998).

In his submission to this Inquiry, Professor Farrell notes that NSW Health has instituted Hepatitis C projects at a total cost of $600,000 to "try and devise appropriate shared-care programs and to promulgate attempts to prevent the disease". As Farrell notes:

> *to have reached this stage by 1997 when we have known about the importance of this disease in NSW since 1989 is simply a disgrace. There is an overdue need for significant recurrent funding, of the order of $3-5 million per annum to introduce appropriate policies for efficient, shared-care, diagnostic and management services* (Farrell submission).

In its submission to this Inquiry, ANCARD noted that "very little direct funding" has been put into Hepatitis C services despite the thousands in the state who have the disease (ANCARD submission).

NSW Health currently provides recurrent funding for Hepatitis C specific programs.

Departmental allocations to these initiatives are summarised in Table Nineteen below.

TABLE NINETEEN
CURRENT NSW HEALTH HEPATITIS C EXPENDITURE

PROGRAM	AMOUNT OF FUNDING	TYPE OF FUNDING
Hepatitis C Council of NSW	$215,400	Recurrent
Hepatitis C Lookback Program	$480,000	Spread over two years
Printed information to medical practitioners & other health care workers	$95,000	One off
Hepatitis C Taskforce implementation funding	$250,000: 1995-96 $500,000: 1996-97 $515,000: 1997-98	

Source: NSW Health submission

Additional funding is also available for a range of services set up primarily in response to HIV/AIDS such as needle and syringe exchanges and funding for organisations such as New South Wales Users and AIDS Association (NUAA), Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS) and the Haemophilia Foundation. In each case, the role of these services has been broadened to take on additional HCV responsibilities. These services and the amounts allocated to them are recorded in Table Twenty.

TABLE TWENTY
AIDS PROGRAM FUNDED HEALTH SERVICES WITH PARTIAL HCV WORKLOAD

PROGRAM	AMOUNT OF FUNDING	TYPE OF FUNDING
Needle and Syringe Program	$7,527,497	Recurrent
NSW Users and AIDS Association	$885,500	Recurrent
TRAIDS	$150,519	Recurrent
Haemophilia Foundation	$59,200	Recurrent

Source: NSW Health submission

The submission from NSW Health provides information on the costs of fully implementing the recommendations contained in the Taskforce Report. As has been discussed in Section 1.2.2 a comprehensive program of appropriate activities under the health portfolio is estimated to require additional funding of approximately $3,240,000 annually with an additional $1,690,000 in 1998/99 to initiate appropriate actions, making a total of $4,930,000 in 1998/99 (NSW Health submission).

The submission also notes that, within the context of negotiations with the Commonwealth Department of Health and Family Services regarding the establishment of a Public Health Outcomes Funding Agreement, recurrent funding of $3,250,000 for Hepatitis C had been sought. However, at the time of preparing their submission, NSW Health advised the Commonwealth had indicated such funding would not be provided (NSW Health submission). In a supplementary submission provided to the Committee in August 1998 the Department advised "it is likely" NSW will be successful in securing in excess of $1million for a range of Hepatitis C projects under the Public Health Outcomes Agreement. This will, according to the NSW Health "facilitate most of the non-recurrent recommendations of the Taskforce being implemented" (NSW Health supplementary submission). The supplementary submission also noted that the state government had sought to establish a cost-shared program with the Commonwealth through which additional funds could be made available. NSW Health advised that these negotiations have been "unsuccessful" (NSW Health supplementary submission).

Any consideration of funding requirements must be made with a full appreciation of the economic impact of Hepatitis C which was discussed in Section 4.3.2. As that discussion noted, the long term financial impact of the disease upon injecting drug users alone is anticipated to be in excess of $4 billion.

The Committee considers it imperative that financial allocations to Hepatitis C be based upon the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Strategic Plan proposed in Recommendation 31. The Committee also considers federal Hepatitis C funding to date to have been inadequate given the rates of Hepatitis C in New South Wales. The Committee wishes to see the Commonwealth government provide funding allocations which reflect more accurately the rate of Hepatitis C in this state and the need for support services and prevention strategies.

RECOMMENDATION 34:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 35:

That the Minister for Health urge his federal counterpart to provide funding allocations which reflect more accurately the rate of Hepatitis C in New South Wales and the state's need for support services and prevention strategies.

- **Adequate and Appropriate Staffing: Central Agency**

The Department of Health advised the Committee that the staff allocation in the Department's central agency dedicated to Hepatitis C policy work is 4.2 which is made up of the following:

(1.0)	Hepatitis C Policy Analyst (Evaluation)
(0.8)	Policy Analyst Hepatitis
(0.8)	Needle Exchange Policy Analyst
(0.4)	Manager HIV/AIDS/Hepatitis
(0.3)	Social Research Policy Analyst
(0.3)	Surveillance Officer
(0.2)	Medical Epidemiologist
(0.2)	Infection Control Policy Analyst
(0.2)	Director AIDS/Infectious Diseases Unit

TOTAL: 4.2

By comparison, 5.7 staff are allocated to HIV policy work at the central agency. These include:

(1.2)	Needle Exchange Policy Analysts
(1.0)	HIV/AIDS Policy Analyst
(1.0)	Surveillance Officer
(0.7)	Social Research Policy Analyst
(0.6)	Manager HIV/AIDS/Hepatitis
(0.6)	Clinical Services Policy Analyst
(0.2)	Medical Epidemiologist
(0.2)	Infection Control Policy Analyst
(0.2)	Director AIDS/Infectious Diseases Unit

TOTAL: 5.7

This central agency staffing allocation is in addition to Area HIV/AIDS Managers deployed throughout the Department's Area Health Services.

A different perspective on staffing was provided to the Committee by representatives from the Hepatitis C Council, who informed the Committee that:

> *Apart from temporary project staff working in one-off projects, NSW Health has only one dedicated Hepatitis position in the AIDS and Infectious Diseases Branch. This position makes recommendations on policy and on program funding to a manager with overall responsibility for HIV and Hepatitis. This is clearly not enough to match the size of the Hepatitis C problem in NSW, when say, compared with HIV* (Hepatitis C Council submission).

In evidence before the Committee and in response to the Department’s advice that 4.2 staff are allocated to Hepatitis C policy work, Mr Loveday skeptically added that:

> *I suppose if you take 0.1 or 0.2 or a day here and a day there of staff members’ time, and added it to the two Hepatitis-designated workers, perhaps it might add up to 4.2* (Loveday evidence, 30 March 1998).

He further commented that:

> *the Hepatitis policy analyst at NSW Health, not the Hepatitis C policy analyst, as the Health Department stated in their evidence in October last year, looks after all hepatitises, which is a much, much bigger case load than Hepatitis C. The Hepatitis C Evaluation Officer is on a one-year contract and works primarily with the four demonstration projects. So doubtless management and other staff do spend time on hepatitis C policy development work* (Loveday evidence, 30 March 1998).

In Mr Loveday’s opinion, staff are “completely snowed under” (Loveday evidence, 30 March 1998). To illustrate his claim he cited the following examples:

> *a temporary departmental post to oversee and consolidate Hepatitis C surveillance in NSW was unable to be filled, because initially there was no budget to employ them and then no office space could be found for them, and this is to oversee surveillance in New South Wales. Another example, updates on basic Health Department produced information leaflets about other hepatitises gets put on endless backburners. It happened with Hepatitis C as well, until the community group produced one* (Loveday evidence, 30 March 1998).

In their submission to this Inquiry, the Hepatitis C Council called for an expansion of dedicated Hepatitis C staffing positions within the AIDS and Infectious Diseases Branch, NSW Health to “enable adequate overview and coordination of the response to HCV” (Hepatitis C Council submission). The Committee fully supports this proposal.

The Committee wishes to see the Department assign dedicated, full time and permanent staff at appropriate senior levels to drive and implement the NSW Hepatitis C Policy Statement along with the NSW Hepatitis C Strategic Plan.

RECOMMENDATION 36:

That the Minister for Health ensure dedicated, adequate and appropriately graded full time and permanent staff are assigned within the AIDS and Infectious Diseases Branch of NSW Health to oversee the implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

5.4.3 ACTION AT THE REGIONAL LEVEL: THE AREA HEALTH SERVICES

- **Development of Regional Hepatitis C Strategic Plans**

Having argued for NSW Health to develop a Hepatitis C Policy Statement and associated Strategic Plan, the Committee considers the next step to be the development of strategic plans at the regional level to address local needs and issues.

Table Six demonstrated that Hepatitis C rates vary considerably across the state. Area Health Services such as South Eastern Sydney (18% of the NSW notifications), Central Sydney (13.4%), South Western Sydney (11.7%) and Western Sydney (10.2%) have Hepatitis C notification rates far exceeding those in, for example, rural Area Health Services such as Macquarie (0.7%), Far West (0.2%) and New England (1.8%). Figure Three showed that notifications in the Northern Rivers Area Health Service greatly exceed the Area's population on a percentage basis. Clearly it is imperative that those Area Health Services with high rates of Hepatitis C have strategic plans in place to address the issue and give direction to services. It is also essential that funding be available to these Area Health Services to implement their plans.

In considering the option of regional Hepatitis C strategic plans, the Committee is fully aware of the level of autonomy assigned to the state's Area Health Services. The Committee appreciates that the central agency of NSW Health is not able to direct Area Health Services to introduce measures either this Committee or the central agency consider necessary and appropriate. However, the Committee understands that contract performance agreements between NSW Health and the Area Health Services can be used to ensure minimum levels of services are achieved. As Kirketon Road Centre's Director suggested to the Committee:

> *I do think that if the [health] department were able to enter into more binding performance agreements . . . with the Area Health Services such that Area Health Services were required to reach a minimum level of service, and prevention services were tied into that agreement, that would be a positive thing* (van Beek evidence, 6 November 1997).

The Committee is also aware that some Area Health Services such as Central Sydney and Hunter Area Health Services have dedicated Hepatitis C strategies and that others are in the process of developing their strategic plans. The South Eastern Sydney Area Health Service has prepared a draft *Communicable Disease Strategic Directions Statement* that includes, amongst other diseases, Hepatitis C. The document identifies the broad directions of the Strategic Directions Statement and its guiding principles as well as a number of specific goals, which have been linked to objectives and strategies. According to the Statement, the implementation of the strategic goals and objectives will be undertaken by a formal, accountable and participatory process with defined lines of accountability and communication. According to the document, a Communicable Diseases Outcomes Advisory Committee will provide the mechanisms and structures for the integration and co-ordination of communicable disease programs across the area and will enable area wide analysis of trends, patient flows and service utilisation (South Eastern Area Health Service, 1998:59).

The Committee was encouraged by the level of detail enunciated in the Statement. It would appear that considerable thought and effort has been given to the Statement's preparation. The Committee considers it regrettable that such thought and effort is not apparent at the state level. However, the Committee was concerned that Hepatitis C may become "buried" amongst the very large number of communicable diseases covered by this Strategic Directions Statement. The Committee would prefer to see a dedicated HCV strategic plan within the overall communicable disease strategic approach given the extremely large number of known HCV notifications in South Eastern Sydney Area Health Service.

The Committee would like to see those Area Health Services with the highest Hepatitis C notification rates - South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services - develop and implement regional and dedicated Hepatitis C strategic plans. Despite its communicable diseases strategic plan, the Committee has specifically included South Eastern Sydney in this list as it considers it essential that this area have a localised, dedicated Hepatitis C strategy.

RECOMMENDATION 37:

That the Minister for Health direct South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services develop and implement Regional Hepatitis C Strategic Plans in line with the NSW Hepatitis C Policy Statement (as proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (as proposed in Recommendation 31). This measure should be achieved through contract performance arrangements between NSW Health and the Area Health Services.

RECOMMENDATION 38:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the regional Hepatitis C Strategic Plans proposed in Recommendation 37.

- **Adequate and Appropriate Staffing: Area Health Services**

The Department's submission noted that:

> *the majority of Area Health Services do not have staff specifically working on Hepatitis C. Rather Hepatitis C is one of a range of infectious diseases*

> *dealt with by a number of staff employed to work on HIV/AIDS and/or infectious diseases* (NSW Health submission).

The Committee is aware that a few Area Health Services have staff assigned to work on Hepatitis C. Wentworth and Central Coast Area Health Services have part time, temporary staff working under contract, while Illawarra has in the past had a Hepatitis C Manager. Other Area Health Services such as Central Sydney and Western Sydney have clinical nurse consultants working in the area of Hepatitis C - these positions are outside the scope of the current discussion.

The Committee is also aware that many, if not all, Area Health Services have dedicated Area HIV/AIDS Managers who carry out a range of duties such as:

- act as the Executive Officer for the Area HIV/AIDS services;

- consult with health services, hospitals and other relevant agencies to establish the needs and priorities of the Area;

- develop and implement HIV/AIDS treatment/care and prevention/education programs consistent with state HIV planning documents;

- develop, implement and evaluate Area plans, including HIV plans, develop service models, strategies, performance indicators and outcome measures; policies and programs for the treatment/care and education/prevention services;

- facilitate the co-ordination of the various HIV/AIDS services for which the Area Health Service is responsible; and

- consult with health services, hospitals and other relevant agencies to establish the changing needs and priorities of the Area in the development and implementation of HIV/AIDS treatment/care, prevention/education and management programs.

Many of these Managers are being asked to add Hepatitis C related issues to their already heavy workloads. The Duty Statement for the position of Manger - HIV/AIDS Services for the Central Sydney Area Health Service, for example states that “where appropriate facilitate the inclusion of Hepatitis C within existing programs and services” and includes Hepatitis C along with HIV/AIDS in several activities such as “facilitate the coordination of the various HIV/AIDS and Hepatitis C services for which the Area Health Service is responsible” (Central Sydney Area Health Service, undated). Similarly, the duties of the AIDS Coordinator in the New England Area Health Service include participation in the Infectious Diseases Team response to notifications of, amongst other diseases, Hepatitis C (New England Area Health Service, undated).

In terms of HIV/AIDS Managers taking on additional duties, Loveday noted that the Hepatitis C Council:

> *certainly welcomes the expansion of their duties to take on Hepatitis C. But, realistically, to have Hepatitis C just added to their job description on top of in many cases . . . a full HIV-related workload, does not bode well for the known 45,000 and estimated 90,000 people in NSW with Hepatitis* C (Loveday evidence, 30 March 1998).

The Committee considers the practice of requiring Area HIV/AIDS Managers to take on Hepatitis C related issues to be inappropriate, particularly in those Area Health Services that have high rates of both HIV/AIDS and HCV such as South Western Sydney and Central Sydney. The Committee fully agrees with Loveday who proposed that:

> *it would make great sense to fund the appointment of hepatitis services co-ordinating staff in area health services who, with an appropriate budget, would assist in the localised provision of education, information and referral services* (Loveday evidence, 30 March 19998).

However, given that the demand for Hepatitis C management will differ across the state in line with varying Hepatitis C rates, the Committee would like to see a full review conducted across all Area Health Services to determine the specific needs of each Area Health Service in terms of Hepatitis C management.

RECOMMENDATION 39:

That the Minister for Health review all Area Health Services to determine the needs of each Area Health Service for Area Hepatitis C Managers.

While proposing the introduction of Area Hepatitis C Managers, the Committee is fully aware that its recommendation will take some time to implement. It is concerned that in the interim access to Hepatitis C services, care and support will be limited. It therefore proposes Area Hepatitis C Managers be placed in those Area Health Services the Committee considers to be in greatest need, based on Hepatitis C notification rates: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Northern Rivers.

RECOMMENDATION 40:

That the Minister for Health instruct that, as a matter of priority, the position of dedicated Area Hepatitis C Manager be established and filled in the following Area Health Services: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Northern Rivers. The Committee further recommends that the position of dedicated Area Hepatitis C Manager be in addition to existing positions of Area HIV/AIDS Managers which may currently exist in the identified Area Health Services.

RECOMMENDATION 41:

That the Minister for Health ensure dedicated funding is allocated to the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services for the establishment of Area Hepatitis C Manager positions.

RECOMMENDATION 42:

That the Minister for Health instruct that the positions of Area Hepatitis C Manager in the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services be incorporated in the review of Hepatitis C staffing needs proposed in Recommendation 39. The Committee further recommends that, following this review, and where necessary additional staff dedicated to Hepatitis C management at the local Area Health Service level be appointed.

5.5 CONCLUSION

Despite the current Hepatitis C epidemic there are no policies at the state level giving overall direction to the control, treatment, management and prevention of this disease. To overcome the current inadequate situation, the Committee has forwarded a number of recommendations including upgrading the Hepatitis Advisory Committee to the Ministerial Advisory Committee on Hepatitis C; the design, development and implementation of a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; adequate and ongoing dedicated funding for the full implementation of the Policy Statement and Strategic Plan, dedicated, adequate and appropriately graded full time and permanent staff to oversee the implementation of the Hepatitis C Policy and Strategic Plan and, as a matter of priority, Area Hepatitis C Managers assigned to the five Area Health Services with exceptionally high levels of HCV notifications.

CHAPTER SIX

DIAGNOSING HEPATITIS C

The Committee was asked to comment on current diagnostic practices and related policies. While a number of those giving evidence referred to this issue in a general manner, two witnesses spoke in depth on the issue. The Committee has therefore drawn heavily upon the evidence and submissions from these experts: Dr Dominic Dwyer, medical virologist at the Centre for Infectious Diseases and Microbiology Laboratory Service at Westmead Hospital; and Dr William Rawlinson, Associate Professor, University of NSW and Senior Medical Virologist of South Eastern Area Laboratory Services, Virology Division of the Department of Microbiology, Prince of Wales Hospital.

6.1 WHO SHOULD BE TESTED?

Chapter Three identified the population groups most ‘at risk’ of contracting Hepatitis C. These are the groups that will be the focus of testing. The NHMRC report identifies those groups of people that should be offered testing by a clinician if HCV is suspected or a patient requests it including:

- people who have ever injected drugs;
- people who have been transfused with blood or blood products;
- people with abnormal liver function tests or evidence of liver disease, with no other apparent cause;
- people with occupational exposure to HCV such as needlestick injuries;
- people with certain unexplained extrahepatic conditions; and
- people who have been in prison (NHMRC, 1997:29).

The NHMRC also recommended the following groups of people may be at increased risk of HCV infection, and testing can be considered:

- people with tattoos or other body piercing (including acupuncture), where standard infection control guidelines may not have been followed;
- household contacts who share a razor or toothbrush with a HCV infected person;
- people born overseas, especially in Mediterranean countries, Middle East, South -East Asia, Africa, South America and other developing nations;
- children of people infected with HCV;
- sexual contacts of people infected with HCV (overall risk is low);

- health care workers and others in contact with blood;
- renal dialysis patients;
- people who have practised unsafe sex with multiple partners (the risk here is uncertain, but overall low); and
- people who specifically request a test - some people who have no specific admitted risk factors for HCV infection may request a test. They may have hidden risk factors and their request normally should be granted (NHMRC, 1997:29-30).

6.2 TESTING FOR HEPATITIS C

Farrell informed Committee Members that:

> *an important part of diagnostic management in some patients with Hepatitis C is the provision of specialised diagnostic tests. These include, amongst others, PCR to detect the virus directly, genotyping and quantification of HCV. The latter are expensive tests but are useful in planning interferon treatment* (Farrell submission).

Diagnostic tests for Hepatitis C can be divided into two categories:

- serological assays that detect the antibody to Hepatitis C (anti-HCV); and
- molecular assays that detect, quantify and/or characterise HCV RNA genomes within an infected patient (Gretch, 1997:43S).

The following discussion will identify the various diagnostic tests available and current shortcomings in the delivery of diagnostic services.

6.2.1 ANTIBODY TESTS

A person is considered to be infected if HCV antibody positive. Antibodies are usually detected four to six weeks after the initial infection. Seroconversion after initial infection (ie becoming antibody positive) can take some time with the ‘window period’ ranging from 2 to 26 weeks (mean 10 weeks) after infection. This period of time can be very significant in some groups such as injecting drug users.

Serological assays can be subdivided into screening tests for anti-HCV such as the enzyme immunoassay (EIA) and supplemental tests such as the recombinant immunoblot assay (RIBA).

Three generations of anti-HCV tests have been developed and each generation has resulted in an improvement in the sensitivity of detecting anti-HCV. The first generation tests were not particularly sensitive as Batey informed the Committee:

> *we were struggling in the early days with tests which gave us a fifty percent false positive rate, so people were not game to make radical statements knowing that half the patients who thought they had Hepatitis C may not have had Hepatitis C . . .* (Batey evidence, 27 October 1997).

Second and third generation tests have now been developed and the assays currently available are more sensitive and more specific than tests used before 1993. The second generation tests are at least 90 to 95 per cent specific and sensitive. The NHMRC considers these tests to be "reasonably accurate" (NHMRC, 1997:30). Problems still occur though. False negative (ie somebody is infected with HCV but has a negative antibody test) results occur occasionally (NHMRC, 1997:30) or according to Rawlinson, in a "small number" of cases (Rawlinson submission).

The main screening assay for detecting anti-HCV is the enzyme immunoassay (EIA). The EIA has many advantages in the diagnostic setting, including ease of use, low variability, ease of automation and relatively low expense (Gretch, 1997:43-44S). Rawlinson summarised this test as:

> *a well established technology which, with the use of newer second and third generation tests, delivers rapid, reproducible results* (Rawlinson submission).

The rate of false negative results of the anti-HCV tests has created a need for supplemental or confirmatory tests. The recombinant immunoblot assay (RIBA), for example, was developed to aid in the diagnostic evaluation of seemingly healthy individuals who test positive in the anti-HCV screening assay (Gretch, 1997:43S). Immunoblots are a more sophisticated test than the anti-HCV test. They are more labour intensive and therefore more expensive (Rawlinson submission).

As Table Twenty-One shows, both EIA and RIBA tests are relatively inexpensive and are useful for screening populations for previous infection with HCV. They do not distinguish between recent and past infection.

In commenting on the number of tests performed by his laboratories at Westmead, Dwyer told the Committee that:

> *We do about twelve and fifteen thousand hepatitis tests a year. In the first six months of 1997 we have done about ten thousand. It is difficult to predict what would happen but our testing numbers increase generally year by year, and given the increasing publicity, the increasing availability*

> *of treatment, I would expect to continue to see more every year. I could not predict how many it would be but we will certainly see more every year* (Dwyer evidence, 10 October 1997).

TABLE TWENTY-ONE
TESTS AVAILABLE FOR DIAGNOSING AND ASSESSING HCV INFECTION

TEST	FEATURES	APPROXIMATE TOTAL COST ($AUS)
Antibody Detection: HCV antibody	Now use 2nd and 3rd generation tests Only detects past infection Many different commercial assays Assays based on genotype 1 currently will be positive in uninfected and infected neonates or infected mothers (EIA enzyme immunoassay)	$12.00
HCV immunoblot	Confirmatory assay More time consuming than anti-HCV test Fewer suppliers	$50.00
Antigen Detection:		
HCV-PCR	Commercial assay usually Problems with contamination Qualitative assay	$70.00
HCV-bDNA	Commercial assay only Qualitative assay	$70.00
HCV genotyping	Done using line probe assay Problems distinguishing some subtypes	$135.00 - $150.00
	In-house assays using single stranded conformational polymorphism	$50.00
	In-house PCR followed by DNA sequencing	$50.00
HCV serotyping	Murex kit detects genotypes 1-6. Does not detect types 6-11 as well as some genotyping	$135.00 - $150.00
HCV quantification	Viral load measures used as a surrogate for response to therapy	$150.00

Source: Rawlinson submission

In terms of the adequacy of these tests, Dr Dwyer informed the Committee that:

> *the performance of Hepatitis C antibody testing in most major laboratories is just fine. Most major laboratories, now that the antibody tests have improved in quality over the last few years . . . perform these tests very well . . . I think things are adequate* (Dwyer evidence, 10 October 1997).

6.2.2 ANTIGEN DETECTION

Molecular assays have been designed to confirm indeterminate antibody results, aid in management of therapeutic trials, make diagnoses before seroconversion, or as a surrogate measure of infectivity. The primary assay is a polymerase chain reaction (PCR) test, a highly sensitive test of the genetic material of the virus, that detects the virus rather than the antibody to the virus.

There are three types of PCR test:

i. HCV PCR viral detection test which looks for the virus. It can be called a ‘qualitative’ test;

ii. the HCV PCR viral load test looks for the virus and estimates the number of HCV viruses per ml of blood. It may be called a ‘quantitative’ test; and

iii. HCV PCR genotype test which looks for the virus and determines the particular subtype(s) present (Hepatitis C Council, 1998:2).

The development of polymerase chain reaction methods for detecting Hepatitis C RNA has provided a potential means of assessing infected people in terms of their infectiousness: a person is considered to be infected and infectious if HCV antibody and HCV PCR positive; a person is considered to be infected but not infectious if HCV antibody positive and HCV PCR negative. The risk of transmission from people who are positive for Hepatitis C but have negative results by PCR is considered by Dore, Kaldor and McCaughan (1997:333) to be “extremely low”.

The sensitivity and specificity of PCR testing has improved over time. However false-positive and false-negative test results are possible (NHMRC, 1997:30).

The NHMRC proposes that the following are possible clinical applications for PCR testing for HCV RNA:

- assessment of in determinant EIA results;
- early detection of acute Hepatitis C;
- assessment of response to interferon therapy;

- study of transmission (as a research tool);
- investigation of immunocompromised patients whose antibody levels may be low or undetectable;
- determination of chronic infection status;
- determination of infectiousness (as a marker); and
- testing of anti-HCV-positive sources in cases of occupational exposure to assist in determination of transmission risk (NHMRC, 1997:30).

A rebate is available under the Medicare Benefits Schedule for the basic PCR HCV viral detection test, as opposed to the other two that detect viral load or genotype. Medicare covered PCR tests are available only in limited situations including:

- people who have had a positive HCV antibody test and who have normal liver function test results on two occasions six months apart, or
- people who have inconclusive HCV antibody test results, or
- people who have weakened immune systems (such as HIV/AIDS) and want to confirm whether they are Hepatitis C positive or not; or
- people who have experienced a risk exposure (such as a needlestick injury) and want to confirm during the 'window period' whether they have contracted HCV (Hepatitis C Council, 1998:1).

By comparison, ANCARD advised that PCR testing and viral load testing have become "routine" for HIV/AIDS populations (ANCARD submission). Such differences prompted ANCARD to conclude that diagnostic approaches to Hepatitis C are "a little confused" (ANCARD submission).

Further detail of each of these three tests is provided below.

- **Qualitative Tests for HCV RNA**

PCR viral detection tests are mainly used as a confirmatory test when an HCV antibody test is inconclusive. They are also used to check within the six month 'window period' following a risk incident (when antibody tests are unreliable), if a person has contracted HCV. The test can also be used to determine potential infectivity in the event of consistently normal liver function tests (Hepatitis C Council, 1998:2).

- **Quantitative Tests for HCV RNA**

Measuring the level of circulating HCV RNA in serum or plasma specimens represents a potentially important tool for assessing and managing HCV infection, particularly those patients on interferon therapy. The level of circulating HCV RNA in a patient's plasma or serum is referred to as the viral load and is presumably a reflection of both the rate of viral replication and the rate of viral clearance by the infected host.

During interferon therapy, this test can monitor whether the therapy is working effectively or not. Initial PCR viral load testing as early as two to four weeks into treatment will identify people who wouldn't respond over the full 12 month period (Hepatitis C Council, 1998:2).

In addition to the quantitative PCR test, signal amplification technologies, such as branched DNA (bDNA) assay, have been developed to assess HCV RNA levels (Gretch, 1997:44S). The bDNA assay is less sensitive than PCR at detecting the HCV virus, but it is less prone to contamination than PCR.

- **HCV Genotype Testing**

Tests to determine HCV genotype fall into two general categories: screening tests that detect point mutations within the HCV genome; and confirmatory tests that evaluate larger segments of HCV genes (Gretch, 1997:44S). HCV can also be subclassified based on the antigenic reactivity to viral proteins. HCV serotyping assays involve reacting a patient's antisera with recombinant antigen in an immunoblot format. The potential advantages of HCV serotyping tests are low cost and ease of testing compared with molecular genotyping assays (Gretch, 1997:44S).

Genotyping using the Line probe assay (LiPA) or PCR and DNA sequencing is essential for HCV diagnosis and therapy. As has been discussed in Section 2.1.5 different genotypes respond differently to interferon therapy. Therefore

> *if no genotyping were done before commencing individuals on interferon therapy, at least half of them would respond poorly because they carry genotype 1* (Rawlinson submission).

When asked to comment on the adequacy of diagnostic services of the more refined tests Dr Dwyer informed that Committee that:

> *the more refined services, PCR, genotyping for Hepatitis C, I think the services are not adequate because they are not funded. For example, most of the genotyping that we would have done at our hospital, and a lot of PCR is actually being done in the context of drug trials . . . Apart from that there has been virtually no real funding . . .* (Dwyer evidence, 10 October 1997).

Dwyer elaborated further:

> *One reason why we have had to keep a very tight grip on how many tests we actually allow doctors to order is because we cannot fund it. I think what will happen is that there will be an increased drive from doctors and from patients probably to ask for these more specialised tests and if they are not funded there would be no way we could provide the service. Take genotype for Hepatitis C, which I think will turn out to be a very important test, possibly even more important than the PCR. There is no funding for that now . . . There will be more demand for it because people will say "I need to know what my genotype of Hepatitis C is" and there will be more demand for us to do it . . .*(Dwyer evidence, 10 October 1997).

Given this current funding situation, Dwyer concluded that:

> *I think from that point of view it is quite inadequate and I think it will become more so unfortunately* (Dwyer evidence, 10 October 1997).

The issue of funding for diagnostic tests will be considered in the following section.

In summary, EIA for anti-HCV is the most practical screening test for the diagnosis of Hepatitis C infection. The need for, and the choice of, confirmatory tests depends on the clinical setting as is suggested in Table Twenty-two. As that table shows, and as will be discussed in Chapters Seven and Eight, the response to treatment should include documentation of viral clearance by qualitative PCR assay.

TABLE TWENTY-TWO
DIAGNOSTIC EVALUATION OF HEPATITIS C

	RIBA	QUAL[1] PCR	QUANT[2] PCR	BDNA	HCV GENOTYPE
Confirmation of diagnosis	+	+	±	-	-
Assessment of severity of liver disease	-	-	-	-	-
Evaluation for treatment	-	-	+	+	-
Determination of response to treatment	-	+	-	-	-
Monitoring progress of liver disease	-	-	-	-	-

1. Qualitative 2. Quantitative

Source: Lok and Gunaratam, 1997:49S

In February 1998 the ANCARD Hepatitis C Clinical and Virological Advisory Panel and the Clinical Trials and Treatment Advisory Committee (CTTAC) met to finalise CTTAC's recommendations on testing requirements in relation to Hepatitis C management and therapy. The Hepatitis C testing protocol developed is reported in Table Twenty-three. The meeting also agreed upon the following points:

- viral load testing (quantification) was required before treatment but not during or after treatment;
- viral load testing will indicate outcome of treatment response;
- genotype testing should be performed to advise therapy;
- genotype testing could be performed to assist counselling; and
- qualitative tests should be performed following therapy (Report of Meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel, the Clinical Trials and Treatments Advisory Committee and Invited Participants, February, 1998).

TABLE TWENTY-THREE
PROPOSED HEPATITIS C TESTING PROTOCOL

	FORMS OF TESTING RECOMMENDED
Initial Detection: Anti-HCV+	Qualitative PCR
Therapeutic Intervention:	Quantitative PCR Genotype
• S100 indications	
• Anti-HCV x 2	
• Treatment - 12 weeks of therapy	Qualitative PCR
• End of 12 months of treatment	Qualitative PCR
• 6 months follow up	Qualitative PCR
• 18-24 months follow up	Qualitative PCR

Source: Report of Meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel, the Clinical Trials and Treatments Advisory Committee and Invited Participants, Melbourne, 2 February, 1998.

6.3 LABORATORIES

The submission from the Centre for Infectious Diseases and Microbiology Laboratory Service at Westmead Hospital suggested that:

> *given the social and economic impact of Hepatitis C in NSW and Australia, the development of an appropriate laboratory structure, including reference laboratories, is essential. This is required to ensure accurate diagnostic testing, the ability to participate in epidemiologic and applied research and to guide cost effective antiviral therapy* (Centre for Infectious Diseases and Microbiology Laboratory Service submission).

The following discussion outlines the current laboratory structure and inadequacies raised during the course of the Inquiry.

Public hospital and private laboratories currently perform the routine HCV antibody testing using either commercial HCV antibody screening test kits (registered with the Australian Register of Therapeutic Goods) or in-house assays.

The PCR test requires a high degree of technical skill. At the time of giving evidence, NSW Health advised that there were 12 diagnostic laboratories approved to carry out PCR testing for HCV. They include:

- Hunter Area Pathology Service
- NSW Blood Transfusion Service
- South Western Area Pathology Service
- St Vincent’s Hospital
- Prince of Wales Hospital
- General Clinical Laboratories
- Royal North Shore Hospital
- St George Hospital
- Concord Hospital
- Westmead Hospital
- Sugarman’s Pathology
- Royal Prince Alfred Hospital

(NSW Health, tabled document).

The Committee was advised that the structure of the state’s public laboratories has undergone change in the last one to two years. Six major public hospital laboratories in NSW have become “hub” laboratories providing laboratory service not only for their immediate area health service but also specialist laboratory services for smaller public hospitals in both rural and metropolitan areas. The Committee heard, for example, that the ICPMR at Westmead provides laboratory services for the health areas of Far Western, Central West and Central Coast (Dwyer evidence, 10 October 1997). In addition, private laboratories tend to send some of the more expensive assays to these hub laboratories. As a result:

> *both private hospital laboratories and the smaller public laboratories send on difficult work to us [hub laboratories] that we perform at our own expense and this has been a big problem with Hepatitis C* (Dwyer evidence, 10 October 1997).

Dwyer also added that hub laboratories have:

> *to find the sort of income within [the] area health service budget to pay for this [service] which has been a particular problem with Hepatitis C* (Dwyer evidence, 10 October 1997).

6.3.1 REFERENCE LABORATORIES

Access to validation and prognostic testing is fundamental to the successful provision of any HCV related clinical service. Such testing needs to be adequately supervised and subject to quality control. It was suggested to the Committee that an appropriate venue for such testing would be reference laboratories. The submission from the Centre for Infectious Diseases and Microbiology Laboratory Service at Westmead Hospital noted, for example, that:

> *the need for state reference laboratories to undertake confirmatory testing, perform HCV RNA assays using new molecular technology, and the provision of genotyping and other expensive assays cannot be overemphasised.*

The Committee was advised that, currently, hub laboratories are carrying out many of the functions of reference laboratories, but are doing so at their own cost (Dwyer evidence, 10 October 1997).

There is considerable support for the establishment of reference laboratories. The NSW Hepatitis C Taskforce, for example, proposed the establishment of two major reference sites to meet NSW needs (NSW Health, 1995:28). The Taskforce report recommended that:

> *tenders should be called for the establishment of two major reference sites in NSW. Selection should be based on the expertise and experience of the laboratories, the ability to interpret tests and to develop new tests. Reference laboratories should also be allowed to charge referring private laboratories for the costs of validation testing* (NSW Health, 1995:6).

The Taskforce envisaged that, since the reference laboratories would be providing a service to the state as a whole, the resources for this development should be met centrally rather than the hospital's local area health service (NSW Health, 1995:28). In advising the Committee on the implementation of the Taskforce recommendations, NSW Health did not make a comment on these specific recommendations (NSW Health, tabled document). The Committee understands however, that the recommendations have not been implemented. McCaughan told the Committee that he and his colleagues were "very disappointed" that the specific recommendations of the NSW Taskforce were not taken up by the NSW Department of Health (McCaughan evidence, 23 March 1998).

The Taskforce further recommended that the proposed reference laboratories be linked with the National HIV Serology Reference Laboratory in Melbourne and other state reference laboratories (such as the Institute of Medical and Veterinary Science, Adelaide; State Health Laboratories, Nedlands, Western Australia and the Victorian Infectious Diseases Reference Laboratory). In responding to this recommendation, NSW Health noted that laboratories authorised to undertake HCV supplemental testing provide data to the National Serological Reference Laboratory for national collation. No comment was made on links to other state reference laboratories (NSW Health, tabled document).

The establishment of reference laboratories was raised during the course of the Inquiry. Dr Dwyer considered the concept of reference laboratories to be “absolutely critical” as “you really need specialised, high tech if you like, laboratory back-up to the routine testing that is done normally” (Dwyer evidence, 10 October 1997). Dwyer called for:

> *a number of laboratories, one or more depending, I am sure you could justify a couple, that provide a reference hospital, or reference laboratory function for everybody else and this reference function helps other laboratories, either public or private, to carry out the more complicated diagnostic testing, or confirmatory testing, or up market molecular testing* (Dwyer evidence, 10 October 1997).

Dr Dwyer elaborated further:

> *with Hepatitis C my feeling would be that you would really only need a couple of reference laboratories in the state at institutions that already are heavily involved in hepatitis patient management and laboratory aspects . . . you would look at say two to three reference laboratories in NSW. Probably the biggest laboratories undertaking Hepatitis C testing in Australia, particularly the back-ups of drug trials and so on would be the ICPMR at Westmead and Prince Alfred Hospital in Central Sydney Area Health Service* (Dwyer evidence, 10 October 1997).

Dr Rawlinson commented that:

> *I think the role of reference laboratories is very important and I think the role of reference laboratories in sorting out Hepatitis C is terms of therapy as well as diagnosis is extremely important and I think that the role of a diagnostic and research laboratory next to each other is also similarly important . . . I actually think that there is a significant role for reference laboratories . . .* (Rawlinson evidence, 27 October 1997).

Rawlinson proposed that:

> *the requirements for doing reference functioning should be attached to a large*

> *teaching hospital, there should be attachment to a university, there should be a large and vigorous virology laboratory and they should have sufficient expertise both in the diagnostic areas as well as within research areas* (Rawlinson evidence, 27 October 1997),

while Dwyer envisaged the reference laboratories coming from the major hub laboratories "already identified" (Dwyer evidence, 10 October 1997).

The submission from the Centre for Infectious Diseases and Microbiology Laboratory Service proposed that participation in state-wide and national quality assurance programs would also be part of state reference laboratory function.

RECOMMENDATION 43:

That the Minister for Health call tenders for the establishment of three major Hepatitis C reference laboratories in NSW. Selection of the laboratories should be based on the expertise and experience of the laboratories, the ability to interpret tests and develop new tests, and their capacity to participate in state-wide and national quality assurance programs. The reference laboratories should be able to conduct validation testing for private laboratories for a fee.

It was suggested to the Committee that funding for reference laboratories should be specific and outside current allocations made to area health services. Dwyer for example suggested that:

> *Reference laboratory function needs to be funded from outside the kind of local area health service budget, which is the way we operate at the moment* (Dwyer evidence, 10 October 1997),

while the Centre for Infectious Diseases and Microbiology Laboratory Service called for "specific funding" for reference laboratories to carry out their functions (Centre for Infectious Diseases and Microbiology Laboratory Service submission).

Funding problems experienced in the past were raised during the course of evidence:

> *for the cost of $3million a year, the [Hepatitis C Taskforce] recommended the funding of diagnostic mini-reference laboratories to do molecular testing in Hepatitis C. I think those laboratories have been funded to the tune of something like $300,000 or $400,000 across the State. The first set of funding, when it was decided, was delivered to health care areas on 30 June of the financial year. Therefore the laboratories that had been doing the testing never saw the funds for that year because they were delivered on 30 June. The following year, 1996-97, the funds were delivered, but the funds for 1997-98 have not been delivered* (McCaughan evidence, 23 March 1998).

Professor McCaughan went on to state that:

> *The last formal discussion of the Hepatitis C Advisory Committee indicated that the funds were unlikely to be delivered for this financial year. So a laboratory such as mine, which gets around $50,000 to $100,000 a year out of that sort of funding, is now already $50,000 to $60,000 over budget because we are doing those tests. The last financial year was okay because the money came in, but we are told that the money is unlikely to come in this year* (McCaughan evidence, 23 March 1998).

It is not anticipated that the establishment of reference laboratories will incur significant expense. It was suggested that:

> *the provision of specialised expensive testing by reference laboratories will minimise expenses, compared to multiple laboratories performing such tests* (Centre for Infectious Diseases and Microbiology Laboratory Service submission).

RECOMMENDATION 44:

That the Minister for Health ensure adequate funding is available to the Hepatitis C reference laboratories proposed in Recommendation 43 and that the funding allocation to the reference laboratories be made from NSW Health funds rather than the local area health services.

6.4 PRE- AND POST-TEST COUNSELLING

Numerous submissions received from those with Hepatitis C described the shock, panic and fear they experienced when they learned they were HCV positive. The Committee heard, for example that:

> *When I was diagnosed with Hepatitis C 12 months ago I felt my life as I knew it and lived it had come to an end. No words can really express the devastation that I felt and still feel when discovering I was positive* (Submission 33);

> *my first reaction was I was going to die. I felt dirty and unclean. I became very afraid of doing things with my children in case I gave it to them* (Submission 7);

and

> *I don't know how to describe those first few minutes/hours to you. I remember feeling lost, alone and very frightened. I really didn't understand what was happening . . . For a long time I felt dirty. I felt/feel violated* (Submission 20).

Others stated that:

> *when I found out I had Hepatitis C I was devastated. I've become anxious and have outbursts of crying and depression* (Submission 23);

and

> *the shame and horror I felt was devastating to the point where the only thing to do was get away from my wife and children and perhaps end my life* (Submission 76).

Counselling is an important component of the management of a patient known or suspected of being infected with HCV. It was suggested by a number of experts that the provision of pre-test counselling may, for many, lessen the trauma that often comes with learning of a positive result. However, the Hepatitis C Council advised that:

> *counselling prior to testing is conducted, if at all, in an ad hoc manner with too few practitioners spending adequate time to provide information and support or to conduct an assessment of the relative risks of HCV infection. Others will conduct testing without ensuring the person has sufficient time or information to understand the implications of a positive test result* (Hepatitis C Council submission).

The NHMRC suggests that counselling should be a "deliberate process" with three general outcomes:

i. to provide psychosocial support;

ii. to prevent the transmission of HCV; and

iii. to optimise treatment outcomes (NHMRC, 1997:64).

The NHMRC document on managing Hepatitis C (1997) provides some guidance for GPs on pre- and post-test counselling. The Council recommends that pre-test counselling needs to be tailored to the individual patient and should be conducted in private with sufficient time to enable discussion of the issues (NHMRC, 1997:65). According to the NHMRC, the aims of pre-test counselling are:

- to assess the risk factors;

- to provide information on clinical signs and symptoms which lead the practitioner to suspect Hepatitis C;

- to enable the patient to make a decision whether or not to have the test;

- to provide information about the test and possible consequences of testing, including notification and confidentiality of results;
- to provide information on testing benefits;
- to establish the ability to give informed consent for the test; and
- to identify support available to the patient (NHMRC, 1997:65).

The following information should be considered for inclusion in pre-test counselling;

- brief information about the history of the virus and an explanation that it was not able to be identified until 1990;
- routes of transmission of HCV and strategies to prevent transmission;
- the test and its limitations;
- the meaning of a positive, negative or equivocal test result;
- advice that HCV infection generally has an indolent course and that if the test is positive, monitoring may be the only action that is required;
- availability of treatment with interferon for some patients who have active infection;
- likelihood of successful treatment with interferon;
- investigations are continuing into other treatments including a Chinese herbal preparation;
- the impact that different cultural beliefs and practices may have should be recognised, and explored at this time;
- the implications of a positive test result for life assurance;
- issues of confidentiality, in particular a clear and full explanation of the legal requirements for reporting of a positive test result which may vary from one state or territory to another; and
- the prognosis (NHMRC, 1997:65).

The Council also recommends that a brief psychosocial assessment would provide the treating practitioner with some understanding of how the person will react to the knowledge of his/her HCV status (NHMRC, 1997:65).

The NHMRC recommend that the results of an HCV test should “always” be given to the patient in person no matter what the reason for the test or whether the result is positive or negative (NHMRC, 1997:65). However, the Committee has heard that test results are given in a number of ways including phone calls made to people while at work or letters sent through the post. There does not appear to be any set criteria to guide health care workers in imparting test results.

In addition to pre-test counselling, calls have been made for post-test counselling. The aims of counselling at this time are to ensure that the patient understands the meaning and implications of the test results and that appropriate referrals and psychosocial interventions are provided if required (NHMRC, 1997:65). As the NHMRC note, these implications differ with the test outcome. If the test is positive or equivocal, the person given the test result has the professional responsibility to provide or arrange for immediate counselling and support. With a negative test result, counselling should provide information to prevent exposure to HCV (NHMRC, 1997:66)

The Hepatitis C Council proposed that pre- and post- test counselling should be a routine practice. It noted that pre- and post-test counselling is “recommended” as part of good practice around testing for HCV. The Council however proposes that this practice could be ensured through the development and implementation of policy guidelines for practitioners. The Council anticipates that:

> *the development and implementation of a policy on testing, which includes confidentiality provisions, could increase the uptake of testing and ensure the legal rights and obligations of practitioners and persons with HCV* (Hepatitis C Council submission).

The ACT Sexual Health and Blood Borne Diseases Strategic Plan (1998) proposes legislating pre- and post-test counselling requirements for HCV. While the Committee fully supports policy guidelines for pre- and post-test counselling, it does not consider the ACT’s proposal to be necessary.

RECOMMENDATION 45:

That NSW Health recognise the provision of pre- and post-test information and counselling by health care professionals provides best practice patient management in relation to testing for Hepatitis C. The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C proposed in Recommendation 27 develop a set of policy guidelines for pre-and post-testing for Hepatitis C for health practitioners in NSW and that these guidelines ensure pre- and post test counselling are a routine practice for all people considering HCV testing.

6.5 DIAGNOSIS OF PRISON INMATES

A policy directive (CHS:CMED39) for voluntary blood borne communicable diseases screening program, which tests for HIV, Hepatitis B and C and syphilis, was introduced into the state's correctional system in early 1995. Prior to that time (from 1990 to 1994), screening was not voluntary. During the 1990 - 1994 period:

> *inmates would come in, be told to sit down and stick their arm out and that was it. There was no negotiation on having a blood test done* (Harper evidence, 23 March 1998).

The Committee heard that:

> *the problem with the compulsory system is that, for expediency and efficiency it needs to be done - and was done - as part of the reception and exit process . . . They come in withdrawing, detoxing and have other priorities on their mind rather than consenting and taking in what is being said about the inherent risks in prison for blood borne communicable diseases; tattooing, sharing injecting equipment, sharing razors and those types of things . . . from an educational point of view it was not an opportune time and that was the major reason we changed it from that first-day reception process to the following days when those persons have had time to see the other health professionals and have their immediate needs addressed* (Christensen evidence, 23 March 1998).

Vumbacca informed Committee Members that the compulsory system for HIV testing:

> *created a lot of problems in the system. When people refuse to be tested a number of civil and human rights issues are raised. Under HIV, for instance, we used to get calls from various gaols saying "we have someone here who is refusing to be tested for HIV". The law under the Prisons Act states that they are to be tested, so it gets down to whether you punish that person for refusing to give a blood sample, hold them down physically to take the blood and all those sorts of issues* (Vumbaca evidence, 23 March 1998).

The current Corrections Health Service policy is that:

> 1. *all new receptions (without exception) receive education, information, harm minimisation strategies and an individual risk assessment relating to communicable diseases.*
>
>   *Each new reception is to be offered screening/testing for HIV, Hep B, Hep C and syphilis.*
>
>   *Prior to testing pre-test counselling* ***must*** *be attended to facilitate informed consent being obtained . . .*

> 2. *All inmates who identify engaging in at risk activities or behaviours should be offered screening, education and counselling on a three month basis (unless otherwise specified by a Medical Officer)*
>
> 3. *All inmates are to receive the results of screening performed by Corrections Health Service. Post-test counselling, education and reinforcement of harm minimisation strategies are to be given with the test results* (Corrective Health Services, undated).

The current voluntary program is, according to witnesses, "a lot harder" than the previous system because:

> *in the pre-test counselling we have to convince them, particularly if they engage in at-risk behaviour, that it is in their best interests to have the testing done and allow us to run with that and sort that out* (Harper evidence, 23 March 1998).

Under the current voluntary screening program,

> *Not everyone knows they are Hepatitis C positive, so we stand proud of the fact that we diagnose a lot of people in prison. The number of people we inform on their entry to gaol is amazing* (Harper evidence, 23 March 1998).

As the policy states, pre- and post-testing counselling are required (Christensen evidence, 23 March 1998):

> *we spent a significant amount of time putting in a pre-test and post-test counselling procedure to prepare inmates for diagnosis, to look at risks and to provide more health education and information than the former compulsory HIV screening program* (Christensen evidence, 23 March 1998).

The Committee was advised that the benchmark for screening is 60 per cent (Christensen evidence, 23 March 1998). However, as Christensen advised, "we never quite reached that point for a number of reasons" (Christensen evidence, 23 March 1998) and Lloyd suggested only that approximately 30 per cent of new inmates choose to be screened (Lloyd evidence, 30 March 1998).

Professor Lloyd considers the current voluntary screening program to be a "good system" (Lloyd evidence, 30 March 1998).

6.5.1 Compulsory Hepatitis C Screening?

Butler's study referred to in Section 3.2 found that 35% of inmates who tested HCV+ told the researchers that they were negative. These inmates didn't know their HCV status (Butler evidence, 23 March 1998) leading Butler to conclude that:

> *I think there is a big pool of people who do not know their hepatitis status, who come into gaol and probably think they are okay. It is that group we need to get inside in some way* (Butler evidence, 23 March 1998).

This statistic, in addition to the small proportion of inmates choosing to undergo Hepatitis C screening led Committee Members to ask those witnesses with experience working in the corrections system if they considered the introduction of compulsory Hepatitis C screening to be an appropriate strategy. There was not much support for the idea. Christensen, for example, said she "would have a problem with a compulsory [Hepatitis C screening] program" (Christiansen evidence, 23 March 1998).

Mr Gino Vumbaca who heads up the Department of Corrective Services's HIV and Health Promotion Unit admitted that, while he could "see the elements that would make it an appropriate strategy" (Evidence, 23 March 1998), he was not however able to give the strategy his full support given the problems that has occurred with compulsory HIV testing.

The Committee accepts the opinion of the experts and therefore does not recommend the introduction of compulsory Hepatitis C screening in the state's correctional system. However, it would like to see the availability of screening promoted widely and inmates strongly encouraged to avail themselves of testing. This issue will be discussed further in Section 8.6 which looks at the development and introduction of a best practice model for the delivery of Hepatitis C treatment and management services to Hepatitis C inmates.

6.6 CONCLUSION

This chapter's discussion has focussed on available testing for the Hepatitis C virus and the laboratory system that supports that testing. In summary the Committee heard that:

> *laboratory testing for HCV is an integral part of any clinical and therapeutic approach to HCV infection. In the short and long term, appropriate testing can save significant money on therapy, can provide the individual with more detailed, accurate knowledge of their likely outcome, with or without treatment, and will provide data for newer treatments, including vaccines* (Rawlinson submission).

Such testing must be backed up with appropriate and adequate pre- and post-test counselling and support irrespective of the test outcomes.

The Chapter also considers the diagnosis of Hepatitis C within the corrections system and, while the Committee was not prepared to support mandatory HCV screening, the Committee strongly supported greater promotion of the current Hepatitis C screening program.

CHAPTER SEVEN

TREATING AND MANAGING HEPATITIS C:

THE CURRENT SITUATION

The Inquiry's Terms of Reference ask the Committee to look at treatment services available to those with Hepatitis C and the adequacy of policies directing these services. The following discussion identifies and examines treatment policies and currently available treatment regimes and services.

7.1 CURRENT TREATMENT POLICIES

Currently there is only one approved treatment available for those with chronic Hepatitis C and that is drug therapy using interferon alpha (the drug is referred to as interferon throughout this report). Two drug companies currently market interferon in Australia: Roche (under the brand name of Roferon) and Schering-Plough (under the brand name of Intron).

Strict federal policies regulate the administration of this drug in terms of who can receive it, how much can be administered and for how long, and which hospitals can dispense and manage the therapy.

Intron was first approved for the treatment of chronic Hepatitis C by the Therapeutic Goods Administration (TGA) on 9 December 1992 for a treatment duration of six months (Schering-Plough submission). Following evaluations of both clinical and cost effectiveness data by the Pharmaceutical Benefits Advisory Committee (PBAC), the Federal Government released Intron for use in a specific group of Hepatitis C patients, under Section 100 (S100) of the *Commonwealth National Health Act, 1953* scheme for highly specialised drugs on 1 October 1994. The Pharmaceutical Benefits Scheme (PBS) listing was conditional upon adherence to a list of S100 criteria determined by the PBAC and based on advice from the former NHMRC/AHMAC Taskforce on Hepatitis C.

In June 1996 Schering-Plough was successful in gaining TGA approval to extend the duration of treatment with Intron A from six months to up to 18 months. Subsequently the duration of treatment under S100 was extended to 12 months with the new conditions of listing starting from 1 May 1997. The Committee understands that Intron A is the only form of interferon to have both TGA and PBAC approvals for the treatment of chronic Hepatitis C (Schering-Plough submission).

The Highly Specialised Drugs Program is currently under review. In its submission to this Inquiry, ANCARD provided their submission to this review.

The current course of treatment is 3 million units (MU) of interferon administered subcutaneously three times a week for 12 months. In its review of the management of Hepatitis C, the NHMRC considered this dosage to be the optimal schedule (1997:34). It is also the recommended dosage in the United States (National Institutes of Health, 1997:5S) and Canada (Sherman, 1996).

During the course of this Inquiry, the eligibility criteria under the S100 program has altered. At the commencement of the Inquiry, interferon was available to patients who:

- had chronic hepatitis proven by liver biopsy (except patients with inherited coagulation disorder);
- had positive anti-HCV antibody, tested twice over six months with an interval of at least 16 weeks;
- had an ALT level (Alanine Aminotransferase - a commonly cited liver function test) higher than 1.5 times the upper limit of the laboratory reference range on three occasions over a period of six months;
- did not have cirrhosis or other liver disease;
- did not have HIV infection;
- were not pregnant, lactating or exposed to the risk of pregnancy;
- did not have a history of significant psychiatric illness;
- would be likely to attend regularly for treatment and follow-up;
- consumed no more than seven standard drinks a week; and
- had not used illicit injectable drugs within the previous 12 months (PBAC Secretariat, 1997).

At the December 1997 meeting of the PBAC the criteria referring to illicit injectable drug usage and HIV-HCV coinfection were deleted from the criteria listing. The current criteria and its appropriateness will be discussed in further detail in Section 8.1.

Before May 1995 persons under the age of 18 years were excluded from receiving interferon under the S100 program. At that time the criteria were modified and children are now able to receive interferon.

If, after 12 weeks of treatment, the ALT remains higher than the upper limit of the laboratory reference range, treatment ceases to be freely available under PBS. Patients are able to continue therapy but at their own expense.

The course of treatment must be continuous and excludes retreatment of non-responders or patients who relapse (PBAC Secretariat, 1997). Patients eligible for the twelve months' course are therefore new patients and current responding patients who have not completed six months' treatment (PBAC Secretariat, 1997).

Hospitals that have received approval to prescribe and administer interferon are known as Interferon Prescribing Centres. The Health Departments of each state/territory develop the criteria used in approving these centres. The NSW criteria includes:

- physician with adequate experience in the management of Hepatitis C;
- establishment of links between the physician and a teaching hospital with a specialised unit involved in the management of Hepatitis C;
- 24 hour access to medical care (via 24 hour Accident and Emergency Centre);
- facilities for safe liver biopsy;
- a nurse educator/counsellor with some expertise in the management of Hepatitis C; and
- a dedicated outpatient liver clinic (NSW Health submission).

All Interferon Prescribing Centres must undertake to provide data to the National Interferon Data Base based at the John Hunter Hospital, Newcastle.

7.1.1 The National Interferon Data Base

In its 1994 report on Hepatitis C, the NHMRC/AHMAC recommended that a centralised data base of all patients receiving interferon therapy be established. It was envisaged that such a resource would allow ongoing monitoring and evaluation of treatment outcomes and:

> *provide a sound clinical basis for the modification of patient selection criteria, treatment schedules and monitoring as appropriate. It would also provide valuable prospective data on the safety and efficacy of interferon* (NHMRC, 1994:70).

The Hepatitis C National Data Base (NDB) was established by the Gastroenterological Society of Australia in October 1994. The initial financial commitment came from the Commonwealth and Schering-Plough, each contributing $37,000 (Schering-Plough submission). When Roche received reimbursement approval for their product the Commonwealth withdrew from the program and Roche “picked up” the Commonwealth’s share of the contribution (Schering-Plough submission). In commenting on the establishment of the Data Base, Schering-Plough noted that:

> *a unique aspect of the PBS listing of Intron A for the treatment of chronic Hepatitis C was that the company was required by the Federal Government to support financially the setting up and maintenance of a National Hepatitis C Database under the auspices of the Gastroenterological Society of Australia. The supposed primary function of the Database was to collect data on treatment response* (Schering-Plough submission).

The Data Base currently gathers data from the 2700 patients receiving interferon under the S100 Highly Specialised Drug Program both at entry to treatment and in follow-up. The project comes to an end in October 1999. Issues pertaining to the Data Base that have been raised during the course of this Inquiry are discussed in Section 8.1.1.

7.2 AVAILABLE TREATMENT OPTIONS AND MEDICAL PROCEDURES

7.2.1 INTERFERON

Interferon is a protein made by the immune system which acts to fight viral infections. For unknown reasons, Hepatitis C does not stimulate the body to make interferon (Hollinger, 1997:7). Interferon is a global antiviral agent that can affect the life cycle of both RNA and DNA viruses (Hollinger 1997:7).

During the course of this Inquiry, people with Hepatitis C expressed a range of views on the usefulness of interferon therapy and its capacity to improve their health. For some considering treatment, interferon has too many side effects and a low success rate. Others consider that it is the only option they have. For many, however, it has not been an option because of the strict eligibility criteria (Hepatitis C Council submission).

- **Location of Interferon Prescribing Centres**

At the commencement of this Inquiry, there were 22 centres in NSW authorised to prescribe interferon to treat patients with Hepatitis C. The 15 centres based in Sydney metropolitan region included:

- Blacktown Hospital
- Bankstown-Lidcombe Hospital
- Campbelltown Hospital
- Concord Hospital
- Corrections Health Service
- Liverpool Hospital
- Mount Druitt Hospital
- Nepean Hospital
- Prince of Wales Hospital
- Royal North Shore Hospital
- Royal Prince Alfred Hospital
- St George Hospital
- St Vincent’s Hospital
- Sutherland Hospital
- Westmead Hospital

(NSW Health submission).

A further seven Interferon Prescribing Centres were in regional and base hospitals across the state. These included:

- Bega District Hospital
- Bathurst Base Hospital
- Illawarra Area Health Service
- John Hunter Hospital.
- Lismore Base Hospital
- Orange Base Hospital
- Wagga Wagga Base Hospital

At the time of making its submission to the Inquiry NSW Health informed the Committee that applications for Interferon Prescribing Centres received from two Rural Areas were under consideration. During the course of the Inquiry these hospitals received approval and interferon is now able to be prescribed at the Dubbo and Port Macquarie hospitals bringing to 24 the number of Interferon Prescribing Centres in the state.

- **Utilisation of Interferon Therapy**

As of October 1997 approximately 1500 of the state's 40,000 known cases of HCV, or 3.75% of identified cases, have accessed interferon treatment (NSW Health tabled document, 3 October 1997). Across the nation almost 3,000 have commenced treatment (Federal Parliamentary Liaison Group on HIV/AIDS and Related Diseases, 1998:3). The breakdown according to year is reported in Table Twenty-four.

TABLE TWENTY-FOUR
NUMBERS COMMENCING INTERFERON THERAPY
1994 - 1997

YEAR	TOTAL NUMBER COMMENCING THERAPY
1994	151
1995	929
1996	1005
1997	892
TOTAL	**2977**

Source: Federal Parliamentary Liaison Group on HIV/AIDS and Related Diseases, 1998:3.

There are several reasons why the numbers of those on drug therapy relative to the number with the disease are so low. These include:

- the strict eligibility criteria which excludes a large number of people;
- the side effects of the therapy, which for many are quite unpleasant; and

- the relatively low efficacy of the therapy.

The significance of these last two factors is such that NSW Health observed:

> *It is clear that the 40,000 known infected individuals in NSW would not seek interferon treatment even if they were eligible for it* (NSW Health, tabled document).

- **Efficacy of Interferon Therapy**

An individual's response to interferon depends on a number of factors including the amount of virus in the blood, the speed with which it replicates and other factors such as the virus' genotype with some strains being very sensitive and disappearing immediately while others are more resistant to interferon. An individual's response can be measured in one of two ways: end-of-treatment response, and sustained response. Not all studies discussing the effectiveness of interferon therapy identify the type of response under consideration.

Data received by the Committee on the efficacy of interferon therapy varied somewhat and included:

- Roche suggested that 30 per cent of patients will be considered sustained responders at the end of a 12 month treatment (Roche submission);

- in evidence given by NSW Health officials it was suggested that interferon is effective for approximately one in four of those treated (Wilson evidence, 3 October 1997);

- the Hepatitis C Council's submission cited recent studies showing the overall long term response for 12 months of treatment to be between 20-40 per cent (Hepatitis C Council submission);

- Hepatitis C expert, Dr Farrell, suggested to the Committee that the response to interferon ranges from 30 to 60 per cent for genotypes 2 and 3 to less than 10 per cent for genotypes 1 and 4 (Farrell submission);

- data provided by the National Interferon Data Base suggested that after a standard course of six months 14 per cent of those treated achieve a long term benefit (National Interferon Database, 1997, cited in the Hepatitis C Council submission);

- the NHMRC noted that the six month therapy regime was providing a 15 per cent sustained remission rate (NHMRC, 1997:page no);

- the Panel Statement arising from the US-based National Institutes of Health's Consensus Development Conference on Hepatitis C Management suggested a biochemical end-of-treatment response of 40 - 50 per cent after six months of treatment and a biochemical sustained response of 15 - 20 per cent. In terms of virological response, the six month course of treatment has produced an end-of-treatment response of 30 - 40 per cent and a sustained response of 10 - 20 per cent. In the Panel's opinion, increasing the duration of treatment to 12 months is not associated with higher biochemical or virological end-of-treatment response although the biochemical sustained response is increased to 20 - 30 per cent (NIH, 1997:5S). They caution that:

> *although interferon treatment may be associated with favourable effects on biochemical and virological markers, its effects on important clinical outcomes such as quality of life and disease progression remain undetermined* (NIH, 1997:5S).

As the above suggests, expert opinion on the efficacy of interferon ranges from 0 - 40 per cent. It would appear, from the literature, that the rate of one in four cases is the standard 'rule of thumb' in discussing the efficacy of interferon therapy. This is the figure adopted by the Committee. While it may not be possible to cite the exact rate at which people on interferon clear the virus, the rate is clearly unsatisfactory.

In submissions received, the Committee heard from those for whom interferon had been successful:

> *The change in my health was amazing. Several weeks after I started the program I noticed I felt better and I just got better and better. Finally I had energy again and could play with my children, do the house work, gardening etc. Most of my aches and pains were gone; the nausea which I lived with for years had stopped. I felt alive again - as though I had been given a second chance. I was so sure that the interferon was working* (Submission 73).

On the other hand, there were those with less positive experiences:

> *interferon was a dreadful experience and in the end didn't work for me, in fact since the end of the course 18 months ago I have experienced pain in my liver which wasn't there before* (Submission 37).

- **Side Effects of Interferon Therapy**

A major issue relating to interferon is the side effects, both physical and emotional, which, for many, can be debilitating and severe, particularly in the first few months of commencing therapy. Date collected by the National Data Base show that 63 per cent of patients experienced side effects during the first month on interferon. As a person's body develops a natural tolerance to the drug, the severity and number of side effects lessens over time. Data collected from the NDB show that the number of patients experiencing side effects declined from 63 per cent to 21 per cent within a six month period (Hepatitis C National Data Base, 1997:4).

Common side effects experienced include:
Influenza-like: fatigue, fever, mayalgia, malaise, poor appetite, tachycardia, chills, headache, arthralgias;

Neuropsychiatric: apathy, irritability, mood changes, insomnia, cognitive changes;

Miscellaneous: diarrhea, nausea, abdominal pain, back pain, pruritus, alopecia, rhinorrhea; and

Laboratory: decrease in granulocytes, platelet counts, and red blood cell counts, increase in serum triglyceride concentrations, proteinuira, increases in serum alanine and ALT levels (Dusheiko, 1997:113S).

Data provided by the National Data Base show the twelve main side effects reported to be:

- flu like symptoms (21%);
- lethargy (19%);
- gastrointestinal disturbances (14%);
- headaches (12%);
- emotional disturbances (8%);
- depression (4%);
- hair loss (4%);
- skin changes (3%);
- sleep disorders (2%);
- decreased platelet levels (2%);
- neutropenia (2%); and
- local injection site reaction (1.2%) (Hepatitis C National Data Base, 1997:4).

While depression is reported by only 4% of patients registered with the National Data Base, a Clinical Nurse Specialist working with Hepatitis C patients at St. George Hospital suggested to the Committee that:

> *approximately 99% of [Hepatitis C] patients have exhibited flu like symptoms which appear to abate over time . . . However, from my observation, I contend that an under-estimated number of patients experience depression related to the use of interferon, rather than depression stemming from their diagnosis* (Looby submission).

Many of the submissions made by HCV+ people included comments on the side effects they had experienced with interferon. Comments included:

> *The interferon really made me sick . . . After four months I was withdrawn from the programme due to severe side effects. I suffered mainly depression and suicidal tendencies* (Submission 61);

> *I have suffered quite horrific side-effects . .   I have suffered hair loss, mood swings and a worsening of my general health* (Submission 52);

and

> *The side effects made it difficult for me to work in my role as a clinical nurse specialist. My sick leave and recreation leave ran out. I began using my long service leave* (Submission 82).

For many of those who contacted the Committee, their response to interferon is complicated by the fact that their general practitioners were insufficiently informed about these side effects:

> *I have just checked with my local general practitioner about his knowledge of the side effects of interferon because one of his patients is now on Interferon. He said that his knowledge was from a Department of Health book, which he could not find, and he was looking around the room. He said, "The standard effect is flu-like symptoms". I said, "Do you know about diarrhoea and hives?". He said, "No, no one has ever told me that." He is a reasonable doctor, but knowledge is still not easily available to doctors to support people who are on Interferon* (Lamb evidence, 30 March 1998).

The issue of general practitioner education on this and other Hepatitis C related issues is considered in Section 8.4.1.

- **Contraindications to Interferon Therapy**

There are important contraindications to interferon therapy. These contraindications are based largely on the known side effects of the drug and include:

- severe depression;
- decompensated cirrhosis;
- cirrhosis and hypersplenism;
- autoimmune hepatitis;
- hyperthyroidism;
- coronary artery disease;
- renal transplant;
- pregnancy;
- seizures;
- drugs: herbal remedies;
- diabetes/hypertension and retinopathy; and

- laboratory - thrombocytopenia
  leukopenia
  anaemia
  high titers of autoantibodies
  hyperthyroidism (Dusheiko, 19987:118S).

- **The Cost of Interferon Therapy**

Shiell, Briggs and Farrell (1994:269) document the treatment costs (in $1994) of a six month course of interferon as:

Pathology Services (anti-HCV serology, liver function tests, liver biopsy, full blood count, ultrasound)	$920
Hospital Services	$1,990
Interferon (dose 3 x 10^6 IU thrice weekly for 24 weeks)	$3,425
Total Cost, per patient per course	**$6,335**

Shiell *et al's* figures demonstrate advice received by the Committee concerning the extent of indirect costs of therapy. Wodak suggested that the indirect costs of interferon for the considerable work up and monitoring involved with a course of interferon therapy are probably as much again as the direct costs of the drug although much harder to compute (Wodak submission). In addition to monetary costs of the treatment are also those costs borne by the patient including, as has been discussed, the side-effects frequently experienced.

The Federal Government funds the cost of the interferon used on receipt of requests from state and territory governments for eligible patients under the S100 Highly Specialised Drug Scheme, except, as will be discussed in Section 8.4, in the case of prisoners.

Hepatitis currently accounts for a relatively small proportion of expenditure under the Highly Specialised Drugs Program. Of the $143,239,374 spent on all drugs under the program in 1996/97 interferon accounted for only 4.4 per cent of expenditure - $6,286,696 (ANCARD submission to the Review of the Highly Specialised Drugs Program - attachment to their submission). ANCARD's submission to the Review of the Highly Specialised Drugs Program suggests that the supply of interferon under the Highly Specialised Drugs Program has cost approximately 50 per cent of the amount originally predicted. The low uptake is due, the submission suggests, to the restrictive guidelines, the toxicities experienced by many patients and the comparatively low efficacy of the drugs (ANCARD submission to the Review of the Highly Specialised Drugs Program - attachment to their submission).

- **The Cost Effectiveness of Interferon Therapy**

A British study (based on a six month course of treatment) calculated that the discounted cost per year of life saved ranged from £2,142 to £17,128 (Dusheiko, 1995). The study concludes that:

> *the potential usefulness of interferon alpha on the clinical and economic outcome of treatment is indicated from the model. These findings together with the benefits that are likely to accrue from the reduction in infectious individuals, suggest that this therapy has a role to play in public health policy to contain the impact of hepatitis* (Dusheiko, 1995).

An Australian study conducted in the early 1990s looked at the cost effectiveness of interferon in the treatment of Hepatitis C. The results, which are recorded in Table Twenty-five, show that interferon treatment of chronic Hepatitis C patients resulted in a discounted cost per life-year saved of $33,230 in patients with cirrhosis at the start of treatment and $71,950 in patients without advanced liver disease (Shiell, Briggs and Farrell, 1994:268).

TABLE TWENTY-FIVE
COST EFFECTIVENESS OF INTERFERON THERAPY

	CIRRHOSIS AT DIAGNOSIS (N=300)	NO CIRRHOSIS AT DIAGNOSIS (N=700)	ALL PATIENTS (N=1000)
Total Cost	$1,488,500	$4,374,100	$5,862,600
Lives Saved	3.6	7.1	10.7
Cost Per Life Saved	$419,865	$615,755	$550,480
Life-Years Gained	44.8	60.8	105.6
Cost Per Life-Year	$33,230	$71,950	$55,515

Source: Shiell, Briggs and Farrell, 1994:270.

The study's authors are cautious in commenting on the cost effectiveness of interferon noting that:

> *whether or not this is considered cost effective depends on comparisons with other health care interventions with which interferon might compete for resources. Results from published evaluations suggest that interferon is a more expensive way to improve health than many health care interventions or health promotion strategies. However, differences in the methods adopted by*

> *such studies mean that comparisons should be made with care* (Shiell, Briggs and Farrell, 1994:271).

In its submission to the Inquiry, NSW Health confidently claimed that:

> *interferon treatment of people with HCV offers long term savings to the health system by reducing the number of people who progress to serious liver disease requiring liver transplant. Liver failure was estimated to require between $75,000 and $129,000 associated health costs per episode in 1994* (NSW Health submission).

However, Briggs and Shiell are more cautions. They suggested that:

> *Although there may be a role for interferon in reducing the rate of progression from acute to chronic infection commentators agree that more evidence is required before firm conclusions can be drawn* (Briggs and Shiell, 1996:205).

Interferon is expensive, its effectiveness is limited and it can have significant adverse effects. Clearly its cost effectiveness is, as Briggs and Shiell (1996:208) observe, “open to question”.

- **Factors Predictive of a Beneficial Response to Interferon Therapy**

Because most patients do not experience a sustained response to interferon, attempts have been made to identify those individuals who are more likely to respond to therapy. The strongest predictors of response are viral in nature: a low concentration of virus and genotypes other than genotype 1 are more often associated with a favourable response (Hollinger, 1997:7). A number of studies have identified pretreatment patient characteristics that are associated with a greater or lesser likelihood of response to interferon. These have been identified by Davis and Lau as including:

Drug:	dose 3 million units
Demographics:	female sex younger age history of injecting drug use unknown source of infection (sporadic) short duration of infection
Histology:	mild chronic hepatitis absence of fibrosis or cirrhosis
Biochemical:	low serum ALT low gamma glutamyl transpeptidase low serum iron or ferritin

Virologic:	low HCV RNA level genotype 2 or 3 low number of quasispecies multiple mutations in the interferon sensitivity determining region
Interferon Response:	early normalisation of serum ALT early loss of serum HCV RNA (Davis and Lau, 1997:123S).

The identification of such factors has led the National Institutes of Health (NIH) to suggest that:

> *treatment is clearly recommended only in a selected group of patients. In others, treatment decisions are less clear and should be made on an individual basis or in the context of clinical trials* (NIH, 1997:6S).

The NIH's Statement on Hepatitis C management recommends treatment for the group of patients with chronic Hepatitis C who are at the greatest risk of progressing to cirrhosis. These patients are characterised by:

- persistently elevated ALT;
- positive HCV RNA; and
- a liver biopsy with either portal or bridging fibrosis and at least moderate degrees of inflammation and necrosis (NIH, 1997:6S).

In patients with persistent ALT elevations, but with less severe histological changes progression to cirrhosis is likely to be slow, if at all. It is suggested that for this group, observation and serial measurements of ALT and a liver biopsy every three to five years is an acceptable alternative to treatment with interferon (NIH, 1997:6S).

- **Counselling on Interferon Therapy**

The NHMRC have identified a range of issues which should be addressed when counselling a patient on interferon treatment. These include:

- the nature of interferon;
- the mode of action of interferon;
- the effectiveness of interferon in the treatment of Hepatitis C;
- the meaning of "response";

- adverse reaction to interferon;
- duration of therapy;
- action to be taken if the patient relapses;
- predictors of response to interferon;
- administration of interferon;
- liver biopsy;
- pregnancy contraindicated; and
- alcohol consumption (NHMRC, 1997:41).

As will be discussed in Chapter Eight there is often insufficient time in the state's overcrowded liver clinics for these issues to be discussed adequately with patients and their families.

- **Monitoring and Assessing the Efficacy of Interferon Therapy**

The efficacy of interferon therapy currently is defined biochemically as normalisation of serum ALT and virologically as loss of serum HCV RNA. In the Panel Statement arising from the 1997 Consensus Development Conference of the National Institutes of Health, serial ALT testing was recommended for monitoring patients during treatment to document biochemical responses and testing for HCV RNA by qualitative PCR recommended at selected times to document the level and activity of the virus (National Institutes of Health, 1997:5S). PCR testing is therefore being used not only as a confirmatory test for HCV, but also an important tool in the assessment of a person's response to interferon and in the predication of treatment outcomes.

In the main, funding for these tests is provided through pharmaceutical companies and is restricted to certain sites. NSW Health has provided time limited funding for HCV testing, specifically PCR testing but as the Committee was advised "this funding . . . is clearly inadequate for future testing requirements" (Hepatitis C Council submission).

The Panel Statement from the NIH's Consensus Development Conference on the management of Hepatitis C suggests monitoring during therapy at two to four week intervals with serum ALT and complete blood count. Both serum ALT and serum HCV RNA testing should be performed after three months to assess whether the patient is responding to therapy. This should be repeated at the end of therapy to document end-of-treatment response. Follow-up testing, with serum ALT and serum HCV RNA should be performed six months after therapy is stopped to determine whether there has been a sustained response. In the Institutes' opinion, follow-up liver biopsy is not necessary (NIH, 1997:6S).

7.2.2 OTHER MEDICATIONS

- **Ribavirin**

Ribavirin is an oral antiviral agent, discovered in the 1970s, that is effective against some RNA viruses like HCV. It is a nucleoside analogue which inhibits the replication of many different viruses including some related to HCV. Nucleosides are the building blocks of RNA and ribavirin resembles these nucleosides. The virus will mistakenly use it in its life cycle and become defective so that it is no longer infectious (Hollinger, 1997:7).

When used alone ribavirin reduces serum ALT levels in approximately 50 per cent of patients (NIH, 1997:6S). However ribavirin does not lower serum HCV RNA levels, and relapses occur in virtually all patients when therapy is stopped (NIH, 1997:6S). Combining ribavirin and interferon has resulted in virological sustained response rates 40 - 50 per cent higher than interferon alone in six month trials (NIH, 1997:6S).

The drug ribavirin which is currently being used in clinical trials with interferon costs $14,000 to $18,000 for one year of treatment. The cost of one year of treatment with the combination of the two drugs would currently cost approximately $20,000 to $24,000 excluding the salaries of the medical, nursing and laboratory staff supporting the treatment regime (NSW Health tabled document, 3 October 1997).

A randomised, double-blind, placebo-controlled trial study conducted in Norway which combined interferon and ribavirin found that 36% of those on the combined therapy had a sustained virological response compared with 9% in the interferon and placebo group (Reichard, Norkrans, Fryden, Braconier, Sonnerborg, Weiland, 1998:83). At the one year follow-up, the proportion of patients with a virological response was greater in the combined therapy group than the interferon and placebo group. The study concluded that:

> *more patients with chronic Hepatitis C have a sustained virological response with interferon α-2b and ribavirin than with only interferon α-2b treatment. We suggest that patients with high HCV-RNA loads should be treated with interferon α-2b and ribavirin* (Reichard, Norkrans, Fryden, Braconier, Sonnerborg, Weiland, 1998:83).

Farrell suggested that for those who had tried interferon and relapsed, the combination of interferon and ribarivin is about 50 per cent curative (Farrell evidence, 26 November 1997). However the Hepatitis C Council advised the Committee that people receiving combination therapy report a greater number of side effects.

Given the initial promising results of combining interferon and ribavirin, the drug company Schering-Plough has received TGA approval for a ribavirin compassionate use protocol under its Special Access Scheme (Schering-Plough submission).

- **Protease Inhibitor Drugs**

The Committee understands that research into the use of protease inhibitor drug therapies in Europe has commenced. It will, however be four to five years before any meaningful results are available (Hepatitis C Council submission). The Norwegian study cited above recognised that, despite the improved response to combination therapy "many" patients still do not respond. The study called for the development and evaluation of new antiviral drugs such as the protease inhibitors for the treatment of chronic Hepatitis C (Reichard, Norkrans, Fryden, Braconier, Sonnerborg, Weiland, 1998:83).

- **Ursodeoxycholic Acid**

Ursodeoxycholic acid has been used in a number of liver diseases and has been shown to improve liver function tests in some Hepatitis C patients (NHMRC, 1997:37). The mode of action for Hepatitis C remains uncertain and its long-term benefits are unproven (NHMRC, 1997:37).

- **Corticosteroids**

While the use of corticosteroids alone tends to worsen the prognosis for Hepatitis C by facilitating viral replication, the NHMRC suggests there may be some benefit in giving steroids as a "priming" dose in conjunction with interferon (NHMRC, 1997:37).

7.2.3 LIVER BIOPSIES

A liver biopsy is a very accurate method of determining the condition of liver cells. The procedure involves a needle being passed between the ribs into the liver and a small sample of the liver being taken for examination. The procedure is performed under local anaesthetic. Most people with HCV undergo at least one liver biopsy, often as part of the process of being considered for interferon therapy. A biopsy is always performed before commencing interferon therapy, except in those patients with inherited clotting disorder, such as haemophilia. A further liver biopsy may be performed after therapy.

7.2.4 LIVER TRANSPLANTS

Committee Members were repeatedly told during the course of this Inquiry that Hepatitis C is now the most common indication for liver transplantation in Australia. Transplantation is carried out usually for end-stage liver disease and the transplanted organ often becomes infected with Hepatitis C. However, as the NHMRC report notes,

> *The fact that the disease recurs in the transplanted liver has not been a major problem for transplant units as many of these patients are young and the provision of an additional ten years of life for a productive 30 to 40 year old adult appears most appropriate* (NHMRC, 1997:38).

7.2.5 HEPATOCELLULAR CARCINOMA

Those with end stage liver disease are most at risk of developing hepatocellular carcinoma. The Committee was advised that 15 to 20 per cent of people with cirrhosis will get hepatocellular carcinoma (Rallings evidence, 27 October 1997). This particular form of cancer is, as the Committee was told, “a very serious cancer” and “very little is known about the treatment of it and it is very difficult to treat once you get it” (Rallings evidence, 27 October 1997).

As was discussed in Section 2.2.3 there is no accurate statistical information in Australia on the frequency of Hepatitis C related hepatocellular carcinoma. Until this is known, it will be impossible to predict cost savings that might be achieved by transplanting patients with end-stage liver disease before hepatocellular carcinoma develops (NHMRC, 1997:38).

Shiells, Briggs and Farrell (1994:269) have costed (based on $1994) the treatment protocols for hepatocellular carcinoma as:

Without Surgery (67% of patients), cost per patient	$117,895
With Surgery (33% of patients), cost per patient	$28,290
Expected Cost Per Episode	**$88,325**

7.2.6 COMPLEMENTARY TREATMENTS AND THERAPIES

Given the limited efficacy of interferon and its wide range of side effects, many people with HCV use complementary therapies to relieve symptoms and increase their wellbeing. Some people use these therapies regularly as an alternative to conventional medicine while others may use them to treat specific aspects of their illness. For example, some people who have used interferon report taking specific vitamins and herbal treatments to counteract the side effects. Others may choose to use a number of stress reduction techniques such as massage and meditation to assist them with the disease. As the Hepatitis C Council’s submission noted:

> *some people have reported that in the absence of any conventional treatment for HCV, the practice and philosophies of a number of complementary and alternative therapies have provided effective ways of living with HCV* (Hepatitis C Council submission).

According to the National Hepatitis C Councils’ Education Reference Group, the most commonly used therapies are:

- Chinese herbs;
- other herbal treatments (particularly St Mary’s thistle);

- vitamins, minerals and nutritional supplements; and
- acupuncture and homeopathy (National Hepatitis C Councils’ Education Reference Group, 1996:27).

Other therapy used include acupuncture, homoeopathy and oxygen drops (National Hepatitis C Councils’ Education Reference Group, 1996:27).

In the study by Sladden *et al* a range of complementary therapies were trialed by those participating in the study (1998:510). The types of therapies and frequencies are reported in Table Twenty-Six. Percentages presented in the Table tally to more than 100 due to multiple treatments.

TABLE TWENTY-SIX
COMPLEMENTARY HVC TREATMENTS

TREATMENT	FREQUENCY (%)
Naturopathy	48 (10.3)
Anti-nausea	37 (7.9)
Analgesia	34 (7.3)
Homoeopathy	22 (4.7)
Dandelion Root	21 (4.5)
St Mary’s Thistle	16 (3.4)
Acupressure	8 (1.7)
IV Vitamin C	7 (1.5)
Ozone	5 (1.1)
Chinese Herbs	3 (0.6)
Rest	3 (0.6)
Other Treatment	22 (4.7)
No Treatment	337 (72.4)

Source: Sladden *et al*, 1998:510

Clinical trials have been conducted on the role of Chinese herbs in liver inflammation. The initial placebo controlled trial of a tablet form of Chinese herbal medicine (CH100) was conducted at the John Hunter Hospital, Newcastle. Patients were evaluated monthly during the six month treatment by a hepatologist and a traditional Chinese medical practitioner (Hossain, Batey and Bollipo, 1996). At commencement ALT was higher in the active than the placebo group (133 ± 21 sem vs 109 ± 16) and at completion it was lower (82 ± 12 vs 101 ± 13) (Hossain, Batey and Bollipo, 1996). The percentage fall in ALT was 38% in the active and 8.5% in the placebo group (p = 0.048). Six patients, all on active treatment, normalised their ALT during treatment, but in two it was not maintained despite therapy (Hossain, Batey and Bollipo, 1996). A second, larger study using the same tablet formula as used at John Hunter, is currently being conducted in the Northern Rivers Area Health Service (Sladden evidence, 30 March 1998). Assessment of participants was expected to commence in September 1998 with a rolling enrollment over a one year period. Subject to funding approval testing of PCR viral genotype, PCR viral load and PCR viral detection will be undertaken.

Many of the available complementary therapies receive little support from the medical profession. Despite this, the NHMRC recommends a “watching brief” be kept on the use of natural therapies in the treatment of Hepatitis C (NHMRC, 1997:37).

For many the costs of alternative and complementary therapies is an issue. It is not possible to claim a rebate from Medicare for purchases of items such as milk thistle or vitamins or for attending a natural therapist although some private health insurance schemes do cover certain natural therapies. Many people on middle to low incomes find the cost factor simply prohibitive.

A number of those who made submissions to this Inquiry spoke of their experience with using complimentary therapies:

> *I went to a Chinese herbalist who treats quite a few HIV and Hepatitis people. I began on two infusions a day, dropping down to one, then one every second day. I abstained from alcohol, rested, exercised, used a bit of heroin. My health returned rapidly* (Submission 15);
>
> *I use homoeopathic remedies to treat my symptoms. I have found that my liver function tests are effected positively when I do this, so I continue to research and self-treat carefully* (Submission 88); and
>
> *As I have had little help or feedback from conventional medicine I resort to alternative therapies (herbalist and homeopathy) when the hepatitis virus rears its ugly head and I get crook* (Submission 71).

7.2.5 SUMMARY

The current state and future direction of treatment for Hepatitis C was summarised by Wodak as:

> *Treatment is expensive, far less effective than we would like it to be and, unfortunately, accompanied by very significant side effects. The encouraging news is that very effective treatment is on the horizon. The same advances that have occurred recently in HIV treatment - namely the development of protease inhibitors which have really brought about a remarkable difference in the way HIV is now managed and the results we achieve from HIV - are going to become available to people with Hepatitis C within the next few years. It is confidently expected that this will change the picture* (Wodak evidence, 2 October 1997).

However, he noted that, the negative side is that:

> *the treatment will almost certainly be unaffordable, particularly for an epidemic which involves 150,000 Australians. We have a treatment at the moment which is pretty well unaffordable and not very effective. When we have a much better treatment, which will be undoubtedly even more expensive, we are going to have a real problem knowing how to deal with that* (Wodak evidence, 2 October 1997).

7.3 TREATING AND MANAGING HEPATITIS C POSITIVE INMATES IN THE STATE'S CORRECTIONS SYSTEM

7.3.1 TREATING HEPATITIS C POSITIVE INMATES

The process of screening inmates for Hepatitis C was outlined in Section 6.5. Once identified as Hepatitis C positive inmates are able to access specialist medical services for the treatment and management of their Hepatitis C. As Corrections Health Service Acting Clinical Nurse Consultant informed the Committee:

> *We have policies in place for someone who is Hepatitis C positive and is unwell. His history is taken and his liver function tests are monitored according to that policy. People have to meet certain criteria and they are referred to the specialist clinics for a consultation with the specialist. They may go for liver biopsy, if deemed appropriate, and then on to interferon if that is the course of action for that person* (Harper evidence, 23 March 1998).

The Hepatitis C medical needs, including specialist clinics and treatment, of the entire corrections system are based at the Long Bay Corrections Centre. Specialist Hepatitis C clinics are held at the Long Bay complex twice a month staffed by two attending specialists. As one of the specialists told the Committee: “We see 20 or so individuals a month, which is a couple of hundred a year of the many thousands who are infected” (Lloyd evidence, 30 March 1998). Inmates from non-metropolitan centres and females at Mulawa requiring treatment or consultations with the specialists are required to find their way to Long Bay. With reference to female Hepatitis C positive inmates Lloyd informed the Committee, “we do not seek them out” (Lloyd evidence, 30 March 1998).

The Committee heard that these two doctors are “marvellous” because:

> *they will come to the Metropolitan Reception Remand Centre and see people if they can or they will come in on a one-off visit. If a prisoner comes for another appointment Sandra [the Clinical Nurse Specialist responsible for co-ordinating the Hepatitis C specialist clinic] will co-ordinate that and the doctors will pop in. It is very good even though they are so busy. The clients will tell you that they have never had such a good service in that respect* (Harper evidence, 23 March 1998).

- **Liver Biopsies**

All liver biopsies are performed at the Long Bay prison hospital. When asked to comment on the use of pre- and post-medication Lloyd (who performs the biopsies) informed the Committee that:

> *We do offer good amounts of local anaesthetic and pain relief afterwards . . . It is a vexed problem within the prison system generally, probably more than anywhere else, where there is much concern about potential drug misuse of narcotic analgesics, Valium, and benzodiazepine . . . and people are anxious about prescribing often or even at all for any of those things. We usually negotiate carefully for a limited supply and set the time lines for how long it could be available* (Lloyd evidence, 30 March 1998).

- **Interferon Therapy**

Interferon therapy is available to inmates in the NSW corrections system. The Committee was advised that NSW is the only state within Australia with approval to prescribe interferon to prison inmates. Further, NSW is one of the very few prison systems worldwide where interferon therapy is available to Hepatitis C positive inmates (Lloyd evidence, 30 March 1998).

To be eligible to receive interferon, inmates must meet the s100 criteria outlined earlier in this chapter. The Committee was advised that additional criteria are applied to inmates:

> *From our point of view we very carefully select individuals who meet the S100 criteria for interferon therapy, plus some extra criteria that we add to it: not too much psychiatric pathology, a length of sentence that covers the time to biopsy and treatment and not currently using [drugs]* (Lloyd evidence, 30 March 1998).

The Committee was advised that 22 inmates have completed interferon therapy (Parsons evidence, 23 March 1998). Two people had came to gaol on treatment and it was monitored, however one was withdrawn from therapy due to a psychiatric illness and noncompliance with his medication (Parsons evidence, 23 March 1998). The

Committee also heard that, as of March 1998, five male inmates were on interferon therapy and one was awaiting treatment (Parsons evidence, 23 March 1998).

- **Inmates with Established Hepatitis C Related Diseases**

Given the prevalence of Hepatitis C in the state's corrections system, a number of inmates have already progressed to advanced stages of Hepatitis C-related liver damage. The Committee heard that:

> *Individuals within the prison system who have established cirrhosis and have some degree of liver failure I suspect come to our attention or come to medical attention in the centres. I would be surprised if that did not happen. Already a small number of individuals are in overt liver failure and probably have a pre-terminal condition. We have debated whether they should have an early release on medical grounds because of their limited life expectance, but that is pretty rare. That far end of the spectrum is probably well catered for* (Lloyd evidence, 30 March 1998).

7.3.2 MANAGING HEPATITIS C POSITIVE INMATES

It would appear that the primary mechanism available to Hepatitis C positive inmates to manage their illness is the Lifestyle Unit. This Unit is located in the Special Care Correctional Centre at the Long Bay Correctional Centre. It was opened in late 1992 and accommodates up to eight inmates who have voluntarily applied and been accepted to take part in the program provided by the Unit (Taylor, 1997:9).

While in the Unit inmates are able to cook for themselves, and access (free of charge) vitamins, diet supplements and herbal tonics such as milk thistle (Vumbaca evidence, 23 March 1998).

Opportunity to participate in the program is, the Committee heard, "very limited":

> *probably four to six beds are available at any one time for Hepatitis C inmates and they have to be referred through the hepatitis clinic because of the number of inmates that could seek to access that residential lifestyle program* (Christensen evidence, 23 March 1998).

7.4 CONCLUSION

This chapter's discussion has highlighted the limited range of treatment options available to those with Hepatitis C. Not only are there few options available, but those that are available are not particularly effective and often result in a range of debilitating side effects.

Treating and managing Hepatitis C is currently quite unsatisfactory. The Committee therefore agrees with the state's Chief Health Officer who concluded that "the focus has to be on prevention of the disease" (Wilson evidence, 3 October 1997).

CHAPTER EIGHT

TREATING AND MANAGING HEPATITIS C:

GETTING IT RIGHT

The previous chapter identified the various policies and practices of treating and managing Hepatitis C. During the course of this Inquiry a number of inadequacies and shortcomings pertaining to these policies and practices were identified by witnesses and those making written submissions. The following chapter identifies the concerns that were raised and proposes a series of recommendations to address current difficulties experienced by those seeking treatment for their Hepatitis C and the health care professionals working with them.

8.1 INADEQUACIES OF CURRENT POLICIES REGULATING TREATMENT

The Inquiry's Terms of Reference asked the Committee to comment on the adequacy of policies in relation to treatment. Approximately 2% of those known to have Hepatitis C have accessed the only approved form of treatment available. While some choose not to go on interferon therapy because of the drug's side effects, many are not given the option because of the strict criteria regulating who can and who cannot be given interferon. The Committee concluded that current policies regulating the treatment of Hepatitis C are clearly inadequate.

The following section looks at the adequacy of the polices that determine access to treatment, location of Interferon Prescribing Centres, pre-treatment assessment, interferon dosage schedule, and treatment assessment and monitoring.

8.1.1 POLICIES RESTRICTING ACCESS TO TREATMENT

The current assessment criteria for interferon treatment under the S100 program were outlined in Section 7.1. The criteria were devised using the guidelines chosen for the AUSHEP 1 and 2 studies conducted in the early 1990s. Since that time, research has led to a clearer understanding of the drug, its efficacy, safety and potential toxicity.

However, it would appear that much of this research has yet to be taken into account by policy makers and as a result, the current criteria restrict a very large number of people with Hepatitis C accessing interferon therapy. What was appropriate in the early 1990s when the criteria for interferon under the S100 scheme were first developed is, in the light of such research, clearly inadequate. It is imperative that policies regulating the administration of interferon be reviewed and updated regularly to ensure research is taken into account.

Dr Crofts candidly explained the manner in which the criteria were originally established:

> *I was a member of the first NHMRC working party on Hepatitis C and we had two major briefs. One was to make sure that blood supply was under control . . . And the other was to make interferon accessible to a select range of people. By "select" I mean not the 100,000, 150,000, 200,000 people who have got Hepatitis C, or at least that we estimate have got Hepatitis C in Australia, but a select group who would be pliant and*

> *compliant and not disrupt the gastroenterologist's waiting room and not [be] too expensive. If we could find limiting factors so that interferon was made available and thereby get the flood of letters that were coming from the support groups and the drug companies off Graham Richardson's desk then we would be doing our job, but we had to limit that number* (Crofts evidence, 28 November 1997).

Various witnesses to the Committee expressed their concern at the exclusive nature of the criteria. Professor Farrell, for example, noted that:

> *My reservations about treatment . . . [are about] the restricted bandwidth for patients getting interferon treatment* (Farrell evidence, 28 November 1997).

Other witnesses expressed concerns that the assessment criteria were discriminatory:

> *Ethically I find that the S100 criteria are discriminatory against certain sections of the population. They may not have as much to gain as the others, but in the long term if we can help those people there will be less burden on the tax payer, even if we only help 15 per cent to 20 per cent of them, it is still of assistance to the community at large* (Rallings evidence, 27 October 1997); and
>
> *these criteria . . . were totally and utterly discriminatory and had no basis for being there* (Wodak evidence, 2 October 1997).

Concerns from a legal perspective were also expressed:

> *Legally people could look at us and say "what right do you have to exclude us from what is known to be a treatment which may be of benefit or at least have a try"* (Rallings evidence, 27 October 1997).

The NHMRC considers the guidelines to be "relatively restrictive" by excluding patients with cirrhosis, IDUs, heavy drinkers, patients co-infected with HCV and HIV+, and those with slightly raised ALT levels (NHMRC, 1997:35). In its 1997 report, the Council considered that each of these groups could "benefit" from interferon therapy and the Report makes a strong case for liberalising the availability of interferon for Hepatitis C and broadening the base of patients being treated with interferon on that basis that it is "not appropriate" to withhold potentially beneficial treatment from any patient group (1997:35). The Report's recommendation was that:

> *all Hepatitis C antibody positive patients with any elevation of ALT should be considered for treatment with interferon alpha in standard dosage. Patients with normal ALT values should be monitored regularly by their clinician. World experience in the treatment of these patients should be evaluated* (NHMRC, 1997:36).

The approach sought by the NHMRC is considerably more flexible than the current arrangement. The Council proposed individual clinicians being given the option to choose to withhold treatment from individual patients after assessment and for this decision to be discussed in detail with each individual patient. The report calls for an "appropriate assessment" of the patient's psychosocial status, psychological functioning and medical condition. Such an approach, the Report anticipates, will limit the number of people being placed on interferon in a "more equitable way" (NHMRC, 1997:35).

Material provided to the Committee by Schering-Plough compares the current S100 assessment criteria with recommendations made by the NHMRC and the National Institutes of Health (NIH). This table is reproduced in Appendix Four. Table Twenty-seven below summarises the comparisons and shows the degree to which both the NHMRC and NIH recommend less stringent criteria than are currently available.

TABLE TWENTY-SEVEN
COMPARISON OF THE STRINGENCY OF ELIGIBILITY CRITERIA FOR PATIENT GROUPS ALLOWED ACCESS TO INTERFERON UNDER CRITERIA AS RECOMMENDED BY THE NATIONAL INSTITUTES OF HEALTH (NIH) AND NHMRC VERSUS THE SECTION 100 CRITERIA

PATIENT GROUP	NHMRC RECOMMENDATIONS	NIH RECOMMENDATIONS
Hepatitis C patients with positive liver biopsy	Wider than Section 100	Wider than Section 100
Patients with elevated ALT levels	Wider than Section 100	Wider than Section 100
Patients with cirrhosis	Wider than Section 100	Wider than Section 100
HIV positive patients	Wider than Section 100	Wider than Section 100
Pregnant, lactating patients	Same as Section 100	---
Psychiatric illness, auto-immune disease and other contraindications	Same as Section 100	Wider than Section 100
Regular attendance for follow-up	---	---
Intravenous drug users	Wider than Section 100	Wider than Section 100
Relapsers/non-responders	Wider than Section 100	Wider than Section 100
Extrahepatic manifestations	Wider than Section 100	Wider than Section 100

Source: Schering Plough submission.

During the course of this Inquiry, a number of people gave their support to broadening the S100 assessment criteria. The submission from NSW Health, for example, stated that the Department supports the current recommendations of the NHMRC concerning the criteria for interferon and calls for the criteria to be implemented "as a matter of urgency" (NSW Health submission). NSW Health also supports the notion that broadening the assessment criteria should be carefully monitored for a test period of at least two years with patient response data collected for a national data base (NSW Health submission).

The Hepatitis C Council encouraged the Committee to give its full support to NSW Health lobbying and encouraging the Commonwealth to expand the criteria in line with the NHMRC recommendations (Loveday evidence, 22 September 1997). The submission from NUAA also called for the "discriminatory barriers" to interferon treatment to be removed (NUAA submission).

In their submission to this Inquiry, ANCARD attached the submission they had made to the PBS to expand the interferon criteria.

During the course of the Inquiry in early 1998, the S100 criteria were changed giving access to interferon to two specific population groups: current injecting drug users and those coinfected with HIV. The Committee had already gathered considerable evidence supporting these changes which will be reviewed below.

- **Patients Co-Infected with HIV**

Until early 1998 patients testing positive for both HIV and Hepatitis C were unable to access interferon under the S100 program. A representative from the drug company Schering Plough pointed out to the Committee:

> *There are difficulties in treating this group of patients . . . but I am not quite sure why they should be denied the treatment of their Hepatitis C; they already have enough problems with their HIV. Treatment of HIV is improving with the advent of triple treatment now and they are living longer and they could be treated for their Hepatitis C* (Rallings evidence, 27 October 1997).

Apparently at the time of conducting the AUSHEP 1 and 2 studies there were no helpful data indicating the effect of interferon on HIV+ patients and the course of either illness when both were present in the same individual. Erring on the side of caution, those establishing the original S100 assessment criteria excluded these patients.

By the time the NHMRC examined the guidelines in 1997 available research could find no evidence to suggest that Hepatitis C would worsen if treated in an HIV+ patient (NHMRC, 1997:36). The Council concluded that people with HIV infection may benefit from the administration of interferon and recommended the inclusion of this group of patients for interferon treatment. The NIH's Consensus Development Conference on the management of Hepatitis C similarly recommended that patients who have stable

HIV infection with good clinical and functional status should be considered for interferon treatment (NIH, 1997:6S).

- **Injecting Drug Users**

At the commencement of this Inquiry, those accepted for interferon therapy under the S100 program must have not used illicit injectable drugs within the previous twelve months. The Committee received a number of different reasons for this criterion including the possibility of unknown drug interactions occurring if someone is taking drugs and being given interferon concurrently and the possibility of reinfection (Wilson evidence, 3 October 1997). Professor Farrell explained to the Committee that his hesitation regarding treating people who are actively injecting relates to the reinfection issue as well as being “an efficiency problem” as “many of those people do not attend follow-up visits” (Farrell evidence, 28 November 1997) and it is:

> *potentially dangerous for people to not attend follow-up visits when they are on a dangerous form of therapy. It is certainly inefficient to start a course in expensive therapy when there is a significant chance that the course would not be completed* (Farrell evidence, 28 November 1997).

Dr Wodak informed the Committee that “there was both a rationale for this [policy] and also a reason why the rule was silly” (Wodak evidence, 2 October 1997):

> *the rationale is that if someone has injected drugs in the last year there is a high risk that they might return to drug injecting. If we had eliminated the virus from their system and they returned to drug injecting and shared needles, syringes, spoons or cookers with another injecting drug user and became reinfected, several thousand dollars of scarce medication and resources would have been wasted. That was the justification . . .*
>
> *. . . The criticism of that policy was: here is a population that has recently become infected, and we already know that this is the population that is most likely to benefit from an intervention* (Wodak evidence, 2 October 1997).

In response to such criticisms, the NHMRC recommended the S100 assessment criteria be broadened to include current injecting drug users. The Report suggests:

> *all patients would be assessed individually by their managing clinician to determine whether there is any evidence of psychological instability. Patients should be fully informed of the risks of re-infection through unsafe injecting behaviour* (NHMRC, 1997:36).

NSW Health considers such a positive emphasis taken by NHMRC suggests:

> *the lack of a clear rationale (other than short term cost saving) for the current year long waiting period for ex injecting drug users* (NSW Health, tabled document).

During the course of this Inquiry considerable support was given by experts to broadening the criteria for this group of people with HCV. NSW Health, for example, supports the NHMRC recommendation and wishes to see the new criteria monitored for a test period of at least two years. Support for broadening the criteria was also given by a number of agencies including ANCARD, NUAA, and the Hepatitis C Council.

While not personally "a great advocate" of providing interferon to injecting drug users, Farrell told Members of one of his patients who had recently stopped injecting but is unable to commence interferon therapy for another eight months. He stated that he would be "very happy" to start that person on treatment if he felt they were determined to remain clean of substance abuse (Farrell evidence, 28 November 1997). The current system does not provide any flexibility to administer interferon on a case by case basis.

In material provided to the Committee, NSW Health proposed a number of reasons for broadening this specific assessment criterion:

- cost projection estimates imply that, on fiscal grounds alone, there is a pressing need to halt or slow the current epidemic of HCV among injecting drug users;

- research suggests that interferon has a greater chance of clearing the Hepatitis C virus when administered early in the course of the disease. Requiring abstinence from injecting drug use for at least one year before treatment therefore reduces the chance of successful treatment;

- injecting drug users comprise the largest pool of infection. By excluding them from treatment, the prospects of effective treatment contributing to a reduction in disease transmission is significantly reduced;

- the exclusion of injecting drug users appears to be based on the assumption that all injecting drug users are addicted, continue to inject drugs using shared equipment and are at risk of reinfection with other strains of the virus. As will be discussed in Section 10.1 research findings question the validity of the popular stereotype of injecting drug users - many are employed, married with children and mortgages and use drugs only occasionally and recreationally; and

- the exclusion of injecting drug users from eligibility for interferon treatment is viewed by them as "punishment" for their illegal behaviour. Expecting a whole

> year's abstinence from injecting drugs before consideration of the only available treatment option serves to "encourage a feeling of being punished and of being rejected from society in an already marginalised group, and does little to encourage rehabilitation" (NSW Health submission).

NSW Health suggested that given the current NHMRC recommendations:

> *The continuation of the year long "waiting period" could be interpreted as a short term cost containment strategy for the S100 program and institutionalised discrimination against this population group* (NSW Health submission).

The NIH recommends treatment for patients who are actively using illicit drugs should be delayed until drug use has been discontinued for six months. They also recommend treatment for addiction should be provided before treatment for Hepatitis C (NIH, 1997:6S).

The Committee is pleased with the S100 changes that have been made enabling interferon under the S100 program to current injecting drug users. The Committee also considers it important that these patients be fully informed of the risks of reinfection through unsafe injecting behaviours.

- **Patients on a Methadone Program**

Under the current S100 criteria, interferon is not available to those on a methadone program. Evidence presented to the Committee suggested however that some people on methadone do access interferon under the S100 program. One witness told the Committee that:

> *I think a person with less knowledge of the system than I would not be able to do it [access interferon while on methadone] how I did. I snuck through the edges of the system. I found doctors willing to look the other way for my wellbeing. The law was that if you were on methadone you could not access it. The doctors did not ask and I did not tell them that I was on methadone. It was an under-the-table way* (Evidence, 6 November 1997).

The NHMRC Reports suggests there are no convincing data at present to indicate that the combination of interferon and methadone is potentially hepatotoxic or damaging in any way. The Council therefore recommended patients on methadone programs should be considered for treatment with interferon but that, as with injecting drug users, the Council wishes to see these patients assessed by their managing clinician and by appropriate Hepatitis C clinicians to determine whether there are any medical or psychological contraindications to the use of interferon (NHMRC, 1997:36).

The Committee supports the availability of interferon on the S100 program to those on a methadone program.

While some changes have been made to the S100 criteria, there remain several groups who are still exempt. Evidence presented and research findings support the following patient groups being eligible for interferon treatment:

- **Patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV RNA testing**

According to the current S100 assessment criteria patients have to have an ALT higher than 1.5 times the upper limit of the laboratory reference range on three occasions over a period of six months. However, not all patients with chronic Hepatitis C infection have ALT levels this high. A paper presented by Marcellin, Levy and Erlinger to the NIH's Consensus Conference on the management of Hepatitis C noted that, with the development of sensitive and specific means for detection of Hepatitis C in serum, it has become clear that a significant proportion of patients with chronic Hepatitis C infection are asymptomatic and have persistently normal serum ALT levels (Marcellin, Levy and Erlinger, 1997:133S). These patients are potentially infectious and, despite having normal liver tests, may suffer long-term consequences of the chronic liver disease (Marcellin, Levy and Erlinger, 1997:133S).

Marcellin, Levy and Erlinger argue that the absence of symptoms, the limited efficacy and costs of current therapies, and the potential of causing harm make it important to demonstrate clear efficacy in this specific group before the recommendations for patients with abnormal ALT levels can be applied to those with normal ALT levels (Marcellin, Levy and Erlinger, 1997:133S). They conclude by suggesting that there is currently no rationale to treat these subjects (Marcellin, Levy and Erlinger, 1997:136S).

The NHMRC took a slightly different management approach and recommended patients with normal ALT values should be monitored regularly by their clinicians (NHMRC, 1997:35). Patients with minimal ALT elevation or with normal liver function tests and positive HCV serology or HCV RNA testing should qualify for treatment (NHMRC, 1997:36).

In commenting on the current requirement for three ALT tests over a six month period, Schering-Plough argued that:

> *many of these people have had the disease for some time, they have already got a well established history and to make them wait another six months while they get three blood tests which will confirm this fact is probably unnecessary if they have had the history and all it will do is lead to their being more likely to develop cirrhosis and then they will not be allowed treatment anyway in the long run; cirrhosis can develop quite quickly* (Rallings evidence, 27 October 1997).

While the Committee remains unconvinced that a significant number of cirrhosis cases will develop over the six month period it does see merit in the argument that requiring proof of a well established disease may be unwarranted.

The Committee supports the availability of interferon on the S100 program to those with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV RNA testing.

- **Patients with cirrhosis**

Interferon therapy is often more effective in those patients with recently acquired Hepatitis C rather than those who have had it for some time and have developed cirrhosis. The NHMRC Report reviewed available research on the success of interferon for patients with cirrhosis. Patients receiving the standard six month course of interferon demonstrate 8-10% sustained response rate (NHMRC, 1997:35). The AUSHEP3 study has documented a 14 per cent sustained response rate in patients treated with an increased (4.5MU) dose of interferon administered daily (rather than three times a week as is the standard practice) (NHMRC, 1997:35).

Despite these poor response rates, there was considerable support for patients with cirrhosis receiving interferon under the S100 program. Expert witness, Professor Farrell for example, supported these patients accessing interferon therapy (Farrell evidence, 28 November 1997). Schering-Plough considered it to be:

> *rather discriminatory to remove them [patients with cirrhosis] because they are the ones who are nearest to the end stage disease. They are also the ones most at risk of getting hepatocellular carcinoma* (Rallings evidence, 27 October 1997).

The NHMRC recommended interferon be provided for cirrhotic patients in a dosage of 4.5 MU daily for six months (1997:36). In its submission to the Committee ANCARD also suggested that patients with cirrhosis should be allowed access to treatment given in a higher induction schedule with the aim of eliminating the virus and to document viral elimination with PCR testing (ANCARD submission).

On the other hand, the Panel Statement arising from the NIH Consensus Development Conference on the management of Hepatitis C does not support interferon therapy for patients with decompensated cirrhosis (NIH, 1997:6S). Their conclusion is however, based on the standard dose of interferon and relates to decompensated cirrhosis. Consideration is not given to the appropriateness of those with lesser degrees of cirrhosis receiving interferon and increasing the dosage of interferon for these patients.

Arguments supporting the availability of interferon to cirrhotic patients were often based on an economic imperative. Not only are there health care costs involved in managing cirrhosis but cirrhosis is a leading cause of liver transplants. The treatment protocols for both cirrhosis and liver transplants have been costed by Shiells, Briggs and Farrell (1994:269).

The total cost of asymptomatic cirrhosis has been costed (1994$) at:

Specialist Visits (2)	$145
Pathology Services (anti-HCV serology, liver function tests, alpha-fetaprotein, ultrasound, liver biopsy)	$270
Total Cost, per patient per year	**$415**

Treating liver failure has been costed (1994$) at:

Without transplant (60% of patients), cost per patient	$164,340
With transplant (40% of patients), cost of transplant	$75,000
Expected Cost, per episode	**$128,630**

It is imperative, from a costing point of view, if for no other reason, that every attempt be made to minimise HCV induced cirrhosis.

A number of those making submissions to the Inquiry mentioned that they had been excluded from interferon therapy due to their cirrhosis. One wrote:

> *my understanding specialist informed me that, unfortunately, I would not qualify for government assistance with interferon treatment due to the presence of cirrhosis in my liver. This was a devastating blow to me as I had been led to believe that this was the only hope for at least some quality of life and hope for the future. My specialists arranged for me to purchase my own supply of interferon. Being unemployed and unable to continue my usual work as a labourer, I have had to borrow the $1049 required each three months from my mother. The second three month supply was given free of charge by the pharmaceutical company in a humanitarian gesture (according to my specialist)* (Submission 45).

The Committee supports the availability of interferon on the S100 program to those with cirrhosis and that the dosage be increased to 4.5MU daily.

- **Relapsers and non-responders**

In 1997, the duration of interferon therapy was increased from six to 12 months. Directives from the PBAC made it very clear that non-responders or patients who relapsed were excluded from receiving the 12 month course of treatment. This is a cause of concern to a number of experts. Farrell, for example, informed the Committee that:

> *we have been trying now for over two years to get re-treatment made available for people who have only had six months treatment . . . If you re-treat people for 12 months there is a 40 per cent chance you can cure them. . . We have been trying for at least 18 months to get that approved and there have been a lot of difficulties which I would regard as fairly pedantic interpretations of regulations and laws - there has certainly not been any accommodation of ways in which these matters can be brought forward with any haste* (Farrell evidence, 28 November 1997).

Professor Reed, the Chair of the NHMRC report into the management of Hepatitis C, has also expressed his concern that the revised PBS listing ruled out funding for retreatment of patients who had relapsed after a six month course of interferon:

> *this is of particular concern because the evidence indicates that those patients who are re-treated for 12 months will have the same beneficial outcome as previously untreated patients* (Reed, 1997).

Not surprisingly, the drug company, Schering-Plough, also expressed concern at this limitation. In their submission they cite Alberti *et al's* 1997 research which suggests that:

> *a significant number of patients who responded during the initial course but subsequently relapsed have a sustained response when re-treated with interferon* (Alberti, 1997).

The Committee supports the availability of interferon on the S100 program to relapsers and non-responders.

- **Patients with extrahepatic manifestations of Hepatitis C**

The NHMRC recommend that patients with conditions such as casculitis, polyarteritis, nodosa, glomerulonephritis and cryoglobulinaemia - all extrahepatic manifestations of Hepatitis C that are life threatening in their own right - should be considered for treatment with interferon to address the primary cause of their immunological disorder (NHMRC, 1997:36). The Committee supports this recommendation.

Access to interferon under the S100 program is currently unavailable to those with a history of significant psychiatric illness because, as was discussed in Section 7.2.1, one of the side effects of interferon is depression. However Schering-Plough advised Committee Members that "if you screen them [psychiatric patients] well there is no reason why you should not treat them" (Rallings evidence, 27 October 1997) for

> *there is no reason why you should not give anti-depressants with interferon, there is no interaction, there is no reason why you should not do that* (Rallings evidence, 27 October 1997).

While the Committee can see some benefits in introducing a degree of flexibility that would enable appropriately screened and supervised patients with a psychiatric illness to access interferon, the Committee concluded that it had not received sufficient clinical evidence to recommend the availability of interferon on the S100 program to those with a history of psychiatric illness.

- **Conclusion**

Representatives from NSW Health informed the Committee that the current S100 scheme should be extended in line with the NHMRC recommendations (Wilson evidence, 22 September 1997). The Executive Officer of the Hepatitis C Council recommend that this Committee "give its full support" to NSW Health lobbying and encouraging the Commonwealth to expand the criteria in line with the NHMRC recommendations (Loveday evidence, 22 September 1997).

The Committee fully supports a broadening of the S100 assessment criteria as proposed by the NHMRC and supported by evidence to this Inquiry. Such changes would ensure those eligible for interferon include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;

- patients with cirrhosis;

- relapsers and non-responders; and

- patients with extrahepatic manifestations of Hepatitis C.

RECOMMENDATION 46:

That the Minister for Health urge his federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to broaden the assessment criteria for interferon drug therapy under the S100 Highly Specialised Drugs Scheme to include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;
- patients with cirrhosis (dosage - 4.5MU daily);
- relapsers and non-responders; and
- patients with extrahepatic manifestations of Hepatitis C.

The Committee further recommends that the proposed new S100 assessment criteria for interferon be monitored for two years with patient response data continuing to be collected for the National Interferon Database.

- **The National Interferon Database**

As was discussed in Section 7.1, the National Interferon Database was established in 1994 to gather data on all patients receiving interferon therapy. Throughout the Inquiry, various comments were made as to the effectiveness of the Database.

The ANCARD submission to the Highly Specialised Drugs Program review noted, for example, that the Database is "operating below its optimum largely because of inadequate funding". The submission also notes that:

> *Some centres have complained that the extra workload, for which there is no financial compensation, interferes with their work as health care providers. There is inadequate follow-up by authorised prescribers of patients who have ended treatment, and inadequate follow-up (or reporting back) by general practitioners who manage patients post-treatment. The data base does not include those on clinical trials or compassionate access programs. It is unrealistic to expect that the pharmaceutical industry, by itself, will fund such a project to the appropriate level. A comparatively small input from government could be expected to be highly cost effective in improving surveillance, control and utilisation of expensive drugs* (ANCARD submission to the Highly Specialised Drugs Program review - attachment to their submission to this Inquiry).

According to Schering-Plough, one of the two drug companies that finances the Data Base, it is:

> *a mechanism by which the Federal Government is able to control the type and number of patients treated, to minimise the total cost of treatment for Hepatitis C* (Schering-Plough submission).

The drug company elaborated further:

> *the Database has turned out to be far more successful as a de facto gatekeeper, limiting entry to alfa interferon treatment in Australia. The data collected is incomplete and unreliable as some 88% of the patients have been reported to have data missing or do not have follow up treatment and observation data (28% had missing data and 60% did not have follow up data)* (Schering-Plough submission).

Despite criticisms levelled at the Database, it does remain the only source of longitudinal data on the approximately 3000 people who have commenced interferon therapy in Australia. Given that the total number of people is so limited, it is important, from a research perspective, that the only data bank remain in place.

The Committee understands, however, that the Database is facing funding difficulties. It therefore wishes to see the NSW Minister for Health encourage his federal counterpart to continue funding the operation of the National Interferon Database. The Committee considers government funding to be more appropriate than the current arrangement which depends on funding from pharmaceutical companies. Without wishing to question the integrity of such companies, the Committee is aware of their commercial interests and research priorities which compare drugs rather than examine other less expensive treatment strategies or preventive/educative approaches. It is the Committee's concern that limited government involvement in funding the Database could lead to higher overall treatment costs.

RECOMMENDATION 47:

That the Minister for Health urge his federal counterpart to ensure funding continues to be provided to maintain operation of the National Interferon Database and that the intellectual property of the Database remain with the government so that optimum treatment regimes can be ascertained.

- **Management of Patients not Receiving Interferon**

As has been discussed in Section 7.1.2 the majority of those with Hepatitis C cannot or will not undertake interferon therapy. In the opinion of the NHMRC

> *The 99 per cent of patients who have not received interferon alpha clearly represent the most important group of patients with Hepatitis C at the present time* (NHMRC, 1997:42).

The report from the NHMRC urged that adequate counselling be made available to those patients not eligible for interferon therapy to provide information on the natural history of the disease as it is presently understood and on treatment options as they evolve (NHMRC, 1997:42). The NHMRC anticipates that this process will require at least annual contact with the patient to provide them with up-to-date information on the disease and its course. In the opinion of the NHMRC the patient's general practitioner is ideally placed to provide this input (NHMRC, 1997:42).

Support for counselling was also given by the Australian College of Sexual Health Physicians who noted in their submission that:

> *Counselling remains one of the most important components of care in Hepatitis C due to the chronic nature of the infection and the limited range and success of treatment options* (Australian College of Sexual Health Physicians submission).

However, the Committee has heard that the task of managing those patients not able to access interferon requires more than providing them with information. A clinical nurse working in the area noted that:

> *One of my main concerns is that patients who are not receiving interferon may not receive any health promotion education on Hepatitis C and cross-infection. I am unaware that any policy exists that stipulates educational requirements about Hepatitis C for these people. Family and friends of patients would not receive any education unless they directly sought it out themselves. Consequently, this could place them at some level of risk* (Looby submission).

The Committee shares Looby's concerns and considers there to be a very real need for appropriate education particularly as the majority of those with Hepatitis C do not access interferon therapy. The Committee considers it appropriate that the proposed Hepatitis C Policy Statement and Strategic Plan address the issue of managing those who are HCV positive and ineligible for interferon therapy to ensure they are provided with information on subjects including (although not limited to) the natural history of the disease, treatment options, health promotion and information on cross-infection and re-infection. Both the Policy Statement and Strategic Plan should address the counselling needs and psychosocial support for these patients and their families and the role of primary health care providers in giving such support.

RECOMMENDATION 48:

That the NSW Hepatitis C Policy and the NSW Hepatitis C Strategic Plan (proposed in Recommendations 28 and 31) address the management needs of those who are HCV-positive and ineligible for interferon therapy. Issues to be considered are to include (although not be limited to) (i) information on the natural history of the disease, treatment options, health promotion and cross-infection and re-infection; (ii) counselling needs and psychosocial support of these patients and their families; and (iii) the role of primary health care providers in giving this support.

8.1.2 POLICIES LIMITING THE NUMBER OF INTERFERON PRESCRIBING CENTRES

There are over 1000 public and private hospitals across Australia. Of these 66 are recognised Interferon Prescribing Centres. Within NSW there are 303 public and private hospitals, 24 of which are Interferon Prescribing Centres. These Centres and the policy establishing the criteria to be met by hospitals seeking to become Interferon Prescribing Centres were outlined in Section 7.2.1. During the course of this Inquiry, a number of issues concerning the location of these Centres were raised with the Committee.

A major criticism made to the Committee concerned the concentration of Interferon Prescribing Centres in the metropolitan region. The Committee heard, for example, that:

> *the majority of [hospitals], like many health care services, tend to be concentrated in the metropolitan areas and the non-metropolitan country folk tend to miss out. This is a huge problem. Here you have people who live further out and they should come in to an approved centre and come in fairly regularly for treatment. It becomes a such a major burden that they therefore decide not to have the disease treated. It is unfortunate* (Fong evidence, 27 October 1997).

The Hepatitis C Council made similar comments:

> *most people in rural areas who seek access to interferon are particularly disadvantaged because of the distance and expense involved in accessing treatment* (Hepatitis C Council submission).

Access to Interferon Prescribing Centres has been described as “limited” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission). ANCARD considered the situation to be akin to “centralisation of care” and saw this phenomenon as “a potential barrier to treatment for some people, particularly those in rural and outer suburban areas” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission). It called for options to make access “more accessible without compromising clinical standards or cost controls” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).

Submission received by those with Hepatitis C identified some of the practical difficulties they experience as a result of this “centralisation of care”:

> *The adequacy of diagnostic and treatment services in rural NSW is very poor. Only at the major centres (Wollongong and Canberra) can any form of ongoing treatment be obtained, and then the patient is at the mercy of bed availability or access to treatment programs. The local hospital has no blood transfusion facilities . . . so this means a costly and time consuming exercise of visiting a recognised treatment centre at Wollongong* (Submission 39);
>
> *I moved from Sydney to Ulladulla and five months later I was diagnosed with Hepatitis C. What a bad move! I felt stranded!! Two hours drive to Wollongong to the nearest specialist (and to make matters worse we have to pay 80c/litre for petrol, so it makes it a $40 trip each time)* (Submission 38);

and

> *I was referred to a local consulting physician and after blood tests I had my first liver biopsy at Grafton Base Hospital, the results were then referred to a gastroenterologist in Lismore, 150km each way* (Submission 45).

The Committee was concerned that there is just one treatment centre between Newcastle and Lismore, none west of Dubbo, and within the southern half of the state only two centres - those at Bega and Wagga Wagga. Professor Batey, based in the John Hunter Hospital, Newcastle, noted that:

> *we have had patients from most of the major centres up to and including Grafton. Many people once they get to Grafton head north rather than come south. But we have certainly got patients from all the major centres coming to John Hunter and we treat them there* (Batey evidence, 27 October 1997).

Batey considers that:

> *more centres should be able to assess, test and treat patients with Hepatitis C now that we have had this experience with 2,500 patients. This will occur in time* (Batey evidence, 27 October 1997).

While Batey may take comfort in more Centres being available “in time”, the Committee wishes to see the process speeded up to ensure assessment, testing and treatment are more accessible.

The limited number of Interferon Prescribing Centres is both a reflection of the criteria used to establish these Centres and available funding. Short of making additional funding available the Committee considers there to be several approaches to greater accessibility to assessment, testing and treatment. One approach would be to review, and if necessary, modify the current criteria used to establish Interferon Prescribing Centres.

RECOMMENDATION 49:

That the Minister for Health seek the support of his Federal counterpart for a review of the criteria used to establish Interferon Prescribing Centres to enable the expansion of the limited number of hospitals allowed to dispense interferon without compromising clinical standards or cost controls.

The Committee feels that, while it has a role to play, the issue is not one of simply relaxing the current criteria. As will be discussed in Section 8.4.1 a range of models for managing the treatment of Hepatitis C patients must be made available. Such an approach would ensure assessment, testing and treatment are more accessible without compromising clinical standards or cost controls.

8.1.3 POLICIES LIMITING PRE-TREATMENT ASSESSMENT

There is considerable research suggesting that certain genotypes of HCV respond better to interferon therapy than others. Those with genotype 3, for example, appear to respond better to interferon than those with genotypes 1a and 1b. Measurements of viral genotype can therefore be indicative of a person's anticipated response to interferon therapy. Similarly viral load as measured by PCR testing can also be used to indicate the likely outcome of therapy as patients with a high viral load are less likely to respond to interferon therapy than those with low loads (NHMRC, 1997:38).

The availability of tests to ascertain genotype and viral load therefore has important ramifications both for assessing patients before commencing interferon therapy (enabling therapy to be tailored to individuals) and also during the course of their therapy.

With specific reference to pre-treatment assessment, the NHMRC has noted that:

> *most recent studies highlight the importance of pre-treatment assessment, including the measurement of viral genotype and viral load . . . The role of genotype and viral load in determining disease outcome can now be predicted more accurately. In Australia, the epidemic is being largely caused by types 1 and 3 and it would seem appropriate to tailor therapy to the viral type causing the infection in individual patients* (NHMRC, 1997:34, 38).

Despite current research and the NHMRC's observations access to interferon under the S100 scheme is, at this point in time, determined by assessment criteria alone and "no attempt is made to identify either the genotype or viral load in patients presenting for treatment" (NHMRC, 1997:34). This means that some patients are receiving thousands of dollars worth of drug when it is evident that their success rate will be well less than 10 per cent (ANCARD submission).

The Medicare Benefits Schedule does not make it possible to receive a Medicare rebate for PCR testing of genotype or viral load. Currently most of the genotype data in Australia is being generated by using research funds (Farrell evidence, 28 November 1997).

The Committee considers the current limited assessment prior to commencing interferon therapy to be outdated and inflexible - in short, quite inappropriate. Clearly recent advances in testing have to be taken into account particularly when they have the potential to improve cost effectiveness and contribute to overall quality of life as ANCARD noted in their submission to the Review of Highly Specialised Drugs Program:

> *improving pre-treatment assessment is unlikely to reduce direct expenditure, because the current interferon dosage is regarded as the*

> *minimum level for HCV and assessment will also reveal cases in which higher doses are likely to be effective. However, genotype and viral load testing, when introduced, will also greatly improve cost effectiveness and, by withholding a comparatively toxic drug from people who are unlikely to benefit from it, contribute to overall quality of life* (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).

The NHMRC has recommended resources being made available to allow for routine testing of viral load and genotype in all patients assessed for treatment with interferon (NHMRC, 1997:54). The Council proposed that:

> *Genotyping and viral load testing should be available for patients in Australia* (NHMRC, 1997:38).

Similar conclusions were made at a meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel, the Clinical Trials and Treatments Advisory Committee (CTTAC) and invited participants held in February 1998. At that meeting, a proposed Hepatitis C testing protocol was forwarded (see Table Twenty-Three in Section 6.2). Those at the meeting agreed that viral load testing was required before treatment (but not during or after treatment) as it would indicate the outcome of the treatment response, and genotype testing should be performed to advise therapy (ANCARD Hepatitis C Clinical and Virological Advisory Panel and the Clinical Trials and Treatments Advisory Committee, 1998).

During the course of this Inquiry, there was considerable support for genotype and viral load testing to be made more readily available. Not surprisingly the pharmaceutical company, Schering-Plough recommended interferon therapy should not be withheld on the basis of genotype. In their opinion:

> *they should all at least be offered the treatment and given the chance. If at the end of three months they fail to respond and that is determined by their ALT, if it fails to fall then you know they are not going to respond and you take them off* (Rallings evidence, 27 October 1997).

ANCARD suggested (and the Committee fully agrees) that:

> *it would be more appropriate now to be using genotyping to allow more rational approaches to induction therapy to be used* (ANCARD submission).

Professor Farrell would also like to see the test available. However he adds an important caveat - he would like to see them available on a "highly restricted basis" because:

> *it would be very wasteful for everybody on a curiosity basis, even though they might like to know their genotype, if they had very mild disease it isprobably not relevant to know the genotype, and I would have a preference that the test be ordered by someone who is an expert in the area . . . someone who is trying to counsel a patient on whether to have treatment or not* (Farrell evidence, 28 November 1997).

The Committee is convinced that access to viral load and genotype testing would provide an important assessment tool prior to commencing treatment enabling those least likely to benefit from this particular form of therapy to be screened. NSW Health recognises the potential of such testing and the attendant funding advantages:

> *funding specifically for this [genotype testing] could reduce health costs in the long term. For example a $120 test could save $6,000 of interferon treatment if the test result showed that the person was infected with a genotype of HCV non-responsive to interferon* (NSW Health submission).

RECOMMENDATION 50:

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to determine genotyping and viral load in the pre-treatment assessment for patients considering interferon (and other drug) therapy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

8.1.4 POLICIES LIMITING INTERFERON DOSAGE SCHEDULE

The current standard course of interferon therapy, as prescribed by PBAC is 3MU three times a week. All patients receive the same dosage schedule irrespective of their genotype, viral load, or complications such as cirrhosis, despite research demonstrating that cirrhotic patients often respond better when the dosage is increased to 4.5MU. The Committee agrees with the NHMRC who noted that:

> *It is inappropriate to regard all chronic Hepatitis C patients as the same and as requiring the same therapeutic doses of interferon* (NHMRC, 1997: 34).

The ANCARD submission suggests that patients with cirrhosis should be allowed access to treatment given at a higher induction schedule. In its submission to the Review of Highly Specialised Drugs Program ANCARD went a step further and hypothesised that access to genotyping and viral load testing will result in future patients with responsive Hepatitis C (non-fibrotic, genotype 2 or 3, low viral load) receiving the standard course of interferon while those with more resistant disease will automatically receive a higher induction course which would be reduced to maintenance levels once the viral load falls. This would increase the cost of a 12 month course from $3,500 to $10,000. It may, however, still be cheaper than using some of the new antiviral therapies. The cost of a course of Ribavirin is, for example, $20,000 (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).

The ANCARD submission stresses that any discussion of increasing costs of interferon must be keep in perspective. Upward pressure on expenditure will continue to be limited by the side effects commonly associated with interferon and the therapy's limited efficacy (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).

The Committee considers the current practice to be very inflexible with little regard for individual differences. It wishes to see flexibility introduced giving clinicians provision to take into account individual differences and scope to prescribe dosages appropriate to individual patients.

RECOMMENDATION 51:

That the Minister for Health urge his Federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to introduce a degree of flexibility into the S100 Highly Specialised Drugs Scheme enabling the interferon dosage schedule to be increased where necessary and appropriate such as in the case of cirrhotic patients.

8.1.5 POLICIES LIMITING TREATMENT ASSESSMENT AND MONITORING

PCR testing can be used to monitor the efficacy of therapy by measuring the viral load at intervals during therapy. The Committee was advised, for example, that evidence to date suggests that an 80 per cent drop in viral load within the first month of commencing interferon therapy is predictive of a long term response. The PCR test is sensitive enough to determine such a drop.

According to the drug company, Roche, the implications for PCR in the future is its potential to monitor the impact of interferon therapy on the patient. Using PCR to monitor the viral load at baseline and after one month of treatment will result in one of two options for patients:

1. If an 80% drop in viral load is detected, they are likely to be a “sustained responder” and hence continuation of therapy for the full 12 months is necessary; or

2. If there is less than 80% drop in viral load, future treatment strategies may include: increasing the interferon dosage, adding another agent or ceasing therapy altogether (Roche submission).

As Roche pointed out to the Committee, such an approach to treatment will result in:

- patients knowing early in their treatment the likelihood of response thus avoiding unnecessary/ineffective treatment;
- much greater response rates as treatment can be continued to those who are likely to respond; and
- potentially more patients with access to treatment and consequently a reduction in the overall costs of HCV to the Australian government (Roche submission).

The meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel and the Clinical Trials and Treatments Advisory Committee (CTTAC) held in February earlier this year also supported the use of qualitative PCR testing after 12 weeks of interferon. The proposed testing schedule also included PCR testing at the end of interferon therapy, and follow-ups after six months and then again at 18-24 months (ANCARD, 1998).

Currently PCR testing is not freely available for assessing and monitoring interferon therapy. The Committee considers there to be a vital role for PCR, not only in pre-treatment assessment as has been discussed, but also in monitoring interferon therapy and tailoring therapy to ensuring maximum efficacy of treatment and efficient utilisation of resources available. It therefore wishes to see pressure put upon the Federal government to provide a Medicare rebate for PCR testing used to monitor and assess the efficacy of interferon treatment in Hepatitis C patients.

RECOMMENDATION 52:

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to monitor interferon (and other drug) therapy and tailor therapy to ensure maximum efficacy of treatment and efficient utilisation of resources to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

8.1.6 POLICIES LIMITING PCR TESTING FOR HCV+ WOMEN CONSIDERING PREGNANCY

PCR viral load testing can be used to predict the relative risk of vertical transmission during pregnancy. Such information would be of considerable importance to those women who are HCV+ and contemplating pregnancy and, as was discussed in Section 3.6, calls have been made for those contemplating pregnancy to ascertain their PCR status (Sladden *et al*, 1998:293). However, at this stage, testing conducted for this purpose is not covered by the Medicare Benefits Schedule.

During the course of this Inquiry, mothers recounted to Committee Members their angst as they awaited the results of pathology tests carried out on their children and the associated guilt and fear many carried before learning of their children's Hepatitis C status. One witness, a clinical psychologist with considerable experience in counselling those with Hepatitis C, stated that:

> *PCR testing is needed to determine the viral load in the blood of a woman to know whether she has the right to be responsibly pregnant* (Lamb evidence, 30 March 1998).

Hepatitis C positive women wishing to conceive need to be provided with as much information as is available to enable them to make informed choices and decisions. The Committee therefore wishes to see the Medicare rebate on PCR viral load testing available to those women contemplating pregnancy.

RECOMMENDATION 53:

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to predict the relative risk of vertical transmission during pregnancy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

8.2 INADEQUACIES OF THE CURRENT TREATMENT REGIME

In considering the adequacy of the current treatment regime, the Committee concurred with the comment made by a Schering-Plough representative who commented during the course of evidence that the current treatment is "far from optimal" (Kir evidence, 27 October 1997). As the Committee heard:

> *you would have to be a super patient, first to qualify to get the treatment, and then once you qualify, to find the centre and find a specialist that actually has the time and the ability to see you* (Matouk evidence, 27 October 1997).

In considering the current treatment regime, the Committee identified two specific areas of inadequacy: the limited number of treatment options available and the limited success of the one available form of therapy. Both of these issues will be examined in the following discussion and a number of strategies to address these inadequacies proposed.

8.2.1 LIMITED TREATMENT OPTIONS

Proven and approved treatment options for those with Hepatitis C are limited to one: interferon. While other drug therapies are currently being tested, the Committee understands that their widespread introduction is still a number of years away. The

Hepatitis C Council advised that protease inhibitor drug therapy will not, for example, be available for another four to five years (Hepatitis C Council submission).

8.2.2 LIMITED SUCCESS OF AVAILABLE THERAPY

As has been discussed, interferon therapy is only effective for approximately one in four of those treated. As more treatment options become available the success rate may improve, but the introduction of new treatment options is not imminent.

Not only is interferon of limited success, but many experience significant side effects. The Committee heard that these problems are exacerbated for women:

> *when one's liver is not functioning properly, this is from observation rather than medical knowledge and from talking to lots of women with Hepatitis C, one cannot guarantee how one's hormones will function, and that can have disastrous effects . . Women never knew when their periods were due, never knew anything like that. It is worse on interferon. It is a very difficult situation for women* (Lamb evidence, 30 March 1998).

Clearly the limited options for treatment, and the limited efficacy of the one approved treatment regime is a matter of grave concern not only to those affected by Hepatitis C and their families but state and federal governments responsible for the provision and funding of health services both now and in the future.

The Committee fully agrees with the Hepatitis C Council which observed that:

> *there are still too few treatments available for people with HCV and . . there is still a lot to learn about the response of the virus to new initiatives in this area. The advance of treatments for HCV should be strongly encouraged and supported* (Hepatitis C Council submission).

8.2.3 ADDRESSING CURRENT TREATMENT INADEQUACIES

The Committee considered that action in at least four areas must be taken to address the identified current treatment inadequacies: further research into the treatment for Hepatitis C; support for those who do not respond to interferon; support for those on interferon and fast tracking of new drug therapies as they become available. Each will be discussed in the following section.

- **Need for Further Research**

Experts appearing before the Committee stressed the need for considerable research to be undertaken in the area of Hepatitis C. Professor Farrell, for example, commented on:

> *the considerable need for funding of research in this area . . . There is negligible Commonwealth, indeed State research investment in this disease* (Farrell evidence, 28 November 1997).

The Committee understands most research to be funded by pharmaceutical companies and that, during the last three years, less than $150,000 per annum has been expended from the national medical research budget on Hepatitis C (Farrell evidence, 28 November 1997). Such figures “compare very unfavourably” with investment of research in the area of HIV-AIDS which is “several orders of magnitude greater than that” (Farrell evidence, 28 November 1997). Professor Farrell considers it:

> *a national disgrace that not more money has been spent on research extending right from epidemiology, finding out how common it is, who has it, how they are still getting it, through to the social impact of the disease, which is the major thing, the morbidity of the disease, and then ultimately through to trying to prevent people actually dying of the disease* (Farrell evidence, 28 November 1997).

As has been discussed in Section 4.5, $1million for Hepatitis C research was announced in early 1998. While welcoming this initiative, the Committee understands that most of the funding is already earmarked for social and behavioural research and drug trials were specifically excluded (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:3). As important as this research is, the Committee considers it to be unfortunate if that facet alone was to receive all funding allocations. Given the considerable numbers of those in the community with Hepatitis C, and the implications such numbers have upon the health care system (and budget) it is imperative that an effective form of treatment be found.

Funding research into clinical drug studies has traditionally been the domain of pharmaceutical companies. However, the Committee considers the need to find an effective treatment for Hepatitis C to be such a priority that it calls upon both federal and state governments to fund clinical studies to identify and understand new treatments for Hepatitis C.

RECOMMENDATION 54:

That the Minister for Health request his federal counterpart fund and support clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments. The Committee further recommends that the state government match federal funding for this research on a dollar for dollar basis.

- **Need for Support for Those who do not Respond to Interferon**

As was stated in Section 7.1.2, the Committee has adopted the statistic of one in four as the number of people for whom interferon is effective. While this statistic is alarming, the converse of this statistic also needs to be considered: interferon therapy is unsuccessful for three out of four of those who commence therapy and, for those with certain genotypes, the rate of failure can be as high as 90%. Such a high failure rate has its consequences. The Committee heard that:

> *these people who have seen interferon as the only opportunity to improve their health, become disappointed and angry* (Hepatitis C Council submission).

Similar comments were made to the study conducted by the National Hepatitis C Council's Education Reference Group. The study's final report notes that:

> *several participants who had 'failed' on interferon were very angry at the lack of counselling or follow-up provided when they left the programme. They had been told that interferon was the only treatment available so that failing the programme left them in a state of hopelessness* (National Hepatitis C Council's Education Reference Group, 1996:29).

A psychiatrist commented to the Department of Health that:

> *They [ex-interferon patients] may have difficulty in dealing with uncertainly or the disappointment that will accompany treatment failure* (Ryan correspondence, attachment to NSW Health submission).

From information provided to the Committee, it would appear that there are very few support services available to those who do not respond to interferon. The Hepatitis C Council advised the Committee that:

> *Few services currently exist to provide counselling and support to those who have 'failed' on interferon. In interferon treatment centres staff who provide information and monitor people's progress while on treatment are overburdened and under-resourced. When people leave treatment there are few follow-up and counselling services available* (Hepatitis C Council submission).

The Committee is concerned with the limited support mechanisms available for those who fail interferon. It considers it essential that adequate support be provided to these patients to assist them come to terms with their disappointment and anger.

RECOMMENDATION 55:

That the Strategic Plan proposed in Recommendation 31 consider the provision of adequate support mechanisms for people who do not respond to interferon therapy. The Committee further recommends that the Strategic Plan set targets for the establishment of support services in inner city, metropolitan and regional/rural locations.

- **Need for Support for those on Interferon**

As was described in Section 7.1, the side effects of interferon can be quite severe and many of those on the drug therapy find the twelve month period to be a very difficult time both physically and emotionally. Clinical nurse consultants working in the liver clinics are available to provide support for these patients. However it has been suggested to the Committee that the demands placed upon these nurses are such that they have little time to give the support needed by the patients on interferon. To lessen the load of the clinical nurse consultants, the Committee would like to see a range of other health care professionals available to provide support for those on interferon.

Within the health care system, there are a number of professionals who currently provide psychosocial support to those with chronic illness. It is possible that social workers, counsellors, chaplains, drug and alcohol workers could, with training, provide the support needed.

RECOMMENDATION 56:

That NSW Health provide HCV specific training (both initial and ongoing) to existing providers of psychosocial support for people with chronic illness employed within the health care system, such as social workers, counsellors, chaplains, drug and alcohol workers enabling these professionals to provide support to those on interferon therapy.

- **Liver Transplants**

As experts such as McCaughan and Batey reminded Members Hepatitis C is the main indication for liver transplantation in Australia (McCaughan evidence, 23 March 1998 and Batey evidence, 27 October 1997). McCaughan observed this implies more people are being referred to liver transplant units with end-stage liver disease associated with Hepatitis C (McCaughan evidence, 23 March 1998). While liver transplantations started as a federally funded national program, the programs became a state responsibility about three years ago costing approximately \$100,000 - \$120,000 per case (McCaughan evidence, 23 March 1998).

In terms of waiting lists for liver transplants, the Committee heard that:

> *the waiting list for transplantation is blowing out now but the donor rate has not changed that significantly; it has not increased. We used to run a program up until about three years ago in which we had a waiting list of between five and ten people - people tended to die or get a transplant. Now we regularly run a waiting list of between 20 and 30 patients and a third of those now are Hepatitis C . . . That will mean that many people will die before they get a transplant* (McCaughan evidence, 23 March 1998).

In terms of future needs, McCaughan advised that “it is likely that the number of organs will not match the demand” (McCaughan evidence, 23 March 1998). Mr Harvey from the Hepatitis C Council told Committee Members that:

> *estimates are that the demand already outstrips the number of suitable donors and that will increase substantially as more and more people who are now in their 40s become older and these problems develop . . . I cannot see anything on the horizon that is going to improve that, so it is going to be a bad situation* (Harvey evidence, 3 October 1997).

Australia has one of the lowest rates of organ donations amongst developed nations, an issue which is of concern to health departments across the nation. The Committee is concerned with the general issue of organ donations and liver donations in particular and wishes to see increased attention be given to the subject to find innovative and effective solutions to the problem.

RECOMMENDATION 57:

That the Minister for Health, through the forum of the Australian Health Ministers’ Council, urge his federal, state and territory counterparts to recognise Australia’s low rate of organ donation and consider innovative and effective ways to increase the donations of organs in general and liver donations specifically.

8.3 INADEQUACIES OF CURRENT SERVICE DELIVERY

During the course of this Inquiry, a number of comments were made concerning the adequacy, or otherwise, of current service delivery. The following discussion looks at issues raised pertaining to three levels of service - the state/health area level; hospital level; and general practitioner level.

In forming its assessment of inadequacies in the current system of service delivery, the Committee wishes to state clearly that its comments are in no way a reflection on the expertise and commitment of those health care workers within the system. Throughout the course of this Inquiry, the Committee was deeply impressed with the dedication of those health care professionals it met with, many of whom are working within extremely tight budgetary constraints, heavy schedules and competing demands of clinical management, teaching, research and administration.

8.3.1 INADEQUACIES AT THE STATE AND AREA HEALTH LEVEL

The Committee received comments on the inadequacies of the provision of services at all three levels of service delivery: the state; area health boards; and specific hospitals.

In commenting on the statewide situation Batey noted that, "at the moment resources are less than adequate" (Batey evidence, 27 October 1997). In terms of specialist services, Farrell noted that:

> *At the level of speciality services with which I am most familiar because I am a specialist in the area of liver disease there has been no expansion at all of services for the very large number of persons with this disorder, despite clear evidence of its high prevalence, despite evidence of difficulties of patients getting access to special clinics, despite evidence of Hepatitis C becoming the single most common cause for adults requiring liver transplantation in New South Wales during the last five years and despite published evidence of a considerable increase in cases of liver cancer, some of which is attributable to Hepatitis C. At the moment the services that are available are threadbare* (Farrell evidence, 28 November 1997).

At the level of Area Health Boards, the Chair of the Central Sydney Area Health Board advised the Committee that:

> *From the perspective of the area health board, I would have to say that we are not providing the full range of adequate services I should like to be in a position to provide. We are short of both personnel and the necessary financial resources to do so* (Puplick evidence, 7 November 1997).

8.3.2 INADEQUACIES AT THE HOSPITAL LEVEL

In terms of individual hospitals, the Committee heard that both RPA and Westmead hospitals provide a full range of diagnostic and treatment services but they are "underfunded and under-recognised" (Puplick evidence, 7 November 1997). Mr Puplick added that the provision of services at Royal Prince Alfred and Concord hospitals are "inadequate" (Puplick evidence, 7 November 1997).

Also citing the experience of Royal Prince Alfred Hospital the hospital's Nurse Consultant/Coordinator, Hepatitis C Services advised that:

> *We have had no increase in our services since Hepatitis C really took off, since 1990. The only thing that has happened is that my position [nurse consultant/coordinator, Hepatitis C services] has been created . . . there has been no provision for an increase in services* (Pritchard-Jones evidence, 2 October 1997).

As was shown in Table Six Central Sydney Area Health Service has the second highest notification rate of Hepatitis C patients in the state, possibly Australia. This has led to increases in referrals but, not the Committee heard, an increase in services:

> *there has certainly been no increases in our bed allocation numbers, and so patients are having to wait three weeks or so to come in for a transplant assessment* (Pritchard-Jones evidence, 2 October 1997).

Not only are patients having to wait for their assessment, but when they are able to have the assessments done, it is frequently undertaken on an outpatient basis:

> *Quite often they are now having to have their transplant assessment done, which involves coming into hospital and having a significant amount of testing done, such as angiography, CT scans, etc., on an outpatient basis* (Pritchard-Jones evidence, 2 October 1997).

The Committee heard that such an arrangement:

> *is not really adequate but there is really no other way we can run things at the moment* (Pritchard-Jones evidence, 2 October 1997).

- **Waiting Lists**

The pressure on clinical services is, not surprisingly, resulting in waiting lists. The Chief Health Officer of the NSW Department of Health admitted to the Committee that

> *there is a significant delay in that primary assessment process and referral process* (Wilson evidence, 3 October 1997).

The Red Cross confirmed that waiting time for metropolitan liver clinics can vary from "weeks to months" (Red Cross submission) while Batey informed Members that:

> *In the major clinics when we last looked at waiting times they were anything from three to twelve months to get an appointment to see a hepatologist to be assessed for treatment . . . I think that waiting time may well have come down, it has certainly come down for me to less than six months now* (Batey evidence, 27 October 1997).

According to the NSW Department of Health, waiting times for interferon assessment and liver biopsy vary widely depending on the individual clinician and centre involved. Waiting times for liver biopsy also depend on the extent of assessment by the general practitioner before referral to a gastroenterology clinic. However, the Department did provide several examples of waiting times which are recorded in Table Twenty-eight.

TABLE TWENTY-EIGHT
EXAMPLES OF WAITING LISTS IN NEW SOUTH WALES

	ASSESSMENT BY REGISTRAR	ASSESSMENT BY SPECIALIST	LIVER BIOPSY
John Hunter	3 weeks	3 months	1 month
Royal Prince Alfred Hospital	6 weeks	4 months	1 month
Lismore Base	3 months	3 months	3 months

Source: Wilson evidence, 3 October 1997

In reporting to the Committee on waiting lists in his liver clinic, Professor Farrell advised that, as of late November 1997, the waiting time for new patients to attend Westmead's clinic was nine weeks and the follow-up visit, ten weeks. Such current delays are ”not quite as bad as it has been at times” (Farrell evidence, 28 November 1997).

Without appropriate intervention, the problem of waiting lists is set to worsen as those with Hepatitis C move into the chronic stages of their disease. The Committee considers it essential that measures be put in place as a matter of priority to ensure current numbers are handled before the influx occurs and there is a total blowout.

- **Inadequate Provision of Specialist Services**

Professor Farrell advised the Committee that:

> *there are some areas in Sydney where Hepatitis C is exceptionally common where there is not a single liver specialist, South Western Sydney [Area Health Service] is one such example. There does need to be some more specialist services* (Farrell evidence, 28 November 1997).

Farrell also noted that:

> *the South Western Sydney Area Health Services is an area where there is a dearth of specialised liver clinics and liver specialists coordinated with other services in a way to provide treatment and counselling of Hepatitis C* (Farrell correspondence, 6 October 1998).

The lack of a liver specialist or availability of a gastroenterology outpatient liver clinic in the South Western Sydney Area Health Service (SWSAHS) is inappropriate given that, according to Table Six, the area has the third highest notification rate of Hepatitis C in the state. SWSAHS has a large Vietnamese community and the Committee heard that many of those with Hepatitis C travel from the south west to Concord hospital where there is a Vietnamese gastroenterologist who "has a big Vietnamese clientele" (Pritchard-Jones evidence, 2 October 1997).

- **Inadequate Provision of Hepatitis C Clinical Nurses**

As a result of limited financial resources many nurses in clinical management are financed by drug companies. Not all of those appearing before the Committee supported this practice. ANCARD, for example, observed:

> *it seems inappropriate that drug companies should be providing health department positions to deal with a disease which is causing a considerable load on liver clinics throughout the state* (ANCARD submission).

The issue was taken up when ANCARD Chair, Mr Chris Puplick, appeared before the Committee. He noted that:

> *the general question of allowing any financially self-interested element within the health system is a potential distortion in a way that leads to the interests of the pharmaceutical provider prevailing over the interests of, first, the patient, and second, the public health system. It is not just in relation to liver clinics, it is in relation to just about anything else which is likely to be done on a fee-for-service basis* (Puplick evidence, 7 November 1997).

Professor Farrell also brought the issue to the attention of the Committee:

> *the staffing of a clinic such as my own is heavily embellished by staff who are employed on research funds, not on funds for clinical services . . . There are very few [clinical nurse consultants] engaged in Hepatitis C work and , as far as I can see, very few, if any, of them are supported by the state health budget most of them are supported by research funds for educational grants and pharmaceutical companies who have a vested interest in treatment programs* (Farrell evidence, 28 November 1997).

Farrell concluded such a practice to be "very unsatisfactory" (Farrell evidence, 28 November 1997). Given the potential for a conflict of interest, the Committee considers it inappropriate that nursing staff of liver clinics be financed by drug companies.

- **Inadequate Allocation of Funding**

The inadequate provision of services, waiting lists and lack of specialist services are all directly related to funding, or lack of it. The Committee heard that:

> *there has been no additional state or federal funding for additional liver specialists and nurses to adequately provide treatment and management of Hepatitis C at these [approved] centres* (Schering-Plough submission).

Schering-Plough noted such a need:

> *available evidence on the natural history of the disease shows that if more funds are not made available in the short term, there will be a greater need for even more funds in the medium to longer term to support the more costly, later stages of this disease* (Schering-Plough submission).

Farrell suggested that:

> *What we do need is a very modest but identifiable expansion of clinical services which may be of the order of not more than $5 million* (Farrell evidence, 28 November 1997).

8.3.3 INADEQUACIES AT THE GENERAL PRACTITIONER LEVEL

A recurring theme in both evidence and submissions was the limited knowledge and inexperience of many general practitioners in relation to Hepatitis C, its treatment and management. Both experts and people with Hepatitis C acknowledged this to be an issue of concern.

Expert witness, Dr Wodak, for example, noted that “general practitioners are not yet well educated about Hepatitis C” (Wodak evidence, 2 October 1997) and as a result:

> *general practitioners often refer their patients to liver clinics and the liver clinics in this state and the rest of the country are swamped with people with Hepatitis C* (Wodak evidence, 2 October 1997).

The Red Cross advised the Committee that:

> *the majority of general practitioners and other doctors have only basic knowledge about Hepatitis C and its natural history. Most are inexperienced in the interpretation of serological tests and have no experience in providing lifestyle advice to individuals who are HCV positive* (Red Cross submission).

Drawing upon his experience in working with general practitioners, Hall noted that:

> *Because of a lack of information, specialists and especially general practitioners have been feeding patients with inaccurate, inconsistent or incomplete information. In our understanding of Hepatitis C a lot of information is still evolving, so it is very easy for a GP to give a fudgy, confusing piece of information to patients. That has fed a great deal of patient distrust of the medical system and a great deal of confusion* (Hall evidence, 6 November 1997).

A number of submissions from HCV+ people cited difficulties experienced with general practitioners:

> *the treatment by local general practitioners is largely a hit and miss affair* (Submission 39);

and

> *My general experience with general practitioners and experiences my friends who have HCV share is that when going to the local GP you have him tell you either "I don't know anything for your HCV" or "take a couple of Panadol and lie down". The majority of general practitioners in the community really have no idea at all* (Submission 66).

The submission from an infected health care worker reported an incident that occurred while in a waiting room waiting to see her general practitioner. When the doctor about to treat her discovered her status from the admission notes:

> *He 'freaked' when he read my chart, walking over to the nurse who was in the large room with other patients... and shouted 'This lady is HCV+. What are we going to do with her? Why wasn't I told?' He went on and on until eventually the nurse said 'Look, she's still over there; she's been through here three times before when we didn't know so just get on with your job'* (Submission 81).

During the course of her evidence, another witness recounted the following series of interchanges with doctors, the first in response to her blood tests:

> *he [the doctor] said, "well, it says that you have got Hepatitis C". I said, "What is that?". He said, "Nothing to worry about. It's passed on by dirty hands. You probably got it when you were overseas". This was from a professor of haematology. I thought, "No I don't believe you". I went to my local doctor and told him. He said, "Oh that's bad . . . I don't know anything about it. It has only recently been diagnosed". I went to another doctor and he said "That's good. You've got antibodies in your blood. It means you will never get it"* (Lamb evidence, 30 March 1998).

It would appear that the result of this limited knowledge and inexperience is the inappropriate referral of patients to liver clinics and specialists at tertiary hospitals:

> *If they are detecting and diagnosing Hepatitis C they then refer cases to specialists who do specialist work that is costing a lot of health dollars inappropriately* . . . *At the moment specialist liver clinics are clogged up with inappropriately referred patients* (Hall evidence, 6 November 1997).

The Committee appreciates that the reported reluctance of general practitioners to be actively involved in the management of Hepatitis C patients may not always be a reflection of lack of desire or interest. It may reflect their limited knowledge and understanding of the virus. The Committee heard, "currently there are no consistent resources across the board for general practitioners to tap into in relation to information or education" (Hall evidence, 6 November 1997). Hall further admits "to be fair, they [general practitioners] have not been well placed to take up that role" (Hall evidence, 6 November 1997). Wodak also acknowledged this:

> *One of the ways in which we have been slow to respond is getting education materials out to general practitioners who are the first port of call for people who discover they have Hepatitis C. Many general practitioners are not at the moment well equipped to handle this problem* (Wodak evidence, 2 October 1997).

The Committee understands that, unlike complex diseases such as HIV, the management of Hepatitis C is relatively simple. The Committee heard, for example, that "Hepatitis C generally is a fairly straightforward health issue that can be dealt with by general practitioners at a clinical level" (Hall evidence, 6 November 1997). In Hall's opinion:

> *general practitioners should be the central medical care providers for Hepatitis C patients . . . Because of the long-term chronic nature of Hepatitis C and the long time in which a patient has no symptoms at all, but may have other needs, general practitioners should be the central care providers* (Hall evidence, 6 November 1997).

There is clearly a need to educate general practitioners in the management of Hepatitis C. The NHMRC recognised this need and recommended that:

> *additional efforts be made to improve the education of physicians and general practitioners in the use of interferon alpha and the appropriate responses to variations in liver functions tests in patients* (NHMRC, 1997:38).

8.3.4 CONCLUSION

The Committee considers the current inadequacies in service delivery - at all levels of the system - to be unacceptable. In response, it calls upon the government to state its commitment to providing adequate and appropriate treatment and management service to those in NSW who are HCV+ and that these service be provided at all levels of health care - from primary through to tertiary health care. The Committee further calls upon the government to state this commitment in its Hepatitis C policy statement which the Committee proposed in Recommendation 28 and identify in the Strategic Plan (proposed in Recommendation 31) the way this commitment will be realised.

RECOMMENDATION 58:

That the Minister for Health state his government's commitment to providing adequate and appropriate health care - from primary through to tertiary health care - to all those in NSW who are Hepatitis C positive.

RECOMMENDATION 59:

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly enunciates the Minister's commitment to providing adequate and appropriate health care to all those in NSW who are Hepatitis C positive. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identifies the way in which the Minister's commitment will be realised along with appropriate time frames and funding allocations.

RECOMMENDATION 60:

That the NSW Hepatitis C Strategic Plan be the basis upon which NSW Health allocates funding to treat and manage Hepatitis C.

8.4 RESPONDING TO CURRENT INADEQUACIES

The Committee could readily make specific recommendations to address any one of the inadequacies identified in the preceding discussion such as the appointment of a liver specialist or the establishment of an outpatient liver clinic in the South Western Sydney Area Health Service. However, such a measure would not overcome what appears to be a systemic problem that pervades the state's health system in terms of treating and managing Hepatitis C.

The NSW Hepatitis C Taskforce examined the issue of clinical services and clinical management and identified a number of deficiencies in the then current services which had come about due to “the lack of increased resources at several levels in the face of an expanding clinical need” (NSW Health 1995:30). The deficiencies were similar to those identified during the course of this Inquiry and included:

- delay for patients to be assessed by gastroenterologists and hepatologists;
- a lack of counselling service for patients at the nurse consultant level;
- the huge size (up to 50 patients per session) of some clinics assessing and processing patients;
- the lack of day stay beds in some institutions for liver biopsies; and
- lack of availability of interferon therapy outside the S100 guidelines (NSW Health 1995:30-31).

The Taskforce Report recommended initiatives to overcome the deficiencies in both the short term (1-2 years) and long term (two years and beyond) and at two levels of care: the hospital level and the general practitioner level.

As an overall recommendation, the Taskforce recommended some enhancement of HCV consultant services in most health areas (1995:6). It also recommended that, as a matter of urgency, a comprehensive needs assessment and services planning project be undertaken and minimum service levels, based on a health outcomes approach, be set.

As an interim measure, the Taskforce further recommended the guidelines of the Report’s text be used as the basis for developing a comprehensive HCV clinical capability in New South Wales. The recommended minimum levels of service provision were:

- one nurse consultant/educator per Health Area;
- 1.5 hepatologist (full time Hepatitis C) per 600,000 population;
- 0.5 resident medical officer (full time Hepatitis C) per 600,000 population; and
- adequate liver biopsy day stay beds and adequate ultrasound facilities (NSW Health, 1995:6-7).

The Committee understands that these recommendations were never implemented. The response of the Department to these recommendations was that:

> *consultation with the relevant Departmental Branch suggested that further data are required to justify the stated resource recommendations. Perceptions of needs for clinical services will be re-examined in the light of the evaluation of the current Hepatitis C demonstration projects and a service development exercise is being considered for commencement in 1998* (tabled document - NSW Health, 3 October 1997).

In commenting on the Department's lack of response to these recommendations, Professor McCaughan noted that they were:

> *never delivered, and were thought by the NSW Department of Health to be some sort of pie-in-the-sky overestimation of the need* (McCaughan evidence, 23 March 1998).

Given the inadequacies identified by expert witnesses and discussed above, the Committee considers the Department's response to the Taskforce recommendations to be totally inadequate. The Committee also considers it likely that, had the Department implemented these recommendations in 1995-96 when originally proposed, current inadequacies and shortcomings - or the extent and severity of these shortcomings - may have been avoided.

Having considered all possible options to overcome current inadequacies, the Committee has decided to support fully the original recommendations made by the NSW Hepatitis C Taskforce. This time, the Committee wishes to see the recommendations implemented fully and, as is suggested by the six month deadline proposed, promptly.

RECOMMENDATION 61:

That NSW Health conduct a comprehensive needs assessment and service planning exercise within six months of this Report being tabled. This exercise is to include the provision of services in all health areas and all public hospitals.

The Committee further recommends that the Department set minimum service levels based on a health outcomes approach.

RECOMMENDATION 62:

That NSW Health incorporate the implementation of the results of the needs assessment and the service planning exercise into the Strategic Plan proposed in Recommendation 61.

RECOMMENDATION 63:
That the Minister for Health allocate funding for the implementation of the results of the needs assessment and service planning exercise proposed in Recommendation 61.

The Committee is aware that needs assessment and service planning activities have and are being conducted across the state, albeit in a somewhat *ad hoc* manner. In May 1997, for example, a review of the Hepatitis C services was undertaken in the Central Sydney Area Health Service (CSAHS). The aim of the mapping exercise was broader than that proposed above and included mapping out the range of HCV surveillance, prevention, counselling and treatment services within CSAHS provided by the public, private and non government organisations. The exercise also sought to identify the needs and gaps in the services and propose strategies to meet these gaps; identify ways to improve the coordination of HCV services; and secure commitments to develop a more integrated service with defined referral and continuum of care pathways (Morrow Centre submission). In informing Members of the mapping exercise McCaughan noted that it:

> *tried to pull together people in the Central Sydney Area Health Service outside of the gastroenterology and liver programs who should be coming in contact with a lot of Hepatitis C patients . . . the mapping exercise pushed Hepatitis C in the face of all those groups who should have been making a major contribution to the handling of the illness. That started to bring Hepatitis C much more into focus amongst those groups. They have responded and are now starting to make available more significant time and resource commitments for Hepatitis C which they were not doing before* (McCaughan evidence, 23 March 1998).

The Committee is also aware that most, if not all, of the demonstration projects reviewed in Section 8.4.2 include a mapping component.

Having addressed the issue of needs assessment and service planning, the Committee then considered two questions pivotal to responding to current inadequacies: who should treat and manage Hepatitis C patients?; and where should these patients be treated and managed? Traditionally Hepatitis C has been treated and managed by specialists and clinical nurse consultants in liver clinics in tertiary level hospitals. The problems that have arisen through such an approach have been identified and discussed above. Clearly there is a need for different models and approaches to be introduced to overcome these inadequacies.

8.4.1 WHO SHOULD TREAT AND MANAGE HEPATITIS C?

Hepatitis C has primarily been treated by hepatologists and gastroenterologists with minimal involvement from general practitioners. Two projects are currently underway to encourage greater involvement of general practitioners: the national shared care program which envisages general practitioners working with specialists to treat and manage Hepatitis C; and the national Hepatitis C education program for general practitioners which seeks to educate general practitioners in a number of Hepatitis C related issues such as detection and management (though not necessarily treatment). Both programs are reviewed in the following discussion.

- **Specialists and General Practitioners Working Together: the Hepatitis C National Shared Care Project**

Dr Kaldor noted that:

> *up until now under the models of care for Hepatitis C, you can get a diagnosis of Hepatitis C from a general practitioner or you can get advanced forms of care at hospital-based sites, but there has been very little development of shared care models or indeed ways of getting a better level of Hepatitis C care in primary health settings. It has been very much the model of referral to hospital specialists and hospital specialists, if they were to try to deal with the number of people who actually have the infection, would be soon overwhelmed* (Kaldor evidence, 3 October 1997).

Shared care is a clinical management principle that refers to general practitioners and medical specialists “sharing” the care of patients. The concept is already common in a number of medical disciplines such as mental health, HIV/AIDS, pediatrics and obstetrics and is gaining increasing support as a management tool for patients with Hepatitis C. Dr Gold, Director of the Albion Street Centre told the Committee that:

> *shared care has been one of the stable underpinnings of medicine ever since there was a division between general practitioners and specialists. There has always been a concept of shared care between day-to-day management by general practitioners and intermittent management by clinical specialists* (Gold evidence, 26 February 1998).

In the past patients on interferon have attended specialist liver clinics every one to two months to have their therapy monitored. But as Farrell observed:

> *a lot of that monitoring obviously can be done in general practice. It can be done safely by general practitioners who are well educated. That would be more user friendly to the patients because they would not have to wait as long, they could go to their local general practitioner who they know . . .* (Farrell evidence, 28 November 1997).

The NHMRC (1997) saw the potential of shared care in the treatment and management of HCV+ patients and recommended its introduction in its report:

> *Care of patients may be initiated in the approved centres and carried on for the first three months by providers in other towns or in other parts of the same city. The practitioners providing follow-up care may be specialist physicians, gastroenterologists, or in some cases, general practitioners. It is evidence from experience that appropriate education can be provided to facilitate the care of many patients living distant from treatment centres* (NHMRC, 1997).

The report went so far as to propose a protocol for shared care (see Table Twenty-nine below) and management guidelines for general practitioners (see Appendix 1, NHMRC, 1997:59).

TABLE TWENTY-NINE
SHARED CARE PROTOCOL AS PROPOSED BY THE NHMRC

WEEK	REVIEW	INTERFERON PRESCRIPTION	LIVER FUNCTION TEST	FULL BLOOD COUNT	REPORTING	TSH[1] TEST
0	Liver clinic	X		X	X[2]	
2	GP		X		X[3]	
4	Liver clinic	X	X		X[2]	X
8	GP		X		X[3]	
12[4]	Liver clinic	X	X	X		X
16	GP		X		X[3]	
20	Liver clinic	X	X		X[2]	X
24	Liver clinic	X	X	X	X[2]	

[1] Thyroid Stimulating Hormone test

[2] the liver clinic is required to forward patient management data to the National Hepatitis C-Interferon Database, John Hunter Hospital, Newcastle

[3] following each GP visit the practitioner must provide relevant clinical information tot he treating liver clinic and the National Data Base

[4] if ALT abnormal at 12 weeks, subsidy for treatment will cease

Source: NHMRC, 1997:71

The Committee understands that the process of putting the concept of shared care into practice is currently underway in the form of a project known as the National Shared Care Project. The project is being coordinated by the Royal Australian College of General Practitioners, the Australian Gastroenterology Institute and Schering-Plough. The focus of the project is to develop a coordinated, shared care program between gastroenterologists and general practitioners in the treatment and management of Hepatitis C (Schering-Plough submission).

Schering-Plough advised the Committee in early October 1998 that the Shared Care protocol was ready and expected to be launched in November 1998 (Nair correspondence, 3 October 1998).

The Committee fully supports the concept of joint patient management between gastroenterologists and general practitioners. It wishes to see opportunity made available for patients to be managed jointly by a liver clinic and an accredited GP under a "shared care" protocol.

RECOMMENDATION 64:

That the Minister for Health accept the principle of shared care as a viable and practical clinical management tool for Hepatitis C and ensure NSW Health takes all possible measures for shared care of Hepatitis C patients to be introduced into the New South Wales health care system.

- **A Greater Role for General Practitioners: the National Hepatitis C Education Program for General Practitioners**

The National Hepatitis C Education Program for General Practitioners is sponsored by the Royal Australian College of General Practitioners (RACGP). It is a two year Commonwealth funded project. The project is staffed by a full time coordinator and a part time (two days a week) clerical assistant.

The Program's mission statement is:

> *to enable general practitioners to respond effectively to the challenges posed by Hepatitis C infection, to contribute in minimising the spread of the infection, caring for those already infected, reducing discrimination and educating others* (RACGP, 1998:1)

During the course of evidence, the program's coordinator, Mr Steven Hall, commented that:

> *the general goal of the project is to help GPs to feel more confident and competent in dealing with Hepatitis C, ranging from detection, diagnosis, management and prevention . . . The project involves developing a program with a range of resources and program services and working with existing projects and people working in the field from around Australia* (Hall evidence, 6 November 1997).

The goals of the Program include:

- to enable general practitioners to diagnose Hepatitis C infection, provide counselling, advice and support on management, treatment and care for people affected by Hepatitis C;

- to provide a trained general practitioners workforce for the care and management of people with Hepatitis C infection; and
- to promote prevention and public health measures to minimise the impact of Hepatitis C infection both at an individual level and at a community level (RACGP, 1998:1).

Outcomes of the Program include:

- ensuring that general practitioners recognise Hepatitis C are able to take measures to minimise the spread of the infection, manage those who are infected and can assess up-to-date information on its management;
- identification of general practitioners education and support needs in relation to Hepatitis C;
- identification of core knowledge, skills and attitudes for general practitioners in the detection and management of Hepatitis C in a communicable diseases framework;
- provision and reinforcement of core information;
- development of supporting educational material which takes into account new information and technology;
- establishment of sustainable educational initiatives, where applicable, within existing general practitioner structures; and
- establishment of a national network to support, sustain and assist with on-going education in relation to Hepatitis C (RACGP, 1998:3).

The program is made up of a series of components. The first component looks at roles, infrastructure and coordination. It aims to develop sustainable and coordinated infrastructure and policy that defines and supports the primary role of general practitioners in the long-term shared care of HCV positive patients, in collaboration with other health care services. The objectives of this component of the program include:

1. RACGP and Australian Gastroenterology Institute (AGI) to provide collaborative leadership to support Division-based initiative and specialist services;
2. to define, endorse and support the primary role of general practitioners in the long-term, shared care of HCV positive patients;

3. to link all general practitioners with liver clinics, specialists and other relevant health care services;

4. to link and support all general practitioners with a special interest in HCV with Division-based clusters (Tabled document, 6 November 1997).

The program's second component is concerned with programs/services and resources. This facet of the program aims

> *to ensure all general practitioners are able to effectively detect, diagnose, manage and prevent HCV infection, in collaboration with other health care workers* (Tabled document, 6 November 1997).

Its objectives include:

1. all general practitioners to understand their primary role in health promotion, as well as the clinical management of HCV infection;

2. all general practitioners to have ongoing access to consistent, up-to-date, relevant and sustainable core information and education programs/services and resources;

3. division-based clusters of general practitioners, with a special interest in HCV, to access further relevant education, information and support (Tabled document, 6 November 1997).

The third component involves vocational training and undergraduate education. This component seeks to:

> *prepare registrars to deal confidently with the detection/diagnosis, management and prevention of HCV infection and to expose undergraduate medical students to generic Hepatitis C competencies* (Tabled document, 6 November 1997).

The objective of this component include:

1. registrars to develop core HCV competencies (specific and generic) within the Vocational Training Program;

2. undergraduate medical students to be exposed to generic HCV competencies, integrated within relevant parts of the teaching program;

3. undergraduate education and vocational training curriculum to be consistent and complementary (Tabled document, 6 November 1997).

The Program has been instrumental in devising a series of Hepatitis C management guidelines in partnership with the Gastroenterology Society of Australia (GESA) - Hepatology Section. The guidelines are currently in draft form and endorsement by both the RACGP and GESA of the complete management guide is being sought before its planned release in October 1998 (Hall, 1998:799).

The series of charts that make up the guidelines are a step-by-step guide to managing and caring for Hepatitis C patients who are:

- HCV sero-status unknown;
- antibody testing equivocal or positive;
- have chronic Hepatitis C;
- Hepatitis C and the antenatal patient;
- post interferon management (Hall, 1998:799-803).

The Committee fully supports the GP education program and agrees with ANCARD which suggested that:

> *the GP education program in Hepatitis C care and management being developed by the Royal Australian College of General Practitioners should be implemented and appropriately resourced on a national basis* (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).

The program is working to a two year time frame and, at this stage, it is too early to comment on its effectiveness. Tenders to evaluate the project have been called for and consultants appointed. They anticipate presenting a draft final report to the College's Reference Group in November 1998 (Mackdacy correspondence, 23 July 1998).

The Committee wishes to congratulate the RACGP for its initiative in introducing and sponsoring the program and its commitment to general practitioner education on this vital issue.

RECOMMENDATION 65:

That the Minister for Health ensure all measures are taken for the full and unhindered implementation of the National Hepatitis C Education Program for General Practitioners in New South Wales.

- **Training Those who Treat and Manage Hepatitis C**

Pivotal to the successful treating and managing of those with Hepatitis C is adequate training for the health care professionals. This issues has been pursued by the Hepatitis C Council, which in July 1998 conducted a Hepatitis C Health Care Worker Education Planning Workshop funded by NSW Health (Hepatitis C Council, 1998b). The key findings of the workshop were that:

- the current medical and illness focus does not provide the range of information and services needed for people living with Hepatitis C, of for health care workers;
- there is considerable ignorance of all aspects of Hepatitis C, which is contributing to discrimination, fear based behaviour and impacts on the quality of care;
- the lack of a central coordination point results in lack of knowledge of existing resources and initiatives and duplication of effort;
- there needs to be a broad base of concern and action, involving all health care workers and associated administrators and managers;
- there will be increasing demand for education services; however resources will not increase significantly;
- there is a need to target education processes, based on the role and experience of health care workers;
- existing education and learning processes are not always appropriate and relevant, and are not always accessible to all health care workers, particularly in rural areas;
- education and learning related to Hepatitis C needs to be integrated with other health education processes, and draw on the experience and diverse needs of people living with Hepatitis C;
- education and learning processes developed for health care workers are often also appropriate for increasing awareness and understanding in the general community; and
- any strategy needs to draw on the skills, expertise, resources, influence of other health and education organisations and recognise the cultural diversity of society (Hepatitis C Council of NSW, 1998b:1-2).

The Workshop identified the need for a Hepatitis C education strategy for health care workers and proposed a range of strategies including:

- increased coordination through a clearinghouse;
- identification of health care workers' role and their learning needs;
- establishment of partnerships and alliances;
- greater involvement of people living with Hepatitis C; and
- the development of an integrated education and learning strategy (Hepatitis C Council of NSW, 1998b:3-6).

The Committee fully supports the development and introduction of a Hepatitis C education strategy for health care workers. The Committee anticipates that the focus of the strategy would be to ensure that appropriate material, resources and training are available, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the education strategy be integrated with other education and training activities and initiatives.

RECOMMENDATION 66:

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) address the issue of a Hepatitis C Education Strategy for Health Care Workers. The Education Strategy is to ensure that appropriate material, resources and training are available to health care workers throughout the state, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the Education Strategy be integrated with other education and training activities and initiatives. The Committee further recommends that the Minister for Health ensure the Hepatitis C Education Strategy for Health Care Workers is adequately funded.

8.4.2 WHERE SHOULD HEPATITIS C BE TREATED AND MANAGED?

Given current waiting lists and crowded specialists liver clinics, there is a need for alternative venues to be found for treating and managing Hepatitis C. Several options were raised with Members during the course of the Inquiry. Sladden, for example, outlined to Members his "best practice model":

> *if we look at a clinic that might be the best practice, the model for it would include counsellors, perhaps a part-time gastroenterologist and general practitioners who could attend the clinic, and a clinical nurse consultant who could assist with procedures conducted by the clinic. It could provide the routine range of services for people with Hepatitis C, such as liver function tests and biopsies and interferon prescribing, all of the current treatment practices . . . Furthermore, such a clinic could be*

> *combined with a support group for other forms of support for people with Hepatitis C* (Sladden evidence, 30 March 1998).

Sladden envisaged his model being incorporated into a “shopfront” or clinic that provided health services enabling those wishing to access the service as much confidentiality as possible (Sladden evidence, 30 March 1998).

The Committee made site visits to observe first hand two different models of service delivery: the Kirketon Road Clinic (Kings Cross) and the Albion Street Centre (Darlinghurst). Both of these contain elements which the Committee considered important in appropriate service delivery. The Albion Street Centre is, for example, a centre for clinical management as well as a service directed at support for and education of health care workers including the Centre’s national information reference centre for Hepatitis C, the NSW infection control resource centre and the NSW needle-stick injury hotline (Gold evidence, 26 February 1998).

One of the Committee’s more mature witnesses was very specific in identifying where she did not want to go for treatment and management:

> *quite often community health centres [in rural areas] are run with skeleton staff and the services tend to get bunged in all together. For instance, on the Central Coast one went to the sexual health clinic to get information and help on Hepatitis C, and I objected to going to the sexual health clinic. It seemed inappropriate, when I was not sexually active, to go to the sexual health clinic. It is rather ironic* (Evidence, 30 March 1998).

The Committee is aware that, in addition to these examples of service delivery presented to, or observed by Members, NSW Health is currently sponsoring four demonstration projects and federal and state funding has been made available to a Hepatitis C coordinated care trial known as HepCare. Each of these projects is reviewed in the following discussion.

- **The NSW Health Demonstration Projects**

NSW Health is currently financing four 12 month demonstration projects in Hepatitis C prevention, treatment and care across seven of its Health Areas. According to the Department, these projects aim

> *to improve HCV case management by developing a system of integrated and sustained arrangements that offer equitable access; and to establish closer links between prevention, surveillance, treatment and care services to facilitate the control of HCV* (NSW Health supplementary submission).

McCaughan put it a slightly different way:

> *the aim of [the projects] is to try to develop much stronger community links with various groups that have involvement with Hepatitis C, to take a little bit of the pressure off our services* (McCaughan evidence, 23 March 1998).

The specifications of the projects require HCV services to:

- be integrated;
- be multidisciplinary;
- be accessible and acceptable to the majority of people with HCV;
- provide a high standard of care including education, information and counselling;
- ensure appropriate assessment and follow up of people with HCV;
- provide access to specialist hepatology and pathology/laboratory services;
- include policy research;
- improve HCV surveillance; and
- reduce duplication of clinical services (NSW Health supplementary submission).

The four demonstration projects are being carried out in the following Health Areas:

1. Northern Rivers/Mid North Coast/New England: the aim of this project is to improve access to treatment and support for people with HCV in rural areas and to improve the coordination of their care. The project commenced in October 1997;

2. Central/South Eastern Sydney: this project aims to set up specialist mobile HCV clinics outside traditional settings to improve access to, and coordination of care for, groups such as injecting drug users and other marginalised groups who often do not access traditional clinical and support services. The project will also upskill general practitioners in the area. The project commenced in November 1997;

3. Western Sydney: this project will develop a model of care for HCV positive methadone clients as well as develop a counselling/psychosocial support model for HCV in conjunction with the Liver Clinic and the Department of Psychiatry at Westmead Hospital. The project commenced in December 1997; and

4. South Western Sydney: this project aims to address the specific issues of access, information, treatment and care for people from non English speaking backgrounds. The project commenced in February 1998 (NSW Health supplementary submission).

The objectives for each project are in Appendix Five.

The projects will map current services and resources in each of the Health Areas and develop models of service provision for people with HCV, including shared care models. Each will include a substantial education component for general practitioners and other health care workers including the development of management protocols for HCV (NSW Health supplementary submission).

Support for the demonstration projects was given by a number of expert witnesses appearing before the Committee. McCaughan, for example, said that the projects are to be “applauded” (Evidence, 23 March 1998).

However, a number of concerns were raised relating to the delay in introducing the projects, the limited funding allocated to each and the short time frame.

Farrell was critical of both the department’s delay and the limited funding made available:

> *NSW Health has instituted Hepatitis C projects (total cost $600,000) to try and devise appropriate shared care programs and to promulgate attempts to prevent the disease. To have reached only this stage by 1997 when we have known about the importance of the disease in NSW since 1989 is simply a disgrace. There is an overdue need for significant recurrent funding, of the order of $3-5 million per annum to introduce appropriate policies of efficient, shared care, diagnostic and management services* (Farrell submission).

Pritchard-Jones also commented on inadequate funding for the Central Sydney/South Eastern Sydney Area Health Service demonstration project she is involved in: “the funding is $150,000 which is not adequate for what we have to do” (Evidence, 2 October 1997). Professor McCaughan also noted that the projects are “grossly underfunded” (McCaughan evidence, 23 March 1998).

McCaughan also commented on the one year time frame of the demonstration projects:

> *just as we get the [project] off the ground, maybe get them started and have some sort of idea about how effective they are and whether they can take pressure off bottlenecks in the system, we are not sure whether they will continue to be funded* (McCaughan evidence, 23 March 1998).

Loveday of the Hepatitis C Council commented that the four demonstration projects across seven health areas are “just scratching at the surface of need” (Evidence, 30 March 1998).

- **The Hepatitis C Coordinated Care Trial (HepCare)**

In 1996/97 the Commonwealth Department of Health and Family Service sought submissions from state and territory governments to trial a different way of delivering health care. The aim was to test a model of coordinated care that was able to maintain health outcomes and decrease health care costs. NSW Health invited the Northern Sydney Area Health Service to prepare a proposal for a hepatitis C trial. The Hepatitis C Coordinated Care Trial, known as HepCare, was one of 12 trials that received federal funding to commence stage one of the trial process - the development stage. Through a process of negotiation with staff of NSW Health, the Hunter Area Health Service and the Northern Sydney Area Health Services it was decided that the Northern Sydney Area Health Service should be the trial intervention area and the Hunter Area Health Services the trial control area.

The aim of the HepCare Management Trial is to enhance the health outcomes and well being of those with HCV. The primary objective is to develop, implement and test models of case management for persons with hepatitis C that:

- are responsive to participants’ assessed needs;
- are organised through individual care plans based on clinical guidelines;
- are not detrimental to equity, access to care and privacy issues;
- result in improved health and well being of participants; and
- result in identifying the total health care expenditure of persons with Hepatitis C against this model (NSW Health, 1997a:5).

HepCare will test the models of case management with persons with Hepatitis C to examine the extent to which they:

- contribute to improved delivery of services which are individually and collectively more responsive to participants’ assessed needs;
- are more efficient in delivering services; and
- result in improved health outcomes and well being of the participants (NSW Health, 1997a:5).

The trial is testing two basic models of case management. Both have a range of core services including case management; provision of services based on assessment through existing service providers and reduction in the duplication of assessments and service provision. The models will differ in terms of the nominated case manager. In one model the designated case manager is a general practitioner. In this model the number of participants per case manager will be in the order of 1:5 to 1:10. In the other model the case manager is a non-general practitioner responsible for ensuring all the defined functions of case management are carried out in partnership with the general practitioner. In this model the number of clients will be approximately 1:70 (NSW Health, 1997a:6).

The trial is unique in that there is no single mechanism that currently supports the improvement of health care for persons with Hepatitis C. The trial will coordinate the care of participants by the use of individual case managers. A person with Hepatitis C, in the absence of case management, may visit multiple health care providers and receive conflicting management. One very significant difference for persons in this trial is the capacity to work with a case manager to plan all their health care needs. This mechanism has not previously been trialed and is not accessible within any other framework than that offered by this trial (NSW Health, 1997a:8).

Mr Graham Stone, HepCare Manager told Committee Members that:

> *we are . . . trying to maximise access to health care and welfare services for people with Hepatitis C. We are looking at whether, as a result of developing a single point of accountability through the processes of care planning, that a person's health care outcome may alter. Essentially we are looking at whether we can, in layman's terms, rejig the system in a slightly better way . . there are a number of aims of the project but clearly it is to see whether the way in which we structure this trial will make any difference to the way existing health care has been provided* (Stone evidence, 27 February 1998).

The project is receiving just over $1million in funding from both NSW Health ($250,000) and the Commonwealth ($830,000 including the evaluation costs) (Stone evidence, 27 February 1998). The Commonwealth also contributed $600,000 from February 1997 to October 1997 to instigate the project. The project has, not surprisingly, been labelled "Australia's best funded initiative to improve care and support" (Loveday evidence, 30 March 1998).

As of late February 1998, when the HepCare Manager gave evidence, just under 500 participants had been recruited. Stone envisaged the trial cohort of approximately 800. Ages range from 13 years through to people in their 60s and 70s with the average age from about 27 through to 48 years. The recruitment strategies encourage people from diverse cultural backgrounds and range of areas to be involved (Stone evidence, 27 February 1998).

It is anticipated that the trial will be completed in December 1999 with the evaluation completed by 1 March 2000.

8.4.3 CONCLUSION

The Committee considers it vital that best practice models for service delivery be found to ensure existing health care is more responsive to the clinical needs of those with Hepatitis C than it has been in the past. These models must take into account the two questions posed at the beginning of this section: who should treat and manage Hepatitis C and where that treatment and management should occur. The models also have to provide flexibility to meet the diverse needs and localities of those with Hepatitis C. It is likely, for example, that an appropriate model for service delivery for a retired health care worker living in the far north coast would differ from that appropriate for a young injecting drug user living in the inner city or a recent migrant with limited English skills from south western Sydney.

In devising best practice models for service delivery, the Committee considers it important that NSW Health utilise the results of evaluations shortly to be conducted on the various projects and trials currently in place such as the RACGP's National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects and the HepCare trial. In addition, the Committee expects that the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 will also provide substantial material that can be used in devising best practice models for service delivery.

RECOMMENDATION 67:

That NSW Health develop a model of best practice for the delivery of services to those with Hepatitis C in New South Wales. The Committee stipulates that the best practice model be flexible to provide delivery services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C. The Committee further recommends that NSW Health take into account the evaluations of the RACGP's National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects, the HepCare trial and the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 in developing best practice models for the delivery of services to those with Hepatitis C.

RECOMMENDATION 68:

That the strategies to be implemented in establishing the model of best practice for the delivery of services to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 69:

That the Minister for Health ensure adequate funding is available for the implementation of the model of best practice for the delivery of services to those with Hepatitis C in NSW.

8.5 TREATING HEPATITIS C WITH COMPLEMENTARY THERAPIES

As was discussed in Section 7.2 many people use complementary therapies as an alternative to conventional medicine or to treat specific aspects or symptoms of their illness. Many of those with Hepatitis C report considerable success yet the medical profession remains wary of the benefits. With the exception of the Chinese herb trials conducted at John Hunter Hospital, little scientific testing has been undertaken to determine empirically the efficacy of these treatments. It was proposed to the Committee by the Hepatitis C Council that there is a need for trials of specific complementary therapies. Given the limited treatment options available to those seeking to relieve either the symptoms of Hepatitis C or the side effects of interferon, the Committee supports this proposal of the Council's.

RECOMMENDATION 70:

That the Minister for Health urge his federal counterpart to encourage the NHMRC to support and fund research trials of complementary therapies designed to relieve the symptoms of Hepatitis C.

8.6 DIFFICULTIES ENCOUNTERED IN TREATING AND MANAGING HEPATITIS C POSITIVE INMATES IN THE STATE'S CORRECTIONAL SYSTEM

From his extensive experience in delivering specialist health care to Hepatitis C positive inmates, Lloyd identified two critical issues that must be considered:

> *the Hepatitis C infected individuals in the prison and the adequacy of their care, and the transmission within prisons. I believe those issues have great grounds for concern* (Lloyd evidence, 30 March 1998).

Having considered the evidence it received, the Committee concurs with Lloyd that the issues are of "great" concern. The issue of preventing transmission within prisons is thoroughly addressed in Section 10.2. The following discussion examines Lloyd's other concern: the adequacy of treating and managing those infected with Hepatitis C in the correctional system. The following discussion identifies a number of problems and shortcomings that were raised during the course of the Inquiry.

In forwarding the following recommendations for treating and managing Hepatitis C positive inmates, the Committee fully appreciates that, given the inherent nature of prisons, there will always be difficulties in the provision of health care within the corrections system. The Committee heard, for example that:

> *there are added constraints that do not exist outside in the general community. There is no intrinsic antagonism to providing these things; it is just that it is such a vast problem . . . Everything is a challenge in the prison. Health care delivery is not the priority. In general, health care delivery struggles to get maintained in the custodial priority* (Lloyd evidence, 30 March 1998);

and

> *there is a lack of control over activities of daily living, meal times and sleeping times . . . There is little control over the diet, exercise patterns . . . limited access to inmates is one problem. Within each gaol there are structured days on which inmates have to be at certain points at certain times, and health is slotted into that structured day. There are many competing priorities* (Christensen evidence, 23 March 1998).

While there are problems, the Committee is aware that, for many inmates, incarceration provides an opportunity for them to be tested for Hepatitis C and have access to specialist services:

> *the clients will tell you that they have never had such a good service . . . but like everything, once you identify a need and meet it there is then an expectation to expand on it. That is where we are at now* (Harper evidence, 23 March 1998).

8.6.1 TREATING AND MANAGING THE DISEASE

When asked to comment on the adequacy of treatment and management services, Christensen, who has considerable experience in working with Corrections Health Service told the Committee that:

> *management practices are not adequate at this stage to meet the needs of Hepatitis C given the prevalence of Hepatitis C positive inmates in the system* (Christensen evidence, 23 March 1998).

As she told the Committee:

> *The service is in its evolutionary phase although we are in 1998; it is slowly developing* (Christensen evidence, 23 March 1998).

Four specific issues relating to treatment and management were identified by witnesses.

- **Limited Numbers of Health Care Professionals**

The Committee was advised that five designated nurses and two visiting clinical specialists provide the health care to all Hepatitis C positive inmates within the state's correctional system. This limited number of health care workers has a number of implications including:

- limited number of specialist Hepatitis C clinics;
- limited locations of clinical services; and
- limited choice for inmates.

Implication One: Limited Number of Specialist Hepatitis C Clinics

The limited number of specialists working with Hepatitis C positive inmates means that there are limited numbers of Hepatitis C clinics. As has been discussed, specialist Hepatitis C clinics are held twice a month at the Long Bay complex. The Committee does not see the limited provision of clinical services as a reflection of the commitment of the visiting specialists, rather a comment on the low priority assigned to Hepatitis C and related health care within the corrections system.

In commenting on the service he provides, Professor Lloyd informed the Committee:

> *We make no attempt to seek referrals, substantially, of the vast number of inmates. Predominantly we service a very select subgroup which happens to be located on the Long Bay site. But we really do not provide a statewide service to prisoners who have Hepatitis C . . . There is a huge yawning gap between the small amount of clinical services I provide and the identification of infected individuals on entry* (Lloyd evidence, 30 March 1998).

Implication Two: Limited Location of Clinical Services

The specialist Hepatitis C clinics are based solely at Long Bay. Inmates in correctional centres other than Long Bay are required to travel to Sydney to obtain specialist care. The Committee heard that these prisoners, particularly those in rural correctional centres, are "disadvantaged" because they do not have ready access to the kinds of services available to those prisoners in metropolitan areas (Cregan evidence, 23 March 1998).

Witnesses identified a number of problems encountered by inmates seeking to access the specialist clinics in Sydney. Harper identified a range of problems including:

> *trucks breaking down and causing delays. If a stop-work meeting or a search is taking place, if someone has hung himself or slashed out, or if there has been a bashing, all movement ceases at Long Bay. You may get the 10 or 12 inmates to Long Bay from various country gaols. They are housed in that particular gaol but then everything at that gaol stops* (Harper evidence, 23 March 1998).

Christensen identified similar difficulties:

> *There are transport difficulties because the services are concentrated in the metropolitan area. For example, if an inmate from Grafton wants to avail of hepatitis services, he has to get on transport from Grafton down to Long Bay. There may be one truck a week that comes to Long Bay. He comes down and has to wait a week in the Long Bay gaol . . . He may not get to the clinic; there may be security problems the day of his appointment, a lock-down, a shortage of officers or security complications that mean the inmate does not get to the clinic. He may have to wait until the next clinic or, if he does get seen, he may have to wait two to three weeks and go through three gaols to get back to his gaol classification. That causes problems* (Christensen evidence, 23 March 1998).

As a result of such difficulties, some “inmates find it too arduous and do not want to come down to the services” (Christensen evidence, 23 March 1998). The Hepatitis C health care needs of these inmates are therefore simply not met.

Implication Three: Limited Choice for Inmates

A third implication arising from the limited numbers of health care workers is that the choice of inmates to health care workers is limited. As the Committee heard:

> *in gaol there is often only one doctor who visits, who may not visit every day and it is difficult to see anybody else. That doctor services the gaol and the inmate therefore sees that doctor, so there is a lack of choice in prison* (Christensen evidence, 23 March 1998).

- **Inmates’ Diet**

Many with Hepatitis C find a low fat diet to be easier on their liver than a heavier, high fat diet. While in prison, however, inmates have little choice in their diet and, as Lloyd noted, “if you wanted to give all Hepatitis C positive inmates a special diet, half the prison population would be on a special diet” (Lloyd evidence, 30 March 1998).

The Committee heard of attempts by nursing staff to obtain low fat diets for their clients:

> *we always put in a request for a special diet but that did not always translate into them receiving a special diet. That request would go down to the kitchen, the inmates prepared the meals and we would have ongoing battles. I have been to a kitchen about 40 times to try to ensure that one or two inmates got a low fat diet. It is an ongoing problem and it has to be done on a one-to-one basis. There are policies in place and there are all types of procedures, but it often breaks down because of the number of people involved in the chain of command* (Christensen evidence, 23 March 1998).

The Department of Corrective Services representative informed the Committee that,

> *with so many Hepatitis C positive inmates we are looking at such options as providing a liver-friendly diet* (Vumbaca evidence, 23 March 1998).

- **Lifestyle Unit**

Several witnesses commented on the role of the Lifestyle Unit in assisting inmates to manage their Hepatitis C. As has been discussed (see Section 7.3.2) the number of places available is severely limited yet there are no plans to expand the Unit:

> *at this stage there are no plans to expand the lifestyle unit from eight beds. The issue always comes down to money . . . The budget does not exist to expand that program* (Vumbaca evidence, 23 March 1998).

In addition, provision is currently not available for women inmates to participate in the program. The Committee heard however that:

> *The Department of Corrective Services has said that there should be a duplicate service or a service created for women that is equitable to that . . . It is quite difficult with communal living to have a mixture of male and female* (Christensen evidence, 23 March 1998).

The Committee heard of strategies either in place or proposed to enable female inmates to access the Lifestyle Unit program:

> *the people who run the Lifestyle Unit . . . spend a day a week in the therapeutic unit at Mulawa running the program there. They focus mainly on Hepatitis C issues but they also run nutrition classes as well as healthy lifestyles and feel-good-about-yourself classes . . . Also there is an opportunity being investigated now by the department . . . The Lifestyle Unit now has a separate entrance and has been dedicated as a separate area. The opportunity now exists for the department to expand services*

> *to women by bringing an all-female residence group into the centre, and that may or may not go through* (Vumbaca evidence, 23 March 1998).

The Committee is aware of the results of the 1997 evaluation study of the Lifestyle Unit and the recommendation that report made to discontinue the integration of inmates with Hepatitis C into the Lifestyle Unit program (Recommendation 25) (Department of Corrective Services, 1997:20). The report recommended that "serious consideration" be given to the establishment of a separate unit and program, with the same philosophical ideology as the Lifestyle Unit, to cater to the needs of those inmates with Hepatitis C (Department of Corrective Services, 1997:20). The evaluation's results and recommendations were not raised by the Department during the course of the Inquiry either in their submission or during the course of evidence.

The Committee considers there to be potential in the program offered at the Lifestyle Unit and wishes to see the program expanded to reflect, more accurately, the prevalence of Hepatitis C within the corrections system. It also considers it imperative that, given the prevalence of Hepatitis C amongst women prisoners which is substantially higher than among male inmates (see Section 3.2.2), the program be expanded to enable female inmates to participate.

RECOMMENDATION 71:

That the Minister for Corrective Services ensure the program offered at the Lifestyle Unit be expanded (in both scope and size) to respond more adequately to the prevalence of Hepatitis C within the corrections system. The Committee further recommends that the program be extended to include female inmates who are Hepatitis C positive.

- **Post-release Care**

The Committee heard that, in relation to post-release care:

> *inmates are given copies of their serology and follow-up liver function tests to take with them on release. Discharge planning is done for specialist services such as the specialist HIV and hepatitis clinics but in the main it is not done. That needs to be addressed for the continuum of care both in and out of gaol* (Christensen evidence, 23 March 1998).

The Department's reason for not providing post-release care and discharge planning was that "at the moment the volume is too great" (Vumbaca evidence, 23 March 1998). The Committee considers such a response to be totally inadequate.

Vumbaca considered the pilot HepCare program (reviewed in Section 8.4.2) to be a possible option for post-release care but he did admit that:

> *it is only for the Hunter and the northern Sydney areas. A large number of people will miss out because they will not fall within those residential areas when they leave* (Vumbaca evidence, 23 March 1998).

8.6.2 MANAGING THE HEPATITIS C TREATMENT REGIME

With regard to managing the Hepatitis C treatment regime within the corrections system, the Committee heard that, inmates' health status and management requires ongoing monitoring and that this "proves to be a continuing difficulty within the prison system" (Christensen evidence, 23 March 1998). Five specific issues were raised by those working with inmates.

- **Limited Numbers of Inmates on Interferon Therapy**

Data tabled by Ms Parsons, a Clinical Nurse Specialist with the Corrections Health Service, show that, as of mid March 1998, a total of 22 inmates had commenced interferon with five on interferon at that time (Parsons evidence, tabled material). Lloyd thought the total number who had completed interferon to be 25 and felt that there were more than five currently on therapy (Lloyd evidence, 30 March 1998). He admitted the numbers to be a "tiny microcosm" of the whole Hepatitis C infected prison population (Lloyd evidence, 30 March 1998).

When asked to comment on the limited number of inmates who have, or who are currently receiving interferon Lloyd said that it is:

> *Partly a reflection of our limited service capacity, partly a reflection of the fact that we have adopted a very conservative stance in the application of the S100 assessment criteria* (Lloyd evidence, 30 March 1998).

In noting the increasing number of inmates diagnosed with Hepatitis C, the submission from Department of Corrective Services noted that:

> *there is also a corresponding increase in demand for the limited treatment options available. The Department of Corrective Services therefore fully supports the expansion of the criteria for access to treatments, such as interferon, for inmates* (Department of Corrective Services submission).

- **Difficulties in Administering Interferon within the Prisons System**

In the general community many find that administering their interferon in the evening minimises side effects. For inmates, however the Committee heard that:

> *in prison that is difficult because inmates have to have their medication at prescribed times because of the structured day and clinical operations.*

> *That causes a lot of problems initially in trying to get patients their interferon at a time suitable for the gaol and for the inmate* (Christensen evidence, 23 March 1998).

Administering interferon is complicated in some instances such as:

> *If a person is on protection it is difficult to get him to the clinic. If there has been a bashing or a riot it is difficult to get the men to the clinic on time. Inmates may have been given their doses in the morning* (Parsons evidence, 23 March 1998).

- **Training Health Care Workers to Administer Interferon Therapy**

Evidence presented to the Committee suggests the need for nurses working with Corrections Health Service to be trained to understand the interferon regime and possible side effects. The Committee heard for example that:

> *nurses in the clinics are very entrenched. They run the clinics almost in a military style as well, so that apart from the names of new treatments like interferon or a combination of anti-retroviral treatments that come in being quite foreign to them, they have a very set mind fix that it will be given at a particular time and no other time. We have had to be quite up-front with them and we have had a few battles ourselves in letting them know that they do not dictate the times that are the most suitable for the inmate, that this is self-administering and they are self-monitoring. It has been a new learning curve for them and we still have a long way to go. Certainly the nurses need a lot of education to get out of that entrenched way of thinking* (Harper evidence, 23 March 1998).

Christensen suggested there needs to be "upskilling" so medical and nursing staff feel more "comfortable and competent" managing Hepatitis C in the prison environment (Christensen evidence, 23 March 1998). She also noted that:

> *in regard to those inmates who come through the Hepatitis clinics and are prescribed interferon, a whole range of activities are put in place to try to educate the nurses in the local clinic about interferon, its effects and side effects, and patient management issues. It is all done on a one-to-one basis and it is very time consuming* (Christensen evidence, 23 March 1998).

- **Payment of Interferon**

Under present arrangements between the Commonwealth and the states, renumeration of medical expenses is subject on the patient holding a Medicare card. Upon incarceration, a person loses access to their Medicare number. As a result when expensive drugs, especially S100 drugs are prescribed, instead of being a charge against the Commonwealth and Medicare, they potentially become a charge against the NSW Health Department through the Corrections Health Service. Such was the situation with regard to interferon at the outset of this Inquiry. As the Committee heard,

> *that body [Department of Corrective Services] is fairly cash strapped and as a result does not go out of its way to ensure that access to interferon and other treatments, for example, other hepatitis vaccinations, are made readily available* (Puplick evidence, 7 November 1997);

and

> *the departments [of Corrective Services] feel they are unable to meet such commitments out of their present budgets, with the result that prisoners in need of these medications may not receive them* (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).

In a letter to the Commonwealth Human Rights Commissioner the Chairman of ANCARD described this situation which limits access to prescribed treatment as a denial of “basic human rights”:

> *I believe that prisoners have specific health care needs which are not currently being recognised or addressed. Such lack of access surely contravenes a prisoner’s human rights, that of access to prescribed treatment for a chronic illness for which the accepted treatment or therapy is considered standard for all other eligible Australians* (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).

In addressing this issue when appearing before the Committee, Puplick suggested that:

> *the states should be more aggressive in demanding that the Commonwealth stop transferring this financial burden on to them* (Puplick evidence, 7 November 1997).

In late 1997 this situation changed. Under a Commonwealth initiative, drugs on the Highly Specialised Drug Program, including interferon, are now funded by the federal government. The only proviso placed on state and territory governments was that essential hospital based specialist care required to administer and monitor the medication be provided.

- **Length of Stay in Prison**

The Committee heard that, for some inmates, the length of their stay in prison can determine whether they commence interferon therapy:

> *The length of stay can also be an issue affecting the commencement of interferon. If inmates are not going to be in gaol for the period of time that they are on interferon, often they will not be started but will be referred to an outside agency* (Christensen evidence, 23 March 1998).

- **Limiting Progress to Minimum Security Prisons**

The Committee also heard that those patients on interferon are kept in metropolitan gaols as “often it is difficult to get the treatment to them in remote sites”. The result of this is that sometimes:

> *being kept in the metropolitan area can sometimes stop progression to gaols of minimum classification* (Christensen evidence, 23 March 1998).

8.6.3 MANAGING THE SIDE EFFECTS OF HEPATITIS C AND INTERFERON

As has been discussed in Section 7.2.1 many people on interferon experience physical and emotional side effects which can range from mild to chronically debilitating. Inmates are no exception and similarly experience a range of side effects. However, there appears to be little accommodation of these within the corrections system. With particular reference to the common side effect of depression, Cregan noted that:

> *The stress of the environment can increase whatever depression is brought on either by Hepatitis C or the effects of interferon treatment, and those effects can be quite severe. Suicide is a problem in the prison system, as we can see a potential for the effects of the prison environment, coupled with Hepatitis C infection or treatment, to increase the risk of a suicide whilst a person is in prison. Ideally, we would like to see that problem addressed by an increased availability of psychological services, ranging all the way from clinical nursing, through to psychologists, drug and alcohol professionals and psychiatrists* (Cregan evidence, 23 March 1998).

Cregan also noted the effects of lethargy:

> *The primary effect of Hepatitis infection is . . lethargy. Given that the educational level amongst prison staff and administrators about Hepatitis C and its effects is really at a pretty low level at this stage, we see a potential for anyone who is suffering the effects of that Hepatitis C-*

> *induced lethargy to be put in a difficult position in regard to his or her requirements to work, or to attend education, or asking to be included on a clinic list. Obviously, lethargy is traditionally associated with malingering, and malingering is a perennial sort of thing that comes up in the correctional environment* (Cregan evidence, 23 March 1998).

- **Requests for Light Duties and other Dispensations**

Those providing health care to HCV+ inmates referred to attempts to "negotiate arrangements" with prison officers to get "a little bit of a soft deal" for those experiencing Hepatitis C and/or interferon related side effects (Lloyd evidence, 30 March 1998):

> *We try to get people put on light duties if they are having problems as a result of interferon. We try to modify their diet and to get them special dispensation in relation to exercise and resting in the cell* (Christensen evidence, 23 March 1998).

However, despite these attempts, the Committee heard that:

> *If inmates are having health-related problems from the interferon, it is very difficult for them to get what is called a "sick in cell" or rest for the day. They have to go through lengthy procedures so that they are not out in the common yard all day or at work all day* (Christensen evidence, 23 March 1998).

In addressing this issue Lloyd, very bluntly, suggested that:

> *They have to work fairly hard to get things to operate even slightly in their favour. If there is an opportunity to have a lighter workload or a better diet, whatever it may be, and they perceive that Hepatitis C may make that happen, they would not hesitate to manipulate that setting. That is being a bit callous, but I know that happens* (Lloyd evidence, 30 March 1998).

- **Training Prison Officers to be Aware of Hepatitis C/Interferon Side Effects**

It was suggested to the Committee that prison officers are often not aware that certain behaviours or moods of inmates may be due to either Hepatitis C or interferon. As the Committee heard that:

> *officers need to be educated about interferon because people on interferon can experience mood change and anxiety. They can become irritable, which is drug related. Therefore, inmates need access to their cells and the clinic needs to be notified. The inmates are feeling quite*

> *horrible and do not want to be told; they simply want to lie down and rest. The officers have to realise that these guys can become moody although they were not previously . . . . the officers need education about who is on interferon and how we manage it* (Parsons evidence, 23 March 1998).

8.6.4 PROPOSED MODEL OF SERVICE DELIVERY

During the course of his evidence, Professor Lloyd tabled a document he and colleague, Dr Haber, had prepared at the request of Dr Phillip Brown of Corrections Health Service. The paper identifies the “urgent” need to establish a “permanent and integrated clinical service” to address current Hepatitis C needs within the corrections system (tabled document) and identify the components of such a model to be introduced on a state-wide basis.

Lloyd described the principles of the model to Members:

> *the principles of the model are the same sort of things that have been called ‘shared care’ in the general community. It is a hierarchical model using health-care providers of all different levels; educators, counsellors, nurses, general practitioners and at the end of the hierarchy, specialists, gastroenterologists or infectious diseases physicians* (Lloyd evidence, 30 March 1998).

The proposed control and management model is divided into three levels of care:

Level One care commences once an inmate’s HCV antibody test is known to be positive. Trained nursing staff will provide education and counselling. Protocol-driven additional investigations will be performed and periodic liver function tests will also be performed every two months for six months. Inmates who are seronegative for HBV will be offered Hepatitis B immunisation under the existing arrangements. Lloyd outlined this level to Members:

> *in the prison system the idea is to have the same sort of screening program that currently happens for all new inmates, although we would like to have the voluntary uptake rate in testing increased from 30% to a majority at least so that all individuals who come in are screened. We would like to capture those individuals by identifying them as being infected, educate them about the disease which they have and the way in which it is transmitted. . . these tasks to be undertaken by the public health nursing unit in Corrections Health Service* (Lloyd evidence, 30 March 1998).

Level Two care refers to the planned assessment by medical staff at the gaol where the inmates are housed. This will primarily involve clinical and laboratory assessment for chronic Hepatitis. The assessment will evaluate the inmate as to his/her suitability for interferon therapy. A protocol will be prepared to assist career medical officers (CMO who are equivalent to GPs outside the system) in country centres with this structured assessment. Lloyd told Committee Members that this level would:

> *undertake a structured routine of liver function testing, trying to identify the individuals who are chronically infected versus those who are antibody positive but uninfected or have resolved the infection and then have them evaluated by staff medical officers in the prison system - that step would evaluate individuals clinically and make some sense of whether they have other compounding medical diagnoses, whether they are co-infected with other things, use alcohol or have other issues and perhaps undertake investigation on site in Grafton or wherever* (Lloyd evidence, 30 March 1998).

Level Three care is planned to involve specialist treatment of chronic hepatitis and will include the use of interferon in selected individuals under the S100 scheme. This phase required specialised nursing, medical, drug and alcohol, and psychiatric staff. Liver biopsies and specialised pathology would also be performed with inmates' consent. Lloyd described this level to Members as "at the end of the model there would be very selected individuals who would have an evaluation with a view to treatment in prison" (Lloyd evidence, 30 March 1998).

Lloyd's paper identified the additional staff required to implement the model and a draft budget. Staffing requirements and annual budget details include:

LEVEL ONE CARE:	
2 fulltime nurses @ $35,000	$70,000
LEVEL TWO CARE:	
3 CMO sessions per week @$163 per session	$25,000
LEVEL THREE CARE:	
4 VMO physician sessions per wk @ $500 per session	$104,000
2 VMO physician sessions per wk (biopsies)	$52,000
1 VMO psychiatrist session per wk @ $500 per session	$26,000
1 D&A counsellor session per wk @ $120 per session	$6,000
1 clinical nurse specialist	$52,000
TOTAL	**$335,000**

Having outlined his proposed model for Hepatitis C care in the corrections system, Lloyd informed Members that:

> *this is not the first time that I have presented [this model] to the Corrections Health Board. I did the same thing 18 months ago with exactly the same suggestion, which ultimately went in the form of an*

> *enhancement request to the Health Department - it got nowhere. The grapevine tells me that it may have more success this time round* (Lloyd evidence, 30 March 1998).

The Committee can see considerable merit in Lloyd's model of care which, if implemented, would address many of the concerns pertaining to treating Hepatitis C positive inmates that were brought to the Committee's attention. It does not however consider itself to be in a position to recommend the adoption of this particular model by the Department of Corrective Services and Corrections Health Service. However, it is clear to Members that a model of best practice must be adopted and implemented within the corrections system as a matter of priority.

RECOMMENDATION 72:

That the Department of Corrective Services and Corrections Health Service recognise the extraordinarily high rates of Hepatitis C amongst inmates in the state's correctional system and develop a Best Practice Model for the delivery of Hepatitis C health care services to these inmates as a matter of priority. The Committee believes that the Best Practice Model must provide specific care to male and female HCV+ inmates located in both rural and metropolitan correctional centres. The Committee further recommends that the Best Practice Model must overcome shortcomings in the current provision of health care identified in this Inquiry, including the shortage of available health care professionals, the limited number of inmates able to access interferon therapy, and the difficulties currently experienced in administering interferon to inmates.

RECOMMENDATION 73:

That the strategies to be implemented in establishing the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 74:

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system.

Recommendations 72 to 74 address the issue of treating Hepatitis C in the corrections system. However, the introduction of a model of best practice will not necessarily address the management issues identified in the preceding discussion. Clearly this issue must also be addressed. The Committee considers it imperative that the Department of Corrective Services and Corrections Health Service give serious and urgent consideration to the appropriate management of the growing number of Hepatitis C positive inmates. To facilitate this process, the Committee would like to see these two agencies devise a strategic plan for Hepatitis C management in the corrections system and give a sincere undertaking to implement it as a matter of priority.

As always, the Committee is loathe to recommend government agencies form committees or taskforces to consider issues. However, in this particular case, it can see no other option. Considerable thought must be given to the diverse management concerns the Committee has identified and input has to be provided by those involved. The Committee therefore would like to see representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses) form an intersectorial committee to design and develop a strategic plan for Hepatitis C management in the corrections system. This committee is to be serviced by the Department of Corrective Services. Issues to be considered are to include, though not be limited to, provision of low fat diets to HCV+ inmates, availability of light duties for those experiencing Hepatitis C and/or interferon side effects, the education of prison officers on Hepatitis C and/or interferon side effects, in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes, the design of post-release care plans for HCV+ inmates and management difficulties experienced by those on interferon therapy.

RECOMMENDATION 75:

That the Minister for Health and the Minister for Corrective Services form an Intersectorial Committee made up of representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses). This Committee should be required to develop a strategic plan to address issues including, though not be limited to:

- provision of low fat diets to HCV+ inmates;
- availability of light duties for those experiencing Hepatitis C and/or interferon side effects;
- the education of prison officers on Hepatitis C and/or interferon side effects;
- in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes;
- the design of post-release care plans for HCV+ inmates; and
- management difficulties experienced by those inmates on interferon therapy.

RECOMMENDATION 76:

That the implementation details of the strategic plan for the management of Hepatitis C in the state's correctional system proposed in Recommendation 75 be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 77:

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of strategic plan for the management of Hepatitis C in the state's correctional system.

8.6.5 PROVIDING HEALTH CARE WITHIN A DUAL DISCIPLINE FRAMEWORK

Health care within the corrections system operates within a dual discipline framework with health related services provided by Corrections Health Service within Department of Corrective Services institutions. The relationship between the two agencies was described to the Committee as "symbiotic" (Christensen evidence, 23 March 1998).

According to their Annual Report, the Corrections Health Service's mission is to provide medical and health care for inmates comparable to the standard of care and access provided to members of the general public (Corrections Health Service, 1995:6). The Service's objective and goals include the implementation of all appropriate public health initiatives to ensure the health of the inmate population and to improve the health of inmates through health education, promotion and preventative actions (Corrections Health Service, 1995:6).

As the Committee heard:

> *the challenge is to deliver objective health care - try never to get caught up in someone's crime or to run a punitive health system because often there can be a blur* (Christensen evidence, 23 March 1998).

The day to day realities of health care providers working within the corrections system were described to Committee Members in the following way:

> *we work within a dual discipline framework, that is, with the Department of Corrective Services . . . we rely very heavily on them for our security. Basically if there is no officer there is no work. If the officers walk off the job for the day we are paralysed as far as accessing inmates. That is a fairly powerful discipline within which to work . . .*

> *. . . In the past Dr Philip Brown [CEO, Corrections Health Service] had an agreement with Ron Woodham [Assistant Commissioner, Operation, Department of Corrective Services] to allow all the outpatient clinics to flow. However, you must remember that only two or three officers may work on that particular day. You are talking about powerful unionist stuff. You are talking about males and brute force, control and subjugation - I could go on. You may have an agreement so the process could be very slow. You may have three officers instead of eight conducting an outpatients' clinic with five visiting specialists so it is a go slow. Short of Woodham marching down from Roden Cutler House and standing there, which does not happen, you are at their mercy* (Harper evidence, 23 March 1998).

The representative from Department of Corrective Services appearing before the Committee considered his Department's relationship with Health to be "a strong working" one:

> *Regular meetings occur at the policy and program levels to ensure consistent delivery of service in both departments. The Department of Health provides us with a great deal of guidance and assistance in developing our programs to ensure that they are consistent with what is available in the community. It is a very successful relationship and hopefully, it will continue in the future* (Vumbaca evidence, 23 March 1998).

Vambuca recognised "a strain on the relationship at the moment" due to:

> *the need to use existing funds only, HIV funds, to cover a whole range of issues in the system. That is probably the main area of contention - how we keep providing all these new programs and services within the existing budget. We are taking from one area to pay for another* (Vumbaca evidence, 23 March 1998).

Christensen stated that the relationship between the two agencies "sometimes gets strained" (Evidence, 23 March 1998). From her experience she called for "greater collaboration" between the Department of Corrective Services and Corrections Health Service as "sometimes these systems run parallel" (Christensen evidence, 23 March 1998). As Christensen noted:

> *for the maximum outcome of patient support, there needs to be more collaboration between those groups* (Christensen evidence, 23 March 1998).

The Committee is aware of mechanisms in place to ensure communication and relationships between the two organisations are optimal. At the highest level, for example, two senior officers from the Department of Corrective Services and the

Department of Health sit on the Corrections Health Service Board (Corrections Health Service, 1995:15). A Corrections Health Service and Department of Corrective Services Liaison Committee of the most senior officers also meets regularly to consider “matters of operational concern” between the two organisations and to review policies and procedures that impact upon both (Corrections Health Service, 1996:16). A number of conjoint *ad hoc* committees were established to address problems such as the transfer of clinical files with inmates and the extension of the methadone maintenance program (Corrections Health Service, 1996:16).

In its submission to this Inquiry, the Department of Corrective Services called upon the Committee to “enhance and build upon” the relationship that exists between Corrective Services and Health if “beneficial outcomes are to be achieved efficiently” (Department of Corrective Services submission).

Successfully treating and managing Hepatitis C within the corrections system is, and will continue to be, an enormous task. The comments made by witnesses suggest that the mechanisms currently in place may not be sufficient to ensure adequate collaboration between Department of Corrective Services and Corrections Health Service takes place. The Committee wishes to see the Ministers for both agencies take active steps to ensure officers (at all levels) collaborate effectively.

RECOMMENDATION 78:

That the Minister for Health and the Minister for Corrective Services take active steps to ensure officers from the Department of Corrective Services and Corrections Health Service/NSW Health (not only at the central agency level, but at the local correctional centre level) collaborate effectively.

8.6.6 CONCLUSION

Given the numbers of Hepatitis C positive inmates in the state’s correction system, treating and managing those patients is, the Committee has come to appreciate, an enormous task. Vumbaca summed the situation up succinctly when he commented that:

> *The list of issues to be addressed goes on and on . . . With HIV we are dealing with 18 to 20 inmates; it is easy to deal with that level in the system. When you are talking about thousands it becomes a nightmare for us in terms of all the issues that need to be addressed* (Vumbaca evidence, 23 March 1998).

The Committee anticipates that the mechanisms it has proposed to address the treatment and management of Hepatitis C in the corrections system will go some way to rectify the current “nightmare”.

8.7 CONCLUSION

Giving Hepatitis C’s epidemiology, treating and managing the disease will be an enormous task. Clearly models of service delivery are urgently required to be put in place to treat and manage the Hepatitis C epidemic. The Committee anticipates that the proposals it has forwarded will provide an adequate framework for both inmates in the state’s corrections system and those in the wider community.

CHAPTER NINE

SUPPORTING THOSE WITH HEPATITIS C

As Chapter Four demonstrated, the economic and social consequences of Hepatitis C can have profound consequences for individuals, families and carers yet as the Committee heard “Hepatitis C patients have very little support” (Pritchard-Jones evidence, 2 October 1997) and “people are often on their own” (Smart evidence, 26 February 1998). This Chapter looks at various support services available that are designed to assist people with Hepatitis C and identifies some of the gaps in this provision.

9.1 COMMUNITY-BASED ORGANISATIONS SUPPORTING THOSE WITH HEPATITIS C

In its submission to the Inquiry, the Hepatitis C Council noted that effective care and support in the form of counselling and information can make a significant difference to the impact of Hepatitis C on both individuals and the wider community.

Appropriate counselling and information can help an individual adjust to the demands of living with a chronic illness and to optimise their treatment. This may in turn reduce pressure on health and welfare services. The Council also points out that the provision of relevant information about the virus may also reduce the rate of transmission and reinfection (Hepatitis C Council submission). People with Hepatitis C need comprehensive information about the virus, including information about transmission, the prevention of reinfection, the availability and benefits of treatment and legal rights and responsibilities. Information should be updated regularly and presented in an accessible form (Hepatitis C Council submission).

The availability of counselling to assist people with Hepatitis C is, however, very limited. It may be provided by local general practitioners but as has been discussed in Section 8.3.3 there has been little training to assist general practitioners in understanding the virus and its management. Increasingly, the provision of information and support services has been provided by a range of community based agencies that specifically target those with Hepatitis C and even quite specific groups within the Hepatitis C community such as those with medically acquired Hepatitis C and injecting drug users who are HCV+. The following section reviews the agencies that provide support services to those with Hepatitis C.

9.1.1 HEPATITIS C COUNCIL OF NSW

The Hepatitis C Council of NSW is the key non-government agency providing assistance to people affected by Hepatitis C in NSW. The Council, which was incorporated in 1993 grew out of the Australian Hepatitis C Support Group which had been formed two years earlier. Its primary objectives are:

- to coordinate the community sector response to the Hepatitis C epidemic in NSW;
- to provide counselling, support and referral for people affected by HCV;
- to provide information and advice about HCV and, in liaison with other agencies, develop prevention and support strategies to reduce the spread and impact of HCV;
- to act as advocates for people affected by HCV and represent their interests on relevant bodies;
- to eliminate stigmatisation, discrimination and isolation of people affected by HCV through the promotion of community awareness by working to ensure that regressive policies and procedures do not occur; and
- to encourage, assist and promote both health and scientific research into the causes, prevention, treatment and cure of Hepatitis C and related conditions (Hepatitis C submission).

The Council is primarily funded by NSW Health. It has an annual operating budget of $260,000 with an annual grant from NSW Health of $215,000 providing its core operating income. Additional income sources include membership fees, individual and corporate donations and product sales. The Council employs four paid staff and has a team of 40 volunteers.

The Committee received numerous submissions from people with Hepatitis C who specifically identified the Hepatitis C Council as playing an important role in providing support, information and education:

> *The Hepatitis Council of NSW has been a real saviour to me. The first bit of real information I received was after diagnosis, using the telephone support line. I eagerly await the arrival, each quarter, of the 'Hep C Review' as it is the only source of reliable information. I have gained much from readers' stories and the articles about diet and general health have been invaluable* (Submission 45);
>
> *I joined the Hep C Council of NSW and was given a lot of help from them with information which I needed (*Submission 48);

and

> *The Hepatitis C Council is doing a wonderful job but needs more help* (Submission 36).

During evidence, Committee Members heard that:

> *the Hepatitis C Council of NSW has been good to us all. It deserves every support and credit for its work* (Smart evidence, 26 February 1998).

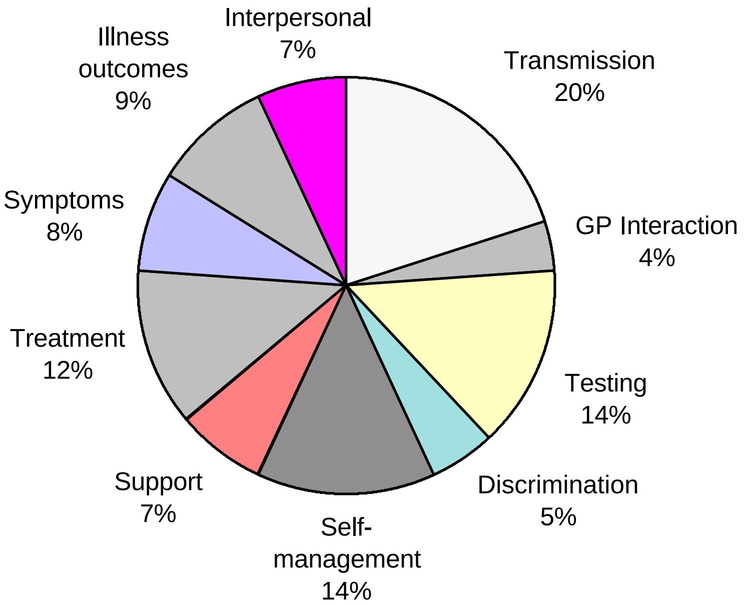
Specific activities of the Council include:

- operation of the NSW Hepatitis C Telephone Information and Support Service (TISS);
- production and distribution of information resources such as *Hepatitis C: a brief introduction* (over 200,000 have been distributed in two years); *Hepatitis C: what you need to know;* information videos and research packs;
- production and publication of a quarterly newsletter the *Hep C Review* which has a print run of 4,000 and an estimated readership of 16,000. This journal is Australia's "foremost regular publication" on Hepatitis C (Hepatitis C Council submission); and
- acting as the key Hepatitis C-specific agency in NSW, ensuring effective referral and networking (Hepatitis C Council submission).

A significant core activity of the Council is the Telephone Information and Support Service which is a 1-800 telephone service that receives over 3,000 calls annually. The service is staffed by a team of 8-15 trained volunteers who are supervised by a project officer who recruits, trains, supervises, manages and supports the volunteers.

Calls are often "extremely complex" and "require great skills to help an often distressed caller" (Loveday evidence, 30 March 1998). They also cover a range of issues. Figure Five shows the breakdown of topics discussed. The three most discussed issues in 1996-97 were transmission (20%); self management (14%) and testing (14%).

FIGURE FIVE
HEPATITIS C COUNCILOF NSW INFORMATION AND SUPPORT LINE
1996-97



TISS operates 24 hours a week including three hour shifts every weekday morning, Monday and Tuesday afternoons and Wednesday evenings. Funding restrictions limit the hours of operation. The Executive Officer of the Council told the Committee that:

> *calls are being missed by this service through our ability to open 24 hours a week given our resourcing. We do the best we can to call back those who leave messages, but we know there would be some who are being missed through people not being able to speak to anybody at the time* (Loveday evidence, 3 October 1997).

TISS is currently the only telephone information and support service available to those with Hepatitis C in NSW. The Committee considers the service to be vital in terms of the information and support it provides, particularly to those in rural and regional areas. The Committee therefore considers it appropriate that funding be increased to enable the service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

RECOMMENDATION 79:

That the funding allocation by NSW Health to the Hepatitis C Council of NSW be increased to enable the Telephone Information and Support Service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

9.1.2 SUPPORTING THOSE WITH MEDICALLY ACQUIRED HEPATITIS C

Two agencies currently provide services to those with medically acquired Hepatitis C: the Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS), and the Haemophilia Foundation Australia (and its NSW counterpart). These agencies and the services they provide to the Hepatitis C community are reviewed in the following discussion.

- **Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS)**

TRAIDS is a unit within the NSW Health Department which supports people infected with HIV and Hepatitis C as a result of a blood transfusion. The Unit, which is based in Parramatta, provides information and counselling on all aspects of Hepatitis C to individuals, families and health care workers. It also plays an important role in advocacy and policy development.

TRAIDS was initially established to support people with medically acquired HIV. In 1994 NSW Health broadened the scope of TRAIDS' services to include blood recipients who received HCV+ blood between the introduction of first and second generation HCV testing. The small number of affected people at the time, 52 in total, had little impact on the resources of TRAIDS as not all those diagnosed required or wanted intensive involvement (TRAIDS submission). The Hepatitis C Lookback program currently being undertaken by the Blood Bank (and reviewed in Section 3.3) is identifying a larger number of people who are HCV+. This is resulting in an increased number of referrals to the Unit.

Despite its increased role the Unit has not received any additional funding or resources to support people with Hepatitis C and all counselling and support is provided by the Unit's one social worker and the Director. According to the Director of the Unit, Ms Pam Shipway, TRAIDS has been able to cope with the additional caseload as the demands of HIV clients have reduced in response to new therapies (Shipway evidence, 10 October 1997). However, if the number of referrals were to increase Ms Shipway advised the Committee that the Unit would require additional counsellors and resources (Shipway evidence, 10 October 1997).

- **Haemophilia Foundation Australia**

The Haemophilia Foundation Australia (HFA) is the primary agency supporting those with haemophilia, von Willebrand Disorder and related bleeding disorders. The Foundation undertakes a range of activities including:

- funding for research;
- member education and interaction through activities such as workshops, family camps, family days; annual forums for doctors, nurses and counsellors;
- activities targeting youth including a Youth Newsletter, Peer Leadership workshops and the Haemophilia Youth Group's Internet home page, "Blood Brothers";
- community education including Haemophilia Awareness Week;
- resource development; and
- specific program development such as the Hepatitis C Program and the HIV/AIDS Program.

In 1996 a Member Needs Survey conducted by the Foundation found many members wanted more information and support on the issue of Hepatitis C. Later that year a decision was made to develop a program specifically addressing Hepatitis C related issues, particularly treatment and transmission. The overall aim of the program was to provide information to people living with haemophilia, related disorders and groups working with them (HFA, 1997:13). The Program was funded by a special grant from the Commonwealth Department of Health and Family Services along with individual HFA contributors.

According to the Foundation, people with haemophilia not only have to deal with the fear of illness and death, but with discrimination in the community, because they are a clearly recognisable group. Appropriate counselling is an important means of helping people to deal with the discrimination they experience:

> *All our families need help with the broad ramifications of Hepatitis C and haemophilia, even those new families who are uninfected, because they still fear the discrimination that belongs with our group* (Ross evidence, 26 February 1998).

However, according to the Foundation, counselling services in NSW are inadequate:

> *our counselling services in New South Wales are definitely a problem. They need to be extended and maintained* (Ross evidence, 26 February 1998).

There has been one counsellor, based at Royal Prince Alfred Hospital, providing support to those with haemophilia in New South Wales. However, as the Committee heard, the counsellor:

> *is employed with HIV funds and she is so outstanding that she has now been seconded to the position of acting in charge of HIV services for her hospital and region and she is only able to manage a few emergency cases for the haemophilia group. As you can understand, this is unsatisfactory for her and for the group* (Ross evidence, 26 February 1998).

In other states it is the Haemophilia Foundation, rather than the Department of Health, which employs counsellors. As a result:

> *these counsellors cannot be whisked off, as happened here at Royal Prince Alfred Hospital, to do another job. The group employs them. Their time cannot be moved by placing them in other areas. The positions are protected* (Ross evidence, 26 February 1998).

Not only are the positions of haemophilia counsellors secure in other states but more counsellors are available. The Committee understands that both Queensland and Victoria (which have smaller caseloads than NSW) have two full time counsellors - one dealing with haemophilia and HIV, the other with haemophilia and Hepatitis C.

The Foundation also offers care and support to its members through various programs, workshops and meetings. The ability of NSW to provide such services is limited by funding which enables the secretary to be employed only on a part-time basis. Again, other states employ secretaries for more hours or employ more people.

9.1.3 SUPPORTING INJECTING DRUG USERS WITH HEPATITIS C

In New South Wales the peak group representing those who use drugs illicitly is the New South Wales Users and AIDS Association (NUAA). NUAA is a community based, non-government organisation established in 1989 to provide health promotion and harm reduction education, information and support to illicit drug users. The Association's Coordinator likened the Association to a "union for drug users" (Madden evidence, 7 November 1997). NUAA employs 13 permanent staff members.

The Association is funded primarily by NSW Health receiving, for example, $885,500 in 1997-98 (NSW Health submisison). Ms Madden, NUAA's Coordinator, went to considerable lengths to assure Committee Members of the organisation's credibility:

> *we have a good working relationship with our funding bodies and we are a well-recognised and highly accountable organisation, which is important in this area, given that the organisation is run by and for drug users* (Madden evidence, 7 November 1997);

and

> *NUAA is very much recognised as a professional organisation with a good reputation. I am sure you will appreciate that the Department of Health would not give us the budget it does and we would not have grown from one staff to 13 in eight years if we were not doing the work we were funded to do* (Madden evidence, 7 November 1997).

The support provided by NUAA to its client base has a strong peer education and community development focus which is described in Section 10.1.1. The projects include TRIBES, CROWS and *NUAA News,* a quarterly newsletter which deals with information of interest to illicit drug users.

9.1.4 CONCLUSION

Mr Loveday from the Hepatitis C Council summed up the role played by community based support services during the course of his evidence:

> *with the current inadequate level of knowledge within the primary health care field, and with the vast majority of people receiving their Hepatitis C diagnosis with inadequate pre- and post-test counselling, if any at all, there is an urgent need to further fund and expand the community based information and support services* (Loveday evidence, 30 March 1998).

The Committee concurs with his statement and fully appreciates the important role played by community based information and support services. While each of these four agencies spoke of inadequate resources, particularly funding, to meet the demands placed upon their services, the Committee found it difficult to recommend outright the allocation of additional funding.

The Committee appreciated the constraints under which these agencies operate and recognised the need for additional funding. However the Committee did not feel it was adequately equipped to make specific recommendations. It considers it more appropriate for a review of these four agencies to be conducted and the adequacy of resources to meet the demand for services ascertained. Once the needs of each agency have been identified, the Committee wishes to see NSW Health ensure sufficient funding is made available to enable these services to meet the needs of the Hepatitis C community in New South Wales.

The Committee wishes to see the review include staffing needs, such as counselling, support, project, policy and volunteer management staff.

RECOMMENDATION 80:

That NSW Health commission an independent review and needs assessment of the services provided by the Hepatitis C Council of NSW, the Transfusion Related AIDS and Infectious Diseases Unit, the Haemophilia Foundation NSW, and New South Wales Users and AIDS Association to determine resource needs (including staffing needs for counselling, support, project and policy work and volunteer management) and demand for services. The Committee further recommends that the proposed review be conducted within six months of the tabling of this Report and that the results are with the Minister for Health no later than December 1999.

RECOMMENDATION 81:

That, upon receipt of the review proposed in Recommendation 80, NSW Health ensure sufficient and recurrent funding is made available to implement the recommendations of the review.

9.2 SUPPORT GROUPS

A number of those making submissions to the Inquiry mentioned the benefit they had received by being involved in a support group specifically designed for those with Hepatitis C. Rural people in particular, seemed to have appreciated this form of support. All of those that wrote of support groups however, wrote in the past tense. While a number of support groups have existed for short periods of time across the state, there have been no more than three or four at any one time and currently there would be no more than two or three (Loveday evidence, 30 March 1998). The mapping exercise of Hepatitis C education, prevention and training initiatives undertaken by NSW Health and updated in March 1998 identifies two support groups: a monthly support group in Wollongong; and the Hunter Hepatitis C Support Group which was scheduled to run for six 2-hourly sessions and would be repeated throughout the year (NSW Health, 1998b:22, 26).

Ms Shipway stressed the importance of support groups during the course of her evidence:

> *support groups can benefit some people by reducing their isolation and by identifying with others in similar situations and being more comfortable with their diagnosis* (Shipway evidence, 10 October 1997).

The Hepatitis C Council told the Committee that:

> *it is very disappointing that when most people phone the information and support service to ask about whether they are able to meet with other people who have Hepatitis C, or talk to somebody who has been on interferon treatment, or join a formal support group to discuss issues brought up by their diagnosis, we have to tell them that there is virtually a complete absence of support groups across the state . . .*
>
> *. . . This is true of both city and rural areas, but the need by people in rural areas, particularly for additional and appropriate local support is amplified by the general isolation and often reduced access to services, coupled with an often bigger potential for discrimination once their Hepatitis C positive status is disclosed* (Loveday evidence, 30 March 1998).

The Council provides those interested in running a support group with information, material and guidelines on appropriate ways to run a small support service:

> *however, lack of local resources, both material and trained expertise, means that the burn-out rate is very high. No amount of community enthusiasm and voluntary input can sustain a support system to the level at which one is required* (Loveday evidence, 30 March 1998).

To overcome the problem, Loveday proposed each Area Health Service allocate sufficient resources, both staffing and financial, to the establishment of local support services. He also considered it important that the local community be fully involved in determining the appropriate style of support system that would meet the needs of the local Hepatitis C community (Loveday evidence, 30 March 1998).

The Committee considers there to be a vital role to be played by support groups for those with Hepatitis C and their families. It wishes to see the Area Hepatitis C Managers proposed in Recommendation 40 take on the role of coordinating local support groups. The Committee does not envisage the Managers actually facilitating the support groups, but overseeing their establishment, ensuring necessary resources are available (venue, photocopying, fax, etc), providing expert input and information as required.

RECOMMENDATION 82:

That the Area Hepatitis C Managers proposed in Recommendation 40 be responsible for instigating Hepatitis C Support Groups in their local Health Areas and, while not necessarily involved in the day to day operation of the groups, provide expert input and information as required, act as a resource/referral person and ensure necessary resources are available.

RECOMMENDATION 83:

That the review proposed in Recommendation 39 take into consideration the need for support groups in each Health Area and the role played by Area Hepatitis C Managers in facilitating these groups.

In terms of appropriate venues for the support groups, the Committee considers Community Health Centres to be well situated to provide a suitable venue. However, the Committee would rather this decision be made in conjunction with the development of best practice models for service delivery proposed in Recommendation 66. It is important though that consideration be given to the administrative needs of the support groups and ready access to basic office equipment such as photocopier, fax and Internet.

RECOMMENDATION 84:

That, in developing a model of best practice for the delivery of services to those with Hepatitis C (as proposed in Recommendation 67), the accommodation needs of local Hepatitis C support groups be taken into account.

9.3 FINANCIAL SUPPORT TO THOSE WITH HEPATITIS C

9.3.1 DISABILITY SUPPORT PENSION

While the Committee did not receive any first hand evidence concerning difficulties people with Hepatitis C have experienced in accessing the pension, the issue was raised during the course of evidence. Mr Mellors, for example, recounted two instances he was aware of in which people with Hepatitis C, one with cirrhosis and moderate to severe depression, the other also with cirrhosis and on antidepressants, found it "very difficult" and "quite a struggle" to obtain the disability support pension (Mellors evidence, 26 February 1998).

The Hepatitis C Council informed the Committee that in 1996 the Committee understands that the Department of Social Security reviewed the impairment tables used by Commonwealth medical officers to establish the level of disability and, in turn, eligibility to receive the disability support pension. A series of changes to the tables was proposed which would have excluded many people with chronic illness, particularly those with an illness which was fatigue related. While Hepatitis C was not specifically identified, fatigue is one of the main symptoms of the disease and the proposed changes would have substantially reduced the numbers of people accessing this particular pension. Under the proposed changes, those with Hepatitis C would have been required to provide medical evidence in the form of liver function tests or liver biopsy results. However, as there is no direct correlation between the level of liver damage and the amount of symptomatic illness a person with Hepatitis C endures, the changes were considered to be inappropriate. The Hepatitis C Council strongly advocated against the changes which were not made as originally proposed.

Currently all those on a disability support pension are being reviewed.

The Hepatitis C Council anticipates that the new tables will provide some structured guidelines to the Commonwealth medical officers conducting the assessments for:

> *in some instances people's ability to work appears to be measured at the whim of an individual Commonwealth medical officer. That is not true across the board certainly, but there is a lot of variation in the assessments. Hopefully these new tables will give clearer guidelines to the medical officers* (Loveday evidence, 30 March 1998).

Given the assurances received from the Hepatitis C Council that the problem appears to have resolved itself, the Committee is satisfied that this is the case. However, it would be concerned if future changes were proposed that restricted those genuinely debilitated by Hepatitis C from accessing the disability support pension. It urges NSW Health to keep a watching brief on the issue and advocate on behalf of those with Hepatitis C should future restrictive changes be proposed.

RECOMMENDATION 85:

That NSW Health maintain a watching brief on the issue of changes to the Disability Support Pension. The Committee further recommends that, should changes be proposed in the future which would restrict those genuinely debilitated by Hepatitis C from accessing the Disability Support Pension, the Minister for Health, through the forum of the Australian Health Minsters Council, advocate on behalf of those with Hepatitis C.

9.3.2 FINANCIAL SUPPORT TO THOSE WITH MEDICALLY ACQUIRED HEPATITIS C

Approximately one-third of submissions received from those with Hepatitis C were from people who had acquired Hepatitis C either through medical procedures (including blood transfusions) or the workplace. Only a handful called for financial compensation or assistance. A nurse, for example, asked for compensation for those like herself “just to cover costs of medical treatment” (Submission 19). One other argued that:

> *Medically acquired HCV sufferers should be able to go on the interferon and riboviron treatment as some type of compensation. We are innocent victims of this virus and I feel strongly that this treatment should be given to us free* (Submission 62).

TRAIDS recommend that financial assistance of a “limited nature” must be a consideration of the Inquiry (TRAIDS submission). Ms Shipway from TRAIDS considered such assistance would be helpful for people with Hepatitis C to “have more choices in their life” (Shipway evidence, 10 October 1997).

Towards the end of this Inquiry, the ACT government announced it would be providing financial assistance to those who contracted Hepatitis C through contaminated blood. The Committee understands that legislation is soon to be introduced into the ACT Legislative Assembly seeking a compensation package of between $2.3 million and $3.7 million over the next two years for 60-80 residents of the Territory who contracted Hepatitis C prior to the screening of blood and blood products by the Red Cross Blood Service (Jackson and Lawson, 1998). The maximum payout would be $100,000 and recipients would waive their right to sue. As far as the Committee can ascertain, this is the first government in Australia to take such action. Similar measures are being taken by the Canadian government which, in March 1998, announced a $1.1 billion package for approximately 22,000 people who received infected blood prior to the introduction of screening (CBC Radio News, 1998).

In 1990 this Committee conducted an Inquiry into medically acquired HIV. The Terms of Reference for that Inquiry were that the Committee report upon, as a matter of urgency:

(a) *whether persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of organ transplant, are receiving adequate and comprehensive health and welfare services;*

(b) *whether persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV are receiving adequate health and welfare services; and*

(c) *whether the Government should provide financial assistance to those persons described in paragraphs (a) and (b) above* (Standing Committee on Social Issues, 1991:iv).

The majority report of that Inquiry recommended that people with medically acquired HIV be entitled to financial assistance (Standing Committee on Social Issues, 1991:46). This recommendation was subsequently adopted by the government and financial assistance was provided.

The Committee is aware that its previous Inquiry and the resultant government action could be seen as setting a precedent for those with medically acquired Hepatitis C. However the Committee is reluctant, at this stage, to recommend similar action for two reasons. Firstly the Committee has been advised that litigation has commenced in relation to forty cases where allegations are made to the effect that NSW Blood Transfusion Service was negligent. With regard to these cases, the Committee was advised that:

> *litigation has been discontinued in three of these forty cases. Solicitors for the plaintiffs have indicated that litigation is to be discontinued in a further three of these cases . . . The claims involve complex legal and factual issues relating to the activities of blood banks throughout the world in the late 1960s, early 1970s up until 1991 . . . No claim involving the New South Wales Blood Transfusion Services has been resolved other than by discontinuance nor has any matter been listed for hearing* (Benjamin evidence, 10 October 1997).

The Committee also took (in camera) evidence from the Queen's Counsel representing the Blood Bank.

Secondly, comments on financial assistance were made by only a very small proportion of those making submissions to the Inquiry. This is not surprising given the Terms of Reference of the Inquiry. However, the Committee concluded that, at this stage, it does not have sufficient evidence to come to any definitive conclusions concerning the appropriateness of providing financial assistance to those with medically acquired Hepatitis C.

The Committee fully recognises however that, at some point in the future, the issue may take on more prominence. Should that be the case, it may then be appropriate for the Committee to conduct an inquiry into the issue.

9.4 COMMUNITY SUPPORT FOR THOSE WITH HEPATITIS C

As has been discussed, the chronic nature of Hepatitis C impacts upon virtually all facets of people's lives. For many everyday tasks such as housework, caring for children, shopping, accessing public transport and paying bills become major chores requiring large amounts of energy and determination. The problem is exacerbated for those with limited support living in rural areas, isolated in the outer suburbs of Sydney and with limited English language skills.

In recounting examples from years of counselling people with Hepatitis C, Ms Lamb told the Committee of:

> *People [with Hepatitis C] living in Housing Commission areas, placed in a fourth-floor flat with two small children having to go up and down to put the washing on the line, so people in that situation do not do the washing. They cannot take the kids down to play because it is too tiring. In recent years the Housing Department has really tried to help* (Lamb evidence, 30 March 1998).

From her own personal experience of utilising Home and Community Care, Ms Lamb suggested to the Committee that:

> *The Home and Community Care service should be extended. That service is regarded as only for the aged. I cannot see why it should be restricted to the aged. The set-up is there but young people also need help. When you ask for community transport, as I had to recently . . . all the questions focused on "are you continent?"* (Lamb evidence, 30 March 1998).

As the long term manifestations of Hepatitis C become evident and increasing numbers of people are debilitated by the disease the Committee anticipates greater utilisation of essential services provided by a range of government agencies such as housing, community service, transport, in addition to health. In many instances, those requiring these services will be younger than those who have traditionally utilised these services. Their need will, however, be no less acute than that of the older members of the community. Given the long term and chronic nature of Hepatitis C, their reliance upon these services will extend over time.

The wide range of inquiries conducted by the Committee over the past ten years has given it considerable experience in observing the manner in which government agencies provide services at the grassroots to address specific social issues. The Committee is very aware that, despite the best intentions of agencies and those in the field, gaps do appear and people with very real needs, do fall through those gaps. Often the problem is a lack of coordination between agencies, limited collaboration and poor communication. The Committee recognises that many people with Hepatitis C will have multiple needs for support, requiring contact with a number of government agencies. It is concerned that, unless coordinating mechanisms are put in place, these people will not be able to access the services they need when they need them.

The Committee therefore wishes to see mechanisms put in place to enhance the coordination and collaboration of government services utilised by those with Hepatitis C.

For much of 1998 the Social Issues Committee conducted an inquiry into parent education and support programs concurrently with this Inquiry. In the context of this second Inquiry, the Committee studied an interesting model: the Interagency Schools as Community Centres project. This project provides various forms of support, education and assistance to families and is based on the concept of full service schools, using the school site as an accessible point in the community where people can access a range of services. As the name implies, one of the features is the interagency component which involves a range of relevant government departments, such as Education and Training, Health, Housing and Community Services, working together to provide services.

A core group of programs are available at each of the project’s four sites however one of the features of the project is that the range and type of programs offered is developed to meet local needs. The core group of programs includes playgroups, parenting information sessions, early childhood health clinics and transition to school programs. Individual sites have developed their own focus of activity ranging from nutrition and food co-operative programs, literacy support programs and a community-school bus service (Standing Committee on Social Issues, 1998:164).

The approach used in the Interagency Schools as Community Centres project was well supported by many participants of the parent education Inquiry. The main benefits cited were the collaborative approach between the government departments involved, the ‘grass-roots’ nature of program development which ensured services are relevant to the needs of parents, and the use of schools as an accessible venue for such services (Standing Committee on Social Issues, 1998:165).

The Committee saw considerable merit in this form of grass-roots, community development and felt there to be scope for the model to be adapted to meet the needs of those with Hepatitis C. Given the debilitating impact and the chronic nature of Hepatitis C many need services offered by a range of government departments such as Housing, Community Services, Health, Transport in addition to local government.

An interagency committee along the lines of the model discussed and operating at the local health area level could ensure these services are readily available and accessible. The Committee would like to see such an approach, to be known as the Interagency Hepatitis C Support Project, trialled by NSW Health.

RECOMMENDATION 86:

That NSW Health trial an Interagency Hepatitis C Support Project to ensure government services required by those with Hepatitis C are readily available and accessible. The Committee further recommends that the government agencies involved include the Departments of Health, Community Services, Housing and Transport in addition to local government representation.

The Committee envisages that the Area Hepatitis C Manager, proposed in Recommendation 40 would act as coordinator and chair of the Committee. The Committee also wishes to see the concept trialed for a two year period in three Health Areas: inner city, suburban and rural. Those considered most appropriate for the trial are the Health Areas of Central Sydney, South Western Sydney and Northern Rivers.

RECOMMENDATION 87:

That the Interagency Hepatitis C Support Project proposed in Recommendation 86 be trialed for a two year period in three Health Areas: Central Sydney Area Health Service (inner city), South Western Sydney Area Health Service (metropolitan) and Northern Rivers Area Health Service (rural). The Committee further recommends that the Area Hepatitis C Managers for each of these Health Areas proposed in Recommendation 40 act as project coordinator and chair of the Committee.

9.5 CONCLUSION

Committee Members have come to appreciate that those with Hepatitis C, and those who care for them, often need adequate and ongoing support. Such support is, however, limited. A range of community-based organisations, such as the Hepatitis C Council, TRAIDS, the Haemophilia Foundation and NUAA, provide a number of support services, but they are often underresourced and stretched to the limit. Accessing available government services such as appropriate housing, community transport and Home and Community Care is often confusing and difficult, particularly for those with limited English language skills or living in rural areas. The proposed recommendations of this Chapter attempt to address current inadequacies and provide a range of support mechanisms which will meet both current and future needs of those living with Hepatitis C.

CHAPTER TEN

PREVENTING THE TRANSMISSION OF HEPATITIS C

The Terms of Reference received by the Committee specifically asked it to give "particular attention to strategies for prevention". The following discussion provides a detailed account of current preventative strategies in place for specific 'at risk' population groups including injecting drug users, inmates in the state's correctional service, recipients of infected blood, health care workers and their patients and those involved in the skin penetration industry. A range of proposed preventative measures proposed to Committee Members during the course of the Inquiry are also reviewed and recommendations forwarded.

The National Hepatitis C Action Plan prepared for the Australian Health Ministers Advisory Council noted the important role to be played by prevention:

> *in the absence of a cure or preventive vaccine for Hepatitis C, education and prevention strategies remain the most important mechanism for controlling the disease in our community* (AHMAC, 1994:22).

The Action Plan considered the issue of a co-ordinated national education and prevention approach. The Plan made three recommendations in the area of prevention:

i. the development of a coordinated national education approach to Hepatitis C;
ii. a review by all states and territories and the Commonwealth of all current Hepatitis C education strategies for youth, injecting drug users, people with Hepatitis C and health service providers; and
iii. the increased availability of sterile injecting equipment (AHMAC, 1994:29-30).

The report proposed a national reference group comprising State and Commonwealth, community and professional representatives be convened to determine the details of a national education approach including priorities, respective roles and responsibilities, detailed strategies including time frames and costings.

Accordingly, an AHMAC Hepatitis C Education and Prevention Reference Group was formed. The Group's report, *The Nationally Coordinated Hepatitis C Education and Prevention Approach*, was endorsed by the Australian Health Ministers' Advisory Council on 20 October 1995.

The Reference Group recognised that a national education and prevention program must address both education for prevention (including the provision of the means of prevention), and education for treatment and care. It therefore developed priority lists of target groups for each of these categories. The priority groups for preventative education included:

1. People who inject drugs;
2. People who provide tattooing services and/or skin penetration services;

3. Key decision and policy makers;
4. Health service providers;
5. Correctional services; and
6. General community (AHMAC, 1995:9).

The following discussion will consider preventative strategies for five of these six groups. Strategies directed at key decision and policy makers will be considered in Section 11.1.

As has been discussed in Chapter One, 1995 also saw the release of the Report of the NSW Hepatitis C Taskforce. Unlike the AHMAC report which took a very broad brush approach to prevention, the recommendations in this report are very specific. Many of the recommendations will be discussed in the relevant sections throughout this chapter.

The issue of preventing the transmission of Hepatitis C was raised with representatives from NSW Health. Those appearing on behalf of the Department identified a range of programs in place to limit Hepatitis C transmission. They were not able, however, to identify the Department's policy to limit Hepatitis C transmission (for example, to reduce the transmission of Hepatitis C in the target populations by X% by a certain year) or identify the strategic direction used to fund and implement this policy. It would appear that the preventative strategies in place have been introduced in a somewhat *ad hoc* manner or are merely an extension of programs introduced in response to the HIV/AIDS epidemic a number of years ago (for example, methadone maintenance therapy, the needle and syringe program and peer based education).

The Department's submission also failed to identify current prevention policy and strategic direction. It merely stated that:

> *the Department has identified preventive strategies among those members of the injecting drug use community who initiate others to injecting drug use and for high risk youth as being a high priority for development* (NSW Health submission).

Despite such strategies being a "high priority for development" the submission falls short of identifying them, leaving the Committee to question whether any strategies have actually been developed.

Appended to the Department's submission was the results of a mapping exercise of Hepatitis C education, prevention and training initiatives provided by Area Health Services and other relevant agencies such as CEIDA, the Hepatitis C Council of NSW, HepCare, Kirketon Road Centre and the HIV and Health Promotion Unit of the Department of Corrective Services. This document does identify preventative programs being introduced and implemented at the local health area level. Such initiatives are commendable as they meet local needs. The Committee is concerned however, that overall strategic direction is not forthcoming from the Central Agency.

The Committee was not able to ascertain the overall direction NSW Health is taking to limit the transmission of Hepatitis C. Given the magnitude of the Hepatitis C epidemic, the lack of policy guidelines and strategic direction is of great concern to the Committee.

It is not surprising then that expert witnesses appearing before the Committee commented on the inadequacies of current preventative policies and strategies. Professor Batey, for example, told the Committee that:

> *I feel [policies] are not adequate for a disease which is transmitted by blood contamination of individuals through broken skin or venous system directly. I think that has got to be hit head on. If we are serious about Hepatitis C rather than serious about stopping drug use in the community by increasing the war strategy, then I think much more needs to be done* (Batey evidence, 27 October 1997).

Professor Batey pragmatically warned that prevention solutions have to be found unless governments:

> *want to be paying out a billion or two [dollars] in the new millennium treating end stage liver disease from this disease* (Batey evidence, 27 October 1997).

The Committee considers it imperative that policy and strategic direction be provided by NSW Health to address the issue of Hepatitis C prevention. It therefore wishes to see both the NSW Hepatitis C Policy Statement and Strategic Plan (proposed in Recommendations 28 and 31) address this issue.

RECOMMENDATION 88:

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly state the Department's policy to prevent the transmission of Hepatitis C amongst target populations. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identify the direction to be taken to prevent the transmission of Hepatitis C amongst target populations. The Plan should identify existing preventative strategies, include a range of new preventative measures that are innovative and effective and be the basis for funding and evaluation.

10.1 PREVENTING THE TRANSMISSION OF HEPATITIS C AMONGST INJECTING DRUG USERS

Numerous witnesses spoke of the need for preventative strategies to target injecting drug users. Farrell, for example, stated that:

> *my top priority would be primary prevention of injecting drug use, because injecting drug use is not the only risk factor, but it is certainly the remaining 95% plus risk factor* (Farrell evidence, 28 November 1997).

Similarly, Batey informed the Committee that:

> *I think our strategies for prevention . . . are not adequately addressing the fact that the biggest group of newly infected people are injecting users and we have to ask why that has to continue as such. People are wrestling with it. I think we need to wrestle a bit harder and come up with different policies fairly quickly* (Batey evidence, 27 October 1997);

and

> *I think the policy now has to focus on those currently using . . . The policy to stop the new cases must tackle the issue of injecting and injectable type drug using because that is where the new ones are coming. If you could stop that eight to ten thousand per annum now and just deal with the 150,000 that we have got, we would be a damn sight better off* (Batey evidence, 27 October 1997).

As has been discussed, there does not appear to be any policy and strategic direction in preventing the transmission of Hepatitis C. The same can be said for the injecting drug users population group. Given the blood borne nature of the Hepatitis C virus and the considerable risk this poses for injecting drug users, the Committee considers it imperative that the prevention of Hepatitis C amongst this group be treated as a priority.

RECOMMENDATION 89:

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) clearly identify the Department's policy to prevent the transmission of Hepatitis C in the injecting drug user population. The Committee further recommends that the NSW Strategic Plan (proposed in Recommendation 31) clearly identifies strategies that will be put in place to prevent the transmission of Hepatitis C amongst the state's drug injecting population.

It was widely recognised and acknowledged by those appearing before the Committee and making submissions (eg. NSW Health submission) that the major barrier to halting the epidemic amongst injecting drug users is the illegality of the activities associated with injecting drug use.

The following discussion examines preventative strategies already in place for injecting drug users as well as discussing a number of proposed prevention measures raised by witnesses during the course of the Inquiry. The discussion also looks at a profile of injecting drug users and the concept of harm minimisation that is the basis of most prevention strategies.

• A Profile of Injecting Drug Users

It is difficult to ascertain with precision the size of the injecting drug using population in New South Wales given that the activity is an illegal and highly stigmatised activity in the general community. People are reluctant to identify themselves as injecting drug users, making accurate and reliable data difficult to gather.

Results of the National Drug Strategy Household Survey suggest that a very small proportion of the Australian population (1-2%) inject drugs (Commonwealth Department of Health and Family Services, 1996).

Witnesses before the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms addressed the issue of number of injecting drug users in Australia. Dr Darke, Senior Lecturer at the National Drug and Alcohol Research Centre suggested to Members that there are 80,000 to 100,000 regular heroin users across Australia while Dr Garsia, Chair of the Ministerial Advisory Committee on AIDS Strategy suggested there were 20,000 regular injecting drug users in NSW (NSW Parliament, 1998:22).

Despite the stereotypical “junkie” image, injecting drug use occurs across the community and there is no certain way to determine who will and who will not inject drugs (NSW Parliament, 1998:19). An analysis of the demographic characteristics of those taking part in the Western Australian Fitpack study (511 respondents) were described by the authors as “inconsistent with the stereotype of the drug injector held by many in the wider non-injecting community” (Lenton and Tan-Quigley, 1997:xiii). The study found that:

- the mean age of respondents was 26.2 years;

- just over two-fifths (43.4%) were women, a similar proportion (44.3%) were married or living with their sexual partner, and 41.7% had at least one child, 33.6% having a child in their care;

- just under one-quarter (23.8%) listed senior high school as their highest level of education completed, 22.4% listed trade or technical school and 6.8% had completed a university or college course;

- 46.4% of respondents were employed and of these 66.4% were in full time employment; 30.3% were unemployed;

- while the majority of respondents (59.6%) lived in rental accommodation, just over one in six (16.8%) owned or were buying their place of residence and just under one in six (15.4%) lived in their parents' home (Lenton and Tan-Quigley, 1997).

While acknowledging that their sample may not be representative of all drug injectors but rather of those who buy their needles through pharmacies, the authors nonetheless conclude that:

> *this study demonstrates that there are many injecting drug users who do not fit the negative stereotype held by some in the community who do not inject drugs. The data presented here challenge the "them and us" view which marginalises and stigmatises drug injectors. Challenging stereotypes and stigma is likely to be important in further supporting efforts to prevent the spread of blood borne viruses such as . . . Hepatitis C* (Lenton and Tan-Quigley, 1997:xvi).

- **Harm Minimisation**

Under current national policy, services which address drug use, both legal and illegal, include harm reduction, demand reduction and supply reduction.

Based on the premise that some individuals will continue to participate in illegal behaviours harm minimisation focuses on reducing the consequences of drug use. In 1985 the philosophy of harm minimisation was identified as the response to be undertaken to the problems caused by the use of alcohol and drugs. This was indicated by the launch of the National Campaign Against Drug Abuse at the 1985 Ministers' Conference (ANCARD submission to Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

A variety of harm reduction strategies appropriate to particular environments and target groups are encompassed in harm minimisation. In the case of injecting drug use strategies they include cessation, reduction of consumption, drug substitution, the provision of sterile injecting equipment, and education about safe administration. With regard to injecting drug use, the submission by NSW Health to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms noted that harm minimisation:

> *recognises that for many people who use illicit drugs, adopting less harmful behaviours is a more attainable objective in the short term than stopping drug use completely* (NSW Health submission to Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The concept of harm minimisation is supported at the highest government levels including NSW Health and the Australian National Council on Drugs chaired by the Prime Minister's appointee, Major Brian Watters. Major Watters has publicly acknowledged the Council's support for harm minimisation as recently as June 1998 (Sydney Morning Herald, 11 June 1998).

Harm minimisation is also supported by some of the nation's most significant organisations in the field such as ANCARD, and at the state level, the Hepatitis C Council of NSW. In ANCARD's submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms the Council noted that:

> *by promoting harm reduction strategies, it is considered that an environment is produced where safer behaviours and changes toward safer behaviour are considered possible by people who use drugs. As a result there is likely to be fewer transmissions of HIV and other blood borne viruses including Hepatitis B and C . . . The reduction of transmission of viral infections such as Hepatitis B and C are anticipated outcomes of harm reduction strategies* (ANCARD submission to Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

As a Key Conclusion in its deliberations, the Committee fully supports the concept of harm minimisation and considers it to be the most effective underlying principle for strategies to prevent the transmission of Hepatitis C amongst injecting drug users. It will be the basis upon which the Committee frames all recommendations directed at injecting drug users (both in the general community and the state's correction system).

10.1.1 PREVENTATIVE STRATEGIES CURRENTLY IN PLACE

A number of health services are currently available to injecting drug users in New South Wales. These services can be categorised in the following way:

- availability of sterile injecting equipment:
    - the needle and syringe program

- treatment services:
    - methadone maintenance therapy
    - detoxification services
    - counselling and outpatient services
    - residential rehabilitation services (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

During the course of this inquiry, numerous witnesses suggested to Committee Members that at least two of these programs, methadone maintenance therapy (MMT), and needle and syringe programs, are appropriate strategies to limit the spread of the Hepatitis C virus amongst injecting drug users. In addition, there was considerable support for peer based education strategies targeting injecting drug users. Each of these three strategies will be reviewed in the following discussion.

- **Methadone Maintenance Therapy**

Methadone maintenance therapy aims at stabilising a heroin dependent person by providing daily doses of methadone which is a long acting and orally administered opioid. The treatment provides the person with an opportunity to disengage from illicit heroin use and the drug subculture and to access and utilise other rehabilitation services such as counselling.

Currently there are 11,400 people on methadone programs in NSW which equates to 4.1 per 1,000 persons aged 15-44 years (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms). The number of MMT clients has risen in recent years, yet Hall suggests there to be a substantial unmet demand (Hall, 1995). Approximately 70% of those receiving MMT are treated by private prescribers with the remaining 30% enrolled in public programs (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

Research data suggest that MMT results in a reduction of heroin use, crime and overdose deaths amongst treated heroin uses (Hall, 1996). In a US randomised control trial of methadone maintenance 25% of drug users who received this form of treatment had returned to prison within a one year period while 100% of untreated subjects had returned to gaol within the same time period (Dole *et al*, 1969).

In terms of cost effectiveness as a treatment option, Professor Wodak told the Committee that, in his view, the cost of MMT (and needle and syringe programs) is “fairly modest” (Wodak evidence, 2 October 1997):

> *We spend about $40 million nationally on methadone across the whole country each year, compared with $1.7 billion each year on illicit drug law enforcement - that is, one-fortieth of what we spend on law enforcement - and we spend only $10 million on needle exchange. The health, social and economic benefits of these interventions are staggeringly large, especially when compared with the modest costs involved. Even if we reduced Hepatitis C transmission by only five percent by expanding methadone clinics and needle exchange, the cost would be modest and there would be many other benefits apart from Hepatitis C* (Wodak evidence, 2 October 1997).

In 1995/96 approximately $8,950,000 was spent on MMT representing just over one-fifth (21.7%) of the state government's expenditure on all drug and alcohol treatment services in NSW (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

In its submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms, NSW Health made the following points on the methadone program:

- methadone maintenance is currently the most significant treatment program in New South Wales. It is well researched and widely recognised as an effective method for managing opioid dependence and reducing individual and social harms associated with dependence;

- a current trend is toward longer treatment duration. As of 30 June 1996, 48% of clients had been enrolled in their current treatment regime for two years or more and 20% of patients had been enrolled for less than six months.

While there is considerable research on the role of methadone in reducing HIV-risk behaviours (ie less frequent injecting, less frequent sharing, fewer sharing partners and lower HIV seroprevalence [see for example Darke]), there is, as yet, limited research addressing the question of whether MMT also reduces the risk of Hepatitis C. Crofts, Nigro *et al* (1997) reviewed the experience of a major MMT general practice with Hepatitis C infection from 1991 to 1995. Of 1741 individuals tested for HCV antibodies at least once, 66.7% were positive. Of 73 injecting drug users who were initially seronegative and were retested at least once, 19 were subsequently seropositive. The overall HCV incidence rate was 22 cases per 100 person-years. This incidence rate did not differ between those on MMT programs (continuous or interrupted) between HCV tests and those not on MMT (Crofts, Nigro *et al*, 1997). The study's results led Crofts *et al* to conclude that the role of MMT in the control of the spread of HCV infection among injecting drug users needs "further assessment" (Crofts, Nigro *et al*, 1997:999).

A major compounding factor in determining the potential of MMT to limit Hepatitis C transmission is the fact that most new entrants to methadone therapy in Australia are already infected with Hepatitis C. As the NSW Hepatitis C Taskforce report notes, methadone will only be an effective preventative measure when it is considerably expanded and has "far greater access for relatively new drug injectors" (NSW Hepatitis C Taskforce, 1995:19).

There was however, support amongst witnesses for methadone programs as a means of preventing the transmission of Hepatitis C. As the above quote from Wodak suggests, he supported an expansion of methadone clinics (Wodak evidence, 2 October 1997). The Hepatitis C Council also saw a role for methadone programs and they recommended NSW Health not only expand but further resource methadone treatment centres to "improve education, counselling and support services" for people with HCV and that particular focus be given to private methadone prescribers (Hepatitis C Council submission).

NUAA supported the role of MMT as a preventative measure against the transmission of Hepatitis C. From their extensive experience in working with the injecting drug use population they consider methadone therapy facilities to be currently underutilised. As the Association's Coordinator informed the Committee:

> *just about everyone on methadone is Hepatitis C positive and the service is a place where you go every day, it is a place where people could potentially access a great deal of information and support, but often they do not because of the quality of those services . . . You go there to get your dose and you go. It is a shame because it is clearly an intervention point* (Madden evidence, 7 November 1997).

The Committee considers MMT to be an appropriate preventative measure to limit the transmission of the Hepatitis C virus. It therefore wishes to see NSW Health recognise and utilise more fully the role of the MMT program and to expand and further resource methadone therapy facilities throughout the state to provide education, counselling and support services to those who are Hepatitis C positive. The Committee considers it vital that special emphasis be given to injecting drug users early on in their injecting career to limit Hepatitis C transmission amongst this particularly vulnerable group.

RECOMMENDATION 90:

That NSW Health recognise and utilise more fully the role that the Methadone Maintenance Therapy Program plays in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that methadone therapy facilities be expanded and made available throughout the state. Resources should be made available to the Methadone Maintenance Therapy Program to provide initial education, counselling and support services for people who are Hepatitis C positive.

NUAA also identified a number of gaps in the current understanding of methadone as it impacts upon those with Hepatitis C. As Ms Madden informed the Committee, there is "no research" into methadone and Hepatitis C (Madden evidence, 7 November 1997). As an example of the current limited understanding of methadone and Hepatitis C Ms Madden recalled how medical specialists commonly advise HCV+ people not to consume alcohol given the load it puts upon the liver. However, methadone contains ethanol (a form of pure alcohol) but the link between this form of alcohol and liver functioning does not appear to be made. As the Committee heard:

> *the information from Glaxco Wellcome Australia Ltd, which makes methadone, is that methadone is contra-indicated for people with hepatic conditions. But there is no research whatsoever about the impact of methadone on the liver . . . There is no research on methadone and interferon and the interactions between these two. There is certainly no information on the impact of methadone and pregnancy and Hepatitis C. Pregnant women on methadone often have to have their dose significantly altered* (Madden evidence, 7 November 1997).

Given the numbers of injecting drug users with Hepatitis C and the role methadone can play in stabilising drug habits, the Committee considers it important that the impact of methadone on those taking interferon or who are pregnant be determined.

RECOMMENDATION 91:

That the Minister for Health, through the Australian Health Ministers Council, urge the National Health and Medical Research Council to commission and fund research into the interaction between methadone and interferon and the impact of methadone on pregnancy.

Given the potential impact of methadone on those undergoing interferon therapy a more appropriate health response may be heroin prescription. The prescription of heroin to registered drug dependent users is gaining acceptance in Australia. In August this year for example, a majority of delegates at the Western Australian National Party's annual state conference supported a motion for a heroin trial (Le Grand, 1998:3). The concept is also supported by the Lord Mayors in a majority of states across Australia in the Australian Capital Cities Resolution on Drugs (Council of Capital City Lord Mayors, 1998:2).

RECOMMENDATION 92:

That, given the high content level of alcohol in methadone and the impact this has upon those on methadone maintenance therapy who are also undergoing interferon therapy, the Minister for Health conduct a rigorous scientific trial of all alternative therapies for this group of people. The Committee further recommends that an independent advisory committee be established to develop the trial protocol, oversee the trial and review the trial's subsequent evaluation.

- **Needle and Syringe Programs**

The first National HIV/AIDS Strategy released by the Commonwealth Government in 1989 provided a framework for an integrated response to the HIV epidemic and a plan for action across a range of policy and program activities. Needle and syringe programs were part of the education and prevention strategy. The rationale behind the scheme was that:

- despite drug education and treatment programs, many individuals will continue to inject illicit and licit drugs for varying periods of time;

- people must be provided with knowledge and skills necessary to make informed choices about risk behaviours; and

- the community as a whole faces a greater danger from widespread HIV infection than it does from the effects of drug use itself (NSW Health, 1994:4).

The program is based on a model of voluntary exchange in which the return of used equipment is an objective rather than a requirement. The program's policy is that the supply of syringes is never denied on the grounds that used equipment is not returned (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms). The program aims to ensure that the rate of return of equipment to the program is maximised, and that equipment not returned is disposed of in other safe ways. Supply of equipment is always accompanied with a fitpack or other approved disposal container (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

In addition to supplying sterile injecting equipment, staff provide clients with information and education about drug use, infection control, health care and safe disposal of syringes; and referral to drug treatment and other health and associated services. NSW Health described this educational work as an "essential component" of the needle and syringe program and the "key" to much of the program's proven effectiveness (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

Needle and syringe programs commenced in NSW in 1988 after a trial scheme the previous year. Similar programs now operate in all other states and territories and most Western nations. In this state, two schemes provide sterile needles and syringes to injecting drug users: the public sector scheme and the pharmacy fitpack scheme. Operational responsibility for the public sector program lies with the state's 17 Area Health Services with policy direction and monitoring by the Central Office of NSW Health. Its 300 outlets are based in hospitals, community health services, drug and alcohol services and associated non-government organisations (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The public sector program distributes sterile injecting equipment in a number of ways to maximise accessibility to the diverse range of people that make up the injecting drug user population. These include:

- conventional services conducted from a fixed premise;
- outreach and mobile services, both vehicle based and on foot;
- use of generalist and specialised agencies as secondary (additional) outlets, such as community health services and youth services (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

In 1995/96 a total of 4,182,000 needles and syringes were distributed. The program expenditure was $5,959,093 with the average cost per syringe distributed being $1.42. The safe disposal rate was approximately 90% (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The Pharmacy Fitpack scheme was established in 1986 by the NSW Branch of the Pharmacy Guild of Australia. The scheme was relaunched as the Pharmacy Fitpack Scheme in 1990 with funding from NSW Health. Clients can either exchange used syringes for free new ones, or purchase required items. Approximately 530 retail pharmacies throughout the state participate in the scheme.

In 1995/96 a total of 2,141,102 syringes were distributed through this program which received a government subsidy of $1,568,404. The average cost per syringe distributed was $1.06 with the government contributing $0.82 and consumers $0.24 per syringe (NSW Health submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

Some Area Health Services such as the Hunter are utilising the needle and syringe outlets to educate clients on Hepatitis C by providing resources and encouraging them to inform others who inject (NSW Health, 1998:24).

The Committee understands that NSW Health has undertaken a state-wide review of the needle and syringe program. According to NSW Health, the first draft of the Review was completed in 1997 after “lengthy consultations” with the Injecting Drug User Working Party. It was then submitted to the Department for approval. NSW Health advised the Committee that it is anticipated the review will be released “in the near future" (NSW Health supplementary submission). Not surprisingly a number of agencies expressed concern to the Committee at the length of time taken by NSW Health to release the results of this review.

NSW Health advised the Committee that it recurrently allocates $7,500,000 to the needle and syringe program (NSW Health submission). This figure has to be viewed within the broader context of cost-effectiveness. Estimates of the cost-effectiveness of needle and syringe programs in Australia in 1991 were developed using base case (the most plausible), best case and worst case assumptions (see Table Thirty below). An estimated 3000 cases of HIV were avoided in Australia in 1991 through the operation of needle and syringe programs. Using gross expenditure (without deducting any direct or indirect cost savings), the cost per life-year saved varied from $50 in the best case to $7000 in the worst case. The most likely cost per life-year saved was $350 (Feachem, 1995:91).

The savings in treatment costs due to prevention of HIV infection more than offset the operating costs of the program. According to Feachem, this means that the programs were cost-saving, even under the worst case assumptions (Feachem, 1995:91). His analysis underestimates the likely cost effectiveness of needle and syringe programs because the program's role in decreasing the transmission of Hepatitis B and C was not factored in. As Feachem notes, if these additional benefits were measured, both the number of years of life saved and the net direct cost savings would be increased (Feachem, 1995:91). Based upon these statistics, the Third National HIV-AIDS Strategy endorsed the ongoing use of the needle and syringe program as a cost-effective response to the spread of Hepatitis C (along with HIV and other communicable diseases) (Feachem, 1995:88).

TABLE THIRTY
COST EFFECTIVENESS OF NEEDLE AND SYRINGE PROGRAMS IN AUSTRALIA, 1991

ITEMS	BASE CASE	BEST CASE	WORST CASE
Data and assumptions [a]			
Cost per needle distributed ($)	1.40	0.70	2.80
No of IDUs per 1000 population	5	10	3
Annual reduction in rate of increase of seroprevalence attributed to program (%)	3.4	6.1	0.6
Effectiveness			
No of cases prevented	2,900	10,300	300
No of life-years saved	24,100	86,300	2,500
Cost effectiveness			
Expenditure per life-year saved ($)	350	50	7000
Net direct cost ($m)	-266.7	-984.3	-11.5

[a] Additional assumptions for all analyses:

- number of needles distributed in Australia was 6.3 million
- lifetime treatment costs is $96,200
- average age of infection of IDUs is 24 years
- average time from HIV infection to death is 12 years

Source: Hurley, Jollley and Kaldor, cited in Feachem, 1995:91.

Findings of numerous studies conducted both in Australia and overseas suggest that needle and syringe programs have been effective in controlling the spread of HIV infection. Overseas studies have shown that the average annual HIV seroprevalence is 11% lower in cities with needle and syringe programs than cities without the programs (Hurley *et al*, 1997).

Results from the Australian Needle Exchange Survey suggest that needle and syringe programs are also having an effect on limiting the transmission of Hepatitis C. The Survey's longitudinal study has found HCV antibody prevalence was significantly lower amongst injecting drug users in selected needle and syringe programs in 1997 than in 1995 and 1996 (63% and 65% vs 50%, p<0.001) (MacDonald, Wodak and Kaldor, unpublished). HCV prevalence was also significantly lower in 1997 than in 1995 and 1996 among respondents new to injecting (22% and 34% in 1995 and 1996 vs. 13% in 1996; 1995 vs 1997 p<0.01) (MacDonald, Wodak and Kaldor, draft). The study concludes that:

> *the first three years of monitoring HCV antibody among injecting drug users attending selected needle and syringe programs throughout Australia indicates that HCV prevalence is declining among this population . . . The reduction was also observed among respondents new to injecting* (MacDonald, Wodak and Kaldor, draft).

A range of studies have documented the fall in rates of needle and syringe sharing across Australia. When asked if they had shared injecting equipment in the previous month, respondents' responses ranged from 13% (Loxley *et al*, 1997:55) and 28% (Lenton, 1995) to 31% (MacDonald 1995). The Australian Needle Exchange Survey conducted in 1995, 1996 and 1997 has also found significant reductions over the three year period of 30% (1995), 28% (1996) and 17% (1997) (MacDonald, Wodak and Kaldor, draft).

In reviewing these findings Loxley cautions that the findings suggest that, because recruitment strategies determine the sub-population tapped, caution should be exercised in drawing too many inferences from a single study (Loxley, 1997:55). She concludes that:

> *despite a wide variety of needle distribution schemes around the country, some needle sharing continues, and clearly at a high enough level to maintain the Hepatitis C epidemic . . . If we are to minimise needle*

> *sharing we have to look at more than just the provision of sterile injecting equipment . . . Our investigations must consider the nature of the social relationships within which sharing takes place, and what injecting drug users believe and understand about these relationships* (Loxley, 1997:55).

Despite the success of needle and syringe programs in limiting the spread of HIV, the program continues to be criticised. Those against the program claim that it results in increasing drug use. The final report from the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms notes however that as "a person who intends to inject drugs will do so whether a new needle is provided or not, it is unlikely that NSEPs have led to an increase in drug usage" (NSW Parliament, 1998:44). The Committee's claim is backed up by US and local research, with the US findings concluding that:

> *there is no evidence that needle exchange programs increase the amount of drug use by needle exchange clients or change overall community levels of non-injecting or injecting drug use* (Lurie and Reingold, 1993).

Similar findings from a Sydney based study concluded that:

> *an increase in the availability of sterile needles and syringes does not appear to lead to an increase in the frequency of intravenous drug use* (Wolk et al, 1990).

Evidence received by the Committee supported these research findings. Sladden, for example, told the Committee that:

> *I do not believe that you could say that [the needle and syringe program] is encouraging drug use. It is a pragmatic harm-minimisation strategy. It is not condoning drug use; it is merely trying to raise awareness and prevent routes of infection* (Sladden evidence, 30 March 1998).

The Committee received evidence of difficulties experienced by injecting drug users visiting needle and syringe outlets:

> *Users have told us many times that often they feel too scared to return used equipment to needle exchanges because they are afraid they will be busted by police on their way to or from the needle exchange . . . police are putting pressure on the users to tell them what the new equipment will be used for. If they admit that they are going to use it for illegal drug use, the police can harass them and make their life difficult. Users need to have only one of these experiences on the way to or from a needle exchange to make it unlikely that they go back to that exchange.*

> *Unfortunately we are hearing those stories in the areas that we can least afford people to stay away from needle exchanges - for example, western Sydney* (Madden evidence, 7 November 1997).

The Committee heard that it is NSW Police Service policy for police not to operate within the parameters of needle and syringe outlets and that police officers on the beat "generally respect and enforce" that policy (Madden evidence, 7 November 1997). However, NUAA told that Committee that:

> *we are increasingly hearing that police are sitting just outside the limit of the parameters of that area and they are coming up to drug users knowing that they have come out of the needle exchange* (Madden evidence, 7 November 1997).

Conscious of such harassment, the Hepatitis C Council recommended to the Committee that cooperation be sought from NSW Police Service to ensure that access to services for people who inject drugs is unhindered and that clients can use needle and syringe outlets without fear of intimidation or arrest (Hepatitis C Council submission).

RECOMMENDATION 93:

That the Minister for Police review the instructions concerning police patrols within the proximity of needle and syringe outlets and that the instructions clearly state that:

i) maximum and effective use of needle and syringe outlets is an effective preventative measure against the transmission of Hepatitis C and other blood borne diseases; and

ii) clients' access to needle and syringe outlets is to be unhindered and without fear of intimidation or arrest.

During the course of this Inquiry, Committee Members visited three needle and syringe outlets. The visited outlets were attached to the Albion Street Centre at Darlinghurst, the Kirketon Road Clinic at Kings Cross and the NUAA headquarters at Bondi. This latter outlet distributes approximately 80,000 needles and syringes each year to injecting drug users across the state with a return rate of 82 per cent. With reference to the NUAA outlet the Committee heard in evidence that:

> *over the past two years, the demand of the needle exchange has increased by 100 per cent each year, which is putting quite a strain on our needle exchange budget. However, we have a commitment to harm reduction and that means that we do not put limits on the equipment we give people because we believe to put limits on the amount of equipment*

> *people can have access to would say to them that we are encouraging them to reuse needles and syringes and we would not do that* (Madden evidence, 7 November 1997).

The Committee received considerable support by witnesses for the continuing use and expansion of needle and syringe programs. Crofts, for example, stated that:

> *My highest [prevention] priority would be stopping the current epidemic and my highest priority within stopping the current epidemic would be to do our utmost to eradicate the sharing of contaminated needles and syringes which means support for needle exchange programs and other ways of distributing needles and syringes* (Crofts evidence, 28 November 1997).

Gold considered needle and syringe programs to be "the major preventative strategy . . . any other strategy is a far second to that" (Gold evidence, 26 February 1998).

Sladden identified expansion of the needle and syringe program as one of the most important preventative strategies in limiting the spread of Hepatitis C. He considered there to be scope within the program to "incorporate further education into the target group injecting drug users to ensure their raised awareness" (Sladden evidence, 30 March 1998).

The Hepatitis C Council's submission stated that needle and syringe programs have a "significant role to play" in the provision of information and education to those at high risk of HCV. Further, the Council's Executive Officer identified needle and syringe programs as the Council's top preventative priority. As Loveday informed the Committee,

> *we strongly suggest that the Standing Committee on Social Issues strongly recommends support for needle exchange expansion and continues to debate and make recommendations for areas where people who choose to inject can do so as safely as possible* (Loveday evidence, 30 March 1998).

Like Sladden, the Council envisaged an expanded role for needle and syringe programs. In their submission to the Inquiry, they called for the program to be expanded to include primary health care, counselling services and safe, supervised injecting areas (Hepatitis C Council submission). The Council's submission noted that in city locations, needle and syringe outlets are "generally isolated" from other health programs and it "may be useful" for the programs to "link" with other community health programs and to become part of a range of services provided for people at risk of, or with HCV (Hepatitis C Council submission).

During the course of evidence, the Council representative suggested needle and syringe outlets to be appropriate venues to target young people who are starting to inject (Loveday evidence, 3 October 1997).

NUAA similarly recommended the expansion of the needle and syringe program to enable primary exchanges to play a more significant role in assessment, referral and general health information provision to injecting drug users. NUAA noted that needle and syringe outlets are currently unable to meet the level of demand for new injecting equipment. As a result,

> *the "new fit every hit" initiative has not been entirely successul in preventing the spread of the [Hepatitis C] virus because the supply of clean injecting equipment including water, swabs, tourniquets and spoons, has not been made readily available to everyone who has chosen to inject drugs . . . It is not possible for drug users to use a "new fit every hit" because needle exchanges cannot presently meet this demand* (NUAA submission).

Given this situation, the Association recommended resourcing levels be expanded to "more adequately" meet the needs of the injecting drug users population (NUAA submission).

Similar recommendations were made by the NSW Hepatitis C Taskforce which identified a "critical goal" of needle and syringe programs to be the provision of sterile injecting equipment throughout the state at all times of day and night while minimising costs and other disincentives to utilisation (NSW Hepatitis C Taskforce, 1995:20). Accordingly, the Taskforce recommended increasing the throughput of the needle and syringe program in NSW to reach a target of 9 million per year by the year 2000 and the identification of "blackspots" in the availability of sterile injecting equipment and the development of strategies to rectify the situation (NSW Hepatitis C Taskforce, 1995:5).

Incorporated into its submission to this Inquiry, ANCARD attached the submission they made to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms. That submission noted that, while needle and syringe programs have been successful in reducing the spread of HIV, the program alone is "not enough" to address Hepatitis C due to the highly infectious nature of the disease:

> *it should be noted that needle and syringe programs are only one component of a harm minimisation strategy, but as there appears to be a continuing unacceptably high rate of transmission of Hepatitis C amongst injecting drug users it is evident that additional and preventative measures are still required* (ANCARD submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

Professor McCaughan also supported an expansion of the needle and syringe programs. He noted that:

> *when we talked about this matter [role of needle and syringe programs in reducing the spread of Hepatitis C] two or three years ago there was general consensus that, although needle exchange was effectively controlling HIV, it was not controlling Hepatitis C. It still is not controlling Hepatitis C but when it is done properly it may have the potential to do so. So I should have thought that the number one priority in containing the spread of this infection is to expand the use of very effective needle exchange programs* (McCaughan evidence, 23 March 1998).

Given that the majority of injecting drug users have already been exposed to the Hepatitis C virus by the time they utilise needle and syringe programs some witnesses expressed a degree of ambivalence, even negativity, toward the program. Hall, for example, stated that:

> *the exchange program has probably hindered the spread of Hepatitis C but has not stopped it . . . the needle exchange program is certainly not the solution that it was for HIV. But I cannot imagine what it would be like without needle exchange and whether it would be much worse. I do not know; it is hard to tell* (Hall evidence, 6 November 1997).

Professor Farrell did not support the use of needle and syringe programs as a means of limiting the spread of Hepatitis C. He noted that:

> *needle exchange has been very successful we think with HIV and that is a triumph. It has been a miserable failure with Hepatitis C* (Farrell evidence, 28 November 1997).

As he noted, the Kirketon Road Clinic data (see Section 3.1.2) show that 89 per cent of under 20 year olds surveyed have Hepatitis C:

> *so we have reasonably good - they may not be perfect - needle exchange programs, but they are not touching Hepatitis C, so I just do not see the efficiency of that approach* (Farrell evidence, 28 November 1997).

Despite Farrell's concerns, the Committee supports the role the needle and syringe program plays in preventing Hepatitis C transmission amongst injecting drug users and wishes to see the Program further developed and extended in its reach and range of services so that outlets throughout the state provide:

- education and information (including available treatment options), counselling and support services to people who are Hepatitis C positive;

- increased after-hours service;
- access to sterile water, alcohol swabs and cotton wool filters; and
- for integrated services in conjunction with other community health programs.

RECOMMENDATION 94:

That the Minister for Health recognise the role of the Needle and Syringe Program in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that the Program be further developed and extended in its reach and range of services so that outlets throughout the state provide:

- education and information (including available treatment options), counselling and support services to people who are Hepatitis C positive;
- increased after-hours service;
- access to sterile water, alcohol swabs and cotton wool filters; and
- for integrated services in conjunction with other community health programs.

RECOMMENDATION 95:

That the Minister for Health ensure the Needle and Syringe Program is adequately resourced to take on the additional functions proposed in Recommendation 94.

As with the MMT program, the Committee particularly wishes to see the needle and syringe program target injecting drug users early on in their injecting careers to limit the transmission of Hepatitis C within this particularly vulnerable group. It therefore wishes to see needle and syringe outlets specifically target injecting initiates particularly young people.

RECOMMENDATION 96:

That NSW Health design strategies targeting those who have just commenced injecting practices to warn them of the inherent dangers of contracting Hepatitis C from unhygienic equipment and to encourage them to utilise fully the services offered by needle and syringe outlets. The Committee further recommends that the Needle and Syringe Program be resourced to implement the proposed strategies.

Given these additional functions assigned to needle and syringe outlets, the Committee recognises that those working in the outlets will need to be skilled and trained to provide HCV specific information.

RECOMMENDATION 97:

That NSW Health ensure workers at needle and syringe outlets are adequately skilled and trained to provide HCV specific information.

- **Peer Based Education Amongst Injecting Drug Users**

The development of peer based education strategies has been used successfully in many areas, most notably HIV. The aim of peer based education is to increase the level of accurate information communicated within the marginalised youth population by young people. The Hepatitis C Council suggested to the Committee that the use of these strategies in the prevention of Hepatitis C may reach a greater number of people at risk of infection and develop more appropriate interventions which take account of the specific cultural and social practices that occur around risk related behaviour (Hepatitis C Council submission).

While the Committee is aware of a number of peer education projects targeting injecting drug users such as those sponsored by the Cellblock Youth Health Service, the agency primarily responsible for peer education amongst injecting drug users appears to be NUAA. Much of the education material prepared and distributed by NUAA now provides information on the Hepatitis C virus and ways to prevent its transmission.

One of NUAA's main peer education and community development projects is known as Tribes. The Tribes project centres on Hepatitis C and drug use (Madden evidence, 7 November 1997). Through this project NUAA directly funds eight to twelve individual projects each year. As the Committee was informed:

> *Tribes operates on the premise that people who use drugs do not always identify primarily as drug users or with mainstream health promotion campaigns* (Madden evidence, 7 November 1997).

The project funds subcultural groups, or "tribes" of drug users, in the community to develop their own health education messages. These projects utilise icons, media and language of the tribe to address harm reduction issues specific to that group.

A total of 35 separate Tribes projects have been funded since the program started in 1992. The projects cover a very diverse range of groups including "Ravers", steroid users, skateboarders in Wollongong, young Indo-Chinese heroin smokers in

Cabramatta, “Rivo Boys”, “Hip Hop Crew”, “Kooris Behind Bars”, “Tattooed Metalheads”, “Bikers”, and trade unions.

NUAA’s other principle education program is known as the Community Resource Outreach Workers (CROW) project. The project targets rural and regional areas of the state. Since 1993 CROW projects have been conducted in Bathurst, Tamworth, Lismore, Dubbo, Bowral/ Moss Vale, Albury, Gosford, Narooma, Newcastle, Armidale, Parkes/Forbes, Coffs Harbour, Nimbin, Broken Hill and Goulburn in addition to a number of metropolitan areas such as St Marys, Blacktown, Liverpool, Campbelltown, and Sutherland/Cronulla (Madden evidence, 7 November 1997).

The project employs six drug users in six different geographical areas for ten hours a week for six months to work with networks of local drug users on issues of local significance. A total of 22 individual drug users have been employed as CROW project workers since 1993 (Madden evidence, 7 November 1997).

NUAA also publishes a newsletter, *NUAA News*, which also contains Hepatitis C relevant information. With an estimated readership of between 40-60,000 per edition, the newsletter is “NUAA’s flagship publication and has a statewide and international reputation and profile” (Madden evidence, 7 November 1997).

The role of peer based education initiatives as a preventative strategy in limiting the transmission of Hepatitis C was recognised by both the Hepatitis C Council and NUAA. The Council recommended peer based education programs and community based peer support groups be extended and funded to adopt fresh approaches to help prevent Hepatitis C transmission (Hepatitis C Council submission). NUAA recommended that peer based education and community development initiatives be “actively supported and funded” by the NSW Government to support the ongoing development and implementation of Hepatitis C prevention strategies among injecting drug users (NUAA submission). NUAA also specifically recommended funding be provided for a state-wide peer based education campaign on the importance of blood awareness for injecting drug users and the development of new innovative disinfection messages.

The NSW Hepatitis C Taskforce “strongly” supported the use of peer based education strategies with active non-tokenistic involvement of injecting drug users in all phases of design and implementation of education strategies (NSW Health, 1995:21).

Crofts and his colleagues suggest that peer education programs are likely to be “the most effective” harm reduction approach among new injectors (Crofts, Louie, Rosenthal and Jolley, 1996:1187).

RECOMMENDATION 98:

That NSW Health provide funding for a state-wide peer based education campaign on the importance of blood awareness amongst injecting drug users. The Committee further recommends that representatives from the Hepatitis C community and other appropriate interest groups be involved in the development and implementation of the proposed education strategies to ensure the strategies are practical and effective and appropriate.

10.1.2 PROPOSED MEASURES TO PREVENT OR DELAY INITIAL INJECTING

Loxley has noted that there is only a “narrow window of opportunity” for preventing Hepatitis C among injecting drug users (Loxley, 1997:54). This limitation has “fuelled” a research interest in people in the early stages of their injecting careers and the first transition to injecting (Loxley, 1997:54). Studies conducted by both Croft, Louie, Rosenthan and Jolley (1996) and Loxley (1997) have found the average age of first injecting in Australia to be around 16 years of age. The desire for the “rush” and curiosity about injecting were given as reasons for injecting in both studies. Respondents also said that injecting was the most cost effective way of using drugs (Loxley, 1997:55).

There is a need to reduce the incidence of new infections among people commencing to inject drugs in order to reduce the long term prevalence of HCV infection in the community. Adolescents are the primary target group. However, the Director of Kirketon Road Clinic, Dr van Beek noted in evidence that there are no specific services targeting people when they start injecting or even before that (van Beek evidence, 6 November 1997).

Adolescents who are beginning to experiment with injecting drugs may not have any knowledge of, or access to, needle and syringe programs, not would they necessarily identify themselves at that stage as injecting drug users who use such programs.

For these reasons, the Committee considers it imperative that the basic message of all preventative strategies to prevent or delay initial injecting behaviour in adolescents is a very clear one that encourages young people not to take drugs.

RECOMMENDATION 99:

That NSW Health and the Department of Education and Training ensure the basic message of all preventative strategies to prevent or delay initial injecting behaviour in adolescents is a very clear one that encourages young people not to take drugs.

The Committee considers it imperative that appropriate measures be put in place to prevent or delay initial injecting. During the course of the Inquiry, witnesses identified two measures they considered appropriate to target this group of young people.

- **Education**

A number of expert witnesses identified school based education programs as a preventative strategy to limit the spread of Hepatitis C. Farrell considered educational programs to be an "investment" (Farrell evidence, 28 November 1997) while McCaughan saw education as an important strategy in limiting the spread of Hepatitis C. He envisaged such education as commencing with 10-12 year old students (McCaughan evidence, 23 March 1998).

Dr Gold regarded school education as "one of the most important prevention strategies" (Gold evidence, 26 February 1998). Sladden considered school education to be "crucial" to enable young people to make informed choices, know what services are available and what risks they are taking before they experiment with drugs. As he told the Committee:

> *We need to look at adolescents and awareness raising in school children prior to any experimental drug-taking behaviour. That is the group we have to raise the awareness of because once they start to inject it is only a matter of time before they become infected. So we have to work with the schools to ensure that children are aware of this issue prior to any experimental behaviours* (Sladden evidence, 30 March 1998).

The Hepatitis C Council suggested education should target:

> *schools at an early age focussing initially on blood awareness and then moving on at older ages to more explicit education about the facts of drug use; accurate information and education for people who are enhanced risk of Hepatitis C infection; and education in establishments other than schools, for example, TAFE and university* (Loveday evidence, 30 March 1998).

The NSW Hepatitis C Taskforce recommended school based education programs provide objective information about risks of injecting drug use and appropriate measures for harm minimisation (NSW Health, 1995:4-5).

NUAA recommended that further funding be provided for the ongoing development of school-based education programs in relation to the prevention of Hepatitis C (and other blood borne viruses) (NUAA submission). Similarly the Hepatitis C Council recommended that NSW Health and NSW Department of Education and Training provide "greater support" and funding to school based education programs in the areas of alcohol and other drug awareness and harm reduction strategies and that access to schools to achieve this be improved (Hepatitis C Council submission).

NSW Health officers advised the Committee that their department annually gives the Department of Education and Training $1million from the National Drug Strategy for drug education in primary and secondary schools. This allocation was confirmed by a representative from the Department of Education and Training who informed Committee Members that such funding had been provided to the Department since 1985-86. The funding “addresses the range of risks to the health of young people associated with drug use” (Kerr-Roubicek evidence, 30 March 1998). As Ms Kerr-Roubicek informed Members:

> *there is an expectation that the Department of School Education will use the funding to address priorities within schools which are consistent with directions established within national and state drug strategies . . . Current priorities relate to the provision of age-appropriate effective education about tobacco, alcohol and cannabis for all students as components of ongoing personal development, health and physical education programs* (Kerr-Roubicek evidence, 30 March 1998).

Ms Kerr-Roubicek also informed Members that current funding is being used to conduct extensive teacher training on drug education and issues associated with the management of drug-related incidents in schools. The funding from NSW Health is also used for ten field-based drug education officers who work directly with schools, providing advice and training on policy, teaching programs and resource for drug education (Kerr-Roubicek evidence, 30 March 1998).

Representatives from NSW Health informed the Committee that the school based education programs includes HCV transmission, prevention and harm reduction (Wilson evidence, 3 October 1997). However, when specifically asked about Hepatitis C educational initiatives and the risks of needle sharing, Ms Kerr-Roubicek informed Members that such information forms a “very small component” of drug education (Kerr-Roubicek evidence, 30 March 1998).

In responding to the evidence received concerning school based drug education, a representative from the Hepatitis C Council told the Committee that he was:

> *a little bemused when NSW Health mentioned that there was a definite school education program. Recently I spoke with a key researcher in Sydney . . [she] said that she was not aware of any planned, co-ordinate Hepatitis C educational program in schools, one about harm minimisation or simply suggesting that people should not inject or take drugs* (Harvey evidence, 3 October 1997).

It would appear that there are discrepancies between the NSW Health's expectations of what is included in drug education and what the Department of Education and Training actually provides. NSW Health appears to assume that Hepatitis C, its prevalence and modes of transmission are being taught to school children. Evidence provided by Education and Training suggests otherwise. The Committee would like to see the current misunderstanding between the two departments clarified.

The Committee also considers it important that agreement be reached between these two Ministers on the aims for Hepatitis C education within the school system. Appropriate aims would be:

- to prevent infection with HCV by discouraging young people from engaging in risk behaviours; and
- to promote harm minimisation for young people who already inject.

RECOMMENDATION 100:

That the Minister for Health and the Minister for Education and Training meet and reach an agreement on the role to be played by the Department of Education and Training in providing Hepatitis C education to children and young people in the state's school system. The Committee further recommends that the two Ministers give consideration to the following aims for Hepatitis C education within the school system:

- to prevent infection with HCV by discouraging young people from engaging in risk behaviours; and
- to provide information on harm minimisation for young people who may have already become involved in drug use.

The aims of Hepatitis C education will give direction to specific strategies to be put in place. The Victorian Hepatitis C strategy document identifies a number of relevant strategies for school-based education programs designed to raise about:

- the nature of HCV, including epidemiology, transmission and risk behaviours;
- a range of strategies to assist students to adopt prevention options or reduce the harm associated with specific behaviours;
- potential behavioural, social and environmental risk factors; and
- appropriate sources of information, support and advice, including testing and treatment information and services (Victorian Department of Health and Community Services, 1995:26-27).

The Committee would like to see similar strategies addressing these issues available to high school students throughout NSW.

RECOMMENDATION 101:

That the Department of Education and Training develop school-based education programs to raise student awareness on issues including:

- the nature of Hepatitis C, including epidemiology, transmission and risk behaviours;
- a range of strategies to assist students to avoid injecting drug use;
- potential behavioural, social and environmental risk factors; and
- accessing appropriate sources of information, support and advice, including testing and treatment information and services.

- **Provision of Youth Services**

Professor Farrell was the only witness appearing before the Committee to take a very broad approach to preventing the transmission of Hepatitis C amongst young people. He saw the:

> *investment in both educational programs and indeed youth services in general as being a very important part of Hepatitis C prevention* (Farrell evidence, 28 November 1997).

In his opinion,

> *We need a supportive society in which kids have proper peer support and have people that they can turn to . . .   If people are not putting their hand up and becoming scout masters, maybe we need programs whereby we have better youth support activities and I think we really need to look at all those things* (Farrell evidence, 28 November 1997)

and

> *maybe funding scout masters would make more impact on Hepatitis C than needle exchange programs* (Farrell evidence, 28 November 1997).

Farrell considers it vital that we “really grapple” with the reasons behind the nation’s current high levels of dangerous drug experimentation and drug abuse and why youth turn to drugs in the first place (Farrell evidence, 28 November 1997).

The Committee fully supports Farrell and the claims he made. His concerns echo many of those issues raised during the course of the Committee's Inquiry into Youth Violence. The final report of that Inquiry made recommendations including:

> *that the Minister for Education encourage the extension of the use of schools for community-based programs and services, especially for initiatives providing support, training and leisure activities for young people (Recommendation 59);*
>
> *that the Minister for Education encourage education regions to consider the involvement of outside experts in the areas of youth programs, youth education and violence prevention in the development of programs addressing youth violence (Recommendation 63); and*
>
> *that the Ministers for Community Services, Sport and Recreation and Education collaborate on the expansion of outside school hours programs specifically designed to meet the needs of 12 to 15 year olds (Recommendation 11)* (Standing Committee on Social Issues, 1995)*.*

10.1.3 PROPOSED PREVENTATIVE MEASURES TARGETING INJECTING DRUG USERS

Four preventative measures targeting injecting drug users were proposed to the Committee. Three of these measures would be considered to be harm minimisation strategies while the fourth, increased availability of treatment options would be considered to be a demand reduction strategy. Subsequent to making their submission and appearing before the Committee, NSW Health provided the Committee with a copy of briefing paper prepared for the National Drug Strategy Committee considering Hepatitis B vaccinations for (amongst others) injecting drug users. This issue, along with the other four already identified will be reviewed in the following discussion.

- **Hepatitis B Vaccinations for Injecting Drug Users**

Co-infection with Hepatitis B and C is associated with more severe hepatic fibrosis and cirrhosis than chronic Hepatitis C infection alone and those with both forms of hepatitis have a higher risk of cancer than those with only one form (NSW Health, 1998:2). The poor prognosis of people who acquire a second hepatitis virus while still infected with the first has led to a generally accepted recommendation that people with Hepatitis C should, where possible, be vaccinated against Hepatitis A and B.

A pilot Hepatitis B vaccination program for methadone clients was presented to the National Drug Strategy Committee Meeting in March 1998. The proposal was subsequently forwarded to the National Centre for Disease Control for consideration but as of mid August 1998, NSW Health advised that no funding had been forthcoming from this source. NSW Health also informed the Committee that a scaled-down project proposal was forwarded to the Commonwealth Department of Health and Family Services to consideration under the Public Health Outcomes Funding Agreement Incentives Program (NSW Health supplementary submission). Advice on the success of this proposal was not available at the time of tabling this report.

Despite difficulties in securing funding for a pilot of Hepatitis B vaccination program for methadone clients, the Committee considers the proposal to have considerable merit and urges the Department to continue applying pressure to the Commonwealth Department of Health and Family Services to provide funding under the Public Health Outcomes Funding Agreement Incentives Program to pilot a Hepatitis B vaccination program for methadone clients in New South Wales.

RECOMMENDATION 102:

That NSW Health continue to urge the Commonwealth Department of Health and Family Services to provide funding under the Public Health Outcomes Funding Agreement Incentives Program for a pilot Hepatitis B vaccination program for methadone clients in New South Wales.

- **Treatment Options**

The Hepatitis C Council suggested reducing the demand for drugs by improving and increasing the resourcing for appropriate treatment facilities to be an appropriate Hepatitis C preventative strategy (Loveday evidence, 30 March 1998). Their submission recommended that NSW Health provide and fund a greater range of alcohol and other drug treatment programs to provide greater options for improved detoxification, rehabilitation, counselling and support services, both to help prevent Hepatitis C transmission and to support those already with HCV (Hepatitis C Council submission). A similar recommendation was made by NUAA who called for a range of treatment options for opioid and psychostimulant dependent users be developed and/or expanded as such services have been shown to have clear harm reduction and disease prevention implications. NUAA saw these options as including the establishment and development of LAAM, Buprenorphine, Naltrexone, slow-release oral morphine and heroin maintenance initiatives for opioid dependent users (NUAA submission).

NUAA also recommended existing drug treatment service providers play a “more direct and active role” in the provision of education and information to injecting drug users as it relates to the education and prevention of Hepatitis C (NUAA submission).

RECOMMENDATION 103:
That the Minister for Health ensure drug treatment services funded by NSW Health play a more direct and active role in providing information on the prevention of Hepatitis C to injecting drug users.

The results of a survey conducted between May and July of this year by the Network of Alcohol and Drug Agencies showed that drug treatment centres in NSW are overwhelmed with requests for treatment. As a result of this demand only 28% of those seeking admission are able to access rehabilitation programs (Bernoth, 1998). According to the Network the government "must double the available service if it is serious about taking the burgeoning drug problem" (Bernoth, 1998). To meet demand, NSW would need 3,064 additional places on top of the 2,321 places currently available. Clearly there is a need for services to be expanded to keep up with the increasing demand for rehabilitation.

RECOMMENDATION 104:
That NSW Health increase the provision of drug treatment and rehabilitation programs as an effective Hepatitis C preventative strategy.

- **Non-Injecting Routes of Administration**

Wodak strongly supports measures to encourage injecting drug users to take the drugs by methods which are "less damaging" to both themselves and the community in general. As he informed Members:

> *This means they would sniff, snort, smoke or swallow the drugs. This does not condone illicit drug use: this is simply to say that these methods are less damaging than plunging a needle in one's arm. If we managed to get people to move from injecting to these other routes of administration there would be other benefits and there would be other risks* (Wodak evidence, 2 October 1997).

Wodak identified the major benefit to be a "sustained" reduction in the overdose death rate, while the major risk would be lung damage (Wodak evidence, 2 October 1997).

In proposing this strategy, Wodak was very aware of its inherent difficulties:

> *How would we facilitate such a transition? It would be very difficult, very awkward in the extreme for Health Ministers or Premiers or Members of Parliament to exhort Australia's drug users to do the right thing by the*

> *country and flag and start taking drugs by these other routes of administration, and I recognise that* (Wodak evidence, 2 October 1997).

He made a similar comment in his submission:

> *one obvious obstacle is the difficulty many political leaders and parties will have embracing such a policy. Another difficulty is how one could actually facilitate such change. The inevitable policy conflict between discouraging tobacco smoking and appearing to encourage heroin smoking is another ground for concern* (Wodak submission).

Support for Wodak's proposal came from the Hepatitis C Council and ANCARD. The Hepatitis C Council recommended NSW Health, in conjunction with the Commonwealth Department of Health and Family Services, oversee and fund the development of strategies to move to alternative routes of drug administration that do not involve the blood contact risks of injecting (Hepatitis C Council submission).

ANCARD's submission to this Inquiry noted that:

> *we need to encourage other ways of using illegal drugs such as inhaling, swallowing or smoking . . . we must couch any program that relates to other routes of drug use on the basis that drug use of any sort carries risks and we are not suggesting that snorting or inhaling is a safe exercise, but it is safer than injecting* (ANCARD submission).

In evidence before the Committee, ANCARD Chair added that:

> *there are non-injecting routes of administration of illegal substances which, if people are determined to take illegal substances, should be considered as a preference over injecting. It is a matter of saying that public policy is in the first instance* ***do not do drugs****. But if you are going to do drugs then look at the way which is least likely to have long-term damaging effect, and that is by non-injecting routes of administration rather than by injecting drug use* (Puplick evidence, 7 November 1997).

When questioned on ways to make such a suggestion politically acceptable, Puplick replied:

> *I do not believe there is any political way of packaging that to make it look particularly attractive but that is part of the larger issue of addressing the fact that a simple "just say no" strategy cannot work* (Puplick evidence, 7 November 1997).

ANCARD's submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms noted, however, that the threat of

Hepatitis C or HIV "may not be sufficient to support a complete shift away from injecting" (ANCARD submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The NSW Hepatitis C Taskforce considered there to be an "inherent plausibility" in encouraging a transition to non-injecting routes of administration. However the Taskforce's report points out that the strategy carries a "theoretical" risk of increasing the numbers using potentially injectable substances, some of whom might subsequently transfer from non-injecting to injecting routes of administration (NSW Health, 1995:22).

The Committee learnt that a major obstacle to Wodak's proposal is the type of heroin available in Australia. As Members heard in evidence:

> *historically, injecting has been the preferred way of taking substances in Australia . . . One of the main reasons for that is that Australia mostly gets its heroin from the Chinese - white no. 4 - and it is not suitable for smoking. You can smoke it - of course there are ways to smoke it - but you lose most of the quality of the drug in the process. It burns too quickly. . . In Europe and the United States, the Chinese white No. 3 which is the more smokeable form, is more available . . It is more available than the No. 4. In places such as Holland, statistics show that two-thirds of people smoke and one-third inject . . . When you are spending your last $50 on a hit of heroin, you are not going to use it in a way that is not very useful to you . . . you are going to use it in the most efficient way possible. Injecting the No. 4 is that way. That is one of the major reasons we see a tendency toward injecting* (Madden evidence, 7 November 1997).

Ms Madden elaborated further that:

> *the issue is that injecting is an efficient way of using drugs - to be a bit crude: you get more bang for your buck. That is what users say about that - you get more effect for your money if you shoot it rather than smoke or swallow it. . . Users get used to injecting, they enjoy the rush that comes from injecting. You do not always get the same feeling from smoking drugs. . . There are also rituals tied up with injecting: the whole process of scoring the illicit drugs, the anticipation and the mixing of those drugs. . . some people prefer to inject drugs, which is hard to understand if you are not an injector* (Madden evidence, 7 November 1997).

Available research suggests that any transition between routes of administration that is occurring in Australia tends to be toward injecting rather than from injecting (Loxley, 1997:56).

- **Drug Policy and Law Reform**

In 1989 the National HIV/AIDS Strategy made recommendations covering multiple aspects of the Australian response to HIV/AIDS including the need for legislative reform. That Strategy did not offer detailed guidance on the majority of legal issues identified. Rather, it recommended the establishment of a Legal Working Party to report through the Intergovernmental Committee on AIDS (IGCA) to the Australian Health Ministers' Advisory Council. ANCARD's submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms summarised the recommendations of the Legal Working Party. They included:

- jurisdictions should repeal existing self-administering offences;

- if this does not occur, then at least the operation of self-administration laws should be limited. A directive should be issued to police that self-administration offences are normally to be dealt with not by laying charges, but by a referral for treatment etc. and specifying that police need approval by prosecuting authorities before laying self-administering charges; and

- all jurisdictions would undertake further work to examine how laws relating to prohibited drugs can best be revised to serve as effective instruments of health policy and to support public health objectives designed to limit the spread of HIV/AIDS. The role of the law in facilitating safer drug use by occasional or recreational drug users, and prison inmates should be particularly considered (ANCARD's submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The Working Party also made a number of specific recommendations concerning the operation of needle and syringe programs and the safe disposal of used equipment.

Puplick considers the Legal Working Party's recommendations to be "an important initiative" (Puplick evidence, 7 November 1997). In commenting on the reforms proposed by the Legal Working Party, Puplick noted that a number had already been implemented. However a few, and he specifically identified the law on self-administration, are yet to be reformed (Puplick evidence, 7 November 1997).

In 1993 the NSW Ministerial Review HIV/AIDS Legal Working Party examined the recommendations made by the IGCA and proposed changes to the laws of NSW to bring them into line with the recommendations of the Second National HIV/AIDS Strategy. This report, *The Courage of Our Convictions,* was delivered to the NSW Minister for Health in 1993.

The Third National HIV/AIDS Strategy also proposed that a supportive legislative environment is integral to Australia's success in responding to HIV, HCV and other related communicable diseases. The Strategy states that:

> *the Commonwealth and the States and Territories should regularly assess policies and legislation to ensure the impediments to the prevention of HIV/AIDS and related communicable diseases continue to be reviewed and removed and that discrimination connected with HIV/AIDS and related communicable diseases is effectively combatted* (Commonwealth of Australia, 1996:67).

Both the Wood Royal Commission and the NSW Police Commissioner have canvassed law reform in relation to minor drug offences and greater concentration of harm minimisation measures in the interest of the community as a whole.

The NSW Hepatitis C Taskforce considered the issue of drug law reform and proposed that a NSW Intersectoral Advisory Committee the following recommendations:

- a review of the current emphasis on law enforcement measures which restrict drug supplies and increase the likelihood of drug use by injection with the aim of facilitating the transition from injecting to non-parenteral drug use;
- including injecting paraphernalia in exemptions for legislation which covers needle and syringe programs;
- self-administration (*Drugs Misuse and Trafficking Act*); and
- reducing the size of prison populations by making drug policy more flexible and improving non-custodial sentencing options for injecting drug users (NSW Health, 1995:5).

In commenting on the implementation of the Taskforce recommendations, NSW Health noted that the recommendations are in the area of responsibility for the Attorney General and the Minister for Police. The Department also noted that similar recommendations were made in the *Prisons and Blood Borne Communicable Diseases, the Community Policy* document (1995) and the Puplick Report entitled *The Courage of Our Convictions. HIV/AIDS: The National Strategy and the Laws of NSW* (1993).

During the course of this Inquiry, a number of witnesses raised the issue of drug policy and law reform as a preventative strategy to limit the transmission of Hepatitis C. The Hepatitis C Council, for example, considered drug policy and law reform to be “vitally important” preventative strategies which can improve the contexts in which HCV is transmitted (Hepatitis C Council submission). The Hepatitis C Council’s Executive Officer, Mr Loveday, elaborated further in evidence before the Committee:

> *if there is one single issue standing in the way of effective reduction of HCV transmission it is the fact that the risk behaviour that leads to the vast majority of new Hepatitis C infections, the injection of illicit drugs,*

> *remains an illegal activity. . . the enormous economic, personal and social cost of Hepatitis C infection will continue to grow year by year until a fresh approach to the way governments and broader society treat people who choose to use drugs illicitly, and to how they view those drugs in the first place. These are drugs which are never going to go away* (Loveday evidence, 30 March 1998).

NUAA also believes current laws “contribute to the transmission of Hepatitis C” (Madden evidence, 7 November 1997). During the course of their evidence the agency tabled their *Drug Law Reform Policy Statement* (NUAA, 1997) which considers how the current drug laws are affecting drug users, why the current drug laws need to change, potential benefits of drug law reform and ten principles for change.

ANCARD’s submission suggested that:

> *every effort must be made to alter drug laws, as our present set of laws acts to increase HCV exposure in our community . . . The Committee should address the whole process of drug reform and suggest that whilst drugs remain illegal, we will continue to have a problem in this community with diseases such as HCV, HBV and HIV* (ANCARD submission).

As ANCARD notes, it is “pointless” suggesting an increase in expenditure of money on the drug war as “this will never be able to outstrip the monies that will be poured into making sure the drugs enter the country” (ANCARD submission).

In appearing before the Committee, ANCARD Chair commented that:

> *The most important legislative reform that could take place in some of these areas is the change in drug laws to enable drugs to be dealt with as a health problem rather than as a criminal problem. That would keep people out of prison for relatively minor drug offences. We have a hierarchy of drug offences in which people who self-abuse in terms of barbiturate and amphetamines are far less likely . . . to end up doing prison sentences than “self-abuse” injecting drug users. We would not send somebody to prison for chronic self-abuse of certain other illegal substances . . . but we send people to gaol for relatively minor drug offences. That exposes them to a far greater public health risk than any public health risk they are exposed to outside prison* (Puplick evidence, 7 November 1997).

Three specific examples of drug policy and law reform were proposed to the Committee. Submissions from NUAA, the Community Working Group on Prisons and Blood Borne Communicable Diseases and the Hepatitis C Council suggested repealing the self-administration and paraphernalia offences detailed in the *Drug Misuse and*

Trafficking Act, 1985. If such a change was made, Mr Loveday suggested that "immediately there would be an easing of the situation in prisons" (Loveday evidence, 30 March 1998).

The Community Working Group on Prisons and Blood Borne Communicable Diseases' submission noted that Australia's success in minimising HIV transmission among injecting drug users resulted from the general moratorium on the enforcement of prohibitions against the possession of equipment for drug use and the establishment of needle and syringe programs. However, both NUAA and the Community Working Group referred to legislative anomalies that impact upon injecting drug users utilising needle and syringe programs. The Community Working Group suggested that the legislation "hampers" the ability of clients of needle and syringe programs to access clean injecting equipment and dispose of used equipment safely (Cregan, DeMarchi, Bond and Selvanera, 1997:4).

Section 11(1A) of the *Drug Misuse and Trafficking Act, 1985* provides that the current offence of having in one's possession "any item of equipment for use in the administration of a prohibited drug": s 11(1) "does not apply to or in respect of a hypodermic syringe or hypodermic needle". According to the Community Working Group this means that "it is legal to possess equipment for self-administration but it is illegal to use that equipment to self-administer". The Group concludes that such a situation is "anomalous" (Cregan, DeMarchi, Bond and Selvanera, 1997:4). If the offence of possession remains, police can prosecute people found in the act of self-administration.

In their submission to the Inquiry, NUAA recommended legislative barriers be removed to lessen the likelihood of people taking risks for fear of arrest and to facilitate users accessing needle exchanges. Similarly, the Community Working Group on Prisons and Blood Borne Communicable Diseases suggested that:

> *Repealing self-administration offences will maximise the effectiveness of the needle and syringe program by allowing people to carry clean injecting equipment and to dispose safely of used injecting equipment* (Cregan, DeMarchi, Bond and Selvanera, 1997:4).

The Hepatitis C Council, NUAA and the Community Working Group on Prisons and Blood Borne Communicable Diseases proposed amending the provision as they relate to the use and possession of small amounts of drugs to remove a criminal offence for these amounts.

The Community Working Group on Prisons and Blood Borne Communicable Diseases also proposed abolishing prison sentences for summary offences for drug use or possession and the sale of drugs not undertaken for commercial gain (the Prisons and Blood Borne Communicable Diseases Community Working Group submission). Mr

Selvanera from the Community Working Group suggested that this change would give effect to the Australian Royal Commission into Drugs undertaken in 1980 which recommended that a distinction be drawn between those people who undertake the sale of drugs for commercial gain and those who undertake the sale of drugs to support their own habits (Selvanera evidence, 23 March 1998).

- **Safe Injecting Rooms**

The term "injecting room" has been defined as a legally sanctioned indoor facility where injecting drug use occurs under the supervision of appropriately trained personnel who could provide access to medical equipment in the event of an overdose. As a harm reduction strategy, sterile injecting equipment is supplied and provision made for the safe disposal of used injecting equipment. Education and information on safe drug use is available and opportunity provided for injecting drug users attending such facilities to consider treatment and rehabilitation (NSW Parliament, 1998:5).

The issue of trialing or establishing safe injecting rooms was examined by a recent Joint Select Committee of the NSW Parliament. The reference was a direct result of a recommendation made by the Royal Commission into the NSW Police Service in which Commissioner Wood concluded that the Commission favoured the establishment of safe injecting rooms. He said:

> *at present, publicly funded programs operate to provide syringes and needles to injecting drug users with the clear understanding they will be used to administer prohibited drugs. In these circumstances, to shrink from the provision of safe, sanitary premises where users can safely inject is somewhat short-sighted. The health and public safety benefits outweigh the policy considerations against condoning otherwise unlawful behaviour . . . For these reasons the Commission favours the establishment of premises approved for this purpose and invites consideration of an amendment of the Drug Misuse and Trafficking Act to provide for the same* (Wood, 1997:226).

During the course of that Inquiry, support for the trial or establishment of safe injecting rooms was given by the NSW Law Society, the NSW Bar Association as well as parents who had suffered the death of a child through drug overdose. There was considerable apprehension in some sections of the community.

The Committee's report identified a number of arguments for and against the establishment or trial of safe injecting rooms under the broad headings of health implications, social implications, economic implications and legal implications. Arguments for establishing or trialing safe injecting rooms included:

- **Health Implications:**
  - may reduce the number of overdose fatalities
  - may reduce the transmission of blood borne viral infections such as HIV,

Hepatitis B and Hepatitis C

- may provide injecting drug users with better access to primary medical care
- may improve access to drug treatment programs
- may improve occupational health and safety conditions for health workers, police officers and ambulance officers

- **Social Implications:**
  - may lead to a reduction in the public nuisance aspects of injecting drug use
  - may provide a venue to improve the likelihood of re-integration of injecting drug users into mainstream society
  - legalising injecting rooms would reduce the opportunities for police corruption
  - allowing injecting drug users to avail themselves of an injecting room may lead to a reduction in certain criminal activities

- **Economic Implications:**
  - may reduce the costs to the community associated with the treatment of overdoses and the treatment of people who contract blood borne viral infections
  - may reduce the social and economic costs to the community of injecting drug users (if injecting room is modelled along the lines of a more general health facility)
  - may mean less time and consequently less money will need to be spent by councils on removing discarded syringes from public areas

- **Legal Implications:**
  - would clarify the role to be adopted by the police in relation to both those using and those running such establishments
  - eliminating the need to pursue self-administration offences in the courts would save police and court time.

Arguments against the establishment or trial of safe injecting rooms identified in the Committee's final report included:

- **Health Implications:**
  - may lead to an increase in drug use and/or the number of injecting drug users
  - may delay injecting drug users from entering rehabilitation
  - there are potential health and safety implications for those who use and staff an injecting room

- **Social Implications:**
  - could lead to the assumption that injecting drug use is condoned may lead to the congregation of drug users
  - areas where injecting rooms are located may become labelled as drug centres
  - may lead to an increase in drug dealing in the nearby vicinity
  - the congregation of injecting drug users where injecting rooms are located may lead to an increase in opportunistic street and property crime
  - there are moral grounds for objecting to the establishment of injecting rooms
  - areas chosen as sites for injecting rooms may feel that they are being treated as social experiments

- **Economic Implications:**
  - concern that spending money on injecting drug users is a waste of resources
  - would have a negative impact on businesses and on property values in the nearby vicinity
  - money spent on injecting rooms would be better spent on alternative drug treatment and rehabilitation programs
  - money spent on injecting rooms would be better spent on increased law enforcement

- **Legal Implications:**
  - making a distinction between behaviour which is legal in an approved injecting room but illegal elsewhere will lead to a creation of “fuzzy” law potential issues of legal liability surrounding incidents occurring in an injecting room (NSW Parliament, 1998:77-122).

The majority of Members on that Committee recommended that the establishment or trial of safe injecting rooms not proceed (NSW Parliament, 1998:188). Four members recommended that a scientific, rigorous trial of safe injecting rooms be conducted in NSW as part of an “integrated public health and safety approach to injecting drug use” (NSW Parliament, 1998:190).

During the course of this Inquiry, a number of witnesses supported the establishment or trial of safe injecting rooms as a preventative Hepatitis C measure. ANCARD supported the trial of safe sanitary injecting rooms under the licence or supervision of NSW Health or another suitable body. The Council’s submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms, which ANCARD provided to this Committee, identified three benefits that would be provided by safe injecting rooms: significant reduction in injecting drug use risks including the transmission of Hepatitis C; reduction in the risk of overdoes; and provision of a point of interaction between support services and users, where health information, referral and counselling can be provided and users can be made aware of available treatment options (ANCARD submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The Hepatitis C Council urged the Committee to give "strong support" to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms which, at the time of making their submission, was still deliberating (Hepatitis C Council submission).

In their submission to this Inquiry NUAA recommended the establishment of a pilot safe injecting room project in a number of locations across the state. They anticipated such facilities would provide a role in the reduction of Hepatitis C transmission amongst injecting drug users in high risk situations as well as provide education and prevention information (NUAA submission).

Sladden informed Committee Members that:

> *I personally feel that we should seriously consider the possibility of approved injecting rooms as another strategy for reducing infection. . . injecting rooms could provide. . . the potential for a trial of injecting rooms to further provide access to those in the most at-risk drug group for harm minimisation strategies as a pragmatic public health approach to reducing new infections* (Sladden evidence, 30 March 1998).

During the course of his evidence he identified a number of benefits associated with injecting rooms: encouragement of sterile techniques; referral to other services; and reduction of public nuisance related to many aspects of injecting drug use (Sladden evidence, 30 March 1998).

- **Future Directions to Limit the Transmission of Hepatitis C amongst Injecting Drug Users**

As the above discussion demonstrates, a range of preventative measures to limit the transmission of Hepatitis C amongst injecting drug users were presented to the Committee. Support for these measures came from reputable and significant organisations actively involved in the Hepatitis C community such as the Hepatitis C Council of NSW, NUAA and ANCARD. In all instances the proposals made by these agencies were supported by research (both local and international) and other high level inquiries (such as the Wood Royal Commission, the NSW Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms and the NSW Hepatitis C Taskforce). In terms of drug law reform and the provision of safe injecting rooms, the Committee finds it difficult to refute the evidence put before it.

In forming its recommendations for the prevention of Hepatitis C transmission amongst injecting drug users the Committee has adopted two basic premises: the health and safety of injecting drug users (along with the broader issue of community public health) and the principles of harm minimisation as supported by, for example, the Prime Minister's National Council on Drugs, and NSW Health.

Having deliberated upon the issue of safe injecting rooms, a majority of Committee Members concluded that an appropriate and pragmatic harm minimisation strategy to limit the transmission of Hepatitis C in the injecting drug community would be for the Minister for Health to conduct a rigorous, scientific trial of safe injecting rooms in NSW in line with the recommendations of the Wood Royal Commission. These Members wished to see the safe injecting rooms be a point of entry for injecting drug users to access services and support including detoxification services, methadone or other treatment programs, primary health care, referral and counselling.

Other Members would not agree to this proposal and considered that the findings of the Joint Parliamentary Committee Inquiry into Safe Injecting Rooms should be respected and upheld by this Committee.

In terms of drug law reform, the Committee considers the recommendations made by the NSW Hepatitis C Taskforce in 1995 to remain relevant and appropriate. The Taskforce saw a role for a state Intersectoral Advisory Committee for Health. NSW Health advised that this Advisory Committee has not yet been formally established. Given that drug policy reform necessitates a cross-portfolio approach, the Committee sees merit in establishing this Advisory Committee to consider and pursue drug law reform.

RECOMMENDATION 105:

That the Minister for Health establish a NSW Intersectoral Advisory Committee for Hepatitis C and invite the Ministers for Corrective Services and Police and the Attorney General to join him on that Committee.

The Committee would like to see the Intersectoral Advisory Committee on Health consider a number of issues including:

- consider the role of drug policy and law reform as a pragmatic measure to limit the transmission of Hepatitis C;
- assess and examine how policies and legislation relating to prohibited drugs (such as the self administration and possession offences, s10 and s12 of the *Drugs Misuse and Trafficking Act, 1985*) can best be revised to serve as effective instruments of health policy and to support public health objectives designed to limit the spread of Hepatitis C;
- encourage public debate about the public health consequences of drug policy reform; and

- examine strategies to improve non-custodial sentencing options.

RECOMMENDATION 106:

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105:

- consider the role of drug policy and law reform as a pragmatic measure to limit the transmission of Hepatitis C;
- assess and examine how policies and legislation relating to prohibited drugs (such as the self administration and possession offences, s10 and s12 of the *Drugs Misuse and Trafficking Act, 1985*) can best be revised to serve as effective instruments of health policy and to support public health objectives designed to limit the spread of Hepatitis C;
- encourage public debate about the public health consequences of drug policy reform; and
- examine strategies to improve non-custodial sentencing options.

10.1.4 NEED FOR RESEARCH

The NSW Hepatitis C Taskforce identified a number of issues it considered to be "research priorities" including:

- reducing the size of the drug injecting population;

- improving the effectiveness of treatment for persons using potentially injectable illicit drugs;

- development of non-reusable injecting equipment;

- behavioural and ethnographic research into young injectors and particularly into initiation injecting and sharing of body fluids; and

- effectiveness of bleach and other agents used for decontamination of injecting equipment (NSW Health, 1995:6).

In response NSW Health assured the Committee that these issues are the "ongoing concerns" of the National Drug and Alcohol Research Centre and that the Commonwealth is the appropriate funding agency for the work of the National Centres (NSW Health submission).

The Committee fully supports the recommendation of the NSW Hepatitis C Taskforce and wishes to see its research priorities receive adequate funding. It would add one issue to their list - factors surrounding the initiating of injecting behaviour. The Committee has included this last point as it agrees with Crofts, Louie, Rosenthal and Jolley who observe that:

> *understanding the circumstances surrounding initiation into injecting and the influences this process has on subsequent injecting behaviour may be important in allowing current harm minimisation strategies to be targeted more specifically to those at greatest risk and new approaches to be devised for the young, beginning injector* (1996:1188).

RECOMMENDATION 107:

That the Minister for Health urge his federal counterpart to fund research into issues including:

- reducing the number of injecting drug users;
- improving the effectiveness of treatment for persons using illicit drugs which can be injected;
- development of non-reusable injecting equipment;
- behavioural and ethnographic research into young injectors;
- the effectiveness of bleach and other agents used for decontamination of injecting equipment; and
- the danger of contracting Hepatitis C from the exchange of body fluids

and that the results of such research be used in devising strategies to target those at risk, particularly young injectors.

10.1.5 CONCLUSION

Sladden's published comment succinctly summarises most of the issues pertaining to the prevention of Hepatitis C amongst injecting drug users brought to the attention of Committee Members. He calls for:

> *transmission prevention and harm minimisation programs, especially targeting adolescents before any experimental drug taking. Community development and peer education of injecting drug users to promote safer injecting practices should be strengthened. The impacts of improved access to needle and syringe exchange and methadone programs, campaigns to encourage non-injecting routes of drug administration, development of non-reusable syringes, . . . provision of "safe house" injecting venues on HCV transmission all need to be investigated* (Sladden *et al*, 1997:293).

As the recommendations forwarded in the above discussion show, the Committee fully agrees with Sladden. Members have sought to forward responsible, albeit pragmatic, recommendations to prevent the transmission of Hepatitis C amongst the injecting drug community. A multi-faceted approach has been taken in line with evidence received:

> *The approach to controlling Hepatitis C must be multifaceted. One facet is to change behaviour, which will be difficult to achieve. . . It covers many topics . . There is no one answer* (Loveday evidence, 3 October 1997).

10.2 PREVENTING THE TRANSMISSION OF HEPATITIS C IN PRISONS

A number of witnesses stressed to the Committee the importance of Hepatitis C prevention within the corrections system. Crofts, for example, considers prisoners with Hepatitis C to be “doubly marginalised, doubly stigmatised” and prisons to be “the real hot spots for Hepatitis C transmission” (Crofts evidence, 28 November 1997). As a result he views prisons as a “key” to controlling the spread of HCV amongst injecting drug users (Crofts, 1997:116). In evidence before the Committee he observed that “we are not going to control Hepatitis C in the community until we control Hepatitis C in the prisons” (Crofts evidence, 28 November 1997).

ANCARD also noted that:

> *efforts must be directed to the prison system to minimise the risk associated with drug use in prison and to minimise exposure to blood in these environments* (ANCARD submission).

The Committee is also aware that:

> *while prisons represent a public health hazard for communicable disease, they also present a corresponding opportunity to deliver education and treatment programs to a group of people for whom such programs are highly relevant* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

The Department of Corrective Services assured Committee Members that it considers Hepatitis C to be a “priority” (Vumbaca evidence, 23 March 1998). As the Committee heard,

> *We [Department of Corrective Services] recognise the sheer numbers of Hepatitis C in the system and that is a priority. Most of our educational work is now focused on Hepatitis C* (Vumbaca evidence, 23 March 1998).

In 1987 the NSW Department of Corrective Services established the AIDS Education Project to provide HIV/AIDS education and prevention programs for inmates and staff. The Project was later renamed the Prison AIDS Project, and a residential Lifestyle program for HIV positive male prisoners was established at Long Bay. In March 1996 the project became the HIV and Health Promotion Unit (HHPU) and its charter was extended to address Hepatitis C and other communicable diseases (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

As the following discussion will demonstrate, Committee Members firmly believe that a multi-faceted approach must be taken to limit the transmission of Hepatitis C amongst inmates in the state's correctional system. Efforts to prevent Hepatitis C must aim at reducing:

- the prevalence or frequency of injecting (through strategies such as methadone maintenance therapy);
- the risk of infection (utilising strategies such as ready access to bleach); or
- the population at risk (through strategies such as diversion programs and Hepatitis B vaccinations (Dolan, 1997).

- **Harm Minimisation Strategies within the Corrections System**

As has been discussed, the Committee is committed to the principles of harm minimisation in all preventative strategies relating to injecting drug users. The representative from Department of Corrective Services appearing before the Committee, Mr Gino Vumbaca told Members that:

> *The Department does have harm minimisation or harm reduction as a goal. One area in which we probably would not fit into the community definition of that is the provision of needles and syringes for various safety reasons . . . Realistically, the Department makes available to inmate many services and programs that are generally of an equitable level to those available in the community* (Vumbaca evidence, 23 March 1998).

Despite his claim, a number of witnesses appearing before the Committee were critical of the Department of Corrective Services for not providing the same range of harm minimisation measures as are available in the general community. Loveday, for example stated that:

> *The absence of harm minimisation facilities within NSW prisons means that effectively nothing can be done about ongoing transmissions* (Loveday evidence, 3 October 1997).

Cregan noted, that Department of Corrective Services:

> *vigorously pursues a policy of surveillance and prosecution with the aim of achieving drug-free prisons - arguably an impossibility, and contrary to harm minimisation approach to containing blood borne communicable diseases which has been demonstrably successful in minimising HIV infections among injecting drug users* (Cregan, 1998:5).

Representatives from NSW Health noted that their Department encourages harm minimisation but they did not consider Department of Corrective Services to have adopted such an approach (Christensen evidence, 23 March 1998). When asked to comment on the different approaches taken by these two departments that work so closely together seeking to prevent the transmission of Hepatitis C in the prisons' system, Ms Christensen admitted that there "is a conflict" (Christensen evidence, 23 March 1998).

Cregan suggested to Members that the concept of harm minimisation when viewed within the prisons' contest is "a delicate issue" and:

> *quite problematic . . . it is helpful to maintain an awareness of the distinction between drug use as an individual health problem and communicable diseases as a public health problem and to acknowledge that harm minimisation strategies as part of a total response to the drug problem are important in protecting public health. It is really important, especially when these things are debated so hotly, to maintain that focus* (Cregan evidence, 23 March 1998).

The Committee fully agrees with Cregan and in proposing the following recommendations has chosen to look at the issue from a public health perspective. This approach is in line with Loveday's suggestion to Committee Members that "drug use should be treated as a health issue within prisons" (Loveday evidence, 30 March 1998).

10.2.1 PREVENTATIVE STRATEGIES CURRENTLY IN PLACE

In terms of preventing the spread of Hepatitis C amongst prison inmates, the Department of Corrective Services informed the Committee that there is a "two-pronged strategy", namely:

> *to increase the knowledge amongst staff and inmates about Hepatitis C and the particular methods of transmission and protection. . . and to reduce the opportunity for exposure to any blood or bodily fluids or for any exposure to be handled safely and correctly* (Vumbaca evidence, 23 March 1998).

The Department currently has a number of programs in place to limit the transmission of Hepatitis C amongst prison inmates. Some of these, such as drug and alcohol counsellors and peer support programs are of a rather general nature while others specifically target those inmates at risk of contracting Hepatitis C. It is these latter programs that will be reviewed in the following discussion.

- **Education and Information**

A range of education material providing information on Hepatitis C is available to prison inmates. This material includes:

- stickers on the back of all cell doors advising inmates of the presence of Hepatitis C and HIV and encouraging inmates to avoid sharing syringes and engaging in at risk behaviours (Vumbaca evidence, 23 March 1998)

- posters (such as *Before the Take the Gee Remember the Hepatitis-C* targeting injecting drug users, and a series of instructional posters on a range of issues including needlestick injury, blood spills and universal infection control guidelines*)* and pamphlets and booklet such as *Hepatitis C Virus*, *Hepatitis C Ten Questions and Answers* (prepared by CEIDA), *Contact Hepatitis C Diagnosis* (prepared by the Hepatitis C Council of Queensland), *Hepatitis C: what you need to know* (prepared by Hepatitis C Council of NSW);

- newsletter; and

- health information sessions.

The range of resources addresses different literacy levels. As the Committee heard:

> *some [resources] are of a low literacy level, some are of a higher literacy level. We do not focus all of our attention on one particular area. We keep updating resources and putting out new things and also address areas such as cultural issues* (Vumbaca evidence, 23 March 1998).

The Department is very conscious of the role played by its education programs not just in impacting upon the transmission of Hepatitis C within the corrections system, but upon the community as a whole. As noted in their submission:

> *the education of inmates on Hepatitis C issues represents a critical intervention point for the transmission of the virus . . . A substantial number of people from the community pass through the correctional system each year. These people then have multiple contacts with a variety of family and friends in the community after release. There is an opportunity to educate people about reducing their risk of exposure to*

> *Hepatitis C if they are negative, and reducing the transmission of the virus to others if they are positive, whilst they are in custody* (Department of Corrective Services submission).

Two issues pertaining to the provision of education and information for prison inmates were raised with Committee Members during the course of this Inquiry. The first pertains to the HIV and Health Promotion Unit which is responsible for producing and disseminating educational material throughout the corrections system. The Committee understands that this Unit currently has only one dedicated worker for each region which represents approximately ten correctional centres per person, or a staff to inmate ratio of 1:200-2500 (Community Working Group on Prisons and Blood Borne Communicable Diseases submission). As the Community Working Group points out, such a staff to inmate ratio may have been adequate in the past to deal with the 20-40 known cases of HIV infection in prisons at any one time. However, it is “clearly inadequate” to provide education and support for the estimated 2,500 HCV positive inmates in full time custody. The Community Working Group recommended that the HIV and Health Promotion Unit be better resourced so that the worker to client ratio can be reduced to a more appropriate level. The Committee supported this recommendation.

RECOMMENDATION 108:

That the Minister for Corrective Services commission a review of the HIV and Health Promotion Unit to ascertain the staffing needs of the Unit and to ensure the Unit is adequately resourced to meet the information and educational needs of Hepatitis C inmates in the state’s correctional system.

The second issue raised concerned the appropriateness and adequacy of educational material provided to inmates. During the course of her evidence, Ms Cregan, a psychologist who ran a Hepatitis C positive prisoners support group in 1997, commented that:

> *the support that is supplied is based on a model that assumes that information is pretty well all that is necessary to change people’s behaviour. My professional knowledge leads me to understand that knowledge, information and facts are necessary but they are not sufficient to change people’s behaviour in regard to risk taking* (Cregan evidence, 23 March 1998).

From her experience she does not believe current educational programs are appropriate. She does not believe:

> *enough thought, preparation and establishment of the needs, methods and world views of these people have been carried out prior to developing the education program* (Cregan evidence, 23 March 1998).

The Committee is concerned with the observations raised by Ms Cregan. It is aware, for example, that the learning model she identified as being utilised is now considered inadequate:

> *In the old days health promoters talked about knowledge, attitudes and behaviours: get the knowledge right and the rest would follow. We know now that this is unrealistically simplistic but accurate knowledge is still pertinent* (Loxley, 1995:56).

The Committee considers it important that appropriate educational strategies be employed in the Department's attempts to provide information to inmates that is relevant and appropriate.

RECOMMENDATION 109:

That the HIV and Health Promotion Unit ensure all educational strategies employed reflect current health promotion practices. The Committee further recommends that representatives from the Hepatitis C community are consulted along with experts in the field of health education and health promotion in the design of educational material produced by the HIV and Health Promotion Unit.

- **Methadone Maintenance Program**

The availability of Methadone Maintenance Therapy to members of the general community was reviewed in Section 10.1. Similar programs are available within the state's correctional system. The aims of the current program are to reduce heroin injection and minimise the spread of blood borne viral infections (Dolan, Wodak and Hall, 1998:154).

Introduced in April 1986 the state's prison methadone maintenance program is the only one in Australia and one of the few such programs in the world (NSW Department of Corrective Services, 1996:51). Representatives from the Community Working Party on Prisons and Blood Borne Communicable Diseases appearing before the Committee acknowledged that NSW is in a "much better position" than most other states and territories (Selvanera evidence, 23 March 1998). As the Working Party's representative, Mr Selvanera noted "that deserves recognition, but obviously things can always be better" (Selvanera evidence, 23 March 1998).

According to a departmental publication, the program has a "high international profile and is one of the best in the world" (NSW Department of Corrective Services, 1996:51). The publication goes on to suggest that:

> *the program has kept many inmates from injecting drugs in gaol and is considered to have a significant impact in reducing the spread of communicable blood borne viruses within NSW correctional centres and thereby reducing transmission back into the community* (NSW Department of Corrective Services, 1996:51).

The Department's 1996 claims were subsequently substantiated by research published in 1998. Dolan, Wodak and Hall's study or MMT in the state's prisons provided the "first evidence" that MMT can reduce injecting risk behaviour among inmates (Dolan, Wodak and Hall, 1998:155). The study found that:

> *in order for methadone treatment to be effective, a moderately high dose of methadone was required and treatment had to be provided for the entire period of imprisonment* (Dolan, Wodak and Hall, 1998:155).

The study concluded that methadone treatment may also "have an important role in preventing HIV, hepatitis B and C in prisons" (Dolan, Wodak and Hall, 1998:156).

Given the prevalence of Hepatitis C within the corrections system discussed in Section 3.2, the Committee is not convinced that the methadone program has actually had a "significant impact" on reducing Hepatitis C transmissions as the Departmental publication suggests. However it fully supports the initiative and commends Department of Corrective Services for its introduction and continuation.

The Committee was advised that methadone programs are available in 23 of the state's 28 gaols (Vumbaca evidence, 23 March 1998). Those not offering the program include the prison camps, Mannus and Kirkconnel, and the young offenders' prison at Parklea (Vumbaca evidence, 23 March 1998). The Committee was also advised that 710 inmates are currently on methadone (Vumbaca evidence, 23 March 1998).

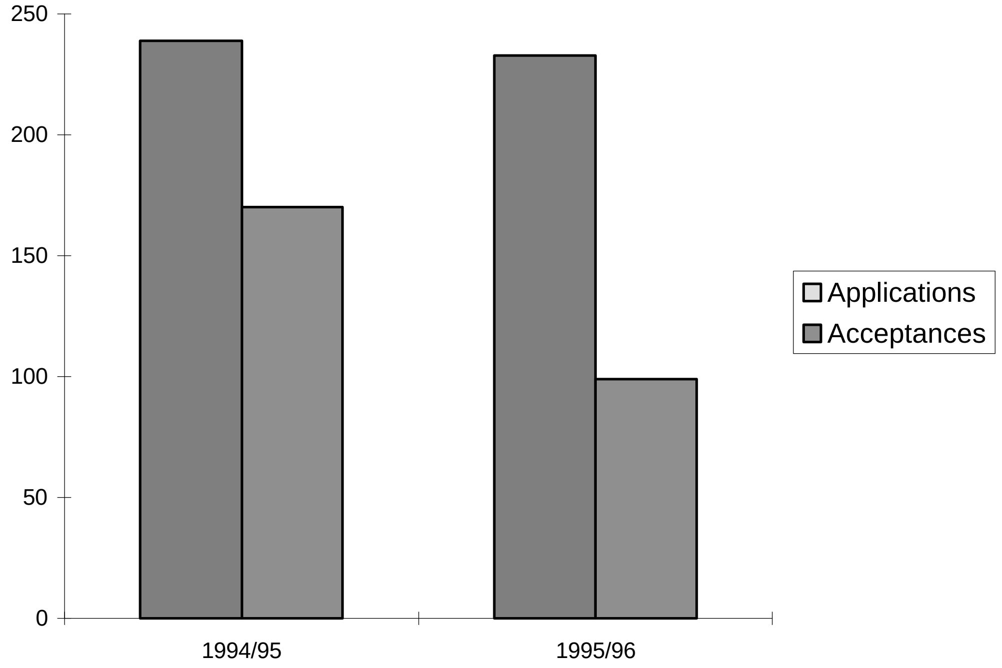
There was considerable support from witnesses for the methadone program. Harper, for example considered the program to be "excellent" (Harper evidence, 23 March 1998) while Christensen thought it to be "a very important strategy in reducing injecting in prisons" (Christensen evidence, 23 March 1998). Lloyd considered there to be a "real setting" for the methadone maintenance program as a way of reducing the likelihood of intravenous drug use in the prison (Lloyd evidence, 30 March 1998).

During the course of the Inquiry, two specific issues related to the prison methadone maintenance program were brought to the Committee's attention. The first issue relates to waiting lists for inmates wanting to access the program.

Departmental guidelines provided to the Committee suggest that in 1996 there was an unmet demand for methadone of approximately 300 to 500 inmates. Christensen's experience substantiated this. She noted that "there are limited places and a waiting list for people who want to go on to methadone" (Christensen evidence, 23 March 1998). The Department's Annual Report documents the discrepancies between applications for the methadone program and acceptances to the program over time (Corrections Health Service, 1996a). These are reported in Figure Six.

Harper considered there to be a need for "more expansion of the methadone program so that it can be more readily available." (Harper evidence, 23 March 1998). Selvanera from the Community Working Party on Prisons and Blood Borne Communicable Diseases similarly recommended an expansion of the prison methadone program (Selvanera evidence, 23 March 1998).

FIGURE SIX
APPLICATIONS AND ACCEPTANCES TO CORRECTIONS HEALTH SERVICES' METHADONE PROGRAM, 1994/95 - 1995/96



While the Committee was not able to ascertain the current unmet demand it anticipates it to be high given the number of people entering gaol who are involved in, or who have a history of, injecting drug use. The Committee understands that the number being placed on methadone is a “small proportion of those applying” (Department of Corrective Services, 1996:52) and that the criteria for being placed on the program are the same as the community program criteria (Department of Corrective Services, 1996:52).

The submission from the Community Working Group on Prisons and Blood Borne Communicable Diseases recommended that there be no limit to the number of prisoners with a history of opiate use, having access to the prison methadone program so that all may receive a therapeutic dose for the duration of their imprisonment or as required by the prisoner (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

Wodak and Hall are currently conducting an evaluation of the state’s methadone maintenance program. Professor Wodak has advised that the data collection stage of the evaluation will be completed by October-November 1998. Vumbaca advised the Committee that he anticipated the review would add 150-200 places to the methadone program (Vumbaca evidence, 23 March 1998). The Committee urges the Department of Corrective Services, in considering the results of Wodak and Hall’s review, to take the current unmet demand, and the recommendation made by the Community Working Group on Prisons and Blood Borne Communicable Diseases into consideration.

RECOMMENDATION 110:

That the Minister for Health ensure any shortcomings identified in the current review of the methadone maintenance program be considered and acted upon as a matter of priority as a pragmatic public health measure to limit the transmission of Hepatitis C within the state’s corrections system and, consequently, the general community.

A second issue identified related to the needs of new inmates with a history of injecting drug use who, during their first few days and weeks in prison are:

> *hanging out looking for a drug and trying to get access to an injecting apparatus and who will very likely use in a risky fashion in prison and get infected* (Lloyd evidence, 30 March 1998).

Lloyd considered it vital that these ‘at-risk’ inmates have access to methadone early in their imprisonment. However, as Lloyd observed,

> *one would have to take away a few of the bureaucratic hurdles to get rapid provision of methadone and expand the potential for the program* (Lloyd evidence, 30 March 1998).

RECOMMENDATION 111:

That the Minister for Health ensure methadone maintenance therapy is available to new prison inmates with a history of injecting drug use to limit the transmission of Hepatitis C within the state's corrections system and, consequently, the general community.

- **Safe Tattooing Project**

As has been discussed in Section 3.2.7 tattooing is an illegal activity in the state's corrections system. The tattooing that does occur uses guns of variable quality which are very difficult to clean. The use of such unsterile equipment poses a risk of Hepatitis C transmission. The Committee was informed that, at one stage, some of the confiscated guns were taken to consultants for advice on how they could be cleaned. The Department was told, given the nature of the makeshift guns, it would be "almost impossible" to recommend an effective cleaning method (Vumbaca evidence, 23 March 1998).

The Safe Tattooing Project arose in response to Departmental research showing inmates were unaware of the risks associated with tattooing while in prison. The Project is made up of several stages. The first stage focused on information and included the preparation of material explaining, for example, the risks of tattooing, and precautions to take (dipping the tattooing gun in bleach and wearing gloves to protect against blood splashes) (Vumbaca evidence, 23 March 1998). A booklet entitled *Gaol Ink* was prepared with advice from the Professional Tattooists' Association and endorsed by celebrities such as Angry Anderson. The Committee heard that the booklet has been circulated to "as many inmates as we could" and it is used extensively in the Department's health promotion programs (Vumbaca evidence, 23 March 1998).

The second stage of the Project will examine the feasibility of providing tattoos to inmates while they are in gaol (Vumbaca evidence, 23 March 1998). At the time of taking evidence a number of options were being explored as part of the feasibility study including holding focus groups with inmates to determine their willingness to pay for their own tattoos if they could be done professionally within the confines of gaol and linking the cost of tattooing to gaol work projects (Vumbaca evidence, 23 March 1998).

The Safe Tattooing Project was developed in 1995 with the endorsement of Corrections Health Board and the NSW Health Department. To date it has not been evaluated (Vumbaca evidence, 23 March 1998).

The Committee heard:

> *we [Department of Corrective Services] are trying to look for innovative ways to reduce [Hepatitis C transmission through tattooing], but it is not easy . . . Obviously the Department will not provide free tattoos to*

> *everybody; that is not even on the board. We have to look at other ways of either reducing the demand, which is difficult, or making it safer for people who cannot afford to get proper ones* (Vumbaca evidence, 23 March 1998).

The Committee considers it somewhat unrealistic to attempt to reduce the demand for what is an entrenched practice within the corrections system. It urges the Department to concentrate its efforts rather on sanctioning the availability of tattoos within the corrections system.

Such an approach was supported by a number of expert witnesses. The Hepatitis C Council, for example, strongly recommended its introduction as an effective preventative strategy. Butler also gave his support. He informed the Committee that:

> *I think tattooing should be made available in gaols. The popularity of it as a part of prison life dictates that it would be a good idea if there were some way of making it more hygienic* (Butler evidence, 23 March 1998).

Crofts commented to the Committee that:

> *I have never understood why tattooing is illegal in prisons or is banned in prisons and the reason I have been given when I have asked the question is security. Tattoos are part of the identification of the prisoner . . Well does it not then make sense to make the tattooing legal and above board so you know when somebody is adding a tattoo to themselves rather than keep it illegal so that people change their tattoos without anyone knowing?* (Crofts evidence, 28 November 1997).

Mr Puplick in appearing before the Committee in his capacity as Chair, Australian National Council on AIDS and Related Diseases called for a change in departmental policies on tattooing in prisons. As he noted:

> *changing prison policy about prisoners getting tattoos from reputable sources will not bring prisons to a shuddering halt in any sense, although it may have some impact in relation to health status* (Puplick evidence, 7 November 1997).

The Committee is aware that introducing tattooing in prisons will not be without its opposition. Mr Loveday from the Hepatitis C Council observed, for example, that "it seems so simple and yet we know it is so very hard, given various attitudes" (Loveday evidence, 30 March 1998).

RECOMMENDATION 112:
That, recognising the role of tattooing in the transmission of Hepatitis C, the Minister for Corrective Services enable tattoos to be available in hygienic conditions within the state's corrections system.

- **Availability of Bleach**

According to the Department of Corrective Services' policy PLY.92.197/1 bleach and disinfectant solutions are available to inmates and have been since 1992. The Committee was advised that bleach dispensers are available in "almost every gaol" (Vumbaca evidence, 23 March 1998) and that,

> *it is used for disinfecting cells and cleaning areas; if they use it for cleaning injecting equipment so be it. We cannot stop people from doing that* (Vumbaca evidence, 23 March 1998).

Corrections Health Service nurses informed the Committee that they strongly encourage inmates to clean their injecting equipment with bleach. However:

> *that was not always possible, because many times bleach was not freely available and inmates were blocked from getting it because if they went up to get bleach they were identified as drug users and they then may have been targeted for cell searches* (Christensen evidence, 23 March 1998).

There is, however, some controversy over the effectiveness of cleaning injecting equipment with bleach as its efficacy as a viricidal agent against both HBV and HCV has not yet been established (Cregan, DeMarchi, Bond and Selvanera, 1997:7). While bleach is the recommended regime to prevent the transmission of HIV, a case study presented to the Committee by Professor Lloyd suggested it may not be adequate in limiting Hepatitis C transmission (Lloyd evidence, 30 March 1998). He told Members of an inmate who injected drugs and complied with the recommended two-by-two-by-two (bleach-rinse-bleach) cleaning regime for his injecting equipment. This inmate has contracted Hepatitis C. Lloyd suggested to the Committee:

> *there is some data, this man in particular, supporting that it [bleach] is an inadequate procedure for Hepatitis C. That is a big issue in the prison because it is the recommended procedure* (Lloyd evidence, 30 March 1998).

The Committee was not able to ascertain whether the Hepatitis C transmission Lloyd reported resulted from inadequate cleaning procedures, or shared injecting paraphernalia.

The Prisons and Blood Borne Communicable Diseases policy recommends that bleach (with a minimum of 5.25% sodium hypochlorite) be freely and confidentially available to prisoners. The Policy also recommended that prisoners be supplied with up-to-date information about the efficacy of cleaning solutions against HIV, HBV and HCV and that all prisoners receive a copy of the *National Cleaning Guidelines for HIV* during induction (Cregan, DeMarchi, Bond and Selvanera, 1997).

Given that bleach is the only preventative strategy available to inmates to clean needles and syringes the Committee considers the ready availability of bleach to be an essential public health measure.

Further, the Committee finds the practice of cell searches following requests for bleach to be totally unacceptable. In many respects the practice is similar to that of police patrolling the parameters of needle and syringe outlets and harassing those seeking to obtain sterile equipment. As has been discussed the police have been directed not to operate within the parameters of needle and syringe outlets. In keeping with the Department's commitment to harm minimisation, the Committee wishes to see access to bleach to be not linked to drug surveillance in any form.

RECOMMENDATION 113:

That the Minister for Corrective Services ensure adequate bleach dispensing machines are available in all correction centres enabling inmates to access bleach freely and anonymously. This should be administered as a Hepatitis C control measure, and should not be linked to drug surveillance.

- **Availability of Toothbrushes and Razors**

In the discussion on household transmission of Hepatitis C (see Section 3.8.2) it was noted that personal grooming items such as toothbrushes and razors may contain traces of blood which may, in turn, result in the transmission of Hepatitis C. While it is relatively easy within a household setting to avoid sharing these items, the Committee was advised that such is not always the case in correctional centres. In some of the older gaols there are communal shower areas and razor blades are often left after showering or they are "put into a big bucket with inmates fishing one out the next day to shave" (Christensen evidence, 23 March 1998). The Committee also heard that a lot of bartering occurs in gaols with prisoners "swapping of razors and toothbrushes that may have blood on them" (Pritchard-Jones evidence, 2 October 1997).

The Committee was advised during the course of evidence, that prison inmates have access to razor blades and toothbrushes (Vumbaca evidence, 23 March 1998). A Disposable Razor Policy and Procedure (PLY.93.251/1) has been introduced. The policy states that:

> a) *all disposable razors issued to inmates will only be carried out on an exchange basis of one to one (ie old razor for new razor);*
>
> b) *all inmates will place their old razor in a suitable sharps container before being issued with the new razor;*
>
> c) *all inmates, employed within correctional centres for the purpose of cleaning wings, units and blocks (ie sweepers), will be issued with the appropriate gloves and sharps containers when they are required to clean ablution (showers and toilets) blocks. In the event that they find any discarded razors, they will then be disposed of immediately and appropriately;*
>
> d) *that educational material (posters and pamphlets) must be displayed and made available to all inmates regardless of classification, housed in correctional centres throughout NSW;*
>
> e) *if inmates continually request exchange razors without a replacement, the monetary cost of the razor be deducted from the inmates private cash* (Department of Corrective Services, 1993).

As the policy statement suggests, the HIV and Health Promotion Unit provides educational material in the form of pamphlets and posters encouraging inmates to use their own razor blade and toothbrushes (Vumbaca evidence, 23 March 1998).

The Committee is satisfied that appropriate measures are currently in place to reduce the likelihood of toothbrushes and razors being possible sources of Hepatitis C virus. The Committee would urge the Department of Corrective Services to remain vigilant in this matter. While the ready availability of toothbrushes and razors may appear to some to be an insignificant measure, the Committee considers it important given the prevalence of Hepatitis C within the corrections system. In the Committee's opinion, every measure, regardless of how small, must be taken to curb the transmission of Hepatitis C in prisons.

RECOMMENDATION 114:

That the HIV and Health Promotion Unit continue to encourage inmates not to share their razor blades and toothbrushes.

- **Diversionary Sentencing Practices**

Given the prevalence of Hepatitis C in the corrections system, considerable support was given by expert witnesses to the use of diversionary sentencing provisions as a means of diverting "at risk" or infected people from the corrections system. Crofts suggested, for example, that Hepatitis C in the community will not be controlled until we "stop locking up injecting drug users" (Crofts evidence, 28 November 1997).

Professor Batey also supported the idea and commented to the Committee that:

> *we need to keep that population out of the prison system if we possibly can. So looking at alternative centres and strategies is important* (Batey evidence, 27 October 1997).

The Hepatitis C Council suggested to the Committee that:

> *Every effort should be made to keep people out of gaols. Where people are imprisoned for drug-related offences, why should they not rather be given the option of treatment programs?. . . Changing the sentencing practices to allow magistrates to consider options other than imprisonment* (Loveday evidence, 30 March 1998).

Mr Vumbaca from Department of Corrective Services also felt that:

> *Obviously keeping people out of prison would be a major source of help for the Department of Corrective Services . . . . If we can reduce the flow into the system of people with those problems it makes it easier for us* (Vumbaca evidence, 23 March 1998).

Recognising that Hepatitis C infections contracted directly in prisons, or indirectly from released prisoners, will provide a "significant ongoing resource burden" to the health system the NSW Hepatitis C Taskforce recommended improving the non-custodial sentencing options for injecting drug users (NSW Health, 1995:19).

Further, the recommendations of the Legal Working Party to the Intergovernmental Committee on AIDS referred to in Section 10.1.2 also proposed that injecting drug users found guilty of drug offences should be kept out of the prison system and that legislation should enshrine the principle of non-custodial sentences for relevant offences and remove any mandatory sentences for minor offences (ANCARD submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

The Community Working Group on Prisons and Blood Borne Communicable Diseases submission identified the benefits to come from utilising diversionary sentencing provisions:

> *diversion of drug offenders from prisons would have the effect of reducing the prison population resulting in better and safer accommodation for those longer term prisoners for whom custodial sentences are appropriate. The presence of fewer injecting drug users in prisons would entail a corresponding decrease in the number of HCV infected inmates and thus lessen the risk of transmission among the remaining prison population* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

The Community Working Group recommended that the Attorney General, through the Judicial Commission, undertake to bring to the attention of the magistracy and other judicial officers appropriate advice to guide their sentencing of offenders with, among other diseases, HCV (Community Working Group on Prisons and Blood Borne Communicable Diseases submission). In evidence, the Working Group representative suggested the use of non-custodial alternatives such as attendance orders or community service orders for injecting drug users who are convicted of minor offences which were committed to support their drug use (Selvanera evidence, 23 March 1998).

As the Committee is aware, his suggestion has a legislative base. The *Justices Act, 1902* s80AB provides that in summary proceedings a Justice "shall not sentence a person to full time imprisonment unless satisfied, having considered all possible alternatives, that no other course is appropriate". Selvanera pointed out to Committee Members that the current government's pre-election corrections policy "enshrined" this principle (Selvanera evidence, 23 March 1998). The Community Working Group on Prisons and Blood Borne Communicable Diseases suggest that s80 might be interpreted to apply to minor possession as well as self-administration offences (Cregan, DeMarchi, Bond and Selvanera, 1997:3). Their preference however would be to amend the *Drug Misuse and Trafficking Act, 1985* to abolish custodial sentences for all summary drug use and possession offences (Cregan, DeMarchi, Bond and Selvanera, 1997:4).

The Community Working Group on Prisons and Blood Borne Communicable Diseases' submission outlined an alternative approach to sentencing repeat minor offenders proposed by Vinson. He recommends that the judiciary be required to justify the imposition of short custodial sentences rather than community based alternatives for these offenders. Under this proposal, prisons should be reserved for more serious offenders serving longer sentences (Cregan, DeMarchi, Bond and Selvanera, 1997: 4).

A number of non-custodial sentencing options are currently available. These include:

- periodic detention which requires the offender to remain in custody for two days of each week for the duration of the sentence (NSW Law Reform Commission, 1996:212);

- home detention which permits an offender to serve part or all of a sentence in the offender's home under strict supervision and subject to conditions (NSW Law Reform Commission, 1996:144). This scheme was given a legislative base with the introduction of the *Home Detention Act, 1996*;

- Griffith bonds which place an offender on remand during which time the offender's behaviour and capacity to be rehabilitated over a period of time is assessed, before the appropriate sentence is passed; and

- community service orders which place restrictions on the time and liberty of offenders by requiring them to carry out up to 500 hours of community service (NSW Law Reform Commission, 1996:96).

The Standing Committee on Social Issues has considered the use of non custodial sentencing options in a previous Inquiry. In its final report for the Inquiry into Children of Imprisoned Parents (1997), the Committee urged that imprisonment of mothers with dependent children be a sentencing option of last resort. The Committee made it very clear in that Report that non-custodial options are not "soft". As the report states:

> *the Committee firmly believes that non-custodial penalties should not be seen or used as a "soft option". They do not mean that an offender has gotten away with an offence. Sentences such as community service orders, periodic detention and home detention are all serious penalties which curtail the liberty of an offender and the use of such options should reflect the gravity of the offence, in the level of curtailment involved* (Standing Committee on Social Issues, 1997:113).

The recommendations forwarded in the Children of Imprisoned Parents Report called for the Attorney General to:

- ensure that, through judicial education, magistrates and judges always use the option of prison as a last resort when sentencing an offender who is the parent of a dependent child (Recommendation 47). In responding to this recommendation the government advised that the Attorney General would write to the Judicial Commission suggesting the issue be considered for inclusion in the Commission's education and training programs;

- monitor the sentencing patterns of magistrates and judges to ensure prison be used as a last resort for parents of dependent children (Recommendation 48). In responding to this recommendation, the government gave "in principle" support;

- develop and implement an education program for judges and magistrates to encourage the use of non-custodial sentencing options for drug and other nonviolent offenders (Recommendation 49) and that information about the Home Detention Program (Recommendation 54), and Griffith Bonds (Recommendation 58) be included. In responding to these recommendations the government advised that the Attorney General would write to the Judicial Commission suggesting the issue be considered for inclusion in the Commission's education and training programs;

- introduce legislation to allow for the requirement of attendance at a drug and alcohol treatment centre as an alternative to imprisonment with appropriate safeguards (Recommendation 53). In responding to this recommendation, the government said that it was "under consideration".

In responding to Recommendation 53, the government identified a number of factors it considered made the implementation of a drug and alcohol treatment program in the periodic detention scheme "impractical". These factors included:

> *A program may need continuous attendance for a length of time and periodic detainees would only be available to attend two days in every seven; the length of sentence may not cover the time required for treatment; and the number of detainees at a particular centre required to attend the program may not be sufficient to make operation of the program viable* (NSW Government, 1998:24).

While recognising that the periodic detention scheme may not be the most appropriate venue for drug and alcohol treatment programs, the Committee still stands by its original recommendation for rehabilitation to be an alternative to imprisonment. It remains convinced that the objections forwarded by the government can be overcome with planning, flexibility and the will to work with drug offenders who want help. Even if counselling were available for the two days (which need not be weekends) progress would be made.

The Committee recognises the potential for non-custodial sentencing options can play in reducing the transmission of Hepatitis C in the corrections system. It wishes to see the NSW Intersectorial Advisory Committee for Hepatitis C proposed in Recommendation 105 give urgent consideration to a range of options including diversionary sentencing, drug courts, and the inappropriateness of mandatory sentences for minor offences.

RECOMMENDATION 115:

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 give urgent consideration to a range of non-custodial sentencing options such as:

- the use of diversionary sentencing;
- utilisation of drug courts; and
- the inappropriateness of mandatory sentences for minor offences

as a means of reducing the transmission of Hepatitis C in the corrections system.

- **Limit Supply of Drugs Entering Correctional Centres**

A number of expert witnesses commented on the ready availability of drugs within the prison system. The Committee heard, for example, that:

> *we know for a fact that drugs and needles and syringes come into gaol no matter how well it is policed - even with the nice new gaol - and inmate will continue to use when they go out* (Harper evidence, 23 March 1998);

and

> *Heroin is no trouble to get; there is never a shortage. There is probably more inside the prison than outside . . . there is an awful lot of use that goes on in the prison. I am sure I meet with a very biased group of prisoners but they are slightly more likely to play it straight with me and tell me the truth, and hardly none of them do not use at some time when they are inside* (Lloyd evidence, 30 March 1998).

The submission from the Community Working Group on Prisons and Blood Borne Communicable Diseases suggested that:

> *It is fallacious to expect that prisons will be drug-free, when 50% of the population are injecting drug users, and for a substantial proportion of them drug use has been a causal factor in their imprisonment* (the Prisons and Blood Borne Communicable Diseases Community Working Group submission).

Crofts was also quite realistic in his appraisal of drugs in gaols:

> *I always chuckle at the idea of the most well motivated and capable public servants sitting in their Department of Corrections or wherever and working on this problem of keeping drugs out of gaol. Even if they are*

> *working intensively, perhaps 20 hours a week, giving it their full attention, trying to devise strategies to keep drugs out of gaol, against them are hundreds and thousands or equally committed and equally intelligent people working 24 hours a day to work out how to bring them in . . . It is a losing battle . . . The drug market in prisons is just a sort of concentrated and highlighted version of the drug market elsewhere. The reasons that people use drugs in prisons are all the same sort of human reasons that they use it on the outside but made more pointed or more sharp in some ways. One of those is boredom and meaninglessness* (Crofts evidence, 28 November 1997).

Support to limit the supply of drugs in correctional centres came from Professor Lloyd who suggested that:

> *all things being equal, it would be foolish for us not to attempt to minimise the supply of drugs within the prison, and that means dealing with prisoners who go on work release and so on, who come back in and deal; as well as dealing with the custodial staff who also deal* (Lloyd evidence, 30 March 1998).

Lloyd fully recognised that such a proposition is “easier said than done, of course” (Lloyd evidence, 30 March 1998).

For drug trafficking to occur into a correctional centre its perimeter must be breached. At correctional centre with secure perimeters this is generally achieved by offenders using three main avenues including:

i. drugs or contraband passing over or under the perimeter;

ii. drugs or contraband going through a visiting section of a correctional centre; or

iii. drugs or contraband passing through vehicle and pedestrian gates by corrupt staff, civilian workers, deliveries and stores, vehicles, inmates on reception, inmates returning to a centre or in inmate mail (Department of Corrective Services supplementary submission).

The Department advised that it employs a wide range of strategies that form a comprehensive drug supply reduction program. The key components of the strategy include:

- the State Investigative and Security Group;
- the Corrective Service Investigation Unit;
- the Corrections Intelligence Group;

- Institutional Intelligence Officers;
- drug detection dogs;
- fan assisted drug detection;
- searching programs;
- video surveillance;
- toilet access for visitors;
- high profile deterrence including public notices and leaflets given to visitors;
- flagging suspect visitors;
- searching powers;
- increased penalties; and
- 1800 Drug Information Hotline (NSW Department of Corrective Services supplementary submission).

- **Hepatitis B Vaccination Program**

The NSW correctional system currently has in place a voluntary Hepatitis B vaccination program. As the Committee heard "slowly the Corrections Health Service is warming to the fact that it is a good idea to immunise inmates against Hepatitis B" (Butler evidence, 23 March 1998).

It is Departmental policy that all correctional centre based staff in contact with inmates be provided with Hepatitis B vaccinations (Department of Corrective Services, 1996, 54). While the Committee was able to ascertain departmental policy on the vaccination program for staff, the policy as it relates to inmates was not so readily accessible.

The Committee heard that:

> *At the moment there are restrictions on length of sentence and a range of other factors come into play before a vaccination would be offered* (Vumbaca evidence, 23 March 1998).

One witness suggested this length of sentence to be six months or more. However, as the average length of sentence ranges from 3.5 to 7.5 months for females and males respectively the Committee heard that there are “problems” and “quite a lot of people were falling through the net based on that criteria” (Butler evidence, 23 March 1998).

The Committee also heard that it is now possible for an inmate, regardless of length of sentence, to request Hepatitis B vaccinations. A 1996 Departmental publication stated that “all inmates” are entitled to free Hepatitis B vaccinations from Corrections Health Service clinics provided they are tested, screened and educated by clinic staff first (Department of Corrective Services, 1996:54). This was supported by Lloyd who told the Committee that inmates who undergo voluntary screening, are not infected and have no immunity against Hepatitis B are offered a Hepatitis B vaccination (Lloyd evidence, 30 March 1998).

From evidence taken from Corrections Health Service nurses it seems that immunisations are occurring regardless of the policy. Corrections Health Service nurses advised Committee Members that they would commence the immunisation schedule with inmates serving one month as they considered this to be a “good health prevention or health promotion activity” (Christensen evidence, 23 March 1998). As Parsons told Members:

> *We also encourage Hepatitis B vaccine in our system. Anyone who is serving a long sentence or is engaging in at-risk behaviour when we are testing . . . we offer Hepatitis B vaccine because a person with Hepatitis C is already compromised. To give another infection would involve a super infection, two viruses on the one liver, so we take that quite seriously and push the Hepatitis B vaccine, especially for the hepatitis guys and anyone who is at risk* (Parsons evidence, 23 March 1998).

However, as Christensen admitted, “I do not know whether the formal policy has actually caught up with that [practice] yet” (Christensen evidence, 23 March 1998).

Given the conflicting advice, the Committee agrees with Butler who suggested that “it was quite difficult to find out what the policy was on hepatitis B vaccinations” (Butler evidence, 23 March 1998).

Butler’s survey referred to in Section 3.2.2 collected data on the Hepatitis B status of inmates. His study found:

- 33% of male inmates and 46% of females inmates were hepatitis B core antibody positive suggesting they have been exposed to the hepatitis B virus;

- 30% of male inmates and 9% of female inmates had not been exposed to the hepatitis B virus nor had they been immunised. Butler suggested that this “at-risk” group needs to be “targeted” for immunisation (Butler evidence, 23 March 1998); and

- approximately 70% of male inmates and 50% of female inmates reported completing the full course of Hepatitis B shots leaving up to 30% of males and 50% of females not receiving all three shots (Butler evidence, 23 March 1998).

There was general agreement for a Hepatitis B vaccination program amongst those witnesses with experience in the prisons system. Butler, for example, considers that "without doubt" it would be a useful policy (Butler evidence, 23 March 1998). The Prisons and Blood Borne Communicable Diseases Policy recommends that a voluntary Hepatitis B vaccination program be implemented and that participation be with the free and informed choice of each prisoner. The Department of Corrective Services representative appearing before the Committee, Mr Gino Vumbaca, also considered it an "appropriate" strategy (Vumbaca evidence, 23 March 1998):

> *Given that people are coming in for short sentences and are coming in on multiple occasions in some areas, I would think that for the cost of a vaccination any protection from Hepatitis B is better than none at the moment. . . Vaccinations should be offered to every inmate* (Vumbaca evidence, 23 March 1998).

Lloyd told Committee Members that vaccinating inmates against Hepatitis B:

> *does the whole community a good service because it captures those individuals and breaks the transmission mode of this virus* (Lloyd evidence, 30 March 1998).

The proposal made by NSW Health to the National Drug Strategy Committee for vaccinating methadone clients against Hepatitis B discussed in the preceding section also proposed that, once "teething problems" had been eliminated, the program be extended to include prison inmates. The proposal recognised that offering free HBV vaccinations to prison inmates (amongst others) could "provoke an initially negative reaction from members of the public and some clinicians" and that:

> *the soundness of preventing HBV in injecting drug users both on the grounds of this policy being a cost effective use of public funds, and which reduces risk to the general public by reducing the number of HBV carriers in the population needs to be stressed* (NSW Health supplementary submission).

A number of concerns with the current process of providing Hepatitis B vaccinations were raised during the course of evidence. One of the issues identified related to managing the immunisation process. It would seem that medical records and immunisation registers are yet to be put on a computer database enabling the records of prisoners reentering the system, or transferring to another correctional centre, to be readily accessed. The present system seems to rely on self-presentation which is not always successful. Butler observed that:

> *We need to consider other issues such as immunisation registers and access to medical records to see if somebody has already been immunised. There is no point in reimmunising people just for the sake of it but if one had access to medical records on entry, that could be determined easily* (Butler evidence, 23 March 1998).

Ms Christensen raised similar concerns:

> *because of frequency of movement inmates will often have injections . . . a card is given and a note made in the medical records, but that relies on an inmate self-presenting at the right time to have the next vaccination, which is fraught with difficulty because the medical records may not accompany the inmate. A database needs to be created that actually tracks records and alerts staff when an inmate is due for subsequent vaccination so that there can be a dual self-reporting as well as follow-up by the nursing staff in the gaol. That is a major limitation of the hepatitis B program at the moment* (Christensen evidence, 23 March 1998).

The introduction of a database for inmate's medical records has implications far beyond efficient management of the Hepatitis B vaccination program. It would appear to be a rather fundamental tool for the Corrections Health Service and clearly one requiring further consideration.

RECOMMENDATION 116:

That the Ministers for Corrective Services and Health establish a medical records database throughout the state's corrections system to facilitate the successful follow-up of inmates and management of their Hepatitis C.

Butler also expressed his concerns that current inadequacies with the Hepatitis B immunisation program could mean that when Hepatitis C or HIV vaccinations are available mechanisms and protocols will still not be in place and adequate protection will not be made available to inmates:

> *It concerns me slightly that we have moved on to Hepatitis C and now we have hepatitis G. We have a condition that is vaccine preventable and one asks whether we are doing enough to prevent it. We have a solution, which is immunisation, but are we using it effectively? I always ask the question: if we find a vaccine for HIV and Hepatitis C are we going to use it in the same haphazard way as we do with hepatitis B? If we get the hepatitis B vaccination right, then when vaccines hopefully come onboard for HIV, Hepatitis C and Hepatitis G we will be in a much better position to implement those systems* (Butler evidence, 23 March 1998).

The Committee was concerned at such a possibility and wishes to see the Hepatitis B vaccination program administered as effectively as possible.

RECOMMENDATION 117:

That the Ministers for Corrective Services and Health collaborate to ensure that the Hepatitis B vaccination program operates effectively in every prison and where possible, every alternative community sentencing program.

It was suggested to the Committee that another difficulty arises when inmates are discharged from prison before they have completed their immunisation schedule. As the Committee heard:

> *With Hepatitis B there are problems because someone to be given a course of three shots may need to receive the third one from a general practitioner on the outside* (Butler evidence, 23 March 1998).

In many instances, the third shot is not received and complete protection from the Hepatitis B virus is not achieved. Accelerated schedules of vaccination (0, 10 and 21 days) are available and one witness proposed such a schedule as an appropriate strategy ensure all three shots are obtained in as short a time as possible and before release from prison.

The cost effectiveness of the Hepatitis B vaccination program has yet to be determined. It was suggested to the Committee that:

> *We need to evaluate what is most cost effective - do we just immunise everybody at one time or do we selectively target certain groups for immunisation? We also need to know the cost implications of that . . . We need to do a study in New South Wales to ensure that we have the most cost effective vaccination policy in place* (Butler evidence, 23 March 1998).

In conducting such a cost effective exercise the Committee would like to see alternate immunisations options such as accelerated schedules included.

RECOMMENDATION 118:

That the Minister for Health commission a cost effectiveness study of the Hepatitis B vaccination program currently conducted by Corrections Health Service and that the study examine a range of immunisation options including the use of accelerated vaccination schedules.

10.2.2 HEPATITIS C PREVENTION MEASURES IMPACTING UPON ALL INMATES

Preventative strategies proposed to the Committee to limit the spread of Hepatitis C fell into two broad categories: measures impacting upon all inmates such as use of barber's shears and cleaning up blood spills; and measures directly targeting injecting drug users within the corrections system. These latter measures will be discussed in Section 10.2.3 while issues pertaining to all inmates are reviewed in the discussion below.

- **Barber's Shears**

During the course of evidence, Professor Lloyd discussed a case study involving the transmission of Hepatitis C through the use of barber's shears. One inmate incurred a laceration from barber's shears which contained blood from a laceration from the scalp of a Hepatitis C infected inmate (Lloyd evidence, 30 March 1998).

The Committee was advised that a trial of barber's shears with detachable heads that could be disinfected without using an autoclave had recently been conducted at Long Bay. In giving evidence, the Departmental officer anticipated that a recommendation would shortly be made that all correctional centres purchase and supply only these shears.

RECOMMENDATION 119:

That the Minister for Corrective Services instruct all correctional centres to purchase and supply only approved barber's shears with detachable heads that can be cleaned readily with bleach and water.

- **Contact with Blood**

The Committee heard that:

> *inmates are often asked to clean up blood spills, whether they be from an accident, an attempt at self-harm or suicide. Policies are in place to say that inmates should be given barrier methods of protection so that they do not come in contact with blood, but that does not always happen. That is something that needs to be constantly promoted and reviewed. At Public Health Services we see a number of inmates presenting after an exposure, after they have had to clean up a large blood spill without gloves or protection* (Christensen evidence, 23 March 1998).

Christensen's comments raise at least two concerns: the risk inmates are exposed to in cleaning up blood spills and attitudes of officers who insist that inmates undertake such tasks.

The Department advised the Section 2.9 of the HIV and Health Promotion Unit's *Policies and Procedures and Management Guidelines* sets out procedures relating to blood spills. The Section does not however clearly state that inmates must be provided with the necessary equipment if they are requested to clean blood spills. The Department advised that this oversight will be amended with the Guidelines are next printed (Department of Corrective Services supplementary submission).

The Committee is concerned that without adequate protection, inmates are put at risk when requested to clean up blood spills. The Committee assumes that inmates would only clean up blood spills upon direction from prison officers. Clearly the onus is upon the officers who give such directions only when adequate protection is available.

RECOMMENDATION 120:

That the Minister for Corrective Services direct that inmates required to clean up blood spills must be provided with adequate protective clothing and appropriate sterilisation solution to minimise their exposure to Hepatitis C.

10.2.3 HEPATITIS C PREVENTION MEASURES TARGETING INJECTING DRUG USERS WITHIN THE CORRECTIONS SYSTEM

A 1993 NSW study showed that injecting drug users are less likely to inject while in prison, but those who do inject are more likely to share injecting equipment than they would have prior to imprisonment (Dolan, Wodak, Hall, Gaughwin and Rae, 1996). In noting these results, the submission from the Prisons and Blood Borne Communicable Diseases Community Working Group notes that those who inject are "forced into sharing networks, among whom the majority may well be already HCV-positive".

The following discussion looks are measures proposed to the Committee to prevent the transmission of Hepatitis C amongst injecting drug users in the corrections system.

- **Education Directed to Injecting Drug Users**

Lloyd stressed to the Committee the importance of providing inmate education strategies that target the most "at risk" group of prison inmates: sero-negative inmates (ie. not yet infected with Hepatitis C) who report they are injecting drug users. As Lloyd stressed to the Committee, these men and women are, in the first few days and weeks in prison, "hanging out" for drugs (see Section 10.2.1 for Lloyd's quote). Lloyd urged the Committee "to think laterally about how we can minimise some of those transmission events" (Lloyd evidence, 30 March 1998).

While only one witness raised this issue of education specifically directed at injecting drug users, the Committee considers it a vital factor in preventing the spread of Hepatitis C in the corrections system. The Committee is very aware of the pressure put upon new inmates during the first few days and weeks in prison and the stress this generates. It considers it vital that every effort be made to minimise the risk of transmission at this time.

RECOMMENDATION 121:

That the Minister for Corrective Services direct that appropriate educational strategies target non Hepatitis C positive inmates who are at risk of infection during their first few weeks in prison.

- **Provision of Sterile Needles and Syringes**

The *Prisons (Syringe Prohibition) Amendment Act, 1991* made it an offence for a person to introduce (or attempt to introduce) a syringe into a prison without the consent of the prison governor; or to supply (or attempt to supply) a syringe to a prisoner in custody, except when authorised to do so by a doctor, and if the prisoner is in prison, with the written consent of the prison governor. As Department of Corrective Services policy PLY.92.162/4 points out the Act includes that an offence may be committed even though only part of a syringe, such as a needle, is involved (Department of Corrective Services, 1996:66). Despite the legislation, there was, during the course of the Inquiry, considerable support given to the provision of sterile needles and syringes to prisoners within the corrections system.

In appearing before the Committee, Crofts reiterated the position he has taken in his published works in stating that "I think the provision of sterile needles and syringes in prisons would largely overcome the risk associated [with sharing]" (Crofts evidence, 28 November 1997).

In their submission to the Inquiry, the Hepatitis C Council called for the establishment of needle and syringe programs in prisons and appropriate amendments to prison regulations to enable such programs to proceed (Hepatitis C Council Submission).

Support for the provision of clean injecting equipment also came from a prison inmate who stated in his submission that:

> *I feel that the main problem in prisons today is the lack of clean needles . . . The spread of HIV/HCV is being allowed to continue due to the*

> *Department not wanting to be seen as condoning the use of intravenous drugs. Surely society would demand the Department of Corrective Services to be responsible for containing the spread of these viruses. . . If we lived in a perfect world then there would be no drug use or wilful spread of these viruses, unfortunately we do not and as such the Department of Corrective Services are being irresponsible for allowing the spread of these deadly viruses to continue* (Lee submission).

Representatives from the Community Working Group on Prisons and Blood Borne Communicable Diseases also supported the introduction of sterile needles and syringes. In their submission to the Inquiry they argued that:

> *the success of needle and syringe exchange programs in the general community demands similar action within the prison system, together with comprehensive information about safe injecting procedures and vein care* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

The Working Group called for a pilot of a “strict” one-for-one needle exchange program within the prison system (Selvanera evidence, 23 March 1998).

The NSW Hepatitis C Taskforce recommended the establishment of a pilot syringe (only) exchange program in a “suitable” correctional facility (NSW Hepatitis C Taskforce, 1995:20). The Taskforce considered the trial would need to be time-limited, strictly “one-for-one” and include a careful examination of possible unintended negative consequences. It was recognised that the recommendation would be “strongly opposed” however, the Taskforce recognised the opportunities to interrupt Hepatitis C transmission in prisons to be “severely limited” (NSW Hepatitis C Taskforce, 1995:20).

Professor Lloyd informed the Committee that “in an ideal setting I would like to have a needle exchange” (Lloyd evidence, 30 March 1998). However, he was very aware of the challenges such a proposal would bring. He envisaged:

> *challenge on a series of levels. In a practical sense it could be dispensed in every prison by the public health nursing unit on an exchange basis. On a political level it has this huge difficulty in that the Department of Corrective Services would have to say implicitly that there are a lot of drugs available in our prisons and it is going to let that continue to be the case* (Lloyd evidence, 30 March 1998).

He was also aware that:

> *currently there are some difficult irreconcilable stumbling blocks primarily linked to the Department of Corrective Services* (Lloyd evidence, 30 March 1998).

Mr Puplick appearing in his capacity as Chair of ANCARD also gave support to the concept of needle and syringe exchange in prisons. As he informed the Committee:

> *from a public health point of view there is no reason that people who have access on the outside to a preventative health measure such as clean injecting equipment should be denied access to that same treatment simply as a result of their incarceration* (Puplick evidence, 7 November 1997).

Both Lloyd and Puplick referred the Committee back to the introduction of condoms in prisons as an example of the successful introduction of a controversial preventative strategy that, at first, received considerable opposition not only from prison officers but the general community.

As a member of the Prison Condom Committee for Corrections Health Service Lloyd reminded Members that the introduction of condoms:

> *is a good example of there being a large amount of paranoia up-front, which basically has resolved. Condoms are out there. Through careful negotiations, dealing carefully with unions, then conducting a structured trial in a set of prisons where the governors were a little more enlightened, and the realisation that there were no big crisis associated with it, we were then able to get it to fly* (Lloyd evidence, 30 March 1998).

Mr Puplick chaired the Committee that, at the request of then Attorney-General, the Hon John Hannaford, MLC, prepared a report into the possible introduction of needles and syringes and condoms in prisons. The final report recommended the introduction of condoms, but not needles and syringes. When questioned on the reasons for not supporting the introduction of needles and syringes at that stage, but his support for their introduction now, Puplick informed the Committee that:

> *our reason for not recommending . . . the availability of syringes in prisons at that stage was the specific issue of . . a syringe as an offensive weapon. . . We were not in a position to look at any overseas evidence at that stage. It is only in the past couple of years that such material, from Germany in particular, has become available. All of the material indicates that controlled self-injecting arrangements within prisons can be made to work in a way that is not in any meaningful sense dangerous to prison officers. That is either because the injecting is done in essentially a self-injecting room within the prison itself or because the control mechanisms for the issue of needles are such that only one needle is issued to a person in a prison. They are then required to be kept in a glass-fronted or perspex-fronted cabinet in their room so that the needle is kept permanently on display. There have been no instances of which I am*

> *aware - certainly none reported in the literature - of any of those needles being used as weapons. Prisoners are not short of significant numbers of sharp instruments of one sort of another, nor indeed are they in any sense short of dirty needles* (Puplick evidence, 7 November 1997).

In his evidence he referred to "substantial overseas evidence" from Germany, Switzerland and to a lesser extent Austria and preliminary data from Spain on the extent to which the provision of clean needles has had a "significant impact" on reducing the rate of HCV infection within the prison system (Puplick evidence, 7 November 1997). Similar evidence was cited to the Committee by Mr Selvanera who informed the Committee that effective needle and syringe exchange programs are operating effectively in at least three jurisdictions: Switzerland, Germany and Spain. He provided the Committee with the following details of the Swiss pilot program:

> *After a 12 month pilot of one of its needle exchange programs the Swiss experience was not a single new case of HIV or Hepatitis B, no new cases of abscesses linked to injecting drug use, not a single instance in which needles were used as weapons against prison staff or other inmates and a fall in drug consumption as measured by the level of demand for new needles over the study period* (Selvanera evidence, 23 March 1998).

The submission from the Community Working Group on Prisons and Blood Borne Communicable Diseases contained further detail of these pilot programs including the various models for implementing needle and syringe exchange within the prison system. Two models identified were the installation of syringe distribution machines which could be accessed anonymously and a system whereby prisoners identified themselves as current injecting drug users with the prison doctor prior to commencement on the program. Syringes are exchanged during visits to the prison health centres. The Working Group's submission notes that both models amend regulations permitting possession of syringes in the toilet area of the prisoners' cells with any syringes and drugs found outside these areas confiscated (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

In referring to these overseas models, Mr Selvanera urged the Committee that Australia does not need to "reinvent the wheel on this issue" and undertake all the policy development given that it has the experience of these countries to turn to (Selvanera evidence, 23 March 1998).

The Department of Corrective Services representative appearing before the Committee made it very clear that "the department has no plan to provide needles and syringes to inmates" (Vumbaca evidence, 23 March 1998). As he went on to elaborate:

> *needles and syringes in prison is an emotive issue, particularly given the recent death of a prison officer who was deliberately infected with HIV by a needle and syringe . . . . The department is not considering the option*

> *of introducing needles and syringes in the same way that they are available through the needle exchange program* (Vumbaca evidence, 23 March 1998).

In response to the evidence presented to it, Committee Members considered it appropriate for the Intersectorial Advisory Committee for Hepatitis C proposed in Recommendation 105 to investigate the appropriateness of introducing a needle and syringe exchange program into the state's correctional system. Should the Advisory Committee consider it appropriate, the Committee proposes this body then develop the guidelines to assist in the program's implementation.

RECOMMENDATION 122:

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 investigate and report on the appropriateness of introducing a needle and syringe exchange program, modelled on the successful European trials, into the state's correctional system and, if necessary, develop guidelines for the program's implementation.

The primary objection to providing needles and syringes to inmates comes from prison officers who are concerned that needles and syringes would be used as weapons. As the Committee heard from the Department of Corrective Services representative:

> *at the moment needles are a valuable commodity within the prison system for inmates who hold them. They are not likely to be misused or given up and they are not handed in by people . . If they were freely available in the system there is a fear amongst staff that the potential for inmates to use them will exist* (Vumbaca evidence, 23 March 1998)

and

> *people have a number of concerns about how needles and syringes could be introduced into the system and yet maintain the safety of staff and other inmates who do not have access to needles and syringes . . .* (Vumbaca evidence, 23 March 1998).

Prison officers are, however, currently put at risk of needle stick injury when conducting cell searches. The Committee was informed by the Department of Corrective Services that there is, on average, one needle stick injury a month amongst prison officers conducting searches. These injuries occur despite Procedural Order ACO:94/138 *Handling and Disposal of Needles and Syringes and Other Sharp Items* which states: "**DO NOT** place hands into areas which you cannot see" and "**DO NOT** rub fingers along or under tables, beds, mattresses etc" (Department of Corrective Services, 1994).

In addition, the Committee was advised officers receive “a lot of training” to ensure they search correctly however:

> *staff are searching incorrectly, forget to search or stick their hands somewhere where they should not and get a needle stick* (Vumbaca evidence, 23 March 1998).

As Vumbaca conceded, providing needles “would probably reduce the level of risk to staff” (Vumbaca evidence, 23 March 1998).

The submission from a prison inmate noted that:

> *I understand that needles and needle stick injuries are a problem for Officers during searches, but once again the facts are that <u>there are needles in here already</u>, and I figure that if it was me, I’d rather be stuck by a clean(er) needle than one that has been around for a long time* (Submission 63).

Both during the course of evidence and in their written submission, representatives from the Community Working Group on Prisons and Blood Borne Communicable Diseases noted that the public sector prison officers’ unions (the Prison Officers Vocational Branch and the Commissioned Officers Vocational Branch of the PSA) are opposed to harm minimisation measures in prisons (despite it being government policy). The level of support for this opposition among the rank and file is, the Committee was advised, “unknown” (Cregan evidence, 23 March 1998 and Community Working Group on Prisons and Blood Borne Communicable Diseases submission). The Working Group noted that representatives of private sector officers employed at the Junee Correctional Centre have expressed their support for harm minimisation principles on the basis that minimising the prevalence of infectious diseases among the inmate population is in their members’ own interest (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

Cregan noted in evidence that one of the features of prison officers is that they are potentially in a position to be an “incredible force for the reduction of health problems” in the corrections system (Cregan evidence, 23 March 1998). Cregan also made reference back to the introduction of condoms into prisons and informed Members that over 50 per cent of prison officers were in favour of condom distribution and non-commissioned officers were “divided about 50-50" in support of and against (Cregan evidence, 23 March 1998). As she concludes:

> *we believe that they could be a force to contributing to better health if they took a different perspective on what harm minimisation means for their own membership* (Cregan evidence, 23 March 1998).

In terms of strategies to bring about attitudinal change, the Working Group suggested that:

> *it is a matter of extreme importance to convince correctional staff of the benefit to themselves as well as to the prisoners in their care, of minimising the level of transmission risk they face in carrying out their duties and the advantage in accepting a harm minimisation approach* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

In the course of evidence Cregan added:

> *the main thing would be to find some way of explaining to the leadership of the organisations that it is their own benefit to reduce the viral pool in prisons, to reduce the number of people who are injecting in prisons and to reduce the potential risks associated with unclean injecting equipment that is in prisons. . . . To help them see . . . that the less occurrence of Hepatitis C amongst prisoners and the safer it is in any potential situation of infection, the more it is in their own interest* (Cregan evidence, 23 March 1998).

The Working Group recommended special education modules on harm minimisation be developed and made compulsory for all staff. The Committee fully supports this proposal.

RECOMMENDATION 123:

That the Department of Corrective Services design, develop and implement an in-service training course for prison officers made up of education modules on harm minimisation and that adequate resources be made available to fund the implementation of the modules. The Committee further recommends that the Minister for Corrective Services direct all prison officers to undertake the proposed in-service training course on harm minimisation.

- **Safe Injecting Rooms**

During the course of the Inquiry support was not only given to the introduction of safe injecting rooms in the general community as has been discussed (see Section 10.1.2), but support was also given to the introduction of safe injecting rooms within the corrections system.

Harper, in her capacity as Acting Clinical Nurse Consultant with Corrections Health Service informed the Committee that:

> *I believe strongly that . . . we should have a room within the confines of the prisons for prisoners to be able to inject in a safe manner using the needle exchange program . . . I would see it as just public health under the guise of the Public Health Unit . . . That is a fairly radical viewpoint that I have but when I look at the age of the young offender who presents now and is Hepatitis C positive I have to say that alarm bells ring very loudly in terms of what we are doing about all of this* (Harper evidence, 23 March 1998).

Representatives from the Community Working Group on Prisons and Blood Borne Communicable Diseases also called for the establishment of supervised safe injecting room areas within prisons. Like Harper the Community Working Group's model saw the rooms being under the authority and supervision of the Corrections Health Service. They did not anticipate the need for legislative amendment, although there would be, they admitted, "some operational directives to be changed at the Department of Corrective Services end" (Selvanera evidence, 23 March 1998). As a Working Group representative informed the Committee:

> *we note that needles and syringes are allowed to go into the gaol premises to be used by clinic staff in the Corrections Health Service for vaccinations and treating diabetics and other medical conditions for which injections are required. As a model we propose that a safe injecting area be set up with a medical focus . . . to treat the dependency on the drug as a medical problem. A safe area could be established within the clinic area under exactly those same provisions - the exemption from the Prisons Act that covers the bringing in of injecting equipment for those other medical treatments* (Cregan evidence, 23 March 1998).

The Working Group identified two advantages in the establishment of safe injecting areas: injecting equipment would be limited to a specific area within the clinic environment so that the risk of needlestick injuries to staff searching cells would be decreased; and prison officers, currently opposed to harm minimisation measures for injecting drug users, would not be involved in running the program (Community Working Group on Prisons and Blood Borne Communicable Diseases submission). The Working Group recommended that the Commissioner for Corrective Services direct the governors of all correctional centres to designate specific areas annexed to prison clinics as safe injecting areas and authorise medical personnel to bring needle and syringes into those areas for the purposes of establishing safe injecting programs (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

The Community Working Group on Prisons and Blood Borne Communicable Diseases suggested that safe injecting rooms could help reduce the number of deaths by overdose that currently occurs in the state's corrections system. They informed the Committee that death by drug overdoes is currently the "primary cause" of death within the state's prisons system and accounts for one-third of all deaths in prisons (Selvanera evidence, 23 March 1998).

The Hepatitis C Council also called for the establishment of safe injecting rooms within the prison system (Hepatitis C Council submission). Lloyd considered a pilot injecting room in prison to be a "bold move" but admitted that he could "live with the idea". He did warn Members that "it would be a popular room, I hate to tell you" (Lloyd evidence, 30 March 1998).

In its submission to this Inquiry, ANCARD attached the submission they made to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms. In that submission ANCARD gave its support to the trial of safe injecting rooms in the prison setting. The submission notes that:

> *ANCARD would support such a trial [of safe injecting rooms] being expanded to include the prison setting . . . Regard must be given to prison officers whose safety may be compromised without ensuring adequate measures are in place. Clean injecting rooms within prisons may overcome the personal security worries of prison staff. The duty of care of prison officers must also be considered* (ANCARD submission to the Joint Select Committee Parliamentary Inquiry into the Establishment or Trial of Safe Injecting Rooms).

For obvious reasons, some departmental officers were reluctant to comment on such a sensitive issue. Others were happy to make a personal, rather than official, comment based on their experience. Mr Butler made such a personal comment when he appeared before the Committee. He noted that:

> *we need to look at options as to whether you introduce a needle exchange scheme or whether you have safe injecting rooms . . . I think that we probably need to do an evaluation of that to determine the most effective way. Safety is also an issue. It is a difficult environment, as we know about the HIV cases* (Butler evidence, 23 March 1998).

Butler envisages a safe injecting room to be run by NSW Health which could involve:

> *perhaps one needle when a prisoner goes in and one needle when the prisoner comes out* (Butler evidence, 23 March 1998)

but as he admitted:

> *one then has to consider whether prisoners would actually use that system, because it might identify them as persons using drugs* (Butler evidence, 23 March 1998).

While supporting the concept, some witnesses such as Christensen and Harper recognised inherent difficulties in the proposal:

> *The way the gaols are currently structured, I would find it quite difficult to see how safe injecting rooms or a needle and syringe exchange program could be operated. While I support that from a public health point of view because it is a valuable strategy, it would take a lot of planning, a lot of implementation and a lot of negotiation* (Christensen evidence, 23 March 1998)

and

> *I suppose you would have a security issue or problem again in that you have to work in conjunction with the Department of Corrective Services to access those inmates. We know that they would never come to the party, given the fact that an officer was stabbed and died last year. I do not believe that putting people in prison and denying them in fact works* (Harper evidence, 23 March 1998).

During the course of his evidence, the Department of Corrective Services representative pointed out to the Committee that:

> *The issue of injecting rooms that was considered in the community may have provided an opportunity for the department at least to consider that as an option for prisoners. As that has not been approved for the community it is unlikely that it will be considered by the department. . . Prisons will not lead the way in this area; they will look at what is available in the community. We are there to provide a level of service that it equitable to that in the community* (Vumbaca evidence, 23 March 1998).

The Committee noted the evidence presented to it concerning the establishment of safe injecting rooms in prisons and the calls for a time-limited safe injecting room trial to be conducted in the public health nursing unit of a carefully selected correctional centre under the authority and strict supervision of the Corrections Health Services. The Committee believed that such a trial in the correctional system would not be appropriate until a proposal for a trial in the wider community had been approved by the Government.

- **Availability of Drug Withdrawal Programs**

Another preventative strategy proposed to the Committee related to the availability of drug withdrawal programs for prison inmates. Lloyd proposed that:

> *there will be selected individuals, like those in the general community, for whom other strategies may well be useful, such as drug withdrawal programs, including long-acting narcotic antagonants such as naltrexone and so on* (Lloyd evidence, 30 March 1998).

However, when the Department was asked to provide advice on rehabilitation and treatment programs available to inmates wishing to give up drugs, the response provided made mention only of the role played by Alcohol and Other Drug Workers and group work programs. While counsellors and group work have a part to play in drug rehabilitation, they may not be appropriate for all inmates. The Committee was disappointed with the limited range of drug withdrawal strategies available to inmates which are available to those in the general community. The Committee wishes to see the Department give serious consideration to introducing a range of drug withdrawal strategies and making these available throughout the correctional system.

RECOMMENDATION 124:

That Corrections Health Service make available a range of drug withdrawal strategies to inmates seeking to give up their drug habit.

- **Abolition of Penalties Associated with Cannabis Use**

As has been discussed in Section 3.2.5 cannabis is not the drug of choice for most prison inmates for a number of reasons: it is harder to obtain than heroin because its importation into prisons is easier to detect and it is less profitable to import per unit volume; and cannabis is detectable more readily through urinalysis than heroin. As a result of these factors, prisoners are more likely to use the less preferred, but more readily available drug. As the Community Working Group on Prisons and Blood Borne Communicable Diseases noted in their submission:

> *This leads to the anomalous situation where cannabis, which is smoked and therefore safe in terms of viral transmission, is currently subject to heavier disincentives to its use than heroin and other injectable drugs, which represent the highest of all risks for HCV transmission* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

To overcome this anomaly, the Working Group propose that:

> *the use of cannabis in prison should be preferred over injectable drugs such as heroin, and a shift in drug use patterns should be encouraged either by ceasing to test for cannabis on urinalysis, or by eliminating penalties for a positive result* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

The Hepatitis C Council made a similar recommendation to the Committee in calling for a change in the current situation to one that encourages prisoners away from the use of powder drugs to the use of cannabis (Loveday evidence, 30 March 1998).

The Working Group made two specific recommendations to the Committee concerning cannabis in prisons. Firstly they recommended that the Department of Corrective Services cease urinalysis testing for evidence of cannabis use by prisoners and that penalties for smoking cannabis be abolished (Selvanera evidence, 23 March 1998; Community Working Group on Prisons and Blood Borne Communicable Diseases submission). Secondly that prison regulations regarding drug trafficking and use be amended so that sanctions against cannabis are lifted (the Prisons and Blood Borne Communicable Diseases Community Working Group submission).

It was suggested to the Committee that such a strategy would bring NSW prisons into line with moves toward law reform in the community and mean that:

> *transition to and from prison would no longer involve a shift for some people from less harmful substances and use practices to more harmful ones while in gaol. Any attempt to make a transition back to safer drug use after release is certain to be made more difficult if dependency has been established in prison* (Community Working Group on Prisons and Blood Borne Communicable Diseases submission).

Committee Members were not able to support the proposals forwarded by the Prisons and Blood Borne Communicable Diseases Working Group.

10.2.4 FUNDING OF HEPATITIS C PROGRAMS

The Committee is fully aware that the proposals it has recommended have costing implications. However given the prevalence of Hepatitis C within the corrections system and the implications such a high prevalence level has upon the general community, the Committee considers its proposals to be cost-effective and financially responsible.

The issue of funding was raised by the Department’s representative. Mr Vumbaca noted that additional funding to finance Hepatitis C preventative initiatives has not been forthcoming and that he has to use:

> *what was dedicated HIV money to cover a whole range of issues now, including Hepatitis C. The money received from the Department of Health is still technically dedicated HIV money* (Vumbaca evidence, 23 March 1998).

Mr Vumbaca further advised that this funding arrangements between the Departments of Health and Corrective Services is "putting a strain on relationships at the moment" (Vumbaca evidence, 23 March 1998). As he noted:

> *What is probably putting a strain on the relationship at the moment is the need to use existing funds only, HIV funds, to cover a whole range of issues in the system. That is probably the main area of contention - how we keep providing all these new programs and service within the existing budget. We are taking from one area to pay for another* (Vumbaca evidence, 23 March 1998).

Utilisation of HIV funding to finance HCV preventative initiatives fails to recognise or acknowledge the extent of Hepatitis C in the prison system. In the Committee's opinion it is inappropriate that funding allocations are not made to address Hepatitis C issues within the corrections system given the extent of the epidemic. The Committee considers it important that funding be allocated to Hepatitis C dedicated projects rather than taken from HIV allocations. The Committee therefore wishes to see all funding used in Hepatitis C programs and projects identified as such.

The absence of HCV specific funding allocations is indicative of a far greater concern of the Committee's - the lack of policies giving direction to strategies designed to prevent the transmission of Hepatitis C in the correctional system. The Committee considers it important that the Departments of Health and Corrective Services collaborate to develop a Hepatitis C prevention policy and associated strategies and that the policy be included in the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the strategies be incorporated into the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 125:

That the Ministers for Health and Corrective Services direct that a policy addressing prevention of Hepatitis C within the state's correctional system and the role played by drugs in the transmission of Hepatitis C be collaboratively developed between the two departments and that the policy be included in the NSW Hepatitis C Policy Statement proposed in Recommendation 28. The Committee further recommends that the two departments also develop strategies to prevent Hepatitis C transmission in the state's corrections system and incorporate these strategies into the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

10.2.5 CONCLUSION

The preceding discussion proposes a wide range of strategies designed to prevent the transmission of Hepatitis C within the state's correctional system. As with the strategies adopted to prevent Hepatitis C transmission amongst injecting drug users the Committee has again chosen a multi-facets approach. This is in line with evidence received. The Committee heard, for example that:

> *I do not think any one measure that one could name is likely to do the trick and resolve the problem . . . there would be a setting for each of those components for individuals within the prison as there is in the outside community* (Lloyd evidence, 30 March 1998).

10.3 PREVENTING THE TRANSMISSION OF HEPATITIS C IN THE HEALTH CARE SETTING

In Chapter Three reference was made to Italian research which identified the risk of surgeons contracting Hepatitis C (Pietrabissa, 1997). Pietrabissa calculated the current risk over a 30 year period to be 34.8%. However, when preventative strategies were introduced, this rate could, according to his calculations, be reduced to 16.6% over the same time period (see Table Thirty-one).

TABLE THIRTY-ONE
ESTIMATED REDUCTION IN THE RISK OF HCV TRANSMISSION
TO THE SURGEON BY ADOPTING PREVENTATIVE STRATEGIES

CONDITION OF 30-YEAR RISK	HVC (%)
Current	34.8
With face shields	32.6
With 50% reduction of sharp injuries	19.2
With all the above precautions	16.6

Source: Pietrabissa, 1997:575

Even if Pietrabissa's estimations are generous, as West implied during the course of his evidence, there are obviously measures that can be taken by surgeons, and other health care workers, to reduce the risk of contracting Hepatitis C from patients. In many instances incorporating such practices will also lessen the risk of health care workers passing the Hepatitis C virus on to their patients. Current and proposed preventative strategies are outlined in the following discussion.

10.3.1 PREVENTATIVE STRATEGIES CURRENTLY IN PLACE

Preventative strategies currently in place to protect both health care workers and their patients include the practice of universal precautions, hospital based Hepatitis B vaccination programs, telephone information lines, and the awareness of health care workers of their Hepatitis C status. The general practitioner education program reviewed in Section 8.4.1 also plays a major role in providing general practitioners with information on preventative strategies.

- **Universal Precautions**

Prior to an appreciation of the nature of blood borne diseases health care workers routinely undertook procedures which would be considered unacceptable today. One nurse writing to the Committee noted, for example, that:

> *many nurses in my era did the following (without gloves):*
> - *shaved open wounds ready for surgery or repair;*
> - *changed blood bottles - often the tubing was tough and the pressure needed to puncture the opening resulted in blood spurting out;*
> - *manual cleaning of theatres and manual washing of blood sponges* (Submission 19).

Universal blood and body fluid precautions ('universal precautions') were originally devised by the US Centres for Disease Control and Prevention in 1985 largely due to the HIV/AIDS epidemic and an urgent need for new strategies to protect hospital personnel from blood borne infections. The new approach placed emphasis, for the first time, on applying blood and body fluids precautions universally to all persons regardless of their infectious status or perceived risk (NHMRC, 1996:10).

Australia adopted a broader definition of Universal Precautions. Unlike the US which excluded faeces, nasal secretions, sputum, sweat, tears, urine or vomitus unless they contained visible blood, all blood and body substances were considered to be potentially infectious in Australia (NHMRC, 1996:11). However, the NHMRC have observed that the term "universal precautions" was perceived to be "ambiguous" resulting in some confusion in its interpretation and false sense of security in its application and they propose use of the terms "standard" and "additional" precautions" (NHMRC, 1996:11).

NSW Health's Infection Control Policy (95/13) recommends the adoption of the 'Standard Precautions' approach to the provision of care to all patients irrespective of their infectious status. This approach is, according to NSW Health, consistent with international best practice and encourages adoption by health care workers of a uniform, minimum level of infection control that is protective against most known hospital pathogens (NSW Health supplementary submission).

The submission received from the Royal College of Nursing, Australia expressed concerns that universal precautions alone will not be enough to prevent cross infection of blood borne viruses such as Hepatitis C between patients in haemodialysis units. The submission notes that haemodialysis has "probably the highest incidence of blood being sprayed several metres" when extra-corporeal blood lines are split or disconnected. While staff wear protective eyeware and gloves when attending patients, concern was expressed for the other patients sitting in close proximity. Hepatitis C patients are no longer required to be treated in separate rooms, only in low traffic areas. The submission questions whether such a precaution is enough to prevent cross infection within this group of patients (Royal College of Nursing, Australia submission).

The submission from the Royal College of Nursing, Australia noted that:

> *the effectiveness of universal precautions rests very much on their application in the workplace by all who are working in the clinical setting. Thus commitment on the part of all employers to staff education and occupational health and safety practices are of vital importance to success in prevention cross infection of blood borne infections*.

- **Hepatitis B Vaccination Program**

In its publication, *Infection Control in the Health Care Setting*, the NHMRC made three recommendations concerning hospital based Hepatitis B vaccination programs:

i. health care establishments should maintain immunisation programs that offer all staff, including trainees, Hepatitis B vaccinations with post-vaccination testing to identify non-responders;

ii. adequate information on the risks/benefits of vaccination should be provided to all staff to encourage participation; and

iii. hospital accreditation should require documented evidence of vaccination programs (NHMRC, 1996:3).

The guidelines also recommend that training establishments should ensure all health care worker students are adequately vaccinated to ensure protection against infections that are likely to be encountered in the course of their training (NHMRC, 1996:7).

NSW Health's policy on HBV vaccination of health care workers is consistent with the NHMRC Guidelines. The policy is spelt out in Departmental Circular 96.40 which states that:

> *it is the employer's responsibility to ensure that all susceptible health care workers whose work may involve activities with the potential for exposure to blood or other body substances are offered, free of charge, a course of Hepatitis B vaccine within ten days of commencing employment at the health care facility* (NSW Health, 1996:4).

The policy was developed in accordance with the following principles:

- employers and health care workers have a legal obligation to care for the health and safety of others in the workplace (this includes both patients and fellow workers) under the *Occupational Health and Safety Act, 1983*; and

- employers and health care workers owe a common law duty of care to their employees and patients (NSW Health, 1996:3).

It is Departmental policy that health care workers are to be offered HBV vaccine, that the offer is to be documented and that appropriate records are to be kept of the date of vaccination, vaccine batch numbers. It is also policy to offer antibody testing and vaccine free of charge to health care workers, although unless they perform exposure prone procedures, they are not obliged to be tested. Health care workers are also at liberty to be tested and vaccinated privately rather than as part of a workplace program. It is not obligatory for health care workers to inform the employer of their HBV antibody status (NSW Health supplementary submission).

The NHMRC Guidelines call for hospital accreditation to require documented evidence of HBV vaccination programs for health care workers (NHMRC, 1996:3). When asked to comment on this proposal, NSW Health noted that hospital accreditation is carried out by the Australian Council on Health Care Standards (ACHS) which looks for evidence of compliance with Infection Control Procedures in a "broad manner" (NSW Health supplementary submission). The Department informed the Committee that they do not have the resources to monitor compliance with the policy. They would "support" the notion that inspection of documentation concerning implementation of a HBV vaccination program (excluding confidential staff records) is appropriate for inclusion in ACHS accreditation procedures (NSW Health supplementary submission).

RECOMMENDATION 126:

That the Minister for Health, through the forum of the Australian Health Ministers' Council, encourage the Australian Council on Health Care Standards to include the inspection of documentation verifying implementation of a Hepatitis B vaccination program for staff (excluding confidential staff records) in the hospital accreditation procedures.

- **Needlestick Injury Hotline**

NSW Health funds a 24 hour hotline which offers expert advice to health care workers who sustain needlestick injuries. The hotline is based at the Albion Street Clinic.

- **Australian Reference Centre for Hepatitis C Information**

Health care professionals are able to access the Australian Reference Centre for Hepatitis C Information (ARCHI) for comprehensive information, reference and referral services. The Centre, which is a joint initiative of the Albion Street Centre, ANCARD and Schering-Plough, has been established to provide accessible information on the Hepatitis C virus clinical manifestations to health care professionals nationwide. A toll free 1800 telephone number (1 800 42 72 44) can be accessed Mondays to Fridays, 9:00am to 5:00pm. The Centre offers the following services:

- an up to date database providing current technical information on HCV management, treatment and policies;
- provision of infection control, transmission and prevention information;
- access to specialist referral services and HCV Centres nationally;
- technical support to health care workers;
- provision of information to researchers;
- referral to appropriate services;
- provision of legal, ethical and socially relevant information; and
- details of upcoming conferences and seminars (ARCHI, 1998).

- **Awareness of HCV Status**

It is NSW Health policy that health care workers who perform exposure prone procedures are obliged to know their status for HIV and HBV and HCV. With regard to surgeons, the Medical Board of NSW requires all surgeons to be aware of their HIV, Hepatitis B and Hepatitis C status. Similarly Dr West advised it is Royal Australian College of Surgeons' policy that surgeons regularly check their HIV, Hepatitis B and C status. In addition, surgeons susceptible to Hepatitis B should be vaccinated. The Committee was advised that any surgeon infected with any of these blood borne diseases should not perform any invasive procedures or operations (West evidence, 28 November 1997). It is possible that an infected surgeon could be accused of professional misconduct. As a result, there is, as Dr West said a “pretty stiff obligation” on those performing exposure prone procedures to know their status (West evidence, 28 November 1997).

The NSW Medical Board has an “impairment program” to support doctors with any disability (including infection) with guidance on what duties they may safely undertake (while remaining registered and insured). There is no comparable program in place for dentists, the majority of whom operate in the private sector (NSW Health supplementary submission).

- **Professional Education**

The Committee is aware of several initiatives to provide Hepatitis C information to health care professionals. NSW Health, for example, has distributed the Hepatitis C Council produced booklet entitled *Hepatitis C: What You Need to Know*, to all medical practitioners in the state including private general practitioners and those based in hospitals. The booklet has also been lodged with the Department’s Better Health Centre where it has been distributed widely. As Table Nineteen in Section 5.4.2 shows, this initiative cost $95,000.

The RACS has produced an educational video entitled *Old Dogs, New Tricks* aimed at educating surgeons and operating theatre staff. In commenting on the video Dr West noted:

> *you have to change attitudes, and that is not easy. We did manage to change attitudes of surgeons and sort of dramatise a video which they could relate to. We did manage, I think, to chance their attitudes, to change techniques in operating theatres to minimise injury, minimise splashes and contamination* (West evidence, 28 November 1997).

But as Dr West noted:

> *the problem is that in our under-staffed, over-worked hospital wards . . . this [change] is not always possible. One of the symptoms of an over-worked ward is it has got a lot of infection* (West evidence, 28 November 1997).

The submission from the Royal College of Nursing, Australia noted that there continues to be a “significant amount of misunderstanding” about the Hepatitis C virus amongst health care professionals. The College informed the Committee that they are committed to keeping nurses informed of current health issues and would be willing to assist NSW Health in providing education programs to the nursing profession.

10.3.2 PROPOSED PREVENTATIVE STRATEGIES

- **Introduction of National Infection Control Standards**

Dr West advised the Committee that each state in Australia has different infection control standards (West evidence, 28 November 1997). Such a situation is considered by the RACS to be unsatisfactory. They would like to see uniform standards set nationally (West evidence, 28 November 1997).

In 1996, the NHMRC and the Australian National Council of AIDS (ANCA) produced guidelines for the prevention of transmission of infectious diseases. The document is based on the key principles of hygiene, cleanliness and sterility. It includes implementation of Standard Precautions and Additional Precautions, design of the premises, choice and type of equipment, occupational health and safety considerations, safe disposal of clinical waste, the appropriate use of antibiotics, regular monitoring of infections and effective and ongoing education and training program for all levels of staff and incorporation of infection control into a comprehensive quality management program (NHMRC, 1996:1). The RACS considers the NHMRC infection control guidelines to be an appropriate basis for national standards (West evidence, 28 November 1997).

Infection control policies have also been produced by the RACS. The first set of policies were devised ten years ago and they are now in their fourth edition (West evidence, 28 November 1997). The document lists precautions that should be taken, particularly in operating theatres.

Dr West informed the Committee that the President of the RACS had raised the issue of infection control standards with the Federal Minister for Health. The reply received was considered by the College to be “wishy-washy” (West evidence, 28 November 1997).

The Committee supports the RACS in its quest for national infection control standards and considers the most appropriate forum for its consideration and introduction to be the Australian Health Ministers’ Council made up of federal, state and territory Health Ministers.

RECOMMENDATION 127:

That the Minister for Health, through the forum of the Australian Health Ministers’ Council, urge his federal, state and territory counterparts to consider the adoption of national infection control standards. The Committee further recommends that the Minister for Health propose the NHMRC’s guidelines for the prevention of transmission of infectious diseases entitled *Infection Control in the Health Care Setting* (1996) be considered as the basis for national infection control standards.

- **Awareness of Patient HCV Status**

The RACS recommends that patients should be tested pre-operatively for HIV, Hepatitis B and Hepatitis C when “it is clinically indicated” (West evidence, 28 November 1997). In evidence before the Committee, RACS representative, Dr West stated that:

> *We think it important to have a knowledge that the patient is infected. If you have knowledge you can do things in an organised way in the best possible circumstances . . . The College believes that it should be a two-way street, that if the surgeons are going to know their status it is not unreasonable for the patients to be aware of their status and to reveal their status if they are going to have a procedures that puts other people at risk* (West evidence, 28 November 1997).

The Committee is aware that the surgeons’ position on this issue is not supported by all in the Hepatitis C community. The Hepatitis C Council considers the RACS’s recommendation to be “unnecessary” stating that:

> *apart from the potential for greater discrimination practices to occur than are currently taking place in health care settings, there are enormous cost implications, as only PCR testing could give a reasonable indication of infectivity status . . . Current infection control practice recognises that any patient could have any infectious disease. With regard to preventing transmission of an infectious disease, where infection control guidelines are properly applied, it becomes irrelevant for any individual patient to warn health care workers of their status* (Loveday correspondence, 28 November 1997).

The Committee is aware that the controversy that surrounded a call by surgeons in the early 1980s for pre-operative HIV testing when it was clinically indicated has dissipated. The Committee does not believe patients should be now required to declare their Hepatitis C status prior to undergoing surgery.

- **The Obligations of Hepatitis C Infected Health Care Workers: NSW Health Policy**

NSW Health advised it is in the process of preparing a policy statement on the obligations of Hepatitis C infected health care workers. The Department included a summary of the policy in its submission. In brief it stated that:

- a health care worker with a confirmed HCV PCR positive test is not to perform exposure prone procedures. Current evidence does not support exclusion from performance of exposure prone procedures of health care workers who are HCV antibody positive but HCV PCR negative;

- to facilitate compliance with the policy, free confidential testing will be made available to health care workers undertaking exposure prone procedures. If the results of the antibody test are positive, a PCR test will be performed and the health care worker told both results together eliminating any period of time of uncertainly regarding whether the worker should continue performing exposure prone procedures. The health care worker will also be referred to a specialist for expert medical assessment and to other agencies for confidential counselling;

- There are three possible outcomes for HCV infected health care workers:

    1. they may be rendered non-infectious by treatment with interferon and able to resume normal practice of exposure prone procedures

    2. they may have a chronic infection that will not resolve in which case they will need to consider moving into a different occupation that does not required the performance of exposure prone procedures; or

    3. they may be able to modify their practice (under specialist advice) to ensure that their patients are not put at risk. For example, an infected surgeon may take extra precautions such as routinely double gloving, using kevlar glove liners and perform only those parts of operations which are low risk for glove perforation while a colleague performs the high risk parts of the operation (NSW Health submission).

An early draft of the policy proposed that the Blood Bank be involved in HCV testing. This was in response to health care worker concerns that staff health service would not offer a sufficient level of confidentiality for HCV testing. The listing of HCV PCR testing on the Medicare Benefits Schedule in July 1998 (HCV antibody testing was already listed) means that health care workers have the option of monitoring both their HCV antibody and PCR status in consultation with any medical practitioner of their choice. There is now an alternative funding option for health care workers who do not wish to take advantage of free HCV testing offered by Staff Health Services at publicly-funded health facilities.

Pending endorsement of the revised proposal by relevant health care workers organisations, NSW Health advised that the HCV Infected Health Care Worker policy will be released “as soon as possible” (NSW Health supplementary submission).

The RACS recommended a number of provisions it wishes to see made available to all health care workers (whether they are employees or working under contract) when the policy becomes available. These provisions include:

TESTING FOR HCV:

- all testing for HCV should be performed at the Department of Health's expense;
- the HCV tests should be performed with the identify of the health care workers encrypted;
- if the health care workers is anti-HCV positive in initial testing, they should not be informed of the results until their infectious status is established by PCR testing.

ASSISTANCE AND COMPENSATION FOR HCV+ HEALTH CARE WORKERS:

- health care workers found to be positive on testing should continue under their existing employment/contract arrangements during treatment which may render them non-infective, or until they are retrained for other duties if they have to cease performing exposure prone procedures;
- the cost of any treatment for infective health care workers should be at the Department of Health's expense;
- counselling and retraining should be made available through the Department of Health using such agencies as are available. The costs of counselling and retraining should be met by the Department of Health;
- no fault compensation should be available (RACS submission).

The NHMRC infection control guidelines propose a range of recommendations for Hepatitis C infected health care workers and students (NHMRC, 1996:5-6). The recommendations proposed that HCWs with Hepatitis C viraemia should not perform exposure prone procedures. Those with indeterminate Hepatitis C test results should not be excluded from performing exposure prone procedures on the basis of test results alone. If test results are positive or indeterminate, HCWs should be clinically assessed by an experienced physician, over a reasonable period of time, for any sign of current/active infection. Where there is insufficient evidence of current/active infection, the testing doctor, or the individual concerned, should seek the advice of a State/Territory health and/or professional advisory board (NHMRC, 1996:6). The guidelines also make recommendations concerning:

- counselling and treatment;
- reporting;
- confidentiality;

- assistance for HCWs who have occupationally acquired a blood borne virus;
- ‘look back’ investigations of patients of health care workers infected with a blood borne virus;
- compliance; and
- health care worker students and training (NHMRC, 1996:6-7).

One of the primary issues faced by Hepatitis C infected health care workers is that of retraining and compensation. Under the *Workers Compensation Act, 1987*, employers have certain obligations regarding rehabilitation of employees. The Department’s policy regarding occupational rehabilitation is set out in Circular 97/89 *Policy and Guidelines for the Management of Occupational Rehabilitation in NSW Public Health Care Facilities*. NSW Health advised that, in the event of occupationally acquired HCV, employees may be provided with alternative duties and retraining where appropriate (NSW Health supplementary submission).

Dr West discussed the consequences for a health care worker of a positive HCV test result with the Committee:

> *if you are going to ask the surgeons to test themselves, there is not much incentive to be tested if the end result is that you cannot work, that is the problem. If this is going to be a public health measure in order for it to work, there has to be some pro quo, in other words, if the surgeon is positive, he then has to be given some assurance that he will be retrained. For employees and visiting medical officers there should be some sort of redeployment or retraining process . . . The place of some sort of compensation should be looked at. The only recourse at the moment is for health care workers to take common law action . . . Even workers compensation provisions are totally inadequate to cope with employees and this sort of thing* (West evidence, 28 November 1997).

He anticipated that there would probably be 40 surgeons throughout Australia who would require retraining and compensation (West evidence, 28 November 1997). He felt that if testing was going to succeed as a public health measure then:

> *some sort of mechanism should be put in place for people who become positive instead of just casting them to the wind so to speak* (West evidence, 28 November 1997).

His view is reiterated in the College’s submission which stated that:

> *for [the policy] to succeed, some form of recompense for those unfortunate individuals found to be positive will need to be established to*

> *ensure health care workers are willing to make themselves aware of their* status (RACS submission).

The Department's *Policy and Guidelines for the Management of Occupational Rehabilitation in NSW Public Health Care Facilities* (Circular number 97/89) would be the appropriate document to ascertain the Department's position on retraining and compensation. The policy states that:

> *The Department of Health and each health care facility shall develop, implement and regularly review an occupational rehabilitation policy and program in accordance with the appropriate WorkCover Guidelines* (NSW Health, 1997:9).

It would appear that the policy is recommending the development of a policy rather than stating the Department's position on rehabilitation. The Committee was not able to ascertain with any certainty what measures are actually taken for Hepatitis C infected health care workers.

The issues surrounding HCV infected health care workers are similar to those faced by professional colleges and health departments in the early 1980s when protocols pertaining to HIV/AIDS infected health care professionals were developed.

- **Quality Assurance for Endoscopic Units**

As was discussed in Section 3.5.3 there have been reports of patients becoming infected with Hepatitis C during endoscopic procedures. Dr West suggested to the Committee that the problem primarily lay in the instruments not being cleaned properly:

> *[transmission] tends to occur in endoscopy units . . . And it is usually related to staff training, new staff . . . We are concerned that [patient-to-patient transmission] is a possibility* (West evidence, 28 November 1997).

The College would like to see a self-regulatory quality assurance system introduced for endoscopic unit covering regular testing of equipment (using broth cultures) and documentation of that testing. According to the RACS such procedures should be "a requirement, not a suggestion" of the Department of Health. As Dr West noted:

> *Gastroscopes are done in major institutions and day surgical units. They should have in place mechanisms to monitor it. It should be part of their accreditation process when they are accredited. All hospitals are accredited* (West evidence, 28 November 1997).

Farrell made similar recommendations. He called for:

> *closer regulation of day surgery and endoscopy procedures to make sure that they all come up to the high standards of sterilisation, and use of disposable medical appliances that have been recommended by responsible bodies such as the Gastrological Society of Australia* (Farrell evidence, 28 November 1997).

The Committee fully supports the proposals made by West and Farrell for tighter regulation of day surgery units performing endoscopic procedures and wishes to see the Minister for Health, within the context of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to consider the adoption of standard procedures for endoscopic units including sterilisation, staff training and use of disposable medical appliances as part of the hospital accreditation process.

RECOMMENDATION 128:

That, within the context of the Australian Health Ministers' Council, the Minister for Health urge his federal, state and territory counterparts to consider the adoption of standard procedures for endoscopic units including sterilisation, staff training and use of disposable medical appliances as part of the hospital accreditation process.

10.4 PREVENTING THE TRANSMISSION OF HEPATITIS C AMONGST BLOOD RECIPIENTS

When asked to identify the most important preventative measures to limit the spread of Hepatitis C Professor Farrell nominated as his first strategy, to "fix up" the blood supply, which, as he noted, as already been done (Farrell evidence, 28 November 1997).

A number of strategies are available to limit the transmission of the Hepatitis C virus through blood and blood products. The NSW Blood Bank currently employs the following strategies: potential blood donors complete a questionnaire and undertake an interview to identify "at risk" behaviours such as injecting drug use prior to donating blood; and all blood and blood products are screen for, amongst other factors, HCV antibodies. As a result of these measures, Dr Benjamin assured the Committee that:

> *to the best of our knowledge anybody who is infected with the [Hepatitis C] virus is excluded from donating as best as medical science can allow us to do* (Benjamin evidence, 10 October 1997).

- **Identification and Exclusion of "at risk" Blood Donors**

In the mid-1980s injecting drug users were excluded from donating blood to NSW Blood Bank as a public health response to the HIV/AIDS epidemic. While it was not appreciated at the time, this action was to have significance far greater than the possibility of transmitting HIV in that it assisted in limiting the spread of HCV through blood transfusion.

Currently two mechanisms are employed to identify those at risk of transmitting the Hepatitis C virus.

Every donor's ability to donate is reviewed at each visit. Prior to donating blood, donors are asked to complete a Donor Questionnaire, undertake an interview and sign a Declaration form.

Questions asked in the Donor Questionnaire cover a number of at risk activities including:

- contact with the HIV/AIDS virus
- male to male sexual activity
- bisexual activity
- injecting drugs not prescribed by a doctor
- sharing needles
- accidental needle stick injury
- sexual activity with male or female prostitutes
- tattoos
- history of jaundice or hepatitis.

Once the questionnaire is completed, the potential donor undertakes an interview conducted by Blood Bank staff. As the Committee heard, it is during this stage that staff ask "hard questions" if necessary:

> *if anybody has in any way erred in their questionnaire, they are put through a fairly quelling set of questions to ensure their honesty and to understand the gravity of what they are doing* (Benjamin evidence, 10 October 1997).

- **Serological Testing for HCV Antibodies**

Once the donor has completed the questionnaire and signed the declaration form blood is taken. That blood is tested and only after the blood is cleared can it be released:

> *blood cannot be released unless there is a clearance on that blood to be despatched* (Benjamin evidence, 10 October 1997).

All blood is serologically tested for Hepatitis C as well as HIV, Syphilis, Hepatitis B and HTLV-1. As with the Donor Questionnaire, all blood is tested on each occasion.

Any potential donor testing positive for any of the diseases is notified in strict confidence. Similarly if a false positive results is obtained the *Human Tissue Act* requires the donor to be notified and the blood to be discarded.

The Committee was informed that:

> *the system has never broken down . . . in all the years that it has been in operation, of a component being released before the virology results are known to have cleared the donation* (Benjamin evidence, 10 October 1997).

The processes in place to safeguard the spread of Hepatitis C and other blood borne diseases has resulted in the Blood Bank being "regarded as being the world's leading Blood Bank" (Benjamin evidence, 10 October 1997).

The Committee commends the Blood Bank for the thorough processes it has in place to limit the spread of Hepatitis C and other blood borne diseases and its commitment to ensuring that only clean blood and blood products are released.

10.5 PREVENTING THE TRANSMISSION OF HEPATITIS C IN THE SKIN PENETRATION INDUSTRY

The NSW Hepatitis C Taskforce recommended that the AIDS/Infectious Diseases Branch of NSW Health revise the skin penetration regulatons and guidelines and develop an effective implementation strategy (NSW Health, 1995:6). The Taskforce further recommended that the strategy should include prisons.

Early on in the Inquiry, NSW Health advised the Committee that a review of the Regulations and associated Skin Penetration Guidelines had commenced. In a supplementary submission received early October 1998, the Department advised that the Skin Penetration Guidelines were in the final review stage and expected to be released by December 1998 (NSW Health supplementary submission).

The National Hepatitis C Action Plan also considered the issue of skin penetration. As part of the Commonwealth's response to the Action Plan it has prepared educational material addressing infection control advice for the tattooing and skin penetration industry. The material is in the form of leaflets entitled *Tattooing and Your Health* (Commonwealth Department of Health and Family Services, undated) and *Tattoo: Hygienic Procedures for Tattooists* (Commonwealth Department of Health and Family Services, undated). Produced by the Commonwealth Department of Health and Family Services in association with the Professional Tattooing Association of Australia the leaflets identify the basic steps to hygienic and health tattooing and related preventative issues.

Infection Control Guidelines have also been produced by the Australian Acupuncture Association. The Guidelines consider a range of issues including aseptic and hygienic clinical practices, cleaning, sterilisation and disinfection procedures, storage of devices and disposal of sharps and other waste. A quick reference guide is also available in both English and Chinese languages.

The Committee is satisfied with the preventative measures currently in place for those working in the skin penetration industry.

10.6 EDUCATING AND INFORMING THE GENERAL COMMUNITY ON HEPATITIS C

According to ANCARD:

> *there are currently over 50 pamphlets relating to Hepatitis C and providing information to the general public, to patients and to health care workers* (ANCARD submission).

Despite this, ANCARD noted that:

> *It is clear that information has not flowed freely to the general community, even though there have been multiple press releases on Hepatitis C, multiple documents produced and multiple programs aired on television for patients regarding this virus* (ANCARD submission).

The issue of educating the general community on Hepatitis C related issues was a recurring theme throughout this Inquiry with considerable support coming from both expert witnesses and those with Hepatitis C who made written submissions. The Executive Officer of the Hepatitis C Council, for example, stated in evidence that:

> *Education is a vital component part of the strategy to reduce both the spread and impact of Hepatitis C transmission* (Loveday evidence, 30 March 1998).

Sladden suggested to the Committee Members that:

> *It is very important that we raise general awareness in the community about this disease and especially about how it is not transmitted and that there are no risks in normal social contact with people with Hepatitis C. That is crucial . . .* (Sladden evidence, 30 March 1998).

Wodak has stated that:

> *there is in my view, no substitute for a big-bang campaign along the lines of the Grim Reaper. Although that campaign was criticised at the time and subsequently for arousing anxiety, there is no doubt that it transformed HIV/AIDS from an issue that occasionally occupied a tiny paragraph on the inside pages to one that involved banner headlines on the front page. And without that attention, Australia would probably be struggling with an AIDS epidemic of US proportions* (Wodak, 1997b:17).

NSW Health's Chief Health Officer considered there to be "substantial benefit for the whole community" in conducting a community based media campaign (Wilson evidence, 3 October 1997).

Calls for increased public awareness and education were also made by those with Hepatitis C who made submissions to the Inquiry:

> *public awareness has to be created in any and every way possible as such a complex problem is difficult even for those who wish to understand* (Submission 70);
>
> *now is the time to curb the spread of this virus though . . . a comprehensive education program* (Submission 80); and
>
> *the matter of concern which I wish to bring to your notice is that I believe not enough is being done to educate people with regard to the transmission of this disease . . . with regard to the simple day-to-day things they would not think of* (Submission 6).

Community education has also been considered by the Nationally Coordinated Hepatitis C Education and Prevention Approach (AHMAC, 1995) (reviewed at the beginning of this chapter) and the NSW Hepatitis C Taskforce (1995). The AHMAC document recommended program of activities for the community included four strategies:

- establish a national Hepatitis C awareness week;
- inform and educate dental, medical and other appropriate journalists;
- develop strategic coalitions with key dental and medical associations and community based organisations; and
- develop public relations strategy and media kits (AHMAC, 1995:16).

The Committee was somewhat surprised (and disappointed) at the limited scope of the proposed education strategy for the general community. The activities are very low key and lack the flair and creativity that characterised the HIV campaign of the early 1980s.

The Committee is not confident that the strategies proposed by AHMAC have the impetus to reduce Hepatitis C transmission by 50% in accordance with the program's aim.

The NSW Hepatitis C Taskforce "supported" the need for mechanisms to raise and maintain high levels of awareness. It did however "question" whether "expensive high profile national education campaigns" achieve the desired outcomes at lowest cost and highest effectiveness (NSW Health, 1995:20). Accordingly, the Taskforce supported the development of less costly, but more effective methods of raising and maintaining high levels of awareness about HCV noting that this would be "required if potentially controversial measures were to gain community support" (NSW Health, 1995:20).

During the course of evidence, NSW Health was asked if consideration had been given to a broad community-based media campaign. Officers informed the Committee that the matter had been considered some 18 months previous (Taylor evidence, 3 October 1997). At that time it was considered the "infrastructure" in terms of skilled general practitioners was not available to "support a massive rush of people" seeking medical advice and testing from their general practitioner (Taylor evidence, 3 October 1997). The Committee feels that the national education project for general practitioners being coordinated by the RACGP (and discussed in Section 8.4.1) will improve the knowledge base of general practitioners enabling them to provide accurate information and advice to their patients.

The Committee was also advised that discussions were taking place with ANCARD regarding the possibility of a national campaign, but, at that time a decision had "not been made" (Fowler evidence, 3 October 1997).

- **Anticipated Outcomes of a National Community Based Education Campaign**

Witnesses identified a number of benefits that would arise from a national community education campaign which included:

- raising GP awareness: Hall, for example, considered that a national public education campaign would

  > *help with GP awareness and with patients connecting with GPs and even thinking about Hepatitis C as an issue* (Hall evidence, 6 November 1997);

- lessening discrimination and stigmatisation experienced by those with Hepatitis C: Sladden, for example, suggested that:

> *We need to raise awareness in the general community to reduce the stigma that people experience* (Sladden evidence, 30 March 1998);

- raising tolerance and compassion towards those with Hepatitis C: the Committee heard for example that:

  > *I can only hope and pray that with increased knowledge and awareness, Hepatitis C sufferers will be treated with more tolerance and compassion, and less alienation* (Submission 41);

- increasing awareness of the disease and how it is transmitted: the Hepatitis C Council's submission noted that:

  > *there is an urgent need to develop public education and awareness campaigns about HCV, not only to increase the general population's understanding about the virus and its transmission but also to reduce the fear and stigma associated with the disease* (Hepatitis C Council submission),

  while a person with Hepatitis C who wrote to the Committee stated that,

  > *If people in the community are told that they can catch Hep C from infected people only if they share razor blades, toothbrushes or needles, they won't treat them as different, as outcasts* (Submission 2);

- giving the disease a profile and putting it on the public agenda;

- reinforcing information obtained in the work setting: within the community are general practitioners and other health care workers, tattooists and acupuncturists, and prison officers. A widely disseminated education campaign would supplement and reinforce the information these people were receiving in their professional capacity;

- alerting those 'at risk' of contracting Hepatitis C such as current injecting drug users and those who may be considering experimenting with the practice; and

- alerting past injecting drug users and prisoners who may have Hepatitis C but have never been tested.

Given such a range of anticipated outcomes arising from a national community education Hepatitis C campaign the Committee fully supports such a campaign being conducted and recommends the Minister for Health approach his federal counterpart encouraging him to support the design and introduction of such a strategy.

RECOMMENDATION 129:
That the Minister for Health encourage his federal counterpart to design and introduce a national community education Hepatitis C campaign. The Committee further recommends that NSW Health fully support the introduction of a community based Hepatitis C education campaign within NSW and provide whatever assistance may be required.

The Committee would like to see the proposed campaign inform and educate the general community on the benefits of preventative strategies in place to limit the transmission of Hepatitis C. Committee Members are aware of community misunderstandings and apprehensions about strategies such as the methadone maintenance therapy program and the needle and syringe program with, often, limited appreciation of the role these programs play in limiting the transmission of Hepatitis C. Members consider it to be beneficial if a greater community appreciation of these strategies could be gained.

RECOMMENDATION 130:
That the national community education Hepatitis C campaign proposed in Recommendation 129 include a component about the role of preventative strategies such as the methadone maintenance therapy program and the needle and syringe program in limiting the transmission of Hepatitis C.

In August 1998 the Minister for Health announced changes to the management of the state's methadone program. Included in that announcement was a commitment to provide $600,000 to Hepatitis C prevention and education programs (Refshauge, 1998). The Committee understands that this one-off allocation has been 'earmarked' to be spent on a Hepatitis C public awareness campaign. The Committee welcomes this funding allocation and the decision to conduct an awareness campaign.

10.6.1 RESEARCH

Sladden informed the Committee that, in developing a community education campaign such as that proposed in Recommendation 129:

> *we need to consider carefully how we go about doing that so that we do not create further concern. We need to do that in a way that does not blow out the situation further* (Sladden evidence, 30 March 1998).

Similar claims for the control and prevention of Hepatitis C to be based on sound research have been made by the NHMRC which has stated that “the control of Hepatitis C requires both education and research” (NHMRC, 1994:5) and the Hepatitis C Council who informed the Committee that social research needs to be undertaken to inform prevention programs (Loveday evidence, 3 October 1997).

The National Hepatitis C Action Plan proposes that:

> *social research should be undertaken during the course of the co-ordinated education response to inform the development of education programs; to establish benchmarks; and assess effectiveness of strategies. It should also be undertaken to explore the cultures and contexts in which risk behaviour occurs* (AHMAC,1994).

The Committee recognises the important role to be played by social research in the design of a successful community education campaign. It considers it imperative that this role be fully appreciated by the federal government in the design and introduction of the recommended national community education Hepatitis C campaign.

RECOMMENDATION 131:

That the Minister for Health urge his federal counterpart support and fund research into the social factors which increase the risk of contracting Hepatitis C. The Committee further recommends that the Minister for Health encourage his federal counterpart to utilise the results of sound social research in the design and introduction of the community based education Hepatitis C campaign proposed in Recommendation 129.

10.7 CONCLUSION

This chapter has canvassed a very wide range of prevention strategies aimed at reducing the transmission of the Hepatitis C virus in all segments of society. The Committee has taken such a broad approach as it is conscious that no one strategy would be appropriate or effective in combatting this pervasive disease. The Committee agrees with Mr Loveday of the Hepatitis C Council who observed that “we need a range of these [preventative strategies]. One alone is not going to work” (Loveday evidence, 30 March 1998).

In proposing this prevention strategy, the Committee is also very conscience of the accuracy of Wodak's claim that:

> *Even if effective prevention measures are adopted in Australia today and implemented vigorously, it will still take many years to bring this dreadful epidemic under control* (Wodak, 1997b:17)*.*

The Committee can only agree with Wodak who observes that:

> *the sooner we start to get real about Hepatitis C the better - there is not a moment to be wasted* (Wodak, 1997b:17).

CHAPTER ELEVEN

CONCLUSION

The purpose of this Inquiry has been to inquire into and report on Hepatitis C in New South Wales. The Committee has examined, in detail, a range of issues that impact upon those with the Hepatitis C virus including diagnosis, treatment, management, support and prevention. This Report represents the findings of the Inquiry.

The evidence taken and submissions received from those with Hepatitis C portrayed the everyday realities of Hepatitis C: the overwhelming and debilitating fatigue; the fear of transmitting the virus to cherished partners, children and grandchildren; uncertainties over the future; and deteriorating health.

Hepatitis C must be viewed within an accurate epidemiological context, and an understanding of the profound social impact it is having (and will continue to have) upon the lives of those with the virus and their loved ones. This Report has attempted to provide such a perspective as well as recognise the economic impact the disease will have upon state and federal funding to health care and ancillary support services.

This Report demonstrates that Hepatitis C is a complex issue. Having considered and addressed all of the relevant issues, the Committee has formed a number of Key Conclusions. These include:

- the **need for policies to deal with all facets of Hepatitis C**: despite the current Hepatitis C epidemic there are no policies at the state level giving overall direction to the control, treatment, management and prevention of Hepatitis C. The Committee is critical of this situation and the limited response to Hepatitis C by NSW Health. The Committee's recommendations seek to provide an appropriate policy context to address all facets of Hepatitis C treatment and management (Recommendation 67) and prevention (Recommendation 88);

- the **provision of information**: there appears to be limited understanding in the community about Hepatitis C, in particular, about the way in which it is transmitted. Many assume it has the same transmission routes as other blood borne viruses such as HIV/AIDS. Health care workers, including medical specialists, often have a poor understanding of the disease. This lack of understanding manifests itself in a number of ways including discrimination and stigmatisation towards those with Hepatitis C, frustration by those with the disease as they struggle to learn about the disease and sort through conflicting information, and a lack of compassion and tolerance in the general community. To redress this situation, the Committee has called for the introduction of a number of strategies including education campaigns targeting all those working in the health care sector (Recommendation 19) and public service (Recommendation 22), the production of an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination (Recommendation 23), support for the National Hepatitis C Education Program for General Practitioners which seeks to inform and educate general practitioners (Recommendation 65), and a national community education Hepatitis C campaign (Recommendation 129);

- the **need for research**: the Committee has forwarded a number of recommendations addressing the need for more research across a range of areas, including ascertaining the incidence and prevalence of Hepatitis C at both the national and state level amongst the general community and the two population groups at greatest risk of contracting the disease: injecting drug users and prisoners. Research is also required into the personal, social and economic impact of Hepatitis C (Recommendation 25), and the effectiveness of complementary therapies on treating the symptoms of Hepatitis C (Recommendation 69);

- a **multi-faceted approach to prevent the spread of Hepatitis C**: prevention strategies to limit the spread of Hepatitis C must be broad, multi-faceted and grounded in the principles of harm minimisation. These criteria are the basis upon which the Committee framed all recommendations directed at injecting drug users (both in the general community and the state's correctional system). In targeting those most at risk, the strategy builds upon services already in place to minimise the transmission of other blood borne diseases such as HIV/AIDS as well as new initiatives. Recommendations are also forwarded to address the transmission of Hepatitis C within the health care setting; and

- **Hepatitis C within the state's correctional system must be addressed as a matter of urgency**: the incidence and prevalence of Hepatitis C within prisons is unacceptable. Those entering prison face a high risk of contracting Hepatitis C and, on release, inmates pose a serious danger of transmitting the virus to the wider community. In the Committee's opinion, these circumstances warrant radical policies to reduce exposure to the Hepatitis C in correction establishments. Treating and managing inmates with Hepatitis C is also fraught with difficulties. The Report forwards recommendations for the development of a Best Practice Model for the delivery of health care (Recommendation 71) as well as the development and implementation of a strategic plan for the management of Hepatitis C in prisons (Recommendation 74).

11.1 ADVOCATING FOR THOSE WITH HEPATITIS C

Unlike HIV, Hepatitis C does not have a corps of articulate, professional, skilled and well connected people such as the gay community that lobbied so successfully in the early 1980s and on for services, support, community awareness and research funding.

The Hepatitis C "community" is much more disparate: current injecting drug users (with the stereotypes and prejudices associated with an illicit activity); past injecting drug users who are now far removed from previous practices which, for many, were just a passing phase; recipients of infected blood as young as eight years and as old as 80 years of age; and prisoners. The Committee is conscious that there is, in fact, no cohesive and united community - no one group to advocate for those with Hepatitis C. In the absence of an advocate, the Committee considers it to be the role of motivated Parliamentarians to come forward to fill the gap.

The Hepatitis C Taskforce noted the important role played by Commonwealth and State Parliamentary Liaison Groups during the formation and implementation of AIDS policies in the 1980s. The Taskforce report noted that:

> *these groups had facilitated multi-party support in controversial areas and prevented a handful of Parliamentarians blocking views supported by a broad consensus* (NSW Health, 1995:20).

At the Federal level at least, the Liaison Group continues to function and has expanded its original brief to include other related diseases such as Hepatitis C.

The Taskforce concluded that it was “unclear” whether or not the HCV area could be considered “sufficient” to warrant such a mechanism, but that, in the absence of Commonwealth and State Parliamentary Liaison Groups a mechanism designed to facilitate multi-party support for control measures and minimise political obstacles to prevention was seen to be of “considerable merit” (NSW Health, 1995:20).

The Hepatitis C Council proposed the formation of a NSW Parliamentary Liaison Group considering that:

> *Such a body is necessary to guide the process of specific policy development and prioritisation that may contain significant political challenges and risks. The group would guide the development and implementation of proposals which may be unpopular among some sections of the general community* (Hepatitis C Council submission).

The Council recognised that,

> *Many Hepatitis C prevention strategies are contentious because they relate to injecting drug use. I do not need to point out examples of emotive public debate about the issue. We recommend that a Parliamentary Liaison Group be established - hopefully this will garner support from both sides of Parliament and the Independents - to facilitate some of those changes* (Harvey evidence, 3 October 1997).

Committee Members see merit in the Council’s proposal. They fully appreciate the role multi-party support could play in minimising political obstacles seeking to limit the spread of Hepatitis C both within the general community and the corrections system.

As was discussed in the introduction to Chapter Ten, the AHMAC Hepatitis C Education and Prevention Reference Group identified key decision and policy makers are a priority group for preventative education. It is anticipated that the formation of a Parliamentary Liaison Group would provide a very strong advocacy role and influence policy makers at the highest state level.

RECOMMENDATION 132:

That the Premier invite his Parliamentary colleagues, from both Houses and all political parties, to form a Hepatitis C Parliamentary Liaison Group. The role of the Liaison Group would be to advocate and support Hepatitis C related policies within the political domain with an overall objective to limit the spread of Hepatitis C in the general community and the corrections system.

11.2 IN CONCLUSION

As this Report has demonstrated, Hepatitis C is a disease that has been neglected - neglected by politicians, health planners, bureaucrats, health care workers and the community in general. Committee Members have been overwhelmed with the enormity of the issue. Listening to and interacting with those who have Hepatitis C was moving. The death of one of the witnesses some seven months after giving evidence was sobering. This is a disease that debilitates. It is a disease that kills.

Committee Members have resolved to address current inadequacies and have unanimously proposed a framework for the state to respond appropriately and adequately to this disease. The Committee now seeks a similar resolve from the government: a resolve that is backed by political will and motivated by compassion. The Hepatitis C epidemic can no longer be neglected.

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APPENDIX ONE

SUBMISSIONS RECEIVED

THE COMMITTEE RECEIVED 31 PUBLIC SUBMISSIONS AND
92 CONFIDENTIAL SUBMISSIONS

NAME	POSITION	ORGANISATION
Dr Andrew Wilson	Chief Health Officer	NSW Health Department
Ms Annie Madden	NUAA Co-Ordinator	NSW Users & AIDS Association Inc.
Mr Martyn Goddard	Program Consultant	Clinical Trials and Treatments Advisory Committee
Dr Anna McNulty	Chair, NSW Chapter	Australasian College of Sexual Health Physicians
Dr Katherine Brown	Convenor, Medical Directors of Sexual Health Clinics	Australasian College of Sexual Health Physicians
Dr William Rawlinson	Medical Virologist, SEALS	Virology Division Department of Microbiology Princes of Wales Hospital
A/Prof Susan Kippax	Director	National Centre in HIV Social Research
Mr Laurence Fong	Associate Director, Pharmacoeconomics & Government Relations	Schering-Plough Pty Ltd
Dr Richard West	Chairman, Advisory Committee on Infection Control	Royal Australasian College of Surgeons
Dr Dominic Dwyer	Medical Virologist	Institute of Clinical Pathology and Medical Research
Mr Matthew Martin	HIV Community Support Worker	Macquarie Area Sexual Health
Ms Suzy Wilds	Clinical Nurse Consultant (HIV/STD/BBV)	Macquarie Area Sexual Health
Ms Jan Cregan	*for* The Community Working Group	Prisons and Blood Borne Communicable Diseases
Dr Susanne Benjamin	Medical Officer, Hepatitis Lookback Unit	NSW Red Cross Blood Bank
Ms Fiona Clark	Product Manager	Roche Pharmaceuticals
Ms Pamela Heikkinen	Business Unit Manager	Roche Diagnostics
Mr Stuart Loveday	Executive Officer	Hepatitis C Council of NSW
Mr Chris Puplick	Chairman	Australian National Council on AIDS and Related Diseases (ANCARD)
Ms Judy James	Executive Officer	Australian Acupuncture Association
Mr Leo Keliher	Commissioner	Department of Corrective Services
Mr Bryan Suter		Hepatitis Australia Pacific

NAME	**POSITION**	**ORGANISATION**
Dr John Smart		Family Medical Centre
Ms Pam Shipway	Director/Co-ordinator	TRAIDS Unit
Prof Geoffrey Farrell	Storr Professor of Hepatic Medicine	Storr Liver Unit Department of Medicine Westmead Hospital
Dr Alex Wodak	Director, Drug and Alcohol Services	St Vincent's Hospital Sydney Limited
Professor W Reed	Chairman	NHMRC Working Party on Hepatitis C
A/Prof G McCaughan	Physician in Charge, Transplant Hepatology	The A. W. Morrow Gastroenterology and Liver Centre
Ms J Pritchard-Jones	Area Hepatitis C Nurse Consultant	The A. W. Morrow Gastroenterology and Liver Centre
Dr Nick Crofts	Head, Epidemiology	The Macfarlane Burnet Centre for Medical Research
Ms Jenny Melrose	Residential Support Worker	Foley House Incorporated
Mr Bill Robertson	Manager	Foley House Incorporated
Ms Jenny Melrose	*for* The Residential Support Workers	Foley House Incorporated
Professor John Kaldor	Deputy Director and Professor of Epidemiology	National Centre in HIV Epidemiology and Clinical Research
Ms Elizabeth Percival	Executive Director	Royal College of Nursing
Ms Anne Looby	Clinical Nurse Specialist	St. George Hospital

APPENDIX TWO

WITNESSES AT HEARINGS

THE COMMITTEE HEARD EVIDENCE FROM 68 WITNESSES

IN ADDITION TO TWO IN CAMERA WITNESSES

THURSDAY, 2 OCTOBER 1997

Dr Alex Wodak	Director Alcohol and Drug Service St Vincents Hospital
Ms Janice Pritchard-Jones	Coordinator Hepatitis C Services Central Sydney Area Health Service

FRIDAY, 3 OCTOBER 1997

Dr Andrew Wilson	Chief Health Officer NSW Health
Mr David Fowler	Manager, HIV/AIDS/Hepatitis AIDS and Infectious Diseases Unit NSW Health
Ms Helen Taylor	Policy Analyst, Hepatitis AIDS and Infectious Diseases Unit NSW Health
Mr Stuart Loveday	Executive Officer Hepatitis C Council of NSW
Mr Paul Harvey	Senior Project Officer Hepatitis C Council of NSW
Dr John Kaldor	Deputy Director National Centre for HIV Epidemiology and Clinical Research University of New South Wales
Ms Margaret MacDonald	Senior Research Assistant National Centre for HIV Epidemiology and Clinical Research University of New South Wales

MONDAY, 10 OCTOBER 1997

Ms Pam Shipway	Director/Coordinator Transfusion Related AID and Infectious Diseases Unit

Dr Susanne Benjamin	Head Hepatitis Lookback Unit NSW Red Cross Blood Bank
Ms Pamela Heikkinen	Business Unit Manager Roche Pharmaceuticals
Mr Pascal Mittermaier	Marketing Manager Roche Pharmaceuticals
Ms Fiona Clark	Product Manager for PCR Roche Pharmaceuticals
Dr Dominic Dwyer	Medical Virologist Department of Virology Institute of Clinical Pathology and Medical Research Centre for Infectious Diseases and Microbiology Laboratories Westmead Hospital

MONDAY, 27 OCTOBER 1997

A/Prof William Rawlinson	Senior Medical Virologist South Eastern Area Lab Service Associate Professor School of Pathology, University of NSW Virology Division, Department of Microbiology Prince of Wales Hospital
Ms Rowena Kir	Director of Regulatory Affairs and Pharmacoeconomics Schering-Plough Pty Ltd
Dr Michael Rallings	Regional Medical Director Schering-Plough Pty Ld
Mr Laurence Fong	Associate Director Pharmacoeconomics and Government Relations Schering-Plough Pty Ltd
Ms Fadia Matouk	Commercial Division Director, Sales Marketing Schering-Plough Pty Ltd
Prof Robert Batey	Director Gastroenterology Department John Hunter Hospital

THURSDAY, 6 NOVEMBER 1997

Dr Anna McNulty	Chair NSW Chapter of the Australasian College of Sexual Health Physicians
Dr Neil Bodsworth	Australasian College of Sexual Health Physicians
Dr Ingrid van Beek	Director Kirkteon Road Centre
Mr Steven Hall	Coordinator National Hepatitis C Education Program Royal Australian College of General Practitioners
Mr Bill Robertson	Manager Foley House
Ms Jenny Melrose	Acting Supervisor Foley House

FRIDAY, 7 NOVEMBER 1997

Ms Annie Madden	Co-ordinator NSW Users and AIDS Association
Mr Tony Rance	Positive Users Development Worker NSW Users and AIDS Association
Ms Fiona Poeder	Tribes Manager NSW Users and AIDS Association
Mr Ron Bennison	Policy Worker NSW Users and AIDS Association
Mr Michael Gersak	NUAA Management Committee NSW Users and AIDS Association
Mr Miles Rooke	Advocacy Worker NSW Users and AIDS Association
Shah Habib	Student
Mr Ron Hill	Financial Co-ordinator NSW Users and AIDS Association

Ms Joanne Lancaster	NSW Users and AIDS Association
Mr Gary Gahan	NSW Users and AIDS Association
Mr Ben Fairleigh	NSW Users and AIDS Association
Ms Carol Charles	NSW Users and AIDS Association
Mr Darren Riley	NSW Users and AIDS Association
Mr Sam Hookey	NSW Users and AIDS Association
Ms Sarah Lord	NSW Users and AIDS Association
Mr John Carey	NSW Users and AIDS Association
Mr Chris Puplick	Chairman Australian National Council on AIDS and Related Diseases

FRIDAY, 28 NOVEMBER 1997

Dr Nick Crofts	Head Epidemiology and Social Research Unit Macfarlane Burnett Centre for Medical Research
Professor Geoff Farrell	Director Storr Liver Unit Department of Medicine, University of Sydney Westmead Hospital
Dr Richard West	Chair Advisory Committee on Infectious Control Royal Australian College of Surgeons
Mr Doug Mellors	HCV+

THURSDAY, 26 FEBRUARY 1998

Dr Julian Gold	Director Albion Street Centre Senior Staff Specialist Prince of Wales Hospital
Ms Jennifer Ross	Executive Director Haemophilia Foundation of Australia

Mr David Richardson	President Haemophilia Foundation of NSW
Rev Harold Smart	HCV+
Mr Peter Garling, SC	Barrister
Mr Graham Stone	Manager, HepCare NSW Health

MONDAY, 16 MARCH 1998

Ms Kathy Sport	Filmaker

MONDAY 23 MARCH 1998

Mr Tony Butler	Project Officer NSW Health
Ms Amanda Christianssen	TB Coordinator NSW Health Former Clinical Nurse Consultant Corrections Health Service
Mr Gino Vumbaca	Manager HIV and Health Promotions Unit Department of Corrective Services
Professor Geoff McCaughan	Acting Director AW Morrow Gastroenterology and Liver Centre Royal Prince Alfred Hospital
Ms Susan Harper	Acting Clinical Nurse Consultant Corrections Health Service
Ms Sandra Parsons	Clinical Nurse Specialist Corrections Health Service
Ms Jan Cregan	Representative of the Community Working Group on Prisons and Blood Borne Communicable Diseases
Mr George Selvanera	Representative of the Community Working Group on Prisons and Blood Borne Communicable Diseases

Monday, 30 March 1998

Mr Tim Sladden	Epidemiologist Northern Rivers Institute of Health and Research Northern Rivers Health Service
Ms Audrey Lamb	HCV+
Ms Helen Kerr-Roubicek	Manger Student Counselling and Welfare Department of Education and Training
A/Prof Andrew Lloyd	Department of Infectious Diseases Royal Prince Henry Hospital Inflammation Research Unit School of Pathology, University of NSW
Mr Stuart Loveday	Executive Officer Hepatitis C Council of NSW

APPENDIX THREE

GOVERNMENT RESPONSE TO NSW HEPATITIS C TASKFORCE REPORT

IMPLEMENTATION OF HEPATITIS C TASKFORCE REPORT RECOMMENDATIONS

Progress on each recommendation of the NSW Taskforce Report was provided by NSW Health in a document tabled on 3 October 1997.

*1.1 State-wide HCV education plan for health care and social welfare workers***.**

In 1995, an Infection Control Education strategy was implemented to support implementation of the revised Infection Control Policy 95/13 and enhance the infection control infrastructure.

Earlier in 1997, a copy of the booklet "Hepatitis C what you need to know" was mailed to all NSW registered medical practitioners, dentists and a long list of other relevant health care workers and institutions. The impact of this initiative will be evaluated.

Since the advent of the Third National AIDS Strategy, HIV/AIDS Coordinators across NSW have become increasingly involved in HCV education and prevention initiatives. NSW Health has recently undertaken a mapping exercise to document the HCV education initiatives being undertaken Statewide.

The demonstration projects being undertaken in 8 Area Health Services across NSW each involve health care worker education regarding HCV. The lessons learned from these projects will help to guide the detail of future policy.

1.2 NSW Health support the establishment of a National HCV Advisory Committee.

The Department supports a National advisory process by providing input to the National Health and Medical Research Council (NHMRC) HCV Committee. The adoption of hepatitis C into the Australian National Council on AIDS and Related Diseases (ANCARD) workplan where hepatitis C has overlap with prevention of HIV/AIDS is a welcomed recent development.

*1.3 Funding for an appropriate statewide response to HCV be considered by the Senior Executive Council of NSW Health***.**

Funding was reviewed and a budget allocated for implementation of the Hepatitis C Taskforce Recommendations. This is currently $515,000 p. a.

2.1 HCV surveillance be improved to identify incidence more effectively and to report on risk factors associated with infection. This will be achieved by a 12 month pilot study, commencing in 1995, elements of which include, on a five percent sample of notifications:

active follow up of seropositive tests to enable optimal ascertainment of incident cases; and

collection of information on risk factors associated with both incident and prevalent cases as they are notified.

Throughout 1995, five percent of new HCV notifications were followed up to ascertain incident cases and collect risk factor information where possible. The Commonwealth Department of Human Services and Health collated data submitted from all states. To date this data is of limited usefulness because of a high proportion of missing risk factor data. Public Health Units have indicated that there are significant difficulties in following up HCV notifications. Recurrent enhancement funds were allocated to public health units to improve surveillance from 1996/7.

2.3 NSW Health draft revised Public Health Act Regulations to allow for risk factor surveys in HCV positive individuals.

The Department's Legal Branch has advised AIDS/Infectious Diseases Branch that this cannot be achieved by revising regulations; the Public Health Act itself would need to be revised.

2.4 NSW Health contribute to, and facilitate monitoring of, HCV research in serially tested populations coordinated by the National Centre in HIV Epidemiology and Clinical Research.

The NHMRC is the main agency with responsibility for research funding. Commonwealth funding of these types of studies is already under way as part of the Australian HIV Surveillance Strategy.

3.1 Low cost and effective mechanisms to raise and maintain high levels of hepatitis awareness be developed including:

- ***school based education campaigns providing objective information about disease risks of drug injecting and other shared exposures, and appropriate measures for harm minimisation;***
- ***education campaigns specifically targeting persons infected with HCV;***
- ***education campaigns specifically targeting Injecting Drug Users (IDUs);***
- ***appropriate telephone advice and counselling services should be developed to disseminate information about hepatitis C. The development and coordination of these programs should be coordinated by the AIDS/Infectious Disease Branch.***

The Department currently directs more than $1.0M p.a. of National Drug Strategy funding towards ensuring that classroom teachers are adequately prepared to undertake this work.

The Hepatitis C Council of NSW is funded by NSW Health specifically to provide information and support including a telephone information service for people affected by HCV.

The NSW Users and AIDS Association (NUAA) and the Needle and Syringe Program also undertake some work in this area.

The Needle And Syringe Programs, NUAA and other providers of education programs targeting injecting drug users already include HCV in their information and education initiatives.

The Department currently directs National Drug Strategy funding to CEIDA to provide the Infectious Disease Project for Drug and Alcohol and allied workers.

3.2 AIDS/Infectious Disease Branch facilitate improved access to sterile injecting equipment by:

- ***increasing the throughput of the needle and syringe exchange program in NSW to reach the target of nine million per year by the year 2000;***
- ***identifying "blackspots" in the availability of sterile injection equipment and develop strategies to rectify the situation;***
- ***establishment of a pilot, and time-limited, needle/syringe program (NEEDLE AND SYRINGE PROGRAMS) in a suitable Correctional facility.***

A recent review of the NSW needle and syringe Program considered these issues in detail and mechanisms of enhancing the availability of sterile equipment for IDU have been recommended.

The Taskforce recommendation concerning prisons is not within the power of NSW Health to implement without full cooperation from the other sectors involved, together with bipartisan political support.

3.3 Public Health Division review treatments for drug users (especially methadone maintenance programs) with a view to increasing the following characteristics: effectiveness; capacity; range of treatment; attractiveness; retention; access to methadone programs in correctional facilities; participation of young drug users and consumer input.

The NSW Methadone Program was reviewed by the Department's Drug and Alcohol Directorate in 1995. Research related to the issues raised in the recommendation occurs in nationally funded drug and alcohol research programs.

3.4 NSW Health support the development of community development organisations to deal with the spread of HCV.

The Department currently funds two community development organisations whose work covers this area. These are the Hepatitis C Council of NSW and the NSW Users and AIDS Association (NUAA). Both of these organisations receive recurrent funding.

3.5 The following recommendations be referred to an appropriate inter-Departmental committee for consideration: (At time of writing, it was presumed that a NSW Intersectoral Advisory Committee for Health would be formed; this has not yet been formally established)

The current emphasis on law enforcement measures which restrict drug supplies and increase the likelihood of drug use by injection should be reviewed with the aim of facilitating the transition from injecting to non-parenteral drug use;

Paraphernalia should be included in exemptions for legislation which covers needle and syringe exchange programs (s19 and s20 of the Self Administration (Drugs Misuse and Trafficking Act 1985);

The size of prison populations should be reduced by making drug policy more flexible and improving non-custodial sentencing options for IDUs;

The recommendations have implications for other government sectors and have not been supported in the past. This has been due in part to lack of community support for such recommendations and the political complexities of the issues.

These issues overlap with those addressed in a document released in September 1995 entitled "Prisons and Blood Borne Communicable Diseases, the Community Policy" which was a joint initiative of the AIDS Council of NSW (ACON), the Hepatitis C Council of NSW, NSW Users and AIDS Association (NUAA) and four other community based organisations.

These recommendations are in the area of responsibility of the Attorney General and the Minister for Police.

Similar recommendations were made in the "Puplick Report - The Courage of our Convictions HIV/AIDS: The National Strategy and the Laws of NSW" Report to the Minister for Health 1993.

Responding to the recommendations in the Puplick Report, the (then) Attorney General advised that "the principle of non-custodial sentences for minor offences is already 'enshrined' in NSW criminal law in that section AB of the Justices Act 1902 provides that in a summary proceedings, a Justice or Justices shall not sentence a person to full time imprisonment unless satisfied, having considered all possible alternatives, that no other course is appropriate".

3.5 cont.: HCV infected individuals should be protected against discrimination.

Legislatively some provision already exists to protect people from discrimination. Part 4A of the Anti-Discrimination Act 1977 deals with discrimination on the grounds of disability. Under the Act "disability" includes the presence in a person's body of organisms causing or capable of causing disease or illness. Thus, the provisions of Part 4A would apply in relation to persons infected with HCV. The Act prohibits unlawful discrimination in the workplace, education and training, provision of goods and services, accommodation and in registered clubs. There is an exception in the Act where the discrimination is reasonably necessary to protect public health.

3.6 The Centre for Research and Development within NSW Health adopt the following as research priorities for NSW:

- ***reducing the size of the drug injecting population;***
- ***improving the effectiveness of treatment for persons using potentially injectable illicit drugs;***
- ***development of non-reusable injection equipment;***
- ***behavioural and ethnographic research into young injectors and particularly into initiation of injecting and sharing of body fluids;***
- ***effectiveness of bleach and other agents used for decontamination of injecting equipment.***

These are the ongoing concerns of the National Drug and Alcohol Research Centre (NDARC). The Commonwealth is the appropriate funding agency for the work of National Centres. NSW Health works closely and cooperatively with this and other relevant research agencies.

3.7 That AIDS/Infectious Diseases Branch revise The Skin Penetration Guidelines and the Public Health Act 1991-Regulation and develop an effective implementation strategy. Such a strategy should include prisons.

The AIDS/Infectious Diseases Branch commenced a review of the Regulation and associated Skin Penetration Guidelines. This review is continuing as part of the work of the Environmental Health unit. Environmental Health Officers have a role in ensuring compliance of these guidelines.

4.1 It is recommended that funding be made available to provide validation testing for all positive screening tests in public patients and appropriate prognostic and antiviral tests. Tenders should be called for the establishment of two major reference sites in NSW. Selection should be based on the expertise and experience of the laboratories, the ability to interpret tests and to develop new tests. Reference laboratories should also be allowed to charge referring private laboratories for the costs of validation testing.

Medicare currently funds the initial antibody testing for HCV, while the more specialised supplementary testing is funded either by the patient or from hospital budgets. Part of the Hepatitis C Taskforce Implementation funding has to date been allocated to Area Health Services for this purpose.

4.2 The reference laboratories be linked with the National HIV Reference Laboratory and state reference laboratories.

Laboratories authorised to undertake HCV supplemental testing provide data to the National Serological Reference Laboratory for national collation.

4.3 A validation algorithm be developed and applied by the Commonwealth to all laboratories testing for HCV. Validation testing for initial positive tests should be rebateable under Medicare.

A validation algorithm provided to the Commonwealth has been approved by the NHMRC and is now in use by authorised laboratories.

4.4 AIDS/Infectious Diseases Branch establish a panel of review to annually review the HCV testing program.

The Department recently convened a working party to make recommendations concerning quality assurance for HCV testing in NSW. These recommendations were presented to the Commonwealth Department of Health and Family Services for consideration as part of the process of updating Commonwealth guidelines.

4.5 Research and development with regard to HCV testing be considered a priority and is an important component of a coordinated plan for HCV.

Clinical research funding is usually provided by the Commonwealth or by relevant industry funding sources.

5.1 Some enhancement of HCV consultant services is required in most health Areas/Districts. A comprehensive needs assessment and services planning project should be undertaken as a matter of urgency, and minimum service levels set based on a health outcomes approach. In the meantime the guidelines in the text of this Report should be used as the

basis for developing a comprehensive HCV clinical capability in NSW. The recommended minimum level of service provision is: one nurse consultant/educator per Area Health Service or per group of Districts (previous Regions); 1.5 hepatologists (full time hepatitis C) per 600,000 population; 0.5 resident medical officer (full time hepatitis C) per 600,000 population; adequate liver biopsy day stay beds and adequate ultrasound facilities.

Consultation with the relevant Departmental Branch suggested that further data are required to justify the stated resource recommendations. Perceptions of needs for clinical services will be re-examined in the light of the evaluation of the current Hepatitis C demonstration projects and a service development exercise is being considered for commencement in 1998.

5.2 Statewide access to interferon under s100 be facilitated by authorising practitioners in each Area/District.

This was made a priority in NSW and there are now 22 authorised Interferon prescribing centres Statewide and two more applications in progress.

5.3 Non s100 listing patients be accepted for interferon treatment on compassionate grounds in carefully selected cases. This should require the approval of more than one hepatologist including an independent opinion from someone outside the treatment centre making the recommendation.

NSW supports the urgent implementation of the current NHMRC recommendations for the broadening of the criteria for interferon treatment, and has made this view known to the Commonwealth.

5.4 All services providing interferon or other treatments be required to provide data to the National Hepatitis C Treatment Database based at the John Hunter Hospital. The database should be extended to include data from liver transplant units.

This is in place as a condition of approval to prescribe interferon as a s100 funded drug.

5.5 The Australian Gastroenterology Institute be contracted under the Health Outcomes program to develop clinical best practice guidelines for HCV management and liver biopsy.

The NHMRC convened a working party (which includes NSW clinicians) to develop clinical best practice guidelines. These were released in August 1997 and are now guiding service provision developments as part of the current hepatitis C demonstration projects.

5.6 A short course in HCV management and counselling be established by AIDS/Infectious Diseases Branch for GPs, Medical Officers and consultant nursing staff. Completion of this course should provide accreditation for GPs wishing to participate in shared care.

This concept is discussed regularly with GP representatives. To date there is no consensus on whether such a program is needed as there are several other initiatives which may achieve the same aims, including the NSW Hepatitis C demonstration projects and several Commonwealth funded projects being conducted by Divisions of General Practice in NSW. The need for such an accreditation program will become clearer following the evaluation of these projects.

5.7 Appropriate coding systems for hepatitis be developed for the medical records system.

The coding of hepatitis is currently under review by the National Coding Centre.

APPENDIX FOUR

INTERFERON CRITERIA COMPARISONS

PATIENT GROUPS ELIGIBLE FOR INTERFERON THERAPY.
A COMPARISON OF CURRENT SECTION 100 CRITERIA WITH NHMRC AND NIH RECOMMENDATIONS/PROPOSALS

Section 100		NHMRC*	NIH
# 1, 2, 3, 12	Patients with chronic hepatitis C evident on liver biopsy (except in patients with inherited coagulation disorders) with repeatedly positive anti-HCV antibody test and an elevated ALT on 3 occasions over a period of 6 months qualify for treatment with Interferon alfa. If the ALT remains greater than the upper limit of the laboratory reference range after 12 weeks, treatment is to cease.	All HCV antibody patients with any elevation of ALT should qualify; but patients with normal ALT values should be monitored regularly by their clinician. Patients with minimal ALT elevation or with normal LFT's and positive HCV serology or HCV RNA testing should also qualify for treatment.	Chronic Hep. C patients with persistently elevated ALT, positive HCV RNA and livery biopsy should qualify for treatment. Patients with chronic hepatitis C at greatest risk for progression to cirrhosis should be treated. Liver biopsy is indicated when histological findings will assist decision making regarding patient management.
4.	Patients who do not have cirrhosis or other liver disease, qualify for treatment.	Patients with cirrhosis should be treated at a higher dosage regimen of 4.5 MIU daily for 6 months.	Patients with decompensated cirrhosis should not be treated but should have liver transplants.
5.	HIV positive patients are excluded from treatment.	HIV positive patients should qualify for treatment. The individual clinician will determine if interferon alfa is appropriate to offer patients with advanced HIV disease.	Patients with stable HIV infection with good clinical and functional status should qualify for treatment.
6.	Patients who are not pregnant, not lactating or are practicing adequate birth control should qualify for treatment.	Patients who are not pregnant, not lactating or are practicing adequate birth control should qualify for treatment.	-
7.	No history of significant psychiatric illness, no history of autoimmune liver disease.	No history of significant psychiatric illness, no history of autoimmune disease.	Contraindications which should be carefully considered are a history of major depressive illness, cytopenia, active alcohol or illicit drug use, hyperthyroidism, renal transplantation or autoimmune disease.
8.	Would be likely to attend regularly for treatment and follow-up.	-	-

Section 100		NHMRC	NIH
9, 10.	Patients who have not utilised illicit drugs within the previous 12 months or take no more than 7 standard alcoholic drinks/week, qualify for treatment.	Injecting drug users and patients on Methadone program should qualify for treatment. Due to the risk of side effects patients should be assessed individually by their managing physician to determine whether there is any evidence of psychological instability.	Treatment of patients who are drinking significant amounts of alcohol or who are actively using illicit drugs should be delayed until habits discontinued for at least 6 months.
11.	The course of treatment is limited to 3 million units subcutaneously three times weekly for up to 52 weeks.	-	-
13.	The course of treatment must be continuous and excludes retreatment of non responders or patients who relapse and thus patients eligible for the 12 months course will be new patients and current responding patients who have not completed 6 months treatment.	Patients who have relapsed following an initial response to a 6 month course of interferon should be treated again with interferon alfa for 12 months.	Non responders should not be treated with the same regimen of interferon but should be considered for combination therapy or enrolment in investigational protocols using different dosages or agents. Patients who have an ETR to a 6 month course of interferon alfa but then relapse, should receive 12 months treatment with interferon alfa or be considered for combination therapy with Interferon alfa plus Ribavirin or other regimens, preferably in a clinical trial.
14.	-	Patients with extraheptic manifestations of hepatitis C should be treated.	Extra hepatic manifestation, ie. mixed cryoglobulinaemia should qualify for treatment.
15.	-	-	Therapy should not be withheld on the basis of high RNA levels, genotype or mode of acquisition.
16.	-	-	Patients with acute Hep. C should be treated.
17.	Children under 18 years of age also qualify for treatment.	Children should be treated. The dose for children under 18 years of age should be 3 MIU/m^2 three times per week (dose not to exceed 5 MIU/m^2).	Firm recommendations cannot be made on patients under 8 years or over 60 years of age because of incomplete data. These patients should be managed on an individual basis or in the context of clinical trials.

* NHMRC, 1997:35 # Numbering maintained as per Section 100 criteria.

Source: Schering-Plough submission

APPENDIX FIVE

NSW HEPATITIS C DEMONSTRATION PROJECTS:

AIMS AND OBJECTIVES

I THE RURAL HEPATITIS C DEMONSTRATION PROJECT

This project aims to improve access to treatment and support for people with HCV in rural areas, and to improve the coordination of their care.

The project's objectives include:

- to map current services and resources;
- develop a model of coordinated care for rural areas;
- develop protocols and guidelines in consultation with other projects;
- identify general practitioners and other health care and support workers who can provide support, information, counselling and treatment for people with and affected by HCV;
- identify specialists interested in becoming interferon prescribers in those areas currently without prescribers, and general practitioners interested in placement with prescribers for further training;
- develop and implement general practitioner and health care worker education sessions in all aspects of HCV, in conjunction with Divisions of General Practice, the RACGP and other relevant agencies;
- establish education support networks to enable the ongoing education of health care workers; and
- identify consumers who can provide education for health care workers and involve them in all aspects of training.

II CENTRAL/SOUTH EASTERN SYDNEY HEPATITIS C DEMONSTRATION PROJECT

The objectives of this project are:

- set up monthly specialist HCV clinics at the Kirketon Road Centre (Kings Cross), Livingstone Road Sexual Health Centre (Marrickville), Newtown NSEP and Bayside Methadone Clinic (Kogarah);
- map current services and resources;
- develop and deliver education and training to general practitioners and other health care workers;
- develop, in consultation with other projects, management and referral protocols; and
- improve surveillance of HCV by improving notification, conducting exposure assessments on incident cases and conducting a survey of HCV related morbidity.

III THE WESTERN SYDNEY HEPATITIS C DEMONSTRATION PROJECT

The aim of this project is to develop a model of car for HCV positive methadone clients. The project will develop a counselling/psychosocial support model for HCV in conjunction with the Liver Clinic and the Department of Psychiatry at Westmead Hospital.

The objectives of the project are:

- map available HCV services in the Area and their level of support;
- document surveillance and notification procedures and referral patterns;
- conduct needs assessments of both people with HCV and service providers;
- train methadone prescribers and clinic staff, and other relevant service providers;
- develop a model for ongoing assessment and referral of methadone clients;
- produce resources for methadone providers and clients; and
- develop indictors and referral protocols for psychiatric/psychosocial support.

IV THE SOUTH WESTERN SYDNEY HEPATITIS C DEMONSTRATION PROJECT

The aim of this project is to address the specific issues of access, information, treatment and care for people from non-English speaking backgrounds.

The objectives of the project are:

- encourage community awareness of HCV through social marketing, community development and consultation;
- increase the skills of targeted general practitioners in diagnosis and management of HCV;
- develop a shared care model involving general practitioners and specialist services;
- develop resources for general practitioners, specialists and other health care workers caring for people of non-English speaking backgrounds; and
- improve HCV surveillance by improving notification of acute cases an the provision of demographic and risk factor information.