Submission No 41

THE IMPLEMENTATION OF PORTFOLIO COMMITTEE NO. 2 RECOMMENDATIONS RELATING TO CROSS-JURISDICTIONAL HEALTH REFORM AND GOVERNMENT CONSULTATION WITH REMOTE, RURAL AND REGIONAL COMMUNITIES

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SUBMISSION – Inquiry into the implementation of Portfolio Committee No.2 recommendations relating to cross jurisdictional health reform and government consultation with remote, rural and regional communities

Dear Committee,

Since 1955, Can Assist's mission has been a constant - equitable access to cancer treatment and care for all residents of Regional, Rural and Remote NSW. Last financial year we delivered $3 million in financial assistance to 4064 patients meeting 12,000 requests. An increase of 26% in funds from the previous year.

Operating from 56 towns with 2885 local community volunteers, each patient receives the unique assistance that meets their needs. Individual branch assistance patterns reveal considerable insight into the different stressors that our communities experience.

As per the terms of reference we seek to share our views regarding the progress of the following recommendations emanating from the 2021/22 Health Inquiry:

Recommendations 1[1] , 5[2] Service gaps and funding inadequacy in relation to community transport (CT).

Where public transport is limited or nonexistent and no personal support ecosystem is available, many people rely on community transport to access treatment. Can Assist routinely fund these ticket prices across country NSW. Whilst IPTAAS is now operating more effectively and with more improvements in the pipeline, the CT sector remains outdated and not fit for purpose. All passengers (isolated or not) are ineligible for IPTAAS when utilizing CT.

Government funding of the CT sector [3] remains broadly fixed at around $39 per trip; be it a 5km trip or a 500km trip, be it a trip to access lifesaving treatment or a shopping trip. Govt funding is allocated upfront according to the "expected" annual demand for trips with no reference to either distance or to the number of trips a provider subsequently delivers. Should the CT provider need to operate trips in excess of this target – they simply don't have access to additional funding.

[1] That NSW Health review the current funding models for all rural and regional Local Health Districts in order to identify any service delivery gaps and provide any recommendations for funding increases
[2] That NSW Health and the rural and regional Local Health Districts actively engage with local community groups and charities to understand the services and resources they provide, and to ensure that where possible and appropriate, service gaps are filled by government.
[3] Whilst the Federal Govt provides the largest contribution to CT via the Aged Care CHSP program (about 85%), the State Govt contributes a further 10% (via the CTP program) and 1% (NGO Health grants) for those ineligible for MAC. Passengers have access only to one of these three funding streams. This is a per trip funding model, with the number of those funded trips being estimates only.

In stark contrast, patient funding under IPTAAS is entirely demand/needs based and increases proportionately with distance travelled. CT funding has no *additional* carve out at all for patients[4] – be they isolated or otherwise.

Whilst some 35% of all CT trips throughout the state are for medical purposes, the so-called NSW Health grants (only made available in some LHDs) contribute to only around 1% of trips[5].

Some CT operators run with close to 100% volunteer drivers, others with far less. Around 30% of CT providers have the backing of their local council should they need it – the majority do not.

How does this manifest in our communities?

a. **Inequity between our towns** - Differing provider cost bases combined with a fixed trip funding model creates a wide variety in passenger ticket pricing

Ticket prices vary significantly across the state - from as low as 17cents per km (e.g., Forbes to Orange) to 49cents per km (e.g. Moree to Tamworth) to 200c per km (Tamworth to Newcastle, HCP or NDIS). Some charge extra for escorts and/or driver meal allowances, some do not. Some offer discounts should there be a second or third patient, others do not.

b. **Inequity between isolated patients according to travel mode –** CT versus Private travel

Over the course of a typical 12-month treatment profile, a rural cancer patient living just 100km away from their regional cancer centre (the shortest distance for IPTAAS eligibility) would typically accumulate a private travel IPTAAS rebate some 2.4 times the size of the equivalent implicit CT subsidy[6]. The disparity between the dollar value of the two subsidies grows with the geographic isolation of the patient, and the implicit government subsidy for CT is always lower than the equivalent subsidy for IPTAAS [7].

Whilst all "isolated patients" are eligible for IPTAAS should they travel privately to treatment, no patient is eligible for IPTAAS when travelling by CT. Further, "Isolated patients" with Home Care or NDIS packages who utilise CT are not even eligible for the meagre $39 CT subsidy. CT charges for this cohort approach between 100c and 200c per km

c. Vulnerable patients turn to Can Assist

On average, a cancer patient will typically need to make around 35-40 trips over the course of a12 month treatment cycle. The seemingly "affordable," $79 return ticket price from Mudgee to Dubbo for example adds up quickly for a radiotherapy patient who typically needs daily treatment over a 5-week period.

"Some people are missing treatment because they cannot afford to pay … It's an under reported unrecorded and unacknowledged problem" Health care professional, Dubbo Health Service.

Accessibility to transport has been made all the harder with the 2023 rollout of the Cancer Council of NSW travel to treatment offering – greater enforcement of their eligibility criteria has reduced service access to many. The Tablelands Community transport operator in Uralla for example has been forced to double their weekly trips to Tamworth since these changes. They are doing their best to pick up the slack; cross subsiding between funding pools to keep prices from rising. Can Assist is receiving an uplift in request for financial support. This is not a sustainable situation. The $50 a day ticket price Armidale-Tamworth return adds up for a radiotherapy patient who typically needs daily treatment for a 5-week period. A patient privately escorted to those same appointments would receive an IPTAAS rebate of $2220 versus a CT subsidy of just $975.[8] Our local Can Assist

[4] Whilst the State Govt issues NGO health grants for patients – this only provides patients access to the same level of funding they would have received should they be a CHSP passenger for e.g. travelling on a shopping trip.
[5] At an annual cost of around $1,000,000
[6] Assume patient lives 100km outside of Tamworth who makes 37 trips to Tamworth and 4 trips to Newcastle. IPTAAS = $3862 versus CT = $1599
[7] 200km is the minimum (return trip) distance a patient must travel to meet IPTAAS eligibility. At 40c per km this implies a minimum IPTAAS rebate of $80 (compared to a fixed $39 CT subsidy)
[8] 25 trips X 222km @ 40c per km = $2220 IPTAAS / versus 25 trips X $39 = $975per trip rebate CT

Armidale branch delivered $95,183 in assistance to 436 patients last financial year; notably, demand for assistance with travel assistance has increased by 60% year on year.

On occasion, patients have not been able to access a CT seat at all. Our volunteers have personally driven them to appointments, a service that falls outside our offering.

Recommendations 44[9] - Inter-ministerial responsibility in relation to community transport

CT funding is sourced via both the State and Federal government. Whilst CT is of vital importance for equitable access to treatment and therefore rural health outcomes, Transport for NSW administers it. Whilst we have no direct insight into how the interplay works a "Health in All Policies Framework" would ensure the centrality of access to treatment in program administration

Recommendation 21[10] - Out of pocket patient oncology costs; regional public and public-private treatment centres

Two significant changes have been implemented in accordance with this recommendation generating significant relief for our communities:

a. **The abolition of out-of-pocket oncology medical treatments at the Riverina Cancer Centre** (RCCC)

Can Assist operate twenty-one branches within the RCCC patient catchment area. Whilst representing only 38% of our entire network, they typically accounted for some 60-65% of our overall (ex-pharmaceutical) medical out of pocket spend across the group. Whilst we are yet to feel the full weight of this from a funding perspective (we are still paying many accounts that predate the July 1st cut off), it will lift a huge burden from our communities. It will mean that Can Assist is able to provide more help in other areas.

Not every country cancer patient is aware of Can Assist and not every cancer patient, is willing to reach out. It is hard to quantify the impact of this measure – anecdotally however, we can share stories of patients who have accommodated at our own Lilier Lodge in Wagga Wagga since this reform who have told us that they simply would not have sought treatment if these out of pockets had remained.

b. **Abolishing the anticipated out of pocket charge for radiotherapy patients at Griffith**

The provision of this service and the equalisation in pricing with the RCCC means less financial stress, less travel and more time with family and loved ones at a time when they are most needed and continue to relieve pressure on our services. We are yet to hear what will happen with respect to out-of-pocket charges for the new radiotherapy unit to be built by the same private provider in Taree.

One significant change in the pipeline:

a. A public Pet Scan at Tamworth – in progress

There are three public PET scans in country NSW – Dubbo, Lismore, and Tweed Heads

The availability of an additional machine in Tamworth will save patients from significant amounts of travel and medical out of pockets. Out of pocket scan costs can be significant, some scans attract no Medicare rebate whatsoever. A cancer patient will typically require at least two of these scans over a 12-month treatment journey – but others many more. A client of ours from Young for example with testicular cancer is required to have a PET scan indefinitely every three months, we have paid for three of these so far, at a cost of $1035 each.

[9] That the NSW Government adopt a Health in All Policies framework (similar to the policy in South Australia) to ensure that the health of people in New South Wales is central to government decision making, and which recognises that community physical and mental health is a responsibility of all Ministers and Departments of government. Further, such a framework should include a requirement that all decisions of government are assessed to determine the impact on human and environmental health to ensure a whole-of-government ownership of health outcomes for people living in New South Wales

[10] That NSW Health working with the Commonwealth and all relevant service providers investigate strategies to ensure public patients being treated in regional cancer centres can access private-public services while reducing out-of-pocket costs

Moreover, there appears to be no uniformity in charges – our volunteers being told of a variety of charges depending on the provider.

Public PET scans are routinely available in metropolitan areas of NSW.

Better awareness and transparency of these costs is essential for all cancer patients.

Recommendation 7 [11] - Slow progress with initiatives identified as meritorious by both State and Federal Governments in relation to radiotherapy in Eurobodalla. The disconnect with SNSWLHD.

Successive Federal Governments since the 2018-19 election cycle have promised $63million for thirteen radiotherapy sites across regional Australia. Seven of those original sites were in NSW. Four have either been built or are in progress[12] by either Government or private providers and three are outstanding[13]. In the case of Eurobodalla, both Federal and State Governments agree that the service is desperately needed. The Federal Government has backed this with an additional $3million in grant funds (taking the total to $8million) and Premier Minns has repeatedly called for the service to be offered. Dr Hollands, BEGA MP who went into politics with health services uppermost in his mind has fought courageously for his community.

SNSWLHD appears to be the roadblock – first claiming the population catchment was not large enough; a theory that has since been debunked by the very same external consultants engaged by NSW Health to investigate the matter. [14] Using the cancer case load data projections of the NSW cancer institute[15] and applying the Ministry of Health's guidelines[16] for radiotherapy treatment, a higher annual patient case load is projected in Eurobodalla/Bega than was expected in Dubbo prior to the provision of radiotherapy services there[17] . These projections render the need for 1.2 linear accelerators in Eurobodalla for 2026.[18]

This is all before it is considered that the Eurobodalla catchment area has a population some 1.5-2.1 times higher than 3 of the 4 recently approved radiotherapy sites under the Federal Govt grant program. Moreover, Aboriginal and Torres Straight Islanders are overrepresented in the Eurobodalla /Bega LGAs[19] . Given the higher incidence and mortality rates for Aboriginal people, combined with a reluctance to travel off country – this is an important consideration.

A second objection from SNSWLHD has been the cost. CEO Margaret Bennett has publicly claimed a cost "in the vicinity of $100 million " [20] This would appear to have no basis in reality, as evidenced and sited by the same NSW Health commissioned external consultant report[21]. Referencing other radiotherapy sites across the state, the cost cannot be expected to exceed $35million.

Noteworthy is the fact that the report referred to here was apparently withheld from public consumption and only finally released under an application to the Freedom of Information Act.

SNSWLHD has never submitted a bid for the Federal Govt grant monies. The two providers who did quoted an annual copayment fee from the State Govt of between $578,000 and $1.5million per annum to ensure zero out of pockets for patients.

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[11] That the NSW Government urgently engage with the Australian Government at a ministerial level to:
• establish clear governance arrangements and a strategic plan to deliver on the health reforms recommended in this report to improve doctor workforce issues
• progress those initiatives that both levels of government have identified as meritorious, but where progress has been slow or non-existent
[12] Tweeds Heads, Mid North Coast , Taree , Griffith
[13] Armidale, Grafton, Eurobodalla
[14] https://canassist.org.au/reports-and-submissions/the-case-for-radiotherapy-in-eurobodalla/
[15] Ibid , page 4
[16] Ibid, page 18
[17] Ibid page 12, i.e. expectations of 480 annual cases in Dubbo versus 512 expected cases in Eurobodalla in 2026
[18] Ibid page 18.
[19] Ibid page 9
[20] Community learns radiotherapy service cost at Eurobodalla Hospital | Bay Post-Moruya Examiner | Batemans Bay, NSW
[21] https://canassist.org.au/reports-and-submissions/the-case-for-radiotherapy-in-eurobodalla/

We wonder, have the budget savings associated with IPTAAS been considered in relation to these numbers? Referencing projections supplied by the NSW cancer institute along with the Ministry of Health's radiotherapy guidelines, the annual patient load is projected at 512 cases in 2026, rising to 554 cases in 2031[22]. Should locals continue to travel to access radiotherapy, the State Govt will be subject to annual IPTAAS claims for radiotherapy alone from over $1.8million in 2026 – rising to $1.99million by 2031[23] – safely exceeding the ongoing copayment requirement of a local service.

This is all before we overlay the human face of suffering which is what our volunteers deal with day in and day out. Not all cancer treatments are equal when it comes to financial toxicity and psychosocial impact. For those not living close to services – these impacts peak with radiotherapy; administered daily, often for treatments as short as 15 minutes, for up to 8 weeks, and delivered as an outpatient. Confronted with the extra costs and family stress some patients simply will not make the journey. We recently had a case in Mudgee where a client refused to leave his dog and insisted on denying radiotherapy treatment in Dubbo – our branch there arranged and paid for a kennel for that dog and the patients accommodation. Further, when the patient is a parent of young children," the impact of split family life and loss of income across partners and extended family can be overwhelming; both financially and emotionally" Liz Basevi, President of Can Assist Eurobodalla.

We talk about the metro-rural divide with respect to access to healthcare, but in truth there are significant inequities within the rural landscape. Can Assist operate three branches with 86 community volunteers along the South Coast: Bega Valley since 2004, Eurobodalla and Shoalhaven since 2010. Whilst the Shoalhaven has a population some 2.5 to 3.0 times larger than both Bega Valley and Eurobodalla, total assistance amounts are markedly higher in Bega (more than double) and Eurobodalla (around 30% higher). *Individual* patient assistance amounts are more than double in Eurobodalla and more than triple in Bega. We believe, the availability of radiotherapy treatment in Shoalhaven (Nowra) is a key driver of this anomaly. Travel and accommodation costs account for up to half of our annual assistance in Eurobodalla and Bega compared to less than 1% of expenditure in our Shoalhaven branch.

The recent increase in IPTAAS rebates for private travel have made a significant impact for patients, noting that more work needs to be done in this area to raise awareness of the scheme and simplify the application process [24]. Can Assist is often placed in the situation of providing financial support as people are over burdened by the paperwork at a time when they just need support to get on the road to access treatment. We often need to remind social workers and patients that the Government scheme is where such support needs to come from freeing our funds to support elsewhere.

For those patients travelling from the Eurobodalla/BEGA LGA's however, bulk billed accommodation is not, however, always available in Canberra, leaving many to face funding upfront the expense of living away from home when receiving treatment.

As outlined above Community Transport (CT) remains an expensive alternative for patients and passengers are ineligible for support via IPTAAS.

"We have clients who would not have taken the recommended cancer treatment without Can assist's financial support" Oncology social Worker, South East Regional hospital "I rely on Can assist enormously…I don't know where we would be without them" Eurobodalla based oncology health professional.

Closing Remarks

We thank the committee for all its hard work over these last few years, we have appreciated the conduit for our communities' voices. Much progress has been made, yet there remains much more to do. We pay tribute to our

[22] Ibid page 18

[23] Assume a 6-week radiotherapy course. Patient accommodated in Canberra Monday – Friday and travels home each weekend. 6 car trips; Eurobodalla – Canberra @ 350km return = $840 / 30 nights accommodation = $2760. Per patient total IPTAAs rebate = $3600. Patient load in 2026 = 512 and in 2031 = 554. Note this estimation does not take into consideration those patients travelling from areas like Bega who will remain eligible for IPTAAS, but with shorter distances compared to Canberra savings remain.

[24] Note work is being conducted on this via the "IPTAAS Forum" a community forum co-chaired by Michelle Maxwell of Regional Health and Can Assist

current and past volunteers who have worked tirelessly for country NSW – they have saved many lives and made life so much brighter for many, not only for cancer patients but for their entire communities.

Yours sincerely,

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