

**Submission
No 31**

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

Organisation: Chris O'Brien Lifehouse

Date Received: 31 October 2024

Submission to the Select Committee on Remote, Rural and Regional Health's Inquiry

Implementation of Portfolio Committee No. 2 recommendations relating to cross-jurisdictional health reform and government consultation with remote, rural and regional communities.

October 2024

Recipient

Select Committee on Remote, Rural and Regional Health
remoteruralregionalhealth@parliament.nsw.gov.au

Contact for Chris O'Brien Lifehouse

Professor Michael Boyer
Chief Executive Officer



About Chris O'Brien Lifehouse

Chris O'Brien Lifehouse (COBL) is a quaternary comprehensive cancer centre in Sydney, providing surgical, oncological, and supportive care services to people with cancer from across NSW.

Across a range of cancer types, including complex head and neck cancer, ovarian cancer, primary and secondary liver cancer, kidney cancer, and breast cancer, COBL performs the highest number of resections in NSW annually. In addition, COBL is a high-volume surgical centre for colon cancer, rectal cancer, lung cancer, melanoma, pancreatic cancer, bone and soft tissue sarcoma, and prostate cancer,¹ performing above the minimum suggested annual case load for cancer resections. Nearly 20% of all patient visits to COBL are by people living in regional or remote (hereafter, rural) NSW.

In addition to providing treatment at our metropolitan centre for rural people with cancer, COBL provides gynaecological oncology and head and neck surgery outreach clinics in towns in rural NSW. Consultant surgeons, fellows and registrars attend outreach clinics on a fortnightly or monthly basis in a fly-in-fly-out model in Dubbo, Port Macquarie, Tamworth and Nowra. Services include providing clinical expertise, performing surgery (either at rural hospitals, for example Port Macquarie Base Hospital, or at COBL for the most complex cases), and follow-up of people with cancer. Under the COBL Rural Access Program, our experts provide regular education to local healthcare providers, rural education institutions, and conduct clinical research. We work in close association and informal partnership with local healthcare experts, multidisciplinary teams and rural educational institutions with the aim of together improving health outcomes for all patients affected by cancer.

These services fill a major gap in care provision for people with complex cancer needs in rural NSW that are not currently provided by the NSW Government. These services are offered without any recognition and funding support from the NSW or Australian Governments – they are funded entirely via philanthropic donations and by COBL. This model is not sustainable without a commitment from both the NSW and Australian Governments to ensure the long-term viability and ongoing delivery of critical cancer services to people in rural areas.

¹ Reporting for Better Cancer Outcomes – Surgical treatment report (Chris O'Brien Lifehouse and Royal Prince Alfred co-located). (2024) Cancer Institute NSW, Sydney.

Executive Summary

COBL welcomes the opportunity to provide input into the Select Committee on Remote, Rural and Regional Health's 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.

Our responses to the Terms of Reference are from the perspective of a large metropolitan cancer centre providing care to rural people with cancer and our suggestions for improvement come from the solutions that COBL have implemented over the last nine years. We have a proven track record in delivering outreach services for people with cancer in rural areas and supporting these people in having treatment in Sydney, where needed.

In this submission, COBL make recommendations for continued work, summarised in Table 1.

Table 1 COBL's recommendations for continued work

Terms of Reference	COBL's Recommendations
<p>1) Long-term strategic planning to improve health services and health outcomes in remote, rural and regional areas, including in relation to primary health</p> <ul style="list-style-type: none"> - Recommendations 1, 7, 8 and 11 	<ul style="list-style-type: none"> - NSW Health works with the Australian Government to explore partnerships with suitably experienced cancer care providers (e.g., COBL) to implement low-cost models of outreach services for people living with and beyond cancer in rural NSW. - NSW Health and the Australian Government engage metropolitan cancer centres (e.g., COBL) with a proven track record in providing expert and high-quality care to rural people with cancer in any future Bilateral Regional Health Forums. - NSW Health (including rural LHDs) and the Australian Government engage with high-volume (i.e., those performing above the minimum suggested annual case load for cancer resections) metropolitan cancer centres to provide training opportunities for rural nurses, doctors, and allied health staff with appropriate funding for trainees and training supervisors. For example, a formal partnership between COBL and Port Macquarie Base Hospital, and between COBL and the Western Cancer Centre Dubbo would cement existing outreach services in these rural areas and ensure long-term viability and impact.
<p>2) Collaboration between NSW Health and Australian Government bodies on particular initiatives, services or training programs</p> <ul style="list-style-type: none"> - Recommendations 14 and 21 	<ul style="list-style-type: none"> - NSW Health and the Australian Government negotiate to expand the number of Commonwealth Government Specialist Training Program (STP) positions in surgical oncology. For example, the number of STP positions in ENT/head and neck surgery at COBL should increase from 1 FTE per year to a minimum of 2 FTE per year to accommodate the increasing number of outreach clinics and occasions of service in rural NSW. This

	<p>increase should be reflected among other tumour streams at COBL and at other centres across NSW.</p> <ul style="list-style-type: none"> - NSW Health and the Australian Government conduct a review of the Rural Support Loading provided under the Commonwealth Government Specialist Training Program to ensure that it sufficiently covers the cost of trainee's travel to and accommodation in rural areas. - NSW Health works with the Australian Government to explore partnerships with suitably experienced cancer care providers (e.g., COBL) to implement low-cost models of outreach services for people living with and beyond cancer in rural NSW. - A partnership between COBL and the NSW Government would cement the high-quality work already being done by COBL, expand existing successful models of care, and most importantly lead to better outcomes for people with cancer in rural NSW.
<p>3) NSW Government consultation with health stakeholders and communities in remote, rural and regional New South Wales, in particular:</p> <p>a) Improving communication between communities and health services, and</p> <p>b) Developing place-based health plans</p> <ul style="list-style-type: none"> - Recommendations 5, 42 and 43 	<ul style="list-style-type: none"> - No specific recommendations.
<p>4) NSW Government action to prioritise the health of regional communities in government decision making</p> <ul style="list-style-type: none"> - Recommendations 36 and 37 	<ul style="list-style-type: none"> - That the Minister for Regional Health appoint staff within the NSW Government (e.g., Cancer Institute NSW) responsible for identifying and engaging with metropolitan cancer centres such as COBL with a proven track record of delivering outreach models of care to share knowledge and explore opportunities to sustainably deliver these services in the future. The Minister for Regional Health (or their delegates) should invite representatives from these centres to quarterly or biannual meetings to discuss effective strategies to work together to deliver successful models of outreach care for people with cancer in rural areas. - NSW Health engage and partner with cancer treatment centres (e.g., COBL) with a proven track record of delivering rural outreach models of care and explore opportunities to sustainably fund and expand these services into the future.

<p>5) Any updates or final observations relating to the progress of implementing any Portfolio Committee No. 2 recommendations that the Select Committee has considered in its previous inquiries</p> <ul style="list-style-type: none"> - Recommendation 2 and 30 	<ul style="list-style-type: none"> - NSW Health and Cancer Institute NSW continue to engage regularly with stakeholders and rural people living with cancer to better understand unmet needs and support needed to appropriately access IPTAAS and financial counselling. - NSW Health and Cancer Institute NSW continue to conduct regular reviews of IPTAAS and publish reports detailing the uptake of clinical trials by rural people with cancer. - NSW Health and Cancer Institute NSW continue to engage with key stakeholders (people with cancer, rural and metropolitan cancer centres, and clinical trial sponsors) throughout its environmental scan and feasibility assessment of Decentralised Clinical Trials (DCTs).
---	---

Contents

About Chris O'Brien Lifehouse	2
Executive Summary	3
Introduction.....	7
Response to the Inquiry	9
1) Cross-jurisdictional cooperation between the New South Wales and Australian Governments, in particular.....	9
2) Collaboration between NSW Health and Australian Government bodies on particular initiatives, services or training programs	11
3) NSW Government consultation with health stakeholders and communities in remote, rural and regional New South Wales.....	14
4) NSW Government action to prioritise the health of regional communities in government decision making	14
5) Any updates or final observations relating to the progress of implementing any Portfolio Committee No. 2 recommendations that the Select Committee has considered in its previous inquiries	15
Conclusion	18

Introduction

COBL is a nationally and internationally recognised comprehensive cancer center uniquely providing public and private cancer services. The majority of patients come from outside of Sydney Local Health District (LHD), in which COBL itself is located. Nearly one-fifth of all patient visits to COBL are from people living in rural NSW.

In our response, we have focused specifically on two tumour streams – head and neck cancer and gynaecological cancers – as these tumour streams have initiated additional service provision to people with cancer in rural NSW through outreach clinics. A snapshot and brief summary of these services is outlined below for context.

Surgical services

Head and neck surgery: The Rural Access Program at COBL started with head and neck outreach clinics in 2016, expanding the provision of expert clinical care and surgery performed on rural patients. In the 2022-2023 and 2023-2024 financial years, COBL performed 558 and 507 head and neck surgical procedures on people from rural NSW.

In the 2022-2023 financial year, COBL provided *public* surgical services to people from the following rural LHDs (in total NWAU): Mid North Coast LHD (146.5), Western NSW LHD (91.0), Hunter New England LHD (86.5), Central Coast LHD (86.3), Illawarra Shoalhaven LHD (77.3), Southern NSW LHD (30.7), Nepean Blue Mountains LHD (63.1), and Murrumbidgee LHD (7.6), equivalent to \$3,052,129 in cost.

Gynaecological oncology surgery: COBL provides surgical services to women with gynaecological cancer or suspected gynaecological cancer and those requiring complex gynaecological oncology surgery. In the 2022-2023 and 2023-2024 financial years, COBL performed 191 and 193 gynaecological oncology surgical procedures on women from rural NSW.

In the 2022-2023 financial year, COBL provided *public* surgical services to women from the following rural LHDs (in total NWAU): Western NSW LHD (57.7), Illawarra Shoalhaven LHD (23.0), Nepean Blue Mountains LHD (17.6), Hunter New England LHD (12.9), Southern NSW LHD (8.1), and Murrumbidgee LHD (4.0), equivalent to \$600,000 in cost.

To date there has been no additional funding provided to COBL to provide these services (either head and neck or gynaecological cancer) to rural people, despite increases in the occasions of service and cost of these services required each year. It is not financially feasible for COBL to continue to provide these services without a change in the funding model.

Outreach clinics

COBL provides outreach services in several rural LHDs.

Head and neck: The Department of Head and Neck Surgery has led the way at COBL and developed a Rural Access Program in 2016, which has since grown to encompass regular (monthly or fortnightly) clinics in Nowra, Port Macquarie, and Tamworth. The aim of this program is to see people with head and neck cancer locally, and work with local healthcare specialists and local infrastructure to address the inequity and shortfall in specialist care to improve outcomes for rural people with cancer.

In the 2023-2024 financial year, there were a total of 3112 patient visits at rural head and neck clinics provided by the COBL specialist team in NSW: Port Macquarie (2345), Tamworth (316), and Nowra (451).

These clinics are led by a specialist head neck surgeon, clinical fellow, and registrar. In addition, the following activities have been undertaken:

- Working with local cancer services (surgeons, radiation oncologists, medical oncologists) and primary care providers to provide continuity of care together with COBL
- Providing head and neck surgical expertise at Port Macquarie Base Hospital
- Providing regular education to local healthcare providers including GPs, dentists, allied health professionals, and medical students
- Research into the healthcare needs, resources, and clinical outcomes of people with head and neck cancer in rural NSW

Gynaecological oncology: COBL has provided outreach clinics for women with a diagnosis of gynaecological cancer or women at risk of gynaecological cancer in Western NSW (Dubbo) and the Illawarra Shoalhaven (Wollongong) LHDs since 2019. The clinics accept both public and private patients and work on a low or no cost model funded by COBL through goodwill, philanthropy, and Medicare billing.

In the 2023-2024 financial year, COBL provided the following clinical occasions of service to women in: Western NSW LHD (263), Nepean Blue Mountains LHD (113), Illawarra Shoalhaven LHD (63), Southern NSW LHD (50), Mid North Coast LHD (26) and Murrumbidgee LHD (26).

Despite costs to COBL to provide a VMO to fly in to Dubbo, rental of private rooms outside of the public hospital (as we were not able to provide a clinic in the existing cancer centre), and provision of our own secretarial and nursing support to run this clinic, we have not received any financial support from Western NSW LHD, or the NSW or Australian Governments.

Response to the Inquiry

1) Cross-jurisdictional cooperation between the New South Wales and Australian Governments, in particular:

a) Long-term strategic planning to improve health services and health outcomes in remote, rural and regional areas, including in relation to primary health

Legislative Council Portfolio Committee No. 2 recommendations include recommendations 1, 7, 8 and 11. Our reflections and recommendations relate to the progress made on all of these recommendations.

Recommendation 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.

Recommendation 7: 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*

Progress since recommendations

We are pleased to see that NSW Health has been involved in undertaking various measures to address these recommendations, including reviews of the NSW Small Hospitals Funding Model, undertaking the National Health Reform Agreement (NHRA) Mid-Term Review, and engaging with the Australian Government in the Bilateral Regional Health Forums in 2022 and 2023.² We acknowledge that the impacts of these initiatives may take several years to demonstrate tangible change in the health outcomes of people in rural NSW. In particular, the National Medical Workforce Strategy 2021-2031, which will contribute toward improving the distribution of the medical workforce across metropolitan and rural areas, could prove impactful.

Practically, however, the initiatives have not yet translated into meaningful change in how cancer care is delivered between our quaternary metropolitan cancer and rural LHDs. We are yet to see engagement or support from NSW Health to collaborate in delivering outreach cancer services, currently conducted by COBL and solely funded by philanthropy and goodwill, for people with head and neck cancers and gynaecological cancers. None of these incentives or documents include any communication or a clear strategic plan made by NSW Health or the Australian Government to develop or support regular rural cancer services by quaternary metropolitan cancer centres such as COBL.

COBL has provided highly valued (Box 1) and effective expert head and neck and gynaecological cancer services to people in rural NSW in conjunction with local LHDs (Mid North Coast, Western NSW, Southern NSW and Illawarra Shoalhaven LHDs) for the past nine years. In order for COBL to continue these vital services, urgent engagement and financial support from NSW Health is needed to ensure ongoing success and long-term viability.

² Progress Report – Parliamentary Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote New South Wales as at 30 June 2024. 2024. NSW Ministry of Health, Sydney. Accessed 22 October 2024. Available from: <https://www.health.nsw.gov.au/regional/Publications/rural-health-inquiry-progress-report-2024.pdf>

Box 1: Quotations from patients providing feedback on the head and neck outreach clinics in Tamworth and Port Macquarie³

“I would have to say that having access to the clinic regionally in Tamworth (as we live 70 km from Tamworth) is more beneficial as compared to travel to Sydney”.

“As the consultation also included physically checking my head and neck, a telehealth conference would have been less satisfactory”.

“If the specialists could come more often to Tamworth that would be a great help for those that have to travel long distances to see them”.

Recommendations for continued work

- NSW Health works with the Australian Government to explore partnerships with suitably experienced cancer care providers (e.g., COBL) to implement low-cost models of outreach services for people living with and beyond cancer in rural NSW.
- NSW Health and the Australian Government engage metropolitan cancer centres (e.g., COBL) with a proven track record in providing expert and high-quality care to rural people with cancer in any future Bilateral Regional Health Forums.

***Recommendation 8:** That the NSW Government investigate ways to support the growth and development of the primary health sector in rural, regional and remote areas, and support the sector's critical role in addressing the social determinants of health and reducing avoidable hospitalisations for the citizens of New South Wales.*

***Recommendation 11:** That NSW Health work with the Australian Government collaboratively to immediately invest in the development and implementation of a 10-Year Rural and Remote Medical and Health Workforce Recruitment and Retention Strategy. This should be done in consultation with rural, regional and remote local government, schools, community services, human services, unions, professional organisations, general practice, pharmacists and community organisations. It should set out a clear strategy for how NSW Health will work to strengthen and fund the sustainability and growth of rural, regional and remote health services in each town including quantifiable targets for tangible improvement in community-level health outcomes, medical and health workforce growth, community satisfaction, and provider coordination and sustainability. It must also address hospital and general practice workforce shortages including General Practitioner, nurses and midwives, nurse practitioners, mental health nurses, psychologists, psychiatrists, counsellors, social workers, paramedics, allied health practitioners and Rural Generalists.*

Progress since recommendations

COBL has developed and implemented strategies to support the primary health sector in rural areas of NSW including:

- Clinical service provision including local clinics, conducting surgery rurally (at Port Macquarie Base Hospital), and supporting local healthcare teams and professionals
- Communication and involvement with metropolitan multidisciplinary teams and meetings
- Education and mentorship to medical students, nurses, allied health staff, local specialists, and general practitioners

³ Venchiarutti *et al.* Patient-reported experiences and satisfaction with head and neck surgery outreach clinics in regional New South Wales, Australia: a cross-sectional survey. *J Eval Clin Pract* 2023 Dec;29(8):1302-1313 doi: 10.1111/jep.13918.

- Research in collaboration with local healthcare professionals and local medical schools
- Expanding the future rural workforce by exposure of advanced trainees and fellows to rural practice

These activities and initiatives by COBL have solely been funded internally (by COBL), via philanthropy, and through goodwill. To date there has been no communication, engagement or offer of support from NSW Health or the Australian Government.

Recommendations for continued work

- NSW Health (including rural LHDs) and the Australian Government engage with high-volume (i.e., those performing above the minimum suggested annual case load for cancer resections) metropolitan cancer centres to provide training opportunities for rural nurses, doctors, and allied health staff with appropriate funding for trainees and training supervisors. For example, a formal partnership between COBL and Port Macquarie Base Hospital, and between COBL and the Western Cancer Centre Dubbo would cement existing outreach services in these rural areas and ensure long-term viability and impact.

2) Collaboration between NSW Health and Australian Government bodies on particular initiatives, services or training programs (including Recommendations 9, 10, 14, 21, 22 and 39)

Legislative Council Portfolio Committee No. 2 recommendations include recommendations 9, 10, 14, 21 22 and 39. Our reflections and recommendations relate to the progress made on recommendations 14, 21 and 22.

Recommendation 14: *That NSW Health work with the Australian Government, the Primary Health Networks, the university sector and the specialist medical colleges to increase rural GP and specialist training positions, integrating these within the new employment and service delivery models recommended in Recommendations 9 and 10.*

Progress since recommendation

As detailed under Point 1, COBL provides specialist oncology training to a wide range of medical, nursing, and allied health professionals. This activity goes some way to addressing the significant disparities in workforce distribution between metropolitan and rural NSW for specialists and allied health professionals.⁴ To date, NSW Health has not engaged or communicated with COBL to advance or support our rural cancer services and education initiatives.

In 2021, COBL was approached by the Royal Australasian College of Surgeons (RACS) and the Australian Society of Otolaryngology Head and Neck Surgery (ASOHNS) seeking our willingness to take on an advanced training position. Given that the COBL Department of Head and Neck Surgery is the largest in NSW and performs the highest number of complex head and neck surgery procedures annually,⁵ we were successful in securing a position as part of the ASOHNS training program. Funding for this position comes from the RACS Specialist Training Program (STP), in part due to our already existing Rural Access Program. However, there is a shortfall in funding due to the salary (NSW Award) and travel and accommodation (the Rural Support Loading component) needed for the trainee to participate in our Rural Access Program. This gap is made up by internally by COBL and philanthropy.

⁴ Evidence base for additional investment in rural Health in Australia. 2023. National Rural Health Alliance. Accessed 29 October 2024. Available from: <https://www.ruralhealth.org.au/sites/default/files/documents/nrha-policy-document/policy-development/evidence-base-additional-investment-rural-health-australia-june-2023.pdf>

⁵ Reporting for Better Cancer Outcomes – Surgical treatment report (Chris O'Brien Lifehouse and Royal Prince Alfred co-located). (2024) Cancer Institute NSW, Sydney.

This position has become one of the most popular in the training program and ASOHNS, COBL, the trainees, and rural LHDs have all derived significant benefit. This program has allowed a trainee to be based at a high-volume cancer centre in Sydney as well as being provided the opportunity to travel to rural NSW, conducting clinics, performing surgery, and participating in local educational programs. Not only is this position an important stepping stone to becoming an ear, nose and throat (ENT)/head and neck surgeon but it also provides unique exposure to specialty practice in rural NSW. It is hoped that this exposure, together with the future support of COBL, will lead to the critical expansion of the rural ENT/head and neck surgery workforce.

We have plans to expand our training program through involvement of other rural sites in NSW. However, unless NSW Health and the Australian Government engages with COBL and provides support and ongoing funding, this program will not be viable in the future.

Recommendations for continued work

- NSW Health and the Australian Government negotiate to expand the number of Commonwealth Government Specialist Training Program (STP) positions in surgical oncology. For example, the number of STP positions in ENT/head and neck surgery at COBL should increase from 1 FTE per year to a minimum of 2 FTE per year to accommodate the increasing number of outreach clinics and occasions of service in rural NSW. This increase should be reflected among other tumour streams at COBL and at other centres across NSW.
- NSW Health and the Australian Government conduct a review of the Rural Support Loading provided under the Commonwealth Government Specialist Training Program to ensure that it sufficiently covers the cost of trainee's travel to and accommodation in rural areas.

Recommendation 21: *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.*

Progress since recommendation

In their progress report⁶, NSW Health report they have made progress in reforming the provision of the Isolated Patients Travel and Accommodation Scheme (IPTAAS). While this reform, and the greater availability of financial counselling for people with cancer provided by the Cancer Institute NSW, are a step in the right direction, we believe there is much more to be done to ensure that people with cancer living in rural areas can access private-public services while reducing out-of-pocket costs.

As stated in our response to Points 1 and 2, we believe that NSW Health and the Australian Government should engage private and public-private cancer care providers and partner in adopting models of care that are proven to be acceptable and cost-effective.^{7,8}

The COBL Rural Access Program for head neck and gynaecological cancers provides regular outreach clinics, works with local healthcare providers and cancer services, and facilitates travel and

⁶ Progress Report – Parliamentary Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote New South Wales as at 30 June 2024. 2024. NSW Ministry of Health, Sydney. Accessed 22 October 2024. Available from: <https://www.health.nsw.gov.au/regional/Publications/rural-health-inquiry-progress-report-2024.pdf>

⁷ Venchiarutti *et al.* Travel-associated cost savings to patients and the health system through provision of specialist head and neck surgery outreach clinics in rural New South Wales, Australia. *Aust J Rural Health* 2023 Oct;31(5):932-943 doi: 10.1111/ajr.13021.

⁸ Venchiarutti *et al.* Patient-reported experiences and satisfaction with head and neck surgery outreach clinics in regional New South Wales, Australia: a cross-sectional survey. *J Eval Clin Pract* 2023 Dec;29(8):1302-1313 doi: 10.1111/jep.13918.

accommodation for all rural people (public and privately insured) requiring complex cancer surgery at COBL. The funding for these activities comes solely from COBL via philanthropic funding, where IPTAAS does not cover the entirety of the costs.

To date there has been no recognition or engagement by NSW Health to support this service. It is therefore critical that NSW Health recognise this and understand the Rural Access Program at COBL, which is providing care to a large number of people with cancer in NSW, is not viable over the long-term without dedicated funding.

Recommendations for continued work

- NSW Health works with the Australian Government to explore partnerships with suitably experienced cancer care providers (e.g., COBL) to implement low-cost models of outreach services for people living with and beyond cancer in rural NSW.

***Recommendation 22:** That NSW Health and the rural and regional Local Health Districts work with the Primary Health Networks and other partners to promote improved communication between service providers, including through the use of shared medical record systems, in order to ensure continuity of care for patients.*

Progress since recommendation

High volume quaternary cancer centres such as COBL should be seen as a partner in the provision of oncology services to people in rural areas. In addition to the initiatives underway as described by NSW Health in their progress report⁹, we strongly believe that more work can be done to support the use of televisual facilities to link in with high-volume, specialised MDTs and the use of these facilities, with appropriate support, to enhance the continuity of care for patients at all stages in their cancer journey. This encompasses diagnosis, treatment, surveillance, management of recurrence, and end of life care (including Voluntary Assisted Dying [VAD]). In addition, there is a need to increase participation of people with cancer in clinical trials, especially in the area of targeted treatments such as immunotherapies which require close monitoring and sub-specialist oncology advice and input with rural oncologists.

Specialist oncology nurses also play an enormous role in communicating with rural GPs to ensure continuity of care, streamlining appointments and pre-surgical planning, communicating with patients before and after surgery, and ensuring IPTAAS forms and supportive care needs are met (e.g., ensuring links with lymphoedema specialists, prehabilitation with rural team members, etc). Currently, these specialist oncology nurses are funded by COBL and philanthropy yet provide care to residents in rural areas for months and years after they have completed treatment. Therefore, there needs to be enhanced funding that recognises this care provision from our service to rural patients across NSW to ensure long-term viability.

Regular and permanent local specialist cancer clinics, such as the head and neck and gynaecological oncology clinics provided by COBL, are vital components of robust and viable expert care and integral to respectful and useful communication with rural healthcare providers. These clinics strengths are that they are linked into a large high-volume metropolitan cancer centre 'hub' with the appropriate resourcing and staffing to provide acute cancer care at the right time, supplemented with follow-up care rurally. We see COBL as a unique, committed and valuable partner to the NSW

⁹ Progress Report – Parliamentary Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote New South Wales as at 30 June 2024. 2024. NSW Ministry of Health, Sydney. Accessed 22 October 2024. Available from: <https://www.health.nsw.gov.au/regional/Publications/rural-health-inquiry-progress-report-2024.pdf>

Government given its not-for-profit, public/private funding model and established track record in excellence in cancer care, education and research.

Recommendations for continued work

- A partnership between COBL and the NSW Government would cement the high-quality work already being done by COBL, expand existing successful models of care, and most importantly lead to better outcomes for people with cancer in rural NSW.

3) NSW Government consultation with health stakeholders and communities in remote, rural and regional New South Wales, in particular:

- a) Improving communication between communities and health services, and**
- b) Developing place-based health plans**

Legislative Council Portfolio Committee No. 2 recommendations include recommendations 5, 42 and 43. While we cannot commence on the progress made on these specific recommendations, COBL would like to reiterate the important role of the community voice for people with cancer in rural areas. Care that can be delivered safely closer to home should be done so, taking into account the preferences of people with cancer.

4) NSW Government action to prioritise the health of regional communities in government decision making (including Recommendations 36, 37 and 44).

Legislative Council Portfolio Committee No. 2 recommendations include recommendation 36, 37 and 44. Our reflections and recommendations relate to the progress made on recommendations 36 and 37.

Recommendation 36: *That the NSW Government maintain a Regional Health Minister in cabinet and provide that Minister with appropriate authority to address issues raised in the inquiry and future issues that affect the rural, regional and remote health system and its communities.*

Progress since recommendation

We were pleased to see that since 2021, the NSW Government has maintained a Regional Health Minister in cabinet. However, as stated throughout this report, to date COBL has not been engaged or approached by either of the Ministers for Regional Health (The Honourable Bronnie Taylor [2021-2023] or The Honourable Ryan Park [2023 to present]) despite our commitment to rural health as a specialist metropolitan cancer centre. In September 2023, we contacted Minister Park's office in attempt to open a dialogue about the work being done by COBL in providing rural cancer services, however following a notification of receipt of documentation that was sent, we received no further follow-up.

We would be more than willing to re-engage with the Minister for Regional Health or their delegates to share our experiences of conducting outreach services for cancer in rural NSW.

Recommendations for continued work

- That the Minister for Regional Health appoint staff within the NSW Government (e.g., Cancer Institute NSW) responsible for identifying and engaging with metropolitan cancer centres such as COBL with a proven track record of delivering outreach models of care to share knowledge and explore opportunities to sustainably deliver these services in the future. The Minister for Regional Health (or their delegates) should invite representatives from these centres to quarterly or biannual meetings to discuss effective strategies to work together to deliver successful models of outreach care for people with cancer in rural areas.

Recommendation 37: *That NSW Health complete and publish the final evaluation of the NSW Rural Health Plan: Towards 2021 before finalising the next rural health plan for New South Wales.*

Progress since recommendation

The *Final Progress Review of the Rural Health Plan: Towards 2021*¹⁰ contained little regarding the provision of cancer services to people in rural areas, so the progress in NSW toward equitable outcomes for people in metropolitan and rural areas cannot be gleaned from this report.

With regard to the *Regional Health Strategic Plan 2022-2032*¹¹, and specifically Priority 1.2 ('Prioritise the attraction and retention of healthcare professionals and non-clinical staff in regional NSW'), we again urge NSW Health to consider adopting and funding successful models of outreach care that are already in place for specialised surgical services for cancer. The model of outreach care for head and neck cancer and gynaecological cancers that COBL has been implementing could be funded as part of NSW Health's core business to improve access to surgical services and outcomes for people with cancer in rural NSW.

Importantly, these outreach clinic models include opportunities for trainee surgeons to gain exposure to practice in rural NSW and to develop an understanding of the challenges faced by patients and clinicians in these areas. These are invaluable opportunities to expose trainee surgeons to working in rural areas and including rural outreach as part of their practice as consultants.

Recommendations for continued work

- NSW Health engage and partner with cancer treatment centres (e.g., COBL) with a proven track record of delivering rural outreach models of care and explore opportunities to sustainably fund and expand these services into the future.

5) Any updates or final observations relating to the progress of implementing any Portfolio Committee No. 2 recommendations that the Select Committee has considered in its previous inquiries.

Recommendation 2: *That the NSW Government review the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) as a matter of priority, with a view to:*

- *increasing the current reimbursement rates for accommodation and per kilometre travel*
- *expanding the eligibility criteria, with consideration given to people participating in medical trials, those that hold private health insurance and those that are referred to treatment centres that are not geographically closest to them due to the urgency of the treatment required*
- *streamlining the application process to make it easier for patients to access the scheme*
- *undertaking on an ongoing basis a public awareness program of the scheme across the state in communities and among health professionals who can then inform patients.*

Progress since recommendation

Our care coordinators at COBL who support rural people with cancer have commented that they believe the changes to the provision and delivery of IPTAAS has been positive. They have observed

¹⁰ NSW Rural Health Plan: Towards 2021 Final Progress Review. 2022. NSW Ministry of Health, Sydney. Accessed 22 October 2024. Available from: <https://www.health.nsw.gov.au/regional/Publications/final-progress-review.pdf>

¹¹ NSW Regional Health Strategic Plan 2022-2032. 2023. NSW Ministry of Health, Sydney. Accessed 22 October 2024. Available from: <https://www.health.nsw.gov.au/regional/Publications/regional-health-strategic-plan.pdf>

that the majority of individuals receive adequate assistance and financial reimbursement for the travel they need to undertake. Older people are noted to require additional support from care coordinators to navigate the scheme.

The expansion of IPTAAS to cover travel and accommodation to attend appointments for non-commercial clinical trials has also been welcomed. Evaluation of similar travel schemes covering clinical trials have shown support for these schemes to address inequities in clinical trial participation and outcomes for rural people with cancer.¹²

Recommendations for continued work

- NSW Health and Cancer Institute NSW continue to engage regularly with stakeholders and rural people living with cancer to better understand unmet needs and support needed to appropriately access IPTAAS and financial counselling.
- NSW Health and Cancer Institute NSW continue to conduct regular reviews of IPTAAS and publish reports detailing the uptake of clinical trials by rural people with cancer.

Recommendation 30: That NSW Health:

- *commit to providing continuity of quality care with the aim of a regular on-site doctor in rural, regional and remote communities*
- *commit to a model of care under which virtual care technology is used to supplement, rather than replace, face-to-face services*
- *where virtual models of medical care are operating, roster additional suitably trained nursing staff to assist in the provision of the physical care usually attended to by the medical officer*
- *provide staff members with training on how to effectively use telehealth and other virtual models of care*
- *create a public information campaign specifically targeted to rural, regional and remote communities in order to assist patients to effectively engage with virtual care, including factsheets and checklists to set expectations and support positive interactions*
- *ensure that the use of virtual care, if required, is undertaken in consultation with community members, health providers and local governments in rural, regional and remote areas*
- *investigate telehealth cancer care models to improve access to cancer treatment and care including the Australasian Tele-trial model to boost clinical trial participation in regional areas.*

Progress since recommendation

Rural patients should not miss out on clinical trial opportunities, and telehealth has revolutionised rural people's participation in trials. The incorporation of telehealth cancer care models has been a success over the last decade. A typical workflow for a metropolitan medical oncologist offering participation in a clinical trial to rural people with cancer is provided in Box 2.

Box 2: Typical workflow for rural patients who are referred to a medical oncologist for a clinical trial (provided by Associate Professor Jenny Lee, Medical Oncologist at COBL)

1. The treating medical oncologist in a rural area will reach out to the metropolitan oncologist for clinical trial options.
2. If we have trial available, the treating oncologist will send a referral.
3. The first consultation will be telehealth [with videoconferencing] – it cannot be a telephone consultation as it is not possible to assess issues like frailty over the phone. During this consultation, I will perform pre-screening and gauge the level of commitment from the patient.

¹² Luiten-Apirana *et al.* The Clinical Trials Assistance Pilot: reducing the financial burden of cancer clinical trials for patients in regional New South Wales. *Aust Health Review* 2023 Oct;47(5):607-613 doi: 10.1071/AH22249.

4. If the patient is eligible for a trial, committed, and willing to participate, I will email a consent form to the patient and follow-up in person within the next week to i) sign consent and ii) start screening (including any necessary scans, procedures and blood tests).
5. If the patient is eligible and interested, but we do not have any appropriate trials, I will reach out to my colleagues in Sydney who treat the same cancer and find an alternative trial for them. Since I have performed the pre-screening already, the next steps will be much more efficient for everyone.

In cases where patients are not familiar with telehealth or computers/smartphones, the local cancer centre and the oncology nurse will set up a clinic room for the patient and help navigate the system. This works particularly well, as clinical trials can sometimes be complex and overwhelming, and they will have an extra layer of support. Once a patient is on trial, telehealth is invaluable for:

1. Trial activities that may not require a patient to be present in person, especially once the patient is in follow-up or in the active surveillance phase of the trial.
2. Toxicity management and follow-up, in which there is a shared care model with the local oncologist, allowing the medical oncologist to touch base with the patients more regularly during toxicity management because it saves patients travelling 4-8 hours once per week.
3. Facilitating more outpatient management, which is always preferred and has the added bonus of cost savings.

Telehealth clearly adds to more positive patient experiences. Patients are often reluctant to travel long distances and especially into Sydney for an 'unknown'. Without telehealth for trials, it would not be uncommon to have patients travelling 8 hours to be told there are no appropriate trials or that they are ineligible for a trial.

In addition, for rare and uncommon cancers such as head and neck cancers, clinical trial sponsors (i.e., pharmaceutical companies) are reluctant to set up a trial site at rural NSW hospitals because of the infrastructure required to ensure optimal delivery of the trial. Hence, telehealth facilitates communication between rural hospitals and metropolitan hospitals (where the clinical trial sites are more likely to be set up) and therefore allows rural people with cancer to access the trial.

Recommendations for continued work

- NSW Health and Cancer Institute NSW continue to engage with key stakeholders (people with cancer, rural and metropolitan cancer centres, and clinical trial sponsors) throughout its environmental scan and feasibility assessment of Decentralised Clinical Trials (DCTs).

Conclusion

There are many opportunities for NSW Health and the Australian Government to continue to work toward addressing the inequities in health outcomes for people in rural NSW, particularly for those with cancer. Many people with cancer in rural areas will at some point need to travel to metropolitan areas for assessment, treatment, or follow-up care.

There are existing models of care to provide specialised cancer care to people in rural areas, but currently these are entirely funded through goodwill and philanthropy. This funding model is not sustainable in the long-term, which means that without investment by NSW Health and the Australian Government, at some point it is likely that these services, particularly outreach clinics, will cease and rural people with cancer will be again left without access to oncology specialists locally.

These models are highly valued by patients and healthcare providers and could easily be adopted by NSW Health in partnership with metropolitan cancer centres. We hope that NSW Health and the Australian Government continue to investigate new models of delivering specialist cancer care for rural people and invest in the health of rural NSW.