New South Wales

Special Commission of Inquiry into Healthcare Funding

Submission Number: 106

Name: Cancer Voices NSW

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The Special Commission of Inquiry into Healthcare Funding

Submission from Cancer Voices NSW

Introduction

Cancer Voices NSW is pleased that the NSW Government, as one of its election commitments, has established the Special Commission of Inquiry into Healthcare Funding ('the Inquiry'). The Inquiry will provide information that can be used by government, and across the NSW health system, to further improve the provision of healthcare services across New South Wales.

In that regard, Cancer Voices NSW (CVN) notes two recent inquiries that were conducted by the NSW Legislative Council that, taken together, cover a significant number of the areas being considered by the Inquiry.

CVN recommends that the Inquiry investigate how the recommendations from both inquiries had been, and are now being, implemented by the government of the day and report on the impact of this implementation in its final report:

- *Current and future provision of health services in the South-West Sydney Growth Region (2020)*
- *Health outcomes and access to health and hospital services in rural, regional and remote New South Wales (2022)*

The benefit of the 2022 inquiry is that people provided an accurate picture of the prevailing conditions in the provision of healthcare services to those in rural, regional and remote locations, notwithstanding that this was largely what was already known. The National Rural Health Alliance (NRHA) in its 2023 report provides both a very telling picture statistically and clear indications of what is required to address inequity and inequality in the health outcomes of the NSW population.

Cancer Voices NSW urges the Commission to assess and report on the current state of the implementation of the recommendations from the 2020 and 2022 reports as they apply across the broader NSW health system, and specifically on the following recommendations:

2020 inquiry report:

- That NSW Health immediately review its funding methodology for Local Health Districts to ensure fairer allocation of resources to growth areas like South-West Sydney. The funding methodology should ensure health funding keeps pace with population growth and accounts for higher health risk profiles (#2)
- That NSW Health develop and implement a real time system of health data reporting across Local Health Districts that is transparent and includes, but is not limited to: capacity reporting, occupancy rates for acute inpatient beds, staff numbers and wait times for patients needing to access outpatient care (#3)
- That NSW Health review the relationship between primary and secondary/tertiary health care with a view to improving integration and supporting the role of primary health care providers to reduce pressure on the local hospital network (#5).

2022 inquiry report:

- the adoption of the nurse practitioner model of care throughout the state (#17)
- more geriatric nurses to ensure the ageing population is provided with the best care when visiting a health care facility (#18)
- strategies to ensure that public patients being treated in regional cancer centres can access private-public services while reducing out-of-pocket costs (#21)
- the lack of adequate palliative care services in rural, regional and remote NSW (#23)
- the funding and support required to deliver against the next Rural Health Plan (#38)
- genuine community consultation on local health and hospital service outcomes and health service planning (#42)
- the development of place-based health needs assessments and local health plans (#43).

Workforce and costs

It was perhaps coincidental that, around the time of the announcement of the Inquiry, there was considerable media interest in the soaring costs associated with third parties who place locums and temporary staff in healthcare facilities. NSW Health should, in its commitment to improved health outcomes for the NSW population, address this issue in a strategic way, including stronger governance arrangements so that money spent on such placements will be instead expended on other aspects relating to the health workforce that are, in the longer term, more beneficial to everyone and the health system overall. (*National Rural Health Alliance. Evidence base for additional investment in rural health in Australia. 23 June 2023 website*)

Who is Cancer Voices NSW?

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW and beyond. In the twenty-three years since our formation in 2000, Cancer Voices NSW has been influential in improving cancer care, information, support and the direction of cancer-related research in NSW.

Our members include people with cancer and cancer survivors, carers, cancer care professionals and interested organisations. As an active network, Cancer Voices NSW provides a forum for those affected by cancer to share their concerns, ideas and experiences. Our representatives offer broad, informed views on cancer issues at local, state and national levels – wherever decisions about us are made.

We are all volunteers of varying backgrounds and ages. Most of us have experienced one of the many different forms of cancer and its treatments. We are also people who want to make a positive difference to the cancer experiences of others.

Our website can be accessed here: https://www.cancervoices.org.au

What organisations do we work with?

Cancer Voices NSW has had long-term relationships with a number of important organisations in the NSW health and cancer environments:

- **Health Consumers NSW**: CVN was instrumental in the establishment of HCNSW in 2010, and continues to work closely with the peak health consumer organisation in the state. Historically, a CVN member (generally an Executive Committee member) has been nominated for HCNSW Board membership, which was continued at the recent HCNSW Annual General Meeting.. In addition, CVN is represented on the HCNSW Consumer Organisations' and Consumer Leaders' taskforces, and two

member of the CVN Executive Committee are engaged by HCNSW for the presentation of its consumer and community involvement training program.

- **Cancer Institute NSW**: Since 2003, NSW has been in the unique position of having a centralised body responsible for the delivery of cancer services to the people of NSW. CVN has been involved with the Institute since it began, including contributing to all five NSW cancer plans. The current plan is testament to the power of the collective. It reflects the engagement of many individuals, organisations, services and agencies partnering and collaborating to develop and then deliver on this plan which has people affected by cancer and equity always at the forefront. CVN is proud of its continuing involvement in this.

  CVN had representation on the NSW Cancer Plan Governance Committee during the development of the latest plan and is now a member of the NSW Cancer Plan Advisory Committee responsible for the ongoing implementation of the plan.

  In addition, members of the CVN Executive Committee meet regularly with CINSW staff to consider the Institute's *Reporting for Better Cancer Outcomes* (RBCO), emerging issues, for information exchange, and the provision of advice on how to most effectively engage consumers in the Institute's cancer research programs.

- **Cancer Council NSW**: CCNSW, the state's leading cancer charity with 95% community funding, provides vital services to the NSW population, including in information and support across a wide range of areas, and in public health policy and promotion.

  CVN has partnered with CCNSW in various areas including the training of cancer consumers, first in advocacy and since 2005 in the training of consumers to ensure research is undertaken with meaningful consumer involvement and that the framework for central and strategic engagement is strong. CVN was involved with the development of the CCNSW Consumer Research Panel criteria and CVN members have regularly participated on this grants funding applications assessment and selection panel.

  The Daffodil Centre, the CCNSW and Sydney University joint venture that is a leading centre on cancer control and policy, is a major funder of world class research, working to reduce the impact of cancer through prevention, early detection, treatment and care which ultimately improves outcomes for those affected by cancer.

  CVN is currently providing its expertise and advice to CCNSW in relation to the role of consumers the activities of The Daffodil Centre.

Cancer Voices NSW is aware that all three organisations have made submissions to the Inquiry.

Our submission

While necessarily cancer-specific, our submission addresses issues that are relevant at the systemic level of the provision of healthcare services in NSW, with our comments relevant across a range of illnesses, syndromes and disease types.

The Cancer Voices NSW submission addresses a number of the Inquiry's terms of reference:

- **Term of Reference A**: The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future
- **Term of Reference B ii**: the engagement and involvement of local communities in health service development and delivery
- **Term of Reference B iii**: how governance structure can support a sustainable workforce and delivery of high quality, timely, equitable and accessible patient-centred care to improve the health of the NSW population
- **Term of Reference C**: The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW
- **Term of Reference F**: The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services, including
    - i: the distribution of health workers in NSW
    - ii: an examination of existing skills shortages
    - vi: the skill mix, distribution and scope of practice of the health workforce
    - ix: opportunities for an expanded scope of practice for paramedics, community and allied health workers, nurses and/or midwives
- **Term of Reference G**: Current education and training programs for specialist clinicians and their sustainability to meet future needs, including:
    - iii: how colleges support and respond to escalating community demand for services
    - v: how barriers to workforce expansion can be addressed to increase the supply, accessibility and affordability of specialist clinical services in healthcare workers in NSW
- **Term of Reference H**: New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation.

***Term of Reference A**: The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future*

Government investment in the funding of healthcare services across the State represents the single largest component of the annual NSW budget. As such, and given the impact of this spending on the health and wellbeing of the NSW population, funding levels must continue to be:

- adequate
- targeted
- high quality
- timely
- accessible and equitable, and
- patient and consumer influenced.

CVN acknowledges the significant expenditure by the previous state government on health infrastructure, including for new and refurbished hospitals, and the establishment of the Western Cancer Centre in Dubbo which opened in 2021. Further, infrastructure investment has also included mobile service provision, tele- and virtual health, and fly in/fly out arrangements.

Given that investment in health care infrastructure and services leads to improved health outcomes in rural, regional and remote locations, which in turn has economic benefits that extend beyond health, future investment in healthcare services must ensure that all facilities and services are appropriately and adequately staffed by trained and experienced clinicians (including doctors, specialists, nurses and midwives, and allied health practitioners) along with support staff such as administrators, cleaners and volunteers who are central to the operation of health infrastructure and service provision.

This is particularly relevant to the rural, regional and remote (RRR) parts of the state. The National Rural Health Alliance (NRHA) in its 2023 report *Evidence base for additional investment in rural health in Australia* indicates that:

> *"rural Australians have a poorer health status, and even before accounting for the increased cost of health service, receive significantly less funding per capita than their urban counterparts"* (p2)

The health-spend shortfall on rural citizens was calculated at $848.02 per capita, per year (p6):

> *"Comparison of disability adjusted life-year data from 2018 by Remoteness Area demonstrates that the burden of disease in remote areas is 1.4x that of Major Cities. Life expectancy declines for both men and women with increasing rurality, with a four and five year drop in life expectancy between Major Cities and Remote and Very Remote settings for men and women respectively."* (p21)

Furthermore, the prevalence of people living with two or more chronic conditions is higher in regional areas compared with major cities, despite lower service availability (p22):

> *"equivalent spending in monetary values between rural and urban areas does not necessarily translate into equal health outcomes"* (p29)
>
> *"rural health is subject to a triple disadvantage, and targeted investment is needed to address it"* (p29)

This triple disadvantage consists of

1. Poor service availability
2. Poor social determinants of health
3. Higher cost of access and delivery.

Inequity of access can be even more pronounced for allied health services. Of particular concern to many people who survive cancer treatment is access to lymphoedema management, usually provided by specially trained physiotherapist, and lymphatic drainage therapists. The very low FTE figures for these professions in regional and rural areas is shown in Table 19 (Appendix a) of the NRHA report.

NSW Health must continue, and continuously, work to address issues associated with current models of care that are not conducive to workforce recruitment and retention which are vital to the provision of stable and long term healthcare services.

Access to the Isolated Patients Travel and Accommodation Scheme (IPTAAS)

While it is pleasing that patients choosing to make use of voluntary assisted dying arrangement in NSW will be able to claim financial support for travel and accommodation costs associated with clinical consultations connected with the VAD approval process (with the simplification of the process for claiming eligibility being put in place), it remains an issue that the IPTAAS claims process continues to be complicated and time-consuming. Any isolated patient in NSW needing to make a claim on IPTAAS during their treatment, for whatever illness or disease, should not be burdened with unnecessarily complicated paperwork.

NSW Health should, as a priority, review IPTAAS arrangements to put in place more equitable access, for example removing the current limit of needing to have travelled 100km in order to claim with a sliding scale based on location for travel undertaken, and by a simplification of the claims and reimbursement process. NSW Health has the capacity to adopt financial innovations that will make the IPTAAS process more straightforward and navigable. Co-design of a streamlined IPTAAS process and application form is recommended.

Voluntary Assisted Dying

With the imminent commencement of voluntary assisted dying (VAD) arrangements in NSW (from 28 November 2023), the NSW Government must ensure continued funding for the provision of palliative and end-of-life care services and expertise, with VAD being seen to be, and practised as, simply another treatment option that patients can choose in managing their end of life.

Education of the NSW population is required to ensure a better understanding that palliative care is about maximising quality of life and is therefore different to end-of-life care. Access to palliative care in regional areas needs to be improved to reduce the current inequity in service provision and health outcomes.

***Term of Reference B ii**: the engagement and involvement of local communities in health service development and delivery*

The current structure of NSW Health, with its fifteen local health districts (six in metropolitan Sydney and nine in rural and regional areas) means that most of the NSW population is grouped into areas where health and well-being issues are likely to be similar. However, disparities in access to healthcare services exist between those in urbanised (including the larger regional towns such as Wagga Wagga, Tamworth and the Port Macquarie area) and those who live in smaller communities and isolated locations such as farms.

It is vital therefore that members of local communities, both urban and non-urban, are engaged and involved in health service development and delivery. Such involvement needs to use the principles of co-design, which 'involves bringing health practitioners, consumers and carers together with equal respect,

combining their knowledge with the shared aim of improving health services where consumers are [not] seen as passive recipients' (*Metro-Regional Intellectual Disability Network (MRID) website*).

CVN supports the NSW Agency of Clinical Innovation (ACI) approach to co-design which:

> .... goes beyond the more traditional partnering methods [and] enables consumers to become equal partners in the improvement process for health services. This means improvements reflect their needs and preferences; not just those of people working within the health system.
>
> The application of co-design methods requires investment in skills, attitudes and behaviour change, at individual and organisational levels, to shift power dynamics and drive real change.
>
> (*NSW Government. Agency for Clinical Innovation website*)

Pleasingly, the NSW *Future Health: guiding the next decade of healthcare in NSW 2022-2032* strategy places patients and consumers at its centre. *Future Health* has been shaped by wide consultation to gather the insights of staff, health partners, and patients and the community to help 'shape our ambitious 10-year plan to deliver a vision for a sustainable health system that delivers outcomes that matter most to patients and the community'. (*NSW Government. NSW Health. Future Health website).*

The associated NSW Health initiatives *All of us* and *Elevating the Human Experience* provide practical guidance and examples of how genuine patient and consumer involvement can be most effectively developed, implemented, monitored, and evaluated.

CVN supports the strong and diverse involvement of consumers through collaboration and partnering aross all facets of cancer care and services delivered in the state. Crucially, this is underpinned by the comprehensive collection and reporting of data that is easy to access, navigate and filter to ensure gaps in care and services can be identified and addressed including Patient Reported Outcomes (PROs) and Patient Reported Outcome Measures (PROMs). The CINSW, CCNSW and CVN are three of many collaborating partners in this process.

See also our discussion of the importance of the remuneration and reimbursement of patients and consumers involved in local health service development and delivery in Term of Reference B iii.

Term of Reference B iii*: how governance structures can support efficient implementation of state-wide reform programs and a balance of system and local level needs and priorities, and*

B v*: how governance structure can support a sustainable workforce and delivery of high quality, timely, equitable and accessible patient-centred care to improve the health of the NSW population*

The current *NSW Cancer Plan 2022-2027* ('the Plan') the fifth such plan, provides 'a whole-of-sector perspective on cancer control and describes how the Cancer Institute NSW's key stakeholders across the state, including NSW Health, will work together to deliver better outcomes' for people affected by cancer (*NSW Government. Cancer Institute NSW. The NSW Cancer Plan website*).

Cancer Voices NSW has been fortunate in its long-term and ongoing relationship with CINSW, including our contributions to all five plans. The current plan's goals to:

1. Reduce inequity in cancer outcomes
2. Reduce the incidence of cancer
3. Increase cancer survival
4. Enhance quality of life and experience for people at risk of and affected by cancer

and its overriding principles of: Equity of outcomes; Person-centredness; and Collaboration, and priorities of:

1. Prevention of cancers
2. Screening and early detection of cancers

3. Optimal cancer treatment, care and support, and
4. Cancer research

have established a solid foundation for the governance structures necessary to help ensure that the cancer ecology in NSW achieves a balance between system and local needs and priorities, and supports a sustainable cancer workforce that delivers high quality, timely, equitable and accessible patient-centred cancer care to improve the health of the NSW population.

In particular, the Plan's system enablers of engaged and well-supported staff, innovation and digital advances informing service delivery, and sustainable management of the cancer system are central to the success of the Plan's implementation as described in the *NSW Cancer Plan Implementation Plan 2022-2023*.

CVN looks forward to contributing to the assessment of the current and subsequent implementation plans, particularly in relation to the current implementation plan's targeted outcomes of the:

- achievement of equitable cancer outcomes for all NSW residents
- reduction of the risk of preventable cancers for people in NSW
- increase in the one- and five-year survival of NSW residents with cancer
- increase in the collection and use of people's reported experience and outcomes to improve care and services.

CVN has as one of its advocacy areas the importance of cancer coordination and navigation services that must be provided to all people living with cancer, not just those fortunate enough to have been diagnosed with a cancer, such as breast and prostate. These cancer types, in addition to standard care provided in the public health system also benefit from third party care provision, such as the breast care nurses from the McGrath Foundation and prostate care nurses who are funded in local health districts by the Prostate Cancer Foundation of Australia.

CVN is contributed to the co-design by Cancer Council Australia of its National Cancer Care Policy, which includes a chapter on navigation in cancer care.

CVN strongly believes that people with cancers that are less common or that are designated as rare cancers, and cancer patients from rural and remote areas, require substantially increased support than they currently receive. The separation of people undergoing treatment for cancer from their family and carers during the Covid pandemic, and at all other times as a result of the travel required to access treatment, highlights the reality faced by many rural and regional families. It does not represent good patient-centred care. No-one should be forced to go through cancer alone.

NSW Health must not just 'acknowledge the important role of family and community in the care of cancer patients' *(NSW Cancer Plan 2022-2027, p15)*, but provide funding to ensure clinicians have the time to develop appropriate and workable partnerships for treatment, including with providers of local health services such as general practitioners and family members and carers. This is essential for good patient-centred care. Doing so will help ensure that NSW Health's approach to patient care is consistent with the *Australian Charter of Health Rights* which includes the right to 'include people that I want in planning and decision making'. (*Australian Commission on Safety and Quality in Health Care. Australian Charter of Healthcare Rights website*)

Remuneration and reimbursement of health consumers

Health Consumers NSW, the state's peak health consumer organisation, has led the way in recognising the need for health consumers, across a wide range of activities, to be appropriately remunerated and reimbursed for their often considerable commitment of time and resources to working with the NSW health system in the improvement of patient outcomes.

HCNSW recommends that 'consumers invited to engage with health services, research institutions, or other health entities should be remunerated for their contribution and reimbursed for expenses. At the very least

consumers should not be out of pocket for their involvement'. (*Health Consumers NSW. Remuneration and reimbursement of health consumers website*)

Further, HCNSW recommends that consumers be reimbursed for any costs related to their engagement such as:

- parking
- travel expenses
- printing costs
- childcare
- respite care.

Remuneration and reimbursement can also be seen as a way of increasing diversity in consumer representation from across all communities. In acknowledging that some health consumers are also in full- or part-time employment and may not be able to afford time away from work, as well as those in low-waged circumstances as a result of their youth or age, gender, and/or culturally and linguistically diverse (CALD) affiliations, adequate and consistent remuneration is likely to lead to a larger and more diverse health consumer 'community'.

It is pleasing therefore that, subsequent to the development and promulgation of the HCNSW approach to consumer remuneration and reimbursement, in April 2023 NSW Health adopted a guideline for *Consumer, carer and community member remuneration* ('the Guideline').

The Guideline indicates that 'NSW Health places a strong emphasis on listening to and collaborating with consumers, carers and community members to improve the quality and safety of the health system [with the Guideline} setting out NSW Health's commitment to remuneration and reimbursement of consumers, carers and community members for their time and contributions to agreed engagement activities. It provides clear and equitable guidance about the circumstances where payments will be made, the rates of payment and the methods of payment. (*NSW Government. NSW Health. Remuneration factsheet for consumers, carers and family members website*)

However, CVN is aware that there is a disparity between local health districts as to how the Guideline is being implemented, particularly in relation to the inclusion of remuneration and reimbursement costs in annual LHD budgets. This lack of equity must be addressed by NSW Health so that health consumers, no matter where they live in NSW, are appropriately recognised, through payment, for their contributions to the planning and operation of healthcare services and thus the overall improvement of the health outcomes of the entire NSW population.

NSW Health should therefore consider upgrading the Guideline to the status of a Policy Directive.

***Term of Reference C**: The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW*

The allocation of resources by NSW Health to support access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW must be seen to be consistent with the ten-year *National Preventive Health Strategy 2021-2030* ('the Strategy'). It is pleasing that the current federal government has committed to the continuation of the strategy that was developed during the term of the previous federal government, and to levels of funding necessary for its successful and equitable implementation.

This commitment must be mirrored by NSW Health in relation to preventive health strategies and programs given that, in relation to health and wellbeing generally 'prevention is better than cure', and a healthy society is a healthy economy. Extensive research both in Australia and overseas clearly demonstrates that,

in relation to cancer, there are recognised health behaviours such as use of tobacco (including vaping products, levels of alcohol consumption, and sun exposure that are direct contributors to a range of cancer types. Preventive health strategies that result in a change of behaviour should, over time, contribute to a reduction in the need for funding of cancer services across the state.

***Term of Reference F**: The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services, including:*
***Term of Reference F i**: the distribution of health workers in NSW*
***Term of Reference Fii**: an examination of existing skills shortages*
***Term of Reference F vi**: : the skill mix, distribution and scope of practice of the health workforce, and*
***Term of Reference F ix**: opportunities for an expanded scope of practice for paramedics, community and allied health workers, nurses and/or midwives*

The current and future distribution of healthcare workers throughout NSW is fundamental to the accessibility, quality and value of healthcare services to the NSW population. However, the reality is that there are complex, diverse and diffuse expectations of the NSW population as to the delivery of their healthcare services.

There is a wide range of issues that NSW Health needs to factor into its budgeting for, recruitment to, and management of its workforce. These include:

- *changes in the nature of general practice*: the concept of the 'family doctor' of the past is now much less common than it once was. The attractiveness of general practice as a career-long profession has shifted in recent decades to a position where many young doctors see it as a first step on the way to a more satisfying and lucrative specialist career.

  Further, the establishment and operation of large 'GP clinics' has meant that it is less likely that a patient will see the same doctor from one visit to the next. This has important ramifications for the ways in which a patient's health issues are monitored, particularly in relation to the identification and response by a GP to their patient's development of a particular disease or syndrome, for example with the use of the Prostate Specific Antigen (PSA) blood test on a regular basis to monitor the presence of prostate cancer.

  Combined with shortages of GPs in non-urban areas, and past difficulties in attracting young doctors to locations that are considered to be 'less desirable' than others means that the overall health and wellbeing monitoring of the NSW population is likely to be less effective than it once was. Delays in the identification, a missed diagnosis and ineffective treatment coordination of a patient by their GP jeopardises the chances of the patient recovering from their disease, with subsequent impacts on the costs of the operation of the NSW health system. This is particularly the case in relation to almost all cancer types.

- *the 'training pipeline*: the locally-provided training of medical practitioners including doctors, nurses and allied health practitioners is a costly and lengthy process. It is pleasing that there are now more tertiary institutions that provide medical training (such as at the University of Newcastle itself and its recently-established joint venture with the Central Coast LHD of the Central Coast Research Institute for Integrated Care (CCRi) that undertakes translational research into the development and implementation of new models of integrated care to support the adoption of integrated care in policy and practice in order to bring tangible benefits to the health and wellbeing of the local community and beyond (*adapted from the CCRI website).* However, NSW Health should look at expanding training opportunities for all health practitioners, including for example recognition of prior learning and

experience for the 'fast tracking' of people with an interest in, and commitment to, a career in medicine.

- *the establishment of Medicare Urgent Care Clinics (UCCs)*: the imminent commencement of fourteen federal government-funded Medicare UCCs across NSW is intended to free up accident and emergency staff to focus on more critical presentations than at present, given that in many public hospitals over half of A&E presentations are for non-urgent or semi-urgent care. (*Emma McBride MP. Member for Dobell. Letter to constituents*)

  NSW Health and the federal Department of Health and Aged Care now need to work in lock step to ensure that members of the community are aware of the existence and nature of UCCs, that confusion is minimised as to where a person should go for treatment, and that the effectiveness and efficiency of UCCs is monitored and evaluated over time to ensure that the freeing up of A&E facilities and expertise actually takes place, and that the investment in Medicare UCCs is justified by improved health and wellbeing outcomes.

- *the role and operation of multi-disciplinary community health services*: for many people in rural, regional and remote locations, particularly First Nations people, the availability, and accessibility, of multi-disciplinary community health services can be literally life saving. However, it was recently announced that Rex Airlines had suspended flight services into some regional centres such as Dubbo, Armidale and Port Macquarie. This is of concern in terms of clinician services for those communities.

  As a successful model of care and service provision, NSW Health should look at expanding the number and geographic spread of such facilities across NSW. Opportunities exist to:

  - maximise the use of tele-and digital health, and
  - address access issues and increase the availability in the facilities of the full range of clinicians who can provide enhanced services, for example on a 'fly in, fly out' basis

***Term of Reference G**: Current education and training programs for specialist clinicians and their sustainability to meet future needs, including*:

***Term of Reference G iii**: how colleges support and respond to escalating community demand for services,* and

***Term of Reference G v**: how barriers to workforce expansion can be addressed to increase the supply, accessibility and affordability of specialist clinical services in healthcare workers in NSW*

Term of reference G

Universities and tertiary training institutions

As the most important providers of tertiary education and training for the range of clinicians, the education and training programs of universities and other institutions must keep pace with new and emerging developments and technologies. Traditionally, doctors have been trained to diagnose and treat and receive a fee for service under Medicare. To be most effective, and to have real impact on improving the health of the NSW population, these programs need to take the prevention and management of co-morbidities as their primary focus.

General Practice

General Practitioners are the entry point and referral pathway to the wider health system and its services. In rural, regional and remote areas, access to a GP is complicated by:

- locations where there are no GPs and/or clinics have closed
- some GPs only work on a part-time basis, with some continuing to work well into their older years
- patients are often required to travel long distances to visit a GP
- GP access is, in a number of locations, only provided by the Royal Flying Doctor Service
- In some instances, GPs may not know who, or may not have somebody, to refer patients to once an issue has been identified.

Cancer Voices NSW is aware of a number of approaches and programs that aim to address GP and physician shortages, including:

- *Rural generalist pathways*: Rural generalists are GPs who provide primary care services, emergency medicine and have training in additional skills such as obstetrics, anaesthetics or mental health services. The National Rural Generalist Pathway recognises the extra requirements and skills of rural generalists and supports them to meet the diverse health needs of regional, rural and remote Australians. Rural generalists give these communities access to a broader range of specialist medical services than are otherwise available (*Australian Government. Department of Health and Aged Care. National Rural Generalist Pathway website*)

- *Regional, Rural and Remote Physician Strategy*: The Royal Australian College of Physicians (RACP) is currently developing an implementation strategy for its commitment to achieve 'equitable health outcomes for Australians … living in regional and rural locations by prioritising, advocating and supporting regional and rural workforce and training initiatives, [involving the facilitation of] collaboration between governments, employers and the College to increase the number of high

quality, well-resourced and attractive accredited training settings and training positions in regional and rural locations so that trainees competitively seek, and consider remaining in, these settings following the completion of their training.'

- *The More Doctors for Rural Australia Program (MDRAP)*: the program's goals are to increase the number of vocationally recognised doctors and improve access to health care for Australians living in rural and regional areas under the federal *Stronger Rural Health Strategy*, and allows doctors with placements working in rural areas to access items from the Medical Benefits Schedule. *(Australian Government. Department of Health and Aged Care. More Doctors for Rural Australia Program website*)

  CVN is also aware that formal recognition of rural generalists as a specialty area of clinical practice has recently progressed (October 2023) to the second stage of the consideration of the application from the Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM) for specialty recognition by the Australian Medical Council. (*NewsGP website. 'Formal recognition of rural generalists one step closer' article. 17 October 2023)*

- RPA [Royal Prince Alfred] Virtual, which was developed during the Covid pandemic by the Sydney Local Health District, has provided a successful model to complement more traditional 'bricks and mortar' environments for healthcare service provision.

Term of Reference G iii

Cancer Voices NSW is aware of the lengthy and detailed process for achieving recognition of new areas of medical specialisation in Australia. Currently, the Royal Australian and New Zealand College of Radiologists (RANZCR) is seeking specialty recognition for interventional radiologists (IRs) and interventional neuroradiologists (INRs). These highly-skilled and intensively-trained specialists provide healthcare services based on the performance of image-guided (such as an MRI) procedures to carry out minimally-invasive and, in many cases, life-saving surgery. Patients treated by IRs include those with some cancer types such as breast and prostate, and by INRs include those who have had a severe stroke, or who have head, neck and spinal tumours.

Interventional radiology and interventional neuroradiology are progressive and evolving specialties of clinical radiology. They are areas of modern medicine delivering precise, targeted treatment for complex diseases and conditions throughout the body. Interventional radiologists and interventional neuroradiologists provide high quality care and treatments that offer many benefits to patients, the health system and the broader community through shorter procedures, faster recovery times, fewer complications and often at a lower cost compared to some surgical and medical procedures. (*adapted from RANZCR. Our Work. Interventional Radiology and Interventional Neuroradiology website*)

However, IRs and INRs do not have recognition in Australia for their specialisations. Such recognition is obtained only after the process for the recognition of new specialties has been carried out. This involves the preparation of extensive paperwork, followed by the Medical Board of Australia considering the advice of the Australian Medical Council and other stakeholders (including other specialist colleges) in deciding whether to recommend that a new or amended specialty be approved by health ministers.

Health ministers will only consider a recommendation for specialty recognition after a public benefit has been demonstrated. Applicants must establish a need for government intervention (that is, regulation) in the interests of the public and that existing arrangements or other alternative non-regulatory options are unsatisfactory. The application process involves a robust regulatory assessment, with extensive stakeholder consultation. (*adapted from Australian Medical Council. Recognition of new medical specialties website*)

NSW Health, as the largest health system in Australia, could advocate at the national level to identify ways in which the complex and lengthy process for the achievement of specialty recognition could be streamlined and shortened as a means of increasing the numbers of clinicians who are trained and qualified to carry out new and emerging areas of clinical practice.

Term of Reference G v

One barrier that currently exists to the expansion of the NSW Health workforce to increase the supply, accessibility and affordability of specialist clinical services in NSW involves the recognition of 'overseas trained doctors'. CVN is aware of government initiatives to encourage such doctors to move to the state to provide their expertise to the NSW population.

If NSW Health is to continue, and expand, the recruitment of internationally-trained medical practitioners, it must take into account the work currently being carried out for the federal government by Robyn Kruk AO (a former director-general of NSW Health and head of the NSW public service) who is providing an *Independent review of overseas health practitioner regulatory settings*. The interim report from the review was provided to the federal government in April 2023, with the final report to have been provided in August this year.

For further discussion of issues raised by Term of Reference G, see our response to Term of Reference F

***Term of Reference H**: New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, change as to scope of practice, workforce innovation, and funding innovation*

There is a pressing need for NSW Health to continue to adopt new models of care and technical, clinical and financial innovations to continuously improve the health and wellbeing of the NSW population including, but not limited to the following:

- *Care navigation across an expanded range of illnesses and diseases*: the diagnosis of a life-limiting or life-threatening disease such as cancer is a traumatic and bewildering experience for most people. The experience of a diagnosis and associated treatment across a range of diseases and syndromes can be made easier with the support of 'care navigators' whose role is to guide a patient and their family through the complexities of the health system. Care navigators are essential in ensuring patients are assessed comprehensively, and that appropriate specialist and allied health care is provided in a timely manner, often early in the care pathway.

  Specialist nurses are a key single point of contact for patients and provide specialist assessment to facilitate access to specialist care. Specialist nurses provide ongoing contact and support for patients throughout the continuum of care, playing a vital coordination and communication role in the wider treatment team . They are often the primary referrer to supportive care. This support extends beyond diagnosis, treatment, and the clinical setting. Specialist cancer nurses provide evidence-based, disease specific, up-to-date information around diagnosis, treatment, symptom management, psychosocial needs and into survivorship.

  NSW is currently well served with specialist nurses for breast cancer and prostate cancer. However, there is a significant need for the same levels of support for other cancers, and for other diseases and syndromes. NSW Health should allocate funding for specialist nurses including ensuring that this funding is equitably allocated across the whole of the state.

- *Adoption of new and emerging technology to enhance patient care*: NSW Health has historically been at the forefront of the adoption of new and emerging technology that enhances patient care.

  NSW Health defines a health technology as an intervention that may be used to promote health, to prevent, diagnose or treat acute or chronic illness, or for rehabilitation. It may take the form of a medical device, procedure or process of clinical management which is substantially different from the alternative.

  NSW Health is committed to delivering outcomes and experiences that matter to patients and the community. Health technologies play an important role in driving value-based healthcare, which means continually striving to deliver care that improves health outcomes that matter to patients, experiences of receiving care, experiences of providing care, and the effectiveness and efficiency of care. (*NSW Government. NSW Health. New health technologies website*)

  Funding must be maintained at current levels to ensure that the NSW population continues to be well-served by the use of cutting-edge technologies in healthcare services. In that regard, the recent announcement by the NSW Government (*NSW Government. NSW Health. Consistent, timely and secure health information: NSW Government to deliver single digital patient record media release, 19 October 2023*) that work is underway on a new single digital patient record (SDPR) system to replace and consolidate the current nine systems used for electronic medical records, ten patient administration systems and five pathology laboratory information management systems into a single streamlined system bodes well for the future of patient care in New South Wales.

  The imminent commencement of the Bragg Centre for Proton Therapy and Research at the South Australian Health and Medical Research Institute (SAHMRI) in Adelaide has raised issues regarding the support for patients to attend treatment centres that are located interstate when that is deemed to be the most appropriate treatment.

  The Australian Bragg Centre for Proton Therapy and Research will be Australia's first proton therapy centre and the first of its kind in the Southern Hemisphere. Proton therapy is a precise, non-invasive radiotherapy that can destroy cancer cells while minimising damage to surrounding healthy tissue including vital organs. Installation of the proton therapy unit is underway. Once installed, there will be a period of testing and calibration before patient treatment begins in 2024. (*SAHMRI. Australian Bragg Centre for Proton Therapy and Research website*)

  Given the likelihood that future innovatory treatment modalities across a range of illnesses and diseases will be offered only in a limited number of locations, NSW Health should be working closely with the Bragg Centre to ensure the availability of, for example, suitable accommodation for patients and their families as a model for such future developments.

  NSW Health should also be working to expand the Isolated Patients Accommodation and Travel Scheme (IPTAAS) so that patients from NSW can access support when they are undergoing treatment at the Bragg Centre. Further, NSW Health could be advocating for the establishment of a national travel and accommodation scheme, or at least a nationally-consistent scheme in all states and territories given the need for patients to travel outside their home state or territory for treatment.

Conclusion

Publication of our submission

Cancer Voices NSW is aware that all submissions to the Inquiry will be treated as suitable for publication. CVN does not have concerns regarding the confidentiality of all or part of our submission.

Further topics of interest

CVN has noted that the Inquiry expects to identify further topics of interest as its work progresses. We look forward to this occurring and will provide further input to the Inquiry based on the relevance of these issues to our organisation.

Public hearings

CVN is aware that details of public hearings and their dates, and a directions protocol for those hearings, will be published shortly. We are interested in participating in the public hearings to further present to the commissioners on the most important elements of our submission, including in relation to:

- cross border issues for those locations in NSW that have a 'twin' location in an adjacent state (such as Albury-Wodonga, and Tweed Heads-Coolangatta) where innovatory approaches to healthcare services provision must be pursued, particularly to ensure that NSW residents are not disadvantaged as a result of their postcode

- the future needs of people who develop cancer that will include genomic analysis as a standard of care. This is currently only accessible through clinical trials, but NSW Health must start planning for the equitable provision of pan-tumour personalised medicine.

As CVN is made up of people who are all volunteers, it would be appreciated if our attendance at a public hearing could take place in 2024.

Contact:

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[redacted]

cancer voices nsw

Cancer Voices is the independent, volunteer voice of people affected by cancer - since 2000.