Cancer Council Queensland

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Committee Secretary
Health and Environment Committee
Parliament House
George Street
Brisbane Qld 4000

By email only: hec@parliament.qld.gov.au

Dear Committee,

Inquiry into the provision of primary, allied and private health care, aged care and NDIS care services and its impact on the Queensland public health system

We thank the Committee for the opportunity to provide this submission to the inquiry into the provision of primary, allied and private health care, aged care and National Disability Insurance Scheme (**NDIS**) care services and its impact on the Queensland public health system (the **inquiry**). We welcome this inquiry as an important opportunity to reflect on the pressures impacting Queensland's public health system and identify opportunities to improve equitable access to quality cancer care for all Queenslanders.

Cancer Council Queensland supports the positions outlined in the joint submission we have made to this inquiry in collaboration with eleven other health NGOs, which highlights the urgent need to ease pressure on the public health system by:

- increasing investment in preventive health;
- addressing health inequities; and
- committing to a coordinated, person-centred approach to healthcare.

In this submission, we would like to focus on opportunities to ease pressure on the public health system by:

1. Embedding the provision of optimal cancer care across the system; and
2. Addressing the financial burden of cancer

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1. Embed the provision of optimal cancer care across the system

Reducing the burden of cancer is a major challenge for healthcare systems worldwide, as we move from systems focused on acute episodic care to providing coordinated care for people with long term conditions.[1] A reorientation of our health system towards integrated management of chronic conditions is essential to ease pressure on the public health system. Strong primary healthcare that is proactive, rather than reactive, has been proven to provide better health outcomes at lower cost.[2] Increasing investment in prevention, reducing risk and addressing health inequities are both key priorities for achieving this goal, as highlighted in our joint submission to this inquiry with other health NGOs.[3]

To further address pressures being experienced by Queensland's public health system, we also need to manage the burden of cancer more appropriately by ensuring the principles of optimal cancer care are embedded throughout the health system. Elements of cancer care are delivered across the system including through primary and allied health care, aged care and NDIS services. The following principles of optimal cancer care must be embedded across all of these services:

- Patient centred care – healthcare that is respectful and receptive to a person's preferences, needs and values.
- Safe and quality care – healthcare provided by appropriately trained and credentialled clinicians, hospital and clinics with the equipment and staffing capacity to support safe and high-quality care.
- Multidisciplinary care – a collaborated and integrated approach to healthcare provided by medical, nursing and allied health professionals to develop an individualised treatment plan for each patient.
- Supportive care – meeting a wide range of physical, psychological, social, information and spiritual needs across the continuum of care.
- Care coordination – a comprehensive approach where healthcare is delivered in a logical, connected and timely manner to meet the medical and psychosocial needs of the person.
- Communication – ensuring the communication needs of a person receiving medical care, their families and carers are met.
- Participation in research and clinical trials – ensuring that, where practical, patients are offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway.

Unfortunately, Cancer Council Queensland frequently hears from people affected by cancer who have experienced sub-optimal cancer care in the health system due to lack of coordination across services, gaps in service delivery, poor communication or workforce capacity constraints. Many of these issues stem from the problems associated with services being provided by different organisations or funded by different levels of government, creating confusion and gaps in coordinated care. For example, we hear many stories from people about gaps in end-of-life cancer care, especially for older Queenslanders in Residential Aged Care Facilities or those who choose to die at home and therefore rely on a combination of primary and community care. Some examples of these stories are provided below:

> *"A family are caring for their loved one with cancer who is end-stage palliative (terminal). The GP made a referral to the community palliative care team, however a week or so later the family had not heard from the community palliative care service.*

> *They tried calling the service and left a message, but did not receive a return phone call. Now, their loved one is deteriorating but it is a weekend and after hours. They call CCQ wanting to know, who can help?"*
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> *"A health professional was on-call covering a shift in a Residential Aged Care Facility and called seeking medication management advice. One of the residents had deteriorated and had been placed on an end of life pathway. We referred her to PallConsult (24/7 support for Nurse Practitioners and GPs). She was unaware of the service".*
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> *"We receive numerous calls where no afterhours contact and plan of care has been provided to families (community situations) should their palliative loved one deteriorate. We find that domiciliary nursing agencies tend not to provide an after-hours support number anymore and families are floundering to know who they can contact after hours. And families are not being given or enquiring with their GP as to whether they provide after-hours palliative support in the community."*
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> *"Cancer Council Queensland has received calls where the carer and their loved one would be eligible for My Aged Care services but they either haven't been assessed for My Aged Care services; or they haven't known they can be re-assessed (for e.g. nursing, personal care hygiene etc) until they speak with us. These callers have loved ones often with advanced and complex health conditions".*
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> *"There have been calls where the person (caller) has been informed by their current community service provider that they can't get additional services as there is "no funding" to provide the services".*

While many of these problems are long-standing, gaps in the provision of coordinated care have become more prominent and more challenging for patients to navigate since COVID-19. At present, workforce challenges remain one of the most significant barriers to optimal cancer care. For example, there has been a large migration of nurses leaving community and residential aged care positions to deliver COVID-19 vaccinations for Queensland Health, which is causing a considerable negative impact on the ability of some community services and Residential Aged Care Facilities to meet resident needs.

We are also aware of significant workforce capacity constraints in allied health. For example, workforce capacity for psychology services is impacting mental health services across the state. Cancer Council Queensland provides psycho-oncology services to people affected by cancer; however, we have experienced challenges recruiting suitably qualified staff in the last 12 months. As a result, our cancer counselling service has temporarily ceased accepting new referrals with our next intake not for another 4 to 6 weeks. We are not unique in this situation, and we are aware it is now common for psychologists to cease accepting new referrals (either for a period or indefinitely). Prior to the COVID-19 pandemic, only one in 100 psychologists were unable to accept new patients, whereas it is now reported to be one in five. Psychologists who are still able to accept new referrals often have long wait times of up to 6 months. This has flow on impacts across the spectrum of care, including increasing pressure on existing services and the public health system. An example from our cancer counselling services is below:

> *"A health professional recently attempted to refer a private patient to a community mental health service. However, because the next available appointment was not until February 2022, they referred the patient to our cancer counselling service. The patient has long-standing mental health issues and needs to be provided support by a long-term mental health service. We are finding this is happening increasingly. We run a short-term psycho-oncology service, but we are being relied upon to support clients with long term mental health conditions due to the lack of services and capacity issues within the services that do exist".*

Our collective ability to address these issues and reduce the impact of cancer on Queenslanders is currently underpinned by a state-wide cancer care strategy which was developed in 2014.[4] However, cancer care has undergone unprecedented changes in the years since this strategy was developed, particularly in light of COVID-19. This has resulted in a situation where individual HHSs are being left to develop their own cancer care strategies to address these challenges, resulting in a potentially fragmented approach. We call for a state-wide commitment to embedding optimal cancer care across Queensland's health system – throughout primary and allied health, private health, aged care, disability services, community services and our public health system. Some examples of where this could be improved include:

- Ensuring timely access to quality data to inform research, service planning and decision making. As demonstrated throughout the COVID-19 pandemic, rapid reporting capability is an essential ingredient for effective public health control. Timely reporting by the Victorian Cancer Registry has been critical to inform health system planning and public health messaging for the Victorian community, which is vital given the pandemic's impact on cancer care.[5] A critical part of easing pressure of Queensland's public health system relies upon the access to quality data for research and service planning purposes.
- Removing barriers to patients participating in clinical trials. Participation in clinical trials is recommended as an important part of optimal cancer care for patients, both in terms of the personal benefit and the contribution it makes to the care of cancer patients in the future.[6] However, there are several barriers to supporting patients to participate in clinical trials in Queensland. For example, the eligibility criteria for the Patient Travel Subsidy Scheme excludes patients travelling for treatment as part of a clinical trial, and thereby impedes equitable access to optimal cancer care for regional and remote Queenslanders.

This month, we welcomed the Commonwealth Health Minister's proposed development of an Australian Cancer Plan, which will be developed over the next two years. To ensure effective outcomes for Queenslanders affected by cancer, it is essential that the Queensland Government also provides a coordinated vision for the delivery of quality cancer care that addresses the unique needs and challenges faced by Queensland communities.

In our view, there is an opportunity for Queensland Health to bring key stakeholders together to discuss the key issues relevant to Queenslanders affected by cancer to determine how the current strategy might be adapted to complement and support the implementation of an Australian Cancer Plan. This is necessary to ensure equitable access to optimal cancer care across the system which will in turn ease pressure on the public health system.

Recommendations

To embed the provision of optimal cancer care across the system, Cancer Council Queensland recommends:

- That Queensland Health coordinate across the system of state-wide cancer care to ensure the interests of Queenslanders affected by cancer are well represented in the development of the Australian Cancer Plan, including addressing the specific workforce challenges being experienced in allied health and nursing, particularly in regional and remote parts of the state.
- Following the development of the Australian Cancer Plan, Queensland Health work with stakeholders to develop a Queensland Cancer Strategy, and support HHSs to then develop local cancer care plans with primary and allied health services, community care organisations and consumers (patients, survivors, carers, families and loved ones). This process must include opportunities for addressing workforce challenges, improving timely data provision and ensuring all Queensland Health policies and programs meet the principles of optimal cancer care.

2. Address the financial burden of cancer

Reducing the financial burden of cancer is an important priority to ease pressure on Queensland's public health system. Many Queenslanders face high out-of-pocket costs associated with their healthcare, which can cause financial stress and lead to people to delay or avoid health services and much-needed treatment.[7] People with a long-term health condition were more likely than those without a long-term health condition to delay or avoid health services they needed due to cost.[8] This can contribute to poor patient outcomes, reduced survival and increased pressure on the health system. [9]

In 2016-17, 50% of patients nationally had out-of-pocket costs for non-hospital Medicare services.[10] This was more common in regional areas, with regional patients more likely to have out-of-pocket costs for non-hospital Medicare services (53%) than those in metropolitan areas (48%).[11] The financial stress caused by this varies across the community. Young people, low-income households and people living in regional and remote areas are at higher risk of experiencing financial burden.[12]

People in regional areas also experience higher costs associated with treatment due to the need to travel significant distances to access specialist cancer treatment and care. Even with costs being subsidised by the Patient Travel Subsidy Scheme, the high cost of travel creates significant out-of-pocket costs for regional cancer patients, in addition to their medical expenses. It also increases time away from family and work, which can also add to their financial pressures. These financial pressures can influence where a person with cancer chooses to be treated, and the type of treatment they receive, or removes choice altogether, both of which can impact health outcomes. Cancer Council Queensland is currently working with Queensland Health and researchers at Flinders University to examine patient usage as well as evaluate patient, health professional and administrator experiences with the PTSS.

According to a 2017 Cancer Council Queensland survey, *Financial burden of cancer treatment for patients,*[13] one in three cancer patients reported that out-of-pocket costs associated with a cancer diagnosis would deter them from seeking treatment. The majority of survey respondents (62%) were not fully aware of the out-of-pocket costs associated with a cancer diagnosis and treatment prior to accessing the service. For example:

> *"I am a self-funded retiree (who works a little part time) and after having FULL private health insurance for around 40 years, did NOT expect to be so far out-of-pocket for my radical prostatectomy.''*
>
> *"I was under the belief I would be covered for that sort of diagnosis. I feel cancer should be covered on all levels of health insurance. My insurance provider was not empathetic at all to my circumstances."*
>
> *"Gap between fees and rebate were extensive at times. Still spent several thousand dollars even though in private health insurance."*

Our survey also found that more than half (51%) of patients with private health insurance were unaware of the option to access cancer treatment in both the public and private system. Given the option, 17% of patients would have opted for public treatment, mainly to reduce financial burden. For example:

> *"If I'd known the surgeon would charge $3000 over scheduled fee, and I'd been advised I could see a surgeon through the public system asap I would definitely have gone through [the] public system."*
>
> *"I can't believe I pay over $6k per year for private health insurance and am still out-of-pocket."*

People who are recently diagnosed with cancer or have private health insurance report higher out-of-pocket costs.[14] Having private health insurance has consistently been found to be a predictor of higher out-of-pocket costs in Australia, with insured patients paying as much as double compared to the uninsured. Many find their private health insurance coverage inadequate at the time of treatment.[15] Patients with private health insurance often feel obliged to use their insurance or assume that private healthcare is their only option.[16]

According to feedback from our 13 11 20 service, it can be challenging for private health patients to ask their oncologist to be referred somewhere else if the cost becomes too great. The onus is on the patient to question the oncologist, do their own research and seek alternative options if they feel they are not coping financially, or if they wish to have other treatment options that not yet been offered (such as palliative care). Many people with cancer feel extremely connected to their oncologist and often fear leaving them and seeking someone new, even if they are starting to struggle financially. There is also stigma surrounding 'going to the public system' compared to the private health system. However, comparisons between public and private health pathways are highly variable; for example, allied health services, such as social work, physio, dietitian and occupational therapy are not always available in private hospitals whereas they are usually a given in the public system. Discharge planning nurses and good quality of discharge planning can also vary in the private system.

Recent research by the Breast Cancer Network Australia shows that high out-of-pocket costs are a major issue for breast cancer patients in the private system.[17] As a result, many cancer patients experience bill shock and financial hardship which causes significant distress and often leads patients to make decisions about their care that may have negative health and ongoing financial impacts.[18]

Cancer Council has partnered with Breast Cancer Network Australia, CanTeen and Prostate Cancer Foundation of Australia to develop a Standard for Informed Financial Consent as a key component of delivering quality care. The Standard guides health professionals and practices to discuss the risks and benefits of treatment including cost. It aims to assist health professionals and practices to be transparent about their fees, informing patients of other health professionals involved in their care, and discussing care options such as where the same or similar benefit can be provided at less cost, to enable patients to better consider the likely financial impact of cancer care. More information is available at www.cancer.org.au/health-professionals/resources/informed-financial-consent.

Despite these tools, we also know that for many Queenslanders, there is no level of out-of-pocket cost that is affordable for them. All Queenslanders should be afforded appropriate income support, so they do not fall below the poverty line if they are unable to work or to find work. Of the 40 per cent of people diagnosed with cancer who are of working age, 46 per cent are unable to work following their diagnosis, resulting in a reduction of $1.7 billion annually to Australia's Gross Domestic Product.[19] For example, our 2017 survey found that:

- Full time employment decreased from 36% at the time of diagnosis to just 8% during treatment. 12 months post-treatment, full-time employment remained low at 14%.
- 13% of retirees had to come out of retirement to manage costs associated with their cancer treatment, and 63% of students had to stop studying.
- Those who reported no income increased from 8% at diagnosis to 18% during treatment.

In the words of our survey respondents:

> *"Loss of one income over [a] long period of time has put significant financial pressure on the family.'"*
>
> *"I was more frightened of the bills than I was of the cancer".*

While Centrelink income supports are intended to offer a safety net for people who are unable to work, many people affected by cancer and their families experience challenges in engaging with Centrelink to access much-needed income support following their diagnosis. We often hear of people with cancer being assessed as ineligible to access the Disability Support Pension or being unable to have their JobSeeker activity requirements waived. This is unacceptable, particularly given people with cancer also face additional costs associated with their healthcare at this time. Examples from our 2017 survey include:

> *"I found Centrelink one of the most stressful components during my treatment. Despite being eligible for sickness benefits, Centrelink kept changing my payments to Newstart Allowance and then suspending them for failure to respond to interviews."*
>
> *"Centrelink mucked us around ... they would only give us support when the doctor wrote terminal on the Centrelink forms … which was sad and gave my husband no hope ... I find Centrelink a heartless organisation."*

Given the impact financial stress can have on people in terms of delaying or avoiding accessing to healthcare, ensuring adequate income support for people unable to work due to a cancer diagnosis must be an important priority for easing pressure on Queensland's public health system.

Recommendations

To address the financial burden of cancer, Cancer Council Queensland recommends:

- Reviewing Queensland Health policies and programs to address financial pressures stemming from a cancer diagnosis, including following through on previous commitments to provide parking concessions for frequent hospital visitor and committing to continuous improvement of the Patient Travel Subsidy Scheme.
- Supporting health professionals across the system to provide patients with information about out-of-pocket costs early in their treatment, and ensuring patients are providing informed financial consent and understand their treatment options.
- Advocating to the Commonwealth for improvements to the suitability of Centrelink programs, including processes and protocols, to support people out of work due to cancer. This must include options to improve the provision of Australian Government funded social security payments to people affected by cancer to ensure no Australian who is unable to work due to cancer falls below the poverty line.

We thank you for the opportunity to bring these issues to your attention and would be happy to provide further information to inform the inquiry to ensure the best possible outcomes in the interests of Queensland affected by cancer, their families and carers, and the wider community.

Yours sincerely

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