



Consumers Health  
Forum OF Australia

SUBMISSION

# A vision for the Australian Cancer Plan

February 2022

Consumers Health Forum of Australia (2022)  
*Submission on A vision for the Australian  
Cancer Plan.* Canberra, Australia

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*Consumers Health Forum of Australia is funded  
by the Australian Government as the peak  
healthcare consumer organisation under the  
Health Peak and Advisory Bodies Program*

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# Introduction

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The Consumers Health Forum (CHF) welcomes the opportunity to contribute to the vision for the Australian Cancer Plan.

CHF is the peak body representing consumers of health services in Australia, regularly consulting with, and working with, consumers to develop and advocate for policies, programs and initiatives to improve practices and shape a consumer centred health system.

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*Fifty, sixty years ago, for any of our children who were diagnosed with cancer, it was a death sentence. "Surviving" was really an aspiration goal back then. But, here in 2022, we need to be changing the conversation to "thriving".*

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The Australian Cancer Plan should cover a full spectrum, from prevention and screening, through to diagnosis, treatment, life after treatment, including both care for survivors and end of life care.

In taking a consumer lens to visualise cancer care in ten years from now, CHF firstly looks to the current experience for patients, their carers and family, to identify the challenges they face, and to develop a pathway to a better future, with a vision of:

***An integrated world class cancer care system that offers consumers accessible, equitable, affordable, personalised and person centred services at every stage.***

This vision sets out the key elements of what consumers want and need. That is:

- the best screening, diagnosis, treatment and care services
- services that are accessible, equitable and consistent, no matter where a person lives, their background, their other needs, or their financial situation
- clinicians and systems that work with patients, their carers and families to give them the information they need, in a way that they can understand, and that share decision making.

CHF has consulted consumers with a lived experience of cancer in developing this submission. Their voices are both reflected and directly included throughout.<sup>1</sup>

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<sup>1</sup> Some responses have been edited/abridged.

## From now to the future

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It is indisputable that cancer treatments, care and support have rapidly progressed, and are more centred on consumer experiences and needs. However, the consumer experience has not progressed at the same rapid rate as clinical advances.

The Government has a real opportunity to transform the current consumer experience to one of optimal care over the next ten years.

### Current consumer experience

As with other health systems, cancer patients have variable experiences. Too many find it difficult to navigate to the services they need, and have different access depending on their circumstances and demographic differences.

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*We couldn't get any help when we needed it. It was awful. I needed advice on how to pull the canula out to change the morphine, but you can't get anyone on the phone at night. They told us to go to the hospital, but we didn't want to move our little one who's dying,*

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Factors can include:

- where they live
- their age
- the type of cancer they have
- whether they have a carer/family support
- the level of community/organisational support
- whether or not they have private health insurance, and the level of cover
- their heritage (for example, Aboriginal and Torres Strait Islander or culturally and linguistically diverse background).

### Optimal care pathways

For most types of cancer, there is an agreed “optimal care pathway” – a map of the optimal patient journey, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences.

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*There are a lot of inconsistencies and inequity. My brother is undergoing treatment for an aggressive brain tumour. He saw the speech pathologist almost immediately, which was wonderful. But then his dietician's appointment took three months.*

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CHF advocates extending optimal care pathways to every type of cancer, and making those pathways consistent for all consumers. That is, an optimal pathway, provided by the health

care team, should deliver the same service and outcome, regardless of a person's characteristics or where they live.

Each optimal pathway should include consumers (patients, carers and family members) and give them:

- choice and flexibility for support in person, through telehealth, by phone or email
- affordable, equitable and swift access to the best therapies and technology
- access to research and clinical trials
- referral to palliative care, with referral at diagnosis.

## Understanding and addressing diverse needs

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Importantly, achieving equity in cancer treatment, care and support means not just considering consumer needs based on their condition, but also on their own personal, family and community circumstances. Every consumer should expect to get the support they need, regardless of where they live, their age, their heritage, their level of education, their financial position or their family circumstances and supports.

*Our children suffer lifelong. They survive this insidious disease and the horrid treatments and side effects, and the long term effects on mind, body, spirit are with them for the rest of their shortened lives.*

*We really need the voices of children, as patients, and their parents [as carers and advocates], to be heard loud and clear.*

## Improving health literacy

Consumers need to be given the information they need to make informed decisions about their treatment options, and they need to be able to make those decisions without facing cost barriers. Consumers also need to understand their rights, and should be directed to the Australian Charter of Healthcare Rights.

People take in information in different ways and there can be misconceptions about treatments and care options. For example, a concern raised by consumers is that some people understand palliative care to mean end of life care, so may refuse support because they feel it is "giving up". Understanding that it can be an effective way to manage their pain, and to get support and connect them to the services they need may result in much better outcomes.

As in other areas of both preventive health and treatment, information and resources need to be provided in plain language and in community languages. Complex documents hinder consumer health literacy and make it difficult for consumers to be active in their own care. The best way to make sure that information products meet consumer needs is to co-design resources, including with consumers from diverse backgrounds and situations.

## Children and young people

The Australian Cancer Plan should include a focus on children and young people who are diagnosed with cancer. It needs to recognise that parents and carers are both an important part of a child's care team, and that the experience affects them, as well as their children. Carers need access to services, including psychological support and support for other family members, including other children in the family. The Plan should set out measures to support carers as their children's advocates and representatives, and to provide them with support in their own right.

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*Cancer is a family diagnosis. When it was my 2 year old, it affected my other two children. And there was nothing for me either. [My child] was in treatment for 27 months. In that time, our primary oncologist asked me about myself twice – and both times it was in reference to whether I'd lost weight.*

*We know many parents come out of the childhood cancer experience with post traumatic stress disorder. It was a parent who had participated in high level army manoeuvres who said to me that [going through the childhood cancer experience] is like being in a war trench.*

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Young people with cancer, too, have particular difficulties finding community and other support, and in connecting with each other. While there are some supports for people aged up to 24 years, once they reach that birthday, they are referred to adult services, which can be dominated by older adults, with entirely different experiences that are unrelatable for young adults. They are left feeling lost and unsupported. This is a cohort that should be explicitly identified in the Plan with some targeted measures.

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*I was diagnosed with bowel cancer in April 2019 at the age of 20. Since then, I've done a lot to try to improve connections with other young people. My experience, for example, is that in hospital I saw a social worker twice and all I was given was options to look up Facebook groups for connections. I was too old for Canteen and Red Kite at 25, and I was pushed aside and treated like anyone who's in their 40s or older, which is a bit tricky. It's a bit of a struggle trying to find the supports I need.*

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## Culturally appropriate services and support

Recognition of language and cultural needs in the Plan should extend to fostering greater understanding, and implementing measures, that enable access and responses for people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. This includes:

- providing information and resources in community languages
- access to interpreter services (not relying on family or community members)
- cultural respect and sensitivity and services with diverse personnel
- connections to community supports, for example, with a registry of support groups
- considering past experiences, such as torture and trauma.

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*We should all have survivorship screening to look at our needs. A lot of the survivorship industry is allied health care, so we are constantly pushed to exercise physiologists, dieticians and psychologists. The people I represent have lived in war zones and these services are not culturally appropriate. But we have a lot of problems with skin, eyes, heart, which bring us to hospital again and again and again.*

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## Participation in trials

Trials for cancer drugs and therapies have been fraught with inequities and inconsistencies and CHF would like the Plan to plot a clear path to improving access to, and participation by, patients and their carers and families.

The Plan should outline targets and measures for:

- greater transparency and consumer focus in where public funds are directed to clinical trials
- greater consumer representation and involvement in trial development and governance
- consumers participating in trials to be treated as part of the team
- pharmaceutical companies' access to the PBAC to be contingent on consumers having access to free access to drugs that are awaiting approval.

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*We see lots of consumer involvement in research currently, but they involve individuals and it's quite tokenistic. I think there is great potential to help researchers, research institutes and consumers to work together to set research agendas and find out what consumers want.*

*Patients should be included in ethics committees, which write consent forms, to protect patients' rights, rather than be there just to give the researchers protection.*

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## Research and evaluation

The Australian Cancer Plan should include measurement of optimal care pathways that are based on experiences directly reported by patients, including through standardised patient reported experience measures (PREMS) and patient reported outcome measures (PROMS).

*There's a really good point in there about pain treatment outcomes and the actual experiences of the patient. I think it's really important to draw out in evaluations and measure whether it was the right treatment at the right time, or what was the outcome or whatever. But they don't actually measure how the patient experienced the treatment or services that they received.*

Transactional research should be tied to the Plan, and there needs to be clear governance over data so that consumers can be assured that their personal information is safe. Results should be used to improve performance, and so that care planning and clinical decisions are guided by evidence and appropriately meet consumers' needs.

## A systems approach

A good start to ensuring national consistency would be to embed the relationship between the Australian Cancer Plan and state and territory plans. The lack of coordination in border areas, where there is often a lack of coordinated services, including end of life care, when a patient is discharged from a hospital in one state, to their home in another, exemplifies the need for a national approach.

Patients with a diagnosis should also have a single 1800 number to guide them to the most appropriate services to meet their needs, and each patient should have a care coordinator, who can support them to navigate health and other support systems, based on their individual concerns, priorities and circumstances.

*We need to know to build better services that meet consumers' needs. There might be theoretical reasons why people might benefit, but we need to know how to build services that connect with people*

Consumers who have cancer need to be supported by a multi-disciplinary teams, with a single care coordinator to help them and their carers and families navigate all the systems. Genomic testing should be routine in providing targeted drugs and equity to everyone with a cancer diagnosis.

The Plan should also include measures to support contemporary models of out of hospital care, such as home based chemotherapy. Recent pilots suggest that they can treatments and care delivered in community settings and in patients' homes offer a better patient experience. These models should be supported, where there is evidence of effectiveness and value to patients.

Consumers should also have equitable access to services after their treatment has ended, whether that's to ensure their quality of life following successful treatment, or to care plans, palliative care and assisted suicide (in jurisdictions where that is an option).

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*My wife died five years ago. One of the major problems with her treatment was lack of involvement of palliative care, until it was far too late. It was three years from when she was diagnosed until she died, and there was no palliative care for the first two and a half years.*

*Once [palliative care] were involved, life became a lot easier for her.*

*I cannot understand why they're not involved officially as part of the multidisciplinary team much earlier in the piece.*

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The Plan should also consider how palliative care could be more widely available, and not confined to end of life care. It is an invaluable support in an interdisciplinary team that can support cancer patients and their carers and family from the time of diagnosis, through treatment, and in surviving and living with cancer.

## Next steps

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Consumer priorities for the Plan include:

- a focus on prevention
- national consistency and equity
- improving quality of life for cancer patients and survivors
- access to drug trials
- access to new therapies and new technology
- service and information navigation support
- consumer centred data collection.

CHF hopes that the Government will invite consumers to work more closely with the Department of Health as the Plan progresses. Consumers seek not only engagement, but the opportunity to co-design a plan that puts their experiences and needs at the centre of its development.