

Public consultation on the refresh of the National Strategic Framework for Chronic Conditions

Consultation [information](#).

Part 2: Objectives of the Framework

Objective 2: Provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life

One of the aspirational outcomes of Objective 2 of the Framework is that people with chronic conditions have equitable access to quality health care. Pages 35-36 of the Framework discuss this in further detail.

6. To what extent do you agree with the following statements?

(Required)	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Not applicable
Australians with chronic conditions can easily access primary care services, including regular care with a GP and/or allied health providers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Australians with chronic conditions can easily access specialty healthcare services when required.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Optional): Please provide further comments about any of your responses to the previous statements.

There is a limit of 1000 characters

Distance to blood cancer specialists and/or hospitals means an increased reliance on high quality primary healthcare for both diagnosis and post-treatment. Patients living outside metropolitan centres are restricted in their access to practitioners and especially to haematologists.

We support the advice as articulated in the blood cancer Optimal Care Pathways:

- "In a setting where no haematologist is locally available (e.g. regional or remote areas), some components of less complex therapies may be delivered by a general practitioner or nurse with training and experience that **enables credentialing and agreed scope of practice within this area**. This should be in accordance with a

detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required."ⁱⁱ

Part 2: Objectives of the Framework

Objective 3: Target priority populations

The Framework aims to act as a broad overarching guidance document that is inclusive of the full spectrum of chronic conditions.

8. To what extent do you agree with the following statements?

(Required)	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Not applicable
1. Australians living with chronic conditions, including myself, friends/family, patients, or members of the organisation I represent if applicable, are recognised in the Framework.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The Framework is representative of the diversity of population groups in Australia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. The Framework recognises the individual needs of the many different groups in Australia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The Framework provides guidance about how the prevention and management of chronic conditions can be tailored to the needs of different population groups.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Optional): Please provide further comments about any of your responses to the previous statements.

There is a limit of 1000 characters

The Framework could be strengthened by better recognition of the challenges faced by people living with chronic cancers.

Blood cancers are the second highest cause of cancer-related death with over 140,000 Australians affected over 120 subtypes.

Unlike many other cancers, blood cancers cannot be prevented through lifestyle change or detected early through population screening.

Some blood cancers develop and progress quickly (acute) and need to be treated as soon as they are diagnosed, whereas others develop more slowly (chronic) and may progress over weeks, months or years.

Patients often feel their blood cancers are not understood:

*"My illness is chronic and doesn't get much understanding because most people ache and get tired. But it never stops. I struggle daily but I'm not sick enough for any financial assistance so I have to work. **There is not much understanding of blood cancers** when compared to breast cancer."*

Part 3: Focus on the Future

10. Potential barriers for people with chronic conditions are shown below. Which of these barriers do you believe significantly impact Australians living with chronic conditions (including yourself if applicable)? Please select all that apply.

(Required)

- Difficulty in finding an appropriate healthcare provider or facility
- Long wait lists
- Lack of coordinated care and communication between health professionals
- Lack of information sharing and exchange between healthcare providers
- Financial cost of healthcare
- Limited awareness and understanding of chronic conditions and/or prevention by patients and/or carers
- Limited understanding of the healthcare system by patients and/or carers
- Limited knowledge of some chronic conditions by healthcare professionals
- Stigma associated with chronic conditions and risk factors
- Stigma of accessing healthcare
- Not being able to attend appointments due to geographical location/transport
- Difficulty using technology to receive or navigate healthcare services
- Lack of health promotion education and prevention activities
- Low English proficiency and other language challenges
- Limited availability of publicly funded health programs

- Lack of access to research and data
- Lack of culturally safe healthcare

(Optional): Are there any other barriers that you would like to draw attention to?

There is a limit of 1000 characters

In addition to the 'financial cost of healthcare' option above, the Leukaemia Foundation highlights that as more diseases are able to be treated as a chronic condition, patients can be put under financial distress due to being ineligible for income support.

Living with a chronic cancer is expensive and often means not being able to work fulltime, on top of medical expenses. Yet the eligibility criteria (e.g. for the disability support pension) that patients must meet to be eligible for many income support schemes often means they are unable to access them.

Part 4: Summary

17. In 1000 words (6000 characters) or less, please provide any additional feedback on the Framework including any other opportunities to improve the Framework.

(Optional):

Better income support through modified eligibility requirements

The current eligibility requirements for the income support are unnecessarily exclusionary of people with cancer, and especially blood cancer with the nuances of its specific diseases.

In addition to diagnosis and treatment costs, the financial burden of blood cancers is compounded by ancillary effects of treatment and being away from home – often required for intensive blood cancer treatments. This is particularly pertinent for blood cancers, for which the treatment can be intensive.

Blood cancers remain among the **mostly costly cancers to treat**, with **myeloma and leukaemia accounting for two of the top three costliest cancers to treat**.

For example, myeloma (an incurable blood cancer) costs the health system about \$46,000 per individual per year, almost triple the average cost incurred by cancer patients in Australia.

A blood cancer diagnosis creates a significant and sudden financial burden. Around 43% of blood cancer patients report out-of-pocket expenses, and more than one in three of these incur more than \$5,000 in cost. ^[1]

In the past year alone, there has been a 37% increase in people reaching out to the Leukaemia Foundation for financial help, with many struggling to make ends meet.

Additionally, treatment can be lengthy, with:

- 42% of patients taking over three months off work
- 30% having to leave their jobs, and
- 50% not being able to return to work.

The Leukaemia Foundation reiterates the need for better access to financial support for cancer patients with chronic disease patients:

- The NDIS and, separately, the Disability Support Payment (DSP) through Centrelink are payments intended to provide support for people living with a disability.
- The **eligibility criteria for the DSP and NDIS, and the nature of blood cancers, mean that people living with blood cancer are effectively excluded from either of these schemes.** For people requiring external financial assistance, their only other option is JobSeeker.
- JobSeeker is a short-term supplement payment for people who are actively seeking employment. It is not intended as a 'safety net' payment.

The Leukaemia Foundation provides limited financial support including reimbursements for groceries, transport petrol and utility bills on top of our accommodation services. Our ability to do much more beyond this is limited.

We were on the reference group which developed the Financial Cost of Cancer national policy (Cancer Council), which is consistent with the information above, and recommend that document is drawn upon as part of the Framework's development.

We recommend reviewing options for the introduction of financial support mechanisms (such as a temporary disability payment) to support people with cancer and other serious illness who require temporary financial support.

Elevating patient-reported outcomes

The Framework would benefit from increasing the emphasis on patient-reported outcomes (PROs) across the continuum of care for people with chronic diseases.

As the treatment of cancer is transforming many cancers from acute, life-threatening diseases to long-term chronic conditions, PROs are increasingly recognised as important tools for symptom and adverse event monitoring to enable better patient care, as well as tools to guide investment in research and regulatory decision making.

PROs are particularly important in oncology because while side-effects are common among patients receiving treatment for advanced cancers, research has found they are undetected by clinicians up to half the time.

Studies have shown PROs in an oncology setting can improve patient satisfaction, symptom detection, therapy adherence, clinician-patient communication and patient involvement in care, as well as management of side-effects and utilisation of supportive care. PRO systems have also been shown to reduce presentation to Emergency Departments, and frequency of hospitalisation. In one recent study, overall survival was also extended and health-related quality of life improved.

Medical research

Research in blood cancers has made tremendous strides in the past 15 years, with therapies for paediatric cancers delivering cures for many children and the advent of tyrosine kinase inhibitor therapies enabling people with chronic myeloid leukaemia (CML) to live effectively normal lifespans.

It cannot and should not be separated from chronic disease delivery, and the Framework could be enhanced by strengthening the link between achieving better outcomes and translation of research into practice.

ⁱ *Optimal care pathway for people with chronic myeloid leukaemia*, p.33:

https://www.cancer.org.au/assets/pdf/chronic-myeloid-leukaemia-1st-edition#_ga=2.199474030.1976630589.1659924132-1517087287.1653444068

ⁱⁱ <https://www.leukaemia.org.au/media/australias-costly-cancer-burden-blood-cancer-patients-facing-impossible-choices-amid-soaring-costs/>