

# **Cancer Australia Peak Body Survey - Draft National Optimal Care Pathways (OCP) Framework**

**Q1. Which group do you represent or most closely associate with? Please select one from the following options.**

- Person affected by cancer, family member, carers, and community
- Aboriginal or Torres Strait Islander people affected by cancer, family members, carers, and community
- Consumer advocate
- General practitioner
- Cancer specialist
- Other medical specialist
- Nurse
- Allied health professional
- Other health professional
- Primary Health Network employee
- Aboriginal Community Controlled Organisation
- Organisation working with Aboriginal and Torres Strait Islander people
- Aboriginal or Torres Strait Islander Health Worker or Health Practitioner
- Researcher or academic
- Policy maker or Government employee
- Peak body employee

**Organisation (optional):** Blood Cancer Taskforce

**Q2. Which state or territory do you reside in?**

- New South Wales
  - Victoria
  - Queensland
  - Western Australia
  - South Australia
  - Tasmania
  - Northern Territory
  - Australian Capital Territory
- Other: \_\_\_\_\_

**Q3. Do you or your organisation represent or identify as (select all that apply):**

- Aboriginal or Torres Strait Islander people
- Lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual people
- Older Australians
- Adolescents or young adults
- Children
- People from culturally or linguistically diverse backgrounds
- People living with disability
- People living with a mental health condition
- People living in a rural or remote area
- People living in a low socioeconomic circumstance
- None of the above
- Prefer not to answer

**Q4. Which elements of the draft OCP Framework do you think will make the most difference on cancer care and outcomes? Please select the top 3.**

- National standards to develop and update OCPs
- Prioritisation for future OCP development
- National endorsement of OCPs
- Improving accessibility of OCPs for patients, carers and community stakeholders
- Improving functionality of the OCPs for clinicians
- Using data to evaluate OCP uptake and alignment with cancer experiences and outcomes
- Evaluation
- Governance arrangements

**Q5. Why do you think these elements will make the most difference? See question above.**

- 'National standards to develop and update OCPs' will help deliver core features of a successful OCP Framework, inclusive of those elements expected to help improve patient outcomes.

The content of the standards, as articulated in the draft, will include important features of OCPs, such as co-design approaches with priority population groups, inclusion of lived experience, key performance indicators and others. Whilst dependent on the final articulation of the standards, and on broad buy-in, national standards should help deliver more equitable cancer outcomes nationally.

Establishing national standards for the development and updating of OCPs also help ensure a consistent, evidence-based approach across all jurisdictions. This uniformity is

important for maintaining high-quality care and ensuring that all patients, regardless of their location, have access to the best possible treatment and support. For blood cancer patients, whose treatment and care pathways can be complex and rapidly evolving with new research, these standards help guarantee that care is based on the latest evidence and best practices.

- 'Prioritisation for future OCP development,' as articulated in the consultation paper, will include developing OCPs in areas of high need, including priority population groups and tumour-specific OCPs for cancers with high mortality and poorer outcomes.

This will help address cancers that do not always receive the attention they need, while also looking to support patients who experience poorer outcomes. OCPs are a resource that aid healthcare professionals in adhering to the optimal standard of care and, especially for rare cancers, OCPs ensure that features of disease are recognised early, and appropriate diagnostics are undertaken within acceptable timeframes.

Blood cancers, being diverse and affecting patients of all ages with varying prognoses, require tailored care pathways that consider the unique challenges and treatment options available. Prioritising the development of OCPs for areas of high need and priority populations can lead to significant improvements in patient outcomes and experiences.

- The other elements are of course still important. National endorsement and national consistency in monitoring the uptake by consumers, the primary care workforce and specialists are also particularly important.
- Finally, regarding 'the most difference,' we caution against applying criteria to assess impact that disadvantages rare cancer patients. In these groups, the raw numbers will not be large, but the difference made to these patients, including to prospective mortality, could be significant. This is also an equity issue.

#### **Q6. The draft National OCP Framework includes national standards so that OCPs are developed and updated in a consistent way (See – Section 5.1 of draft National OCP Framework).**

##### **What other standards should guide the development and update of OCPs?**

We support:

- **Patient-Centred Care** – Standards should explicitly require that OCP development and updates are guided by principles of patient-centred care, ensuring that patient preferences, needs, and values are at the forefront of care planning and delivery.
- **Evidence-Based Practice** – OCPs should be developed and periodically updated based on the latest clinical evidence and research findings. Standards should mandate a systematic review process for incorporating new evidence into OCPs. Further, it is unclear in the draft what the specific trigger is for updating OCPs (as well as what the new Framework and Standards mean for existing OCPs and those in development).

- **Multidisciplinary Collaboration** – The development and updating of OCPs should involve collaboration among a wide range of healthcare professionals, including specialists, general practitioners, nurses, and allied health professionals, to ensure comprehensive care perspectives.
- **Patient and Carer Involvement** – Standards should ensure that patients and carers are actively involved in the development and review process of OCPs, providing valuable insights into patient experiences and care needs.
- **Cultural Competence** – OCPs should be developed with standards that ensure cultural competence, particularly acknowledging the diverse needs of Aboriginal and Torres Strait Islander peoples and other CALD communities in Australia.
- **Accessibility and Communication** – Standards should mandate that OCPs are accessible and communicated in clear, understandable language for both healthcare providers and patients, including the availability of information in various formats and languages as needed.
- **Quality and Safety** – Incorporate standards focused on quality improvement and patient safety, ensuring that OCPs contribute to reducing variations in care and minimising the risk of harm.

**Q7. The draft National OCP Framework provides criteria to prioritise the future development and update of OCPs (See – Section 5.1 of the draft National OCP Framework):**

- **Population-based OCPs for the priority population groups identified in the Australian Cancer Plan**  
(<https://www.australiancancerplan.gov.au/populations>)
- **Tumour-specific OCPs for cancers with high incidence and/or mortality rates and/or poorer outcomes**
- **Development of OCPs aligned to current and emerging government strategies and priorities.**

**Are these criteria suitable? Are there additional criteria that should be included?**

Blood cancers have some of the highest cancer mortality rates, remain a significant challenge in Australia, and outcomes vary across the country.

Optimal care pathways (OCPs), along with clinical guidelines, are the foundations for achieving best practice care and reducing disparities in survival outcomes by ensuring more consistent application of currently available best practice diagnosis, treatment and care.

OCPs remain critical for blood cancers, and modelling undertaken by Insight Economics and commissioned by the Leukaemia Foundation shows 38,200 lives could be saved from blood cancer between now and 2035 if everyone across Australia had equal access to best-practice treatment and care.

In that context, we suggest the emphasis in the criteria on priority populations is needed, and we argue that blood cancers generally fit those criteria.

However, we caution against a blanket exclusion of cancers with lower incidence/mortality/poorer outcomes (as implied by "Development and update of tumour specific OCPs for cancers with high incidence and/or mortality rates and/or poorer outcomes").

Not only is this dependent on definitions and how cancers are grouped, but the advancement of genomics will continue to allow more specificity in identifying cancer types, leading to smaller identified patient cohorts and therefore potentially lower case numbers for some sub-types.

Further, it may unwisely and unfairly discriminate against those cancers where incidence is higher but treatment advances are improving mortality outcomes, and also where 'lower incidence' cancers can lead to other high mortality cancers. Some lower incidence cancers with lower mortality rates can still have devastating effects on patients' lives, and it is unclear in the draft Framework where these would fall.

Regarding the subsequent line in the draft Framework – "this may include development of new OCPs for tumours that are not part of the existing suite, where the broad value to the community of this investment can be demonstrated" – we caution that the use of the term 'value' should not be considered only in terms of a quantum of financial savings. Doing so is unfairly restrictive for rare and less common cancers.

Specific considerations for life stages and circumstances must also be included in the OCPs.

**Q8. Governance of new and updated OCPs will include (See – Section 7 of the draft National OCP Framework):**

- **A project team,**
- **A multidisciplinary Expert Working Group,**
- **Co-design approaches,**
- **National public consultation and**
- **National endorsement.**

**Are there any other governance considerations to include in the draft National OCP Framework?**

We make the following brief comments in relation to governance:

- The scope of the activities listed above may be constrained by funding limitations.
- National endorsement by CAPS (as proposed in the draft Framework) worked well for the recent second tranche of OCPs developed by the Blood Cancer Taskforce, and we are supportive of this approach. This process was more timely than the previous COAG process.

More information would be valuable on the proposal that CAPS "will support [OCPs'] wider dissemination and application across jurisdictions," and particularly on the level of intensity and extent of that support. Dissemination, and jurisdictional application, are difficult for the writers of OCPs to undertake in isolation, and this broader and coordinated support is important and welcome.

- There may be a role for Cancer Australia in assisting the coordinated development and implementation of OCPs, particularly given the numbers of people involved in the list above (e.g. experts, asking consumers, national endorsement etc) and the possibility of multiple OCPs being undertaken simultaneously without those writers having visibility of concurrent OCP processes.
- Some organisations have pre-existing arrangements and these can (and should continue to be) encouraged to be a model to avoid having to re-create and re-construct governance structures regularly.
- Blood cancer treatment is rapidly evolving, with new therapies and technologies frequently emerging. The governance arrangements (and Framework more broadly) will need to have built-in adaptability and responsiveness to integrating these advancements into OCPs promptly.

**Q9. The draft National OCP Framework includes ways to improve the functionality of the OCPs for clinicians (See – Section 5.2 of the draft National OCP Framework). This will include:**

- **Digitising OCPs to make them more accessible for clinicians**
- **Embedding the OCPs into existing clinical workflows**
- **Incorporating cancer specific and population based OCPs into clinical education**

**In what other ways can the functionality of OCPs be improved for clinicians and service providers?**

As stated in the National Strategic Action Plan for Blood Cancers, OCPs make wide ranging evidence-based recommendations for best practice care, from the point of diagnosis, through treatment, survivorship and end-of-life care. OCPs cover a wide range of relevant issues for both patients and clinicians, including opportunities to deliver services and care through integrated and

telehealth models, guidance for managing infection control and palliative care, for example. They are important tools for helping clinicians to understand the importance of providing information and supportive care services but are only useful if they are used.

Consultation with clinicians is important to ensure ongoing ease of use, and that the OCPs are used.

Training and education should also be provided to support their integration and implementation into clinical practice.

### **Q10. What would be the best national quality indicators for OCPs?**

There are a large number of potential quality indicators, and these should be finalised with ongoing consultation with the sector. At a high level, quality indicators could include:

- **Adherence to OCP Guidelines** – Measurement of healthcare provider compliance with the established OCP protocols.
- **Patient Quality of Life** – Assessing the impact of OCPs on the quality of life of patients, including physical, emotional, and social well-being, through patient-reported outcome measures (PROMs).
- **Equity of Access** – Measuring disparities in access to care and treatment outcomes among different population groups, including rural and remote communities, indigenous populations, and socioeconomically disadvantaged groups.
- **Multidisciplinary Care Coordination** – Assessing the effectiveness of coordination among the multidisciplinary teams involved in patient care, ensuring seamless integration of services across the continuum of care.

### **Q11. Are you aware of any datasets that currently collect these indicators?**

Notwithstanding issues of data integration, standardisation, and privacy, possible datasets could include:

- State-based cancer registries and the Australian Cancer Database
- Hospitals and healthcare providers using electronic health records
- Australian Commission on Safety and Quality in Health Care data on adherence to clinical guidelines and healthcare quality indicators
- AIHW 'Cancer Data in Australia' annual report.

### **Q12. What policy levers can be used to support OCP implementation?**

Policy levers to support OCP implementation could include:

- Commitments and regular discussion at the National Health Ministers' Meeting – The Federal and State and Territory Health Ministers could formally agree at a meeting of the HMM to commit to supporting OCP implementation and to working together to facilitate harmonised roll-out nationally.
- Funding and Grants – Allocate targeted funding to healthcare providers and organisations for the adoption and integration of OCPs into clinical practice. This could include financial incentives for meeting specific OCP adherence benchmarks, and for innovative approaches to OCP implementation.

Additional funding is particularly required to develop dedicated awareness activities and campaigns to target healthcare professional and patients to support the understanding and uptake of OCPs. Initiatives may include targeted media for GPs, monitoring GP and specialist usage articles in the Australian Journal of General Practice, presentation of OCPs to health care professionals at events like the Haematology Blood and RACGP conferences and information resources for the relevant Colleges and Societies. Campaigns for patients could be through social media, GP clinic advertising and targeted media through specific communities not accessed by mainstream media.

- Education and Training – Invest in training programs for healthcare professionals on the importance of OCPs and how to implement them effectively. This should also include ongoing professional development opportunities to keep pace with updates to OCPs.
- Evaluation – Fund research to evaluate the effectiveness of OCP implementation strategies and the impact of OCPs on patient outcomes. This evidence base can inform future policy and practice.
- Facilitated partnerships – Direct Cancer Australia to foster partnerships between government, healthcare providers, patient advocacy groups, and the private sector to support OCP implementation. This could also facilitate shared learning and innovation in OCP delivery.

### **Q13. Are there any other comments you would like to make?**

- Further consideration needs to be given to clinical guidelines, and their role alongside OCPs.

As stated in the National Strategic Action Plan for Blood Cancers, clinical guidelines bring together the best available evidence to underpin scientifically valid recommendations for the diagnosis and treatment of patients. They are a key mechanism to improve quality and safety in care and reduce variation in survival outcomes.

Together, clinical guidelines and OCPs can minimise variation and promote best practice care. They are the foundation for achieving best practice and reducing disparities in survival outcomes. There is a critical need to address gaps in OCPs and clinical guidelines for different blood cancer subtypes. OCPs and clinical guidelines are interdependent and to be effective should be fully integrated into clinical practice.

- The development of dedicated communication campaigns, targeted to individuals from non-English speaking backgrounds is required to leverage and implement the considerable investment made to translate these resources (OCPs and disease books). The campaign may cover targeted communications through community and language specific channels.

As part of the 2022 launch of the first tranche of OCPs, the Taskforce implemented a short awareness program towards dedicated health professional and patients. Collateral was distributed through the Taskforce's networks and partners. Activities included advertising the OCPs at the 2022 Blood Conference and the organisation of an online OCP webinar for health care professionals.

In the first eight weeks from the launch, the full OCPs were downloaded over 1,140 times, the quick reference guides over 460 times and the guides to best cancer care over 980 times. Despite this advocacy there is still limited awareness of the OCPs across health care providers (especially at the GP level) and among patients. We recently undertook the largest survey of blood cancer patients in Australia with over 4,600 participants. Less than 6% of patients who took part in the survey knew blood cancer OCPs were available and over 65% of patients were not aware of OCPs.

Development of translated materials (OCPs and disease books), however, is not enough. Ensuring that patients, communities and health care providers know these resources are available and have access to them is just as important. The importance of equitable access to health information for non-English speakers was clearly demonstrated in the recent COVID pandemic. This can also be demonstrated by our recent experience with Optimal Care Pathways. The Guides to Best Cancer Care (patient guide to the OCPs) were translated into the eight most commonly spoken languages in Australia. In the month following their release, the English versions of the Guides to Best Cancer Care were downloaded almost 1,000 times while the translated versions were only downloaded 22 times.

- The Blood Cancer Taskforce has led the development of 11 nationally endorsed OCPs and looks forward to continuing to engage on the Framework's implementation and sharing the 'lessons learnt' during the completion of those OCPs.