Cancer Australia Clinician 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): **VCCC Alliance (Victorian Comprehensive Cancer Centre Alliance). The responses to this survey represent a VCCC Alliance organisation wide response, and are collated from a diverse range of consumers and multidisciplinary clinician/academics, including surgeons, medical oncologists, cancer nursing and primary care specialists.**

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.

Improving Accessibility:
From a consumer perspective:

- There seems to be an assumption that people know about the OCPs. Amongst the consumer group consulted, there was low awareness of the OCPs and uncertainty on the purpose or function of the OCPs
- If guides are part of understanding what optimal care should be, embedding within current and credible information sources is required (e.g., Cancer Council resources)
- Current difficulty in knowing where to access OCPs
- Confusion as to whether cancer care guides and OCPs are one and the same (https://www.cancer.org.au/cancercareguides)?
- For OCPs to be useful for consumers, provide accessible tools (i.e. interactive maps) for individuals to search information, e.g., where and what treatment options are available, financial implications, and where diagnostic tests can be conducted. An overview of what is expected with explicit mention of variances from metropolitan, rural, regional, or remote geographical locations
- For greatest accessibility, including to those of low health literacy, simple language to be utilised
- If improving accessibility to patients, carers and community stakeholders, there are additional governance issues of importance, e.g., who is responsible and who commits to integrating into clinical practice? Who monitors and who is accountable? Who has overall oversight and what are the actions when variations of optimal cancer care are identified?

From a healthcare professional perspective:

- Increasing accessibility will contribute to uptake
- Harmonisation has potential to significantly impact patient outcomes.

Improving Functionality:

- There is an assumption that healthcare professionals are aware of OCPs. Healthcare

professionals providing quaternary care are not necessarily aware of their existence, and have expressed uncertainty regarding their purpose, i.e., clarification of the fact that they are not clinical practice guidelines
- Improving functionality is a key to implementation and achieving the intent of the OCPs
- Improving accessibility from a consumer perspective is irrelevant if functionality not improved in parallel for healthcare professionals. Both stakeholders need to be invested in achieving optimal care
- Implementation includes provision of evidence-based decision-tools for primary care to aid early diagnosis
- Need to be succinct and clearly outline best practice.

Using Data:
- A data-based approach is necessary to monitor uptake, outcomes and assess effectiveness
- For monitoring optimal care delivery, ensure data is collected from both the private and public sector across Australia
- Include Patient Reported Experience Measured (PREMs) and Patient Reported Outcome Measures (PROMs) as implementation metrics
- Effort to address current challenges to collection of PROMs and PREMs necessary, including ensuring: adequate healthcare professional resources who can review and respond in real time; clinical utility of data presented to healthcare professionals, i.e., do not have to work through lengthy questionnaires to find salient data during clinical consultations; IT infrastructure optimised to collate data; prompt completion and storage of data; data captured from those most disadvantaged; and EMRs have functionality for shared visibility of data.

Q6. The draft 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?
- Social determinants of health data should be collected routinely and standardised to build and contribute to a national dataset
- The content of Step 1 (Prevention and early detection) and pre-diagnosis needs to be updated to better account for current evidence around presentation in Primary Care
- The content of Step 2 (Presentation, initial investigations and referral) needs to be evidence based and revised as evidence accrues
- The current format relies on recognition of tumour specific cancer symptoms, rather than significance of symptoms that may be red-flags for multiple cancers
- Appreciate a consistent approach for standardising optimal care, however, every patient has a unique experience. Factor in variations to aid personalised cancer care
- Ensure co-design is genuine and not downgraded to 'consultative' consumer and priority group input. Explicitly state to have mechanisms for genuine, effective, and meaningful consumer involvement, and include self-determination for Aboriginal and Torres Strait Island Communities
- Ensure health care professionals with diverse experience (clinical, research, education and personal) contribute to the development and OCPs to maximise both appropriateness and efficacy
- Standards for supportive care, including distress screening
- Standards for financial limits (range for cost of treatment)
- Standards for survivorship care
- Standards for palliative care

- Missing from the list in 5.1 is explicit mention of rural, regional, and remote patients
- Standards re care being delivered as close to home as possible/alignment with service capability
- Given size of regional population and differences in outcomes suggest a Regional voice in co-design (as well as Aboriginal and Torres Strait Islander People)
- Where possible, align treatment section with international guidelines e.g ESMO, ASCO, NCCN
- Use of digital health to support care through OCP including access to clinical trials.

Q7. The draft OCP framework provides criteria to prioritise the future development and update of OCPs (See - Section 5.1 of the draft National OCP Framework). Are these criteria suitable? Are there additional criteria that should be included?

- Social determinants of health
- Equitable access should include translation of materials into common languages
- As above, ensure co-design is genuine and not downgraded to 'consultative' consumer input. Explicitly state to have mechanisms for genuine, effective, and meaningful consumer involvement, and self-determination for Aboriginal and Torres Strait Island Communities
- Consumers and community involved at the beginning of any new OCP development. Avoid any tokenistic engagement with asking consumers to 'review' an end product
- Agree necessary to develop/update tumour specific for cancers with high incidence and/or mortality rates and/or poorer outcomes, but also those cancers where there has been a change in epidemiology and outcomes e.g., bladder cancer and rare cancers (e.g., some of the upper GI cancers where no OCP currently exists)
- Population specific – consider socio-economic and geographically disadvantaged. Missing from the list is explicit mention of rural, regional and remote patients. Consider development of an OCP for the care of rural, regional and remote population.
- Review of the OCPs to ensure supportive care is the foundational premise upon which all other aspects of cancer care and treatment are built, thus prioritising a system of patient centered care. Emphasis placed on, psychological safety, financial implications, survivorship, healthcare system navigation, health literacy and personalised information needs
- Consider incorporating into each OCP a section that discusses implications for patients which are part of a priority population. These additional considerations could be linked to the full population specific OCP once complete.

Q8. Governance of new and updated OCPs will include (See - Section 7 of draft National OCP Framework). Are there any other governance considerations to include in the OCP Framework?

- OCPs to be evidence driven by high quality data and periodically updated
- Accountability for following the OCP is missing from the framework
- Accreditation as a cancer care provider should be dependent on a commitment to meet OCPs and providers should make available administrative data to show they have been compliant, however only if health services are appropriately resourced to do this, and not penalised when unable to deliver as at capacity and under resourced
- Necessity for governance structure to include effective partnership with consumers
- Necessity to include consumers, regional voice and primary care in Expert Working Group.

Q9. The draft OCP framework includes ways to improve the functionality of the OCPs for clinicians (See Section 5.2 of the draft). Considering functionality, how can OCPs be embedded into clinical practice?

- Development of implementation frameworks/templates for a range of core settings across public, private, community and primary care
- OCPs should be translated into practical day-to-day practice (OCPS are viewed as an administrative guide and have not been widely adopted by healthcare professionals in day-to-day practice)
- Evidence-informed implementation toolkits will assist embedding in under resourced healthcare services
- 'Up-to-date' do it well - include a clear flow of concise information with links embedded for more information. Format needs to encompass key messages for busy healthcare professionals with more information as required
- There is a perceived lack of necessity of OCPs for specialists in quaternary institutions and dealing with cancers that require centralised care, coupled with assumption that the OCPs may be more relevant for those oncologists situated rural/regionally. These misconceptions require improved education and awareness to reframe to 'formal networks of care', traversed by the OCPs
- Provision of education updates annually at oncology group meetings
- Integration into oncology departments and oncology training programs
- A significant proportion of the cancer workforce does not have access to an EMR. Advocacy for EMR may be required to improve functionality.

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

- Timeliness of access to screening and diagnosis (most inequity occurs before people get to acute sector)
- Evidence of improved cancer outcomes for prioritised populations (assuming improvement for these groups will deliver improvement for all)
- Timeliness of events could be more evidence based where evidence exists to ensure maximum time to diagnosis before outcomes deteriorate
- Routinely and widely available administrative data only collects data time points once a patient encounters the hospital setting. There is necessity to define and routinely collect granular data around primary care / general practice encounters
- Invest in primary care data through PHNs and the National Primary Care Data Asset. Utilise to measure additional time points in OCP
- Endorsement by key national organisations
- Incorporation into oncology training programs
- Patient Reported Experience Measured (PREMs) (cognisant of challenges as per Q5)
- Patient Reported Outcome Measures (PROMs) ((cognisant of challenges as per Q5)
- Performance measurement for healthcare professionals, provided there is system level innovation to enable multidisciplinary clinicians/healthcare professionals to achieve optimal care, as per Q8
- Distribution and uptake of printed resources
- Engagement analytics for online resources.

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

- Victorian Integrated Cancer Services linked data assets utilised for the VICS Optimal Tumour Summits (Analysis of Linked Information on Cancer ALIC, Department of Health)
- Data Connect – VCCC Alliance and University of Melbourne utilises linkage of Primary Care Audit, Teaching and Open Network (Patron) general practice data to Centre for Victorian Data Linkage (CVDL)

- Victorian Department of Health CSPI (Cancer Services Performance Indicator) audit data.

Q12. Are there any other comments you would like to make?

- The biggest challenge to implementation is assuming health services can re-model care delivery without additional resources and support to change. To fully benefit from these excellent pathways, the systems of care (especially in the hospital setting) need fundamental change
- Aim for a 'optimal' cancer experience to be the norm and not good luck
- Language and terminology used in the OCPs - a cancer experience is not a linear pathway and implies a path to 'somewhere'. Consider 'Optimal Cancer Care'
- Subject matter experts who have previously been involved in development of OCPs have reported receiving little/no subsequent communication and key messaging.