Joint VCCC Alliance and MPCCC submission

Cancer Australia National Framework for Genomics in Cancer Control Feedback Survey

Background: The *Precision Oncology Roadmap to Equitable Access to Molecular Testing, September 2024* (the Roadmap) was developed collaboratively by the VCCC (Victorian Comprehensive Cancer Centre) Alliance and Monash Partners Comprehensive Cancer Consortium (MPCCC) to address inequities to molecular testing for cancer patients. The comprehensive Roadmap was informed by extensive stakeholder consultation and evidence gathering.

A key component was the Victorian Precision Oncology Summit, held in April 2023, which brought together over 150 multidisciplinary participants including medical oncologists, pathologists, researchers, consumers and government representatives from metropolitan, regional and interstate areas. Preceded by a scoping survey targeting oncologists, the Summit featured tailored educational content, and facilitated discussion groups focusing on barriers to molecular testing, variability in practices, clinician and consumer literacy, and data collection.

Insights from the Summit were supplemented by follow-up consultations with 22 additional stakeholders to address underrepresented perspectives. A white paper summarising key findings informed the Roadmap's final recommendations. Additionally, outcomes from the Summit were published as a Conference Report in *Current Oncology*.

This joint submission to Cancer Australia's draft National Framework for Genomics in Cancer Control feedback survey draws on the eight Recommendations and associated Actions of the Roadmap, and aspires to our collective goal of disseminating initiatives and learnings nationally to improve patient outcomes for all Australians.

Q1. Which group(s) do you or your organisation represent or most closely associate with? Please select all that apply.

☒ Data custodian

☐ Aboriginal or Torres Strait Islander Health Worker or Health Practitioner

☒ Organisation working with Aboriginal and Torres Strait Islander people

☐ Aboriginal Community Controlled Organisation

☒ Person who has experienced cancer

☒ Family member or carer of a person who has experienced cancer

☒ Consumer advocates

☒ Member of the general public

☒ Health professional

☒ Health service employee / administrator

☐ Peak body employee

☐ Primary Health Network employee

☒ Researcher or academic

☐ Policy maker or government employee

Other (please specify)

Q2. Which state or territory do you reside in, or is your organisation based in?

☒ Victoria

Q3. Do you or your organisation represent or identify as any of the following (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. Do you have any comments or feedback on strategic objective 1: prevention and early detection?

The document is not clear about who should have access to evidence-based genomic testing. The wording of "individuals and their families" is not clear. Is this objective targeting affected individuals and their families or unaffected individuals (the more common target in cancer prevention initiatives)? The text seems to have a mix of traditional clinical genetic language (where testing of an affected person can lead to cascade testing of their relatives) yet seems to pitch at population-based risk stratified screening of (presumably) unaffected individuals.

The text also seems to present genomic testing as a stand-alone measure for personalised risk prediction – state of the art risk prediction models relevant to populations incorporate all relevant risk factors (including genomic information) and are essential to enable risk-stratified screening.

We anticipate great benefit from increasing the scope of genomic reference datasets and culturally safe genomic testing linked to our national screening programs.

Q5. Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials?

There is some uncertainty in this document about where clinical trials fit. The inclusion of clinical trials in Foundation Objective 1 at 1.1 and Strategic Objective 2 in the overall goal and 2.2, 2.3, and 2.4 detracts from the importance of clinical trials – they should be presented clearly and strategically in this document. The text included at 2.3 and 2.4 also lacks clarity and adds to the dilution of the importance of clinical trials in this document.

We are delighted to note that the MPCCC Precision Cancer program addresses the actions of this objective with its goal to deliver equitable access of affected people to cancer genomic testing where there is evidence of benefit, access to genomics-informed cancer treatments and clinical trials and promote translational research championed by dedicated clinical oncology fellows.

This is a large and complex strategic objective and better clarity between 2.3 and 2.4 is required. At present these items appear similar and the importance of the specialist and primary care sectors is lost in 2.4. Our Roadmap identifies many of the challenges that need to be addressed to achieve these objectives.

To overcome the many and varied sources of information about testing pathways, eligibility etc that is not well understood and is communicated in a haphazard way; our Roadmap recommends consolidating all the information into one place, so it is easier for clinicians to access the right, up-to-date information that might include tools to assist decision making. Targeted education could also be achieved via MTB attendees.

Q6. Do you have any comments or feedback on strategic objective 3: supportive care?

The patient experience appears key to achieving the goal and realising impactful actions. At present the patient experience is somewhat lost in 3.3 and would do better to be prominent and detached from pharmacogenomic issues.

To contribute to the accumulating understanding of patient attitudes and perspectives on cancer genomics, the Roadmap recommends conducting a systematic review of all Australian patient perspectives on comprehensive genomic testing, including willingness to pay, attitudes, etc. A few studies exist gaining insights on patient perspectives of testing. The VCCC Alliance Personalised Cancer Care program supported a consumer-led study examining patient and care-giver experiences of accessing and receiving tumour genetic profiling in Victoria (manuscript currently in draft). Insights include current gaps in access, awareness, education and training. A consumer-driven systematic review could collate all available evidence into one place to be used as part of advocacy strategy for funding, awareness etc.

Q7. Do you have any comments or feedback on strategic objective 4: awareness and education?

This is an important and complex objective. Some key professionals are addressed in the current text. The Roadmap highlighted the lack of nationally recognised qualifications for data curation scientists, who are critical to genomically informed cancer care. While courses are offered by various organisations, none lead to national qualifications. This inconsistency affects frameworks for competencies, benchmarking, and remuneration. Curation and research scientists must stay aligned with clinical realities and evidence gaps by participating in Molecular Tumour Board meetings and other forums.

Medical students need a stronger foundation in basic genetic principles, with genetics integrated into oncology training. Given the dynamic nature of genomic oncology, clinicians must foster continuous learning. Additionally, it’s essential to identify education gaps in molecular testing for healthcare professionals beyond oncology to develop tailored professional development programs.

Patient education must also address cultural needs, particularly for Aboriginal, Torres Strait Islander, and CALD communities, with these groups represented in governance. All cancer-related educational materials should be consolidated into a trusted, centrally managed platform with clinician- and patient-focused content, supported by a strong communication strategy.

Q8. Do you have any comments or feedback on foundational objective 1: research and data?

The VCCC Alliance and MPCCC recognise the critical importance of a foundation of evidence from cancer genomic research and data that represents the diversity of the Australian population. Our organisations have a number of initiatives that continue to address inequities of access to clinical trials that incorporate genomics.

- **Equity in Genomic Research:** The underrepresentation of rural/regional and culturally diverse populations in genomic research is addressed in our Roadmap. The Roadmap proposes a targeted approach to make genomic testing available to all Victorians and capture and link genomic data from all Victorians (including priority populations) to address systemic inequities. *Recommendation (R)8 Action (A)8.1, A8.2 and Appendix (App)4*

We also recognise the importance to collect, store and share cancer genomic data safely and securely and we further promote the benefits that are likely to flow from data integration approaches such as:

- **Integrated Data Ecosystems:** The Roadmap advocates leveraging existing data repositories and linkage platforms (e.g., BioGrid Australia and the Monash Clinical Outcomes Registries) to integrate molecular testing data with clinical and patient reported outcomes, ensuring consistency in data collection and facilitating population-wide research. *R8 A8.1 and App4*
- **Piloting Data Models:** It recommends piloting integrated data systems for selected cancers to assess feasibility, which aligns with building adaptable national genomic data frameworks. *R8 A8.1*

Further, we also anticipate work required for system readiness for equitable, Australian-wide comprehensive genomic profiling. We recommend that the assessment of system readiness for comprehensive genomic profiling rollout be prioritised to anticipate resource and infrastructure needs, ensuring a sustainable and equitable national implementation strategy. *R8 A8.1*.

We unreservedly support culturally safe approaches and Data Sovereignty principles to govern genomic data and commend the prominence of this approach in foundational objective 1.

Q9. Do you have any comments or feedback on foundational objective 2: workforce and models of care?

The VCCC Alliance and MPCCC recognise the 5 actions in this foundational objective to be important to the success of the framework. In addition to these, the work of our Roadmap provided additional and valuable insights that could strengthen Cancer Australia's Framework. The Roadmap emphasises building workforce capacity and fostering integrated care models to ensure equitable access to precision oncology services. Key contributions include:

- **Workforce Development:** The Roadmap identifies critical gaps in workforce training, including the lack of formalised accreditation pathways for variant curators and insufficient genomic education for medical, nursing, and allied health professionals. It recommends national benchmarks and competency frameworks to ensure consistency and enhance statewide workforce capacity, emphasising the importance of customised professional development for the broader workforce. *R1 A1.1 and R3 A3.1*
- **Genomics Integration into Training:** Advocacy for embedding genetics and genomics education into graduate medical and oncology specialist training aligns with the

Framework's goal of equipping healthcare providers with essential genomic competencies. *R2 A2.3*

- **Collaborative Multidisciplinary Care:** The Roadmap supports embedding genomic expertise within care teams by integrating curators and pathologists into Molecular Tumour Boards (MTBs) and standardising variant interpretation and reporting to streamline decision-making processes. *R2 A2.1, A2.2*
- **Culturally Responsive Models of Care:** Addressing the educational needs of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) communities is emphasised, advocating for co-designed, community-informed care models to improve genomic literacy and engagement. *R4 A4.1 and App4*

Q10. Do you have any comments or feedback on foundational objective 3: Funding, quality, and safety?

These issues were a feature of our Roadmap. Our recommendations reinforce the need for streamlined access to reimbursed genomics testing including advocating for Medicare Benefits Schedule (MBS) reimbursement of Comprehensive Genomic Profiling (CGP) for solid tumours and highlights the inequities arising from out-of-pocket costs and calls for government-supported programs to reduce patient financial burdens, particularly in regional and underserved communities. *R8 A8.1.*

We also found the following to be important considerations for this foundational objective:

Testing pathways: The Roadmap considers quality in terms of streamlining testing pathways and seeks standardisation of molecular test interpretation and reporting processes, including the adoption of consistent variant tier systems. The latter is identified as a priority to reduce variability and enhance the clinical utility of genomic testing. *R2 A2.2, R6 A6.1*

Pilot Programs and Evidence Generation: The Roadmap advocates for piloting state-wide Molecular Tumour Boards (MTBs) for rare and less common cancers and linking genomic testing outcomes with clinical data to inform quality assurance and future funding strategies. *R7 A7.2*

Addressing Systemic Barriers: Broader barriers such as fragmented pathology systems, lengthy report turnaround times, and funding limitations for public hospital inpatients are highlighted in *App4*, underscoring the need for cohesive federal and state funding approaches.

Q11. Do you have any comments or feedback on the draft 'Framework at a Glance' graphic?

The draft graphic summarising the Cancer Australia Framework is functional, however the following recommendations may improve clarity for diverse stakeholders:

- **Visual Appeal and Inclusivity:** The graphic may benefit from more dynamic visuals or imagery to enhance engagement. While it appears to target a broad audience, there is no explicit mention of consumers. Including representations of patients, families, and advocates could create a stronger connection to those directly impacted by cancer genomics.

- **Policy and Advocacy:** There is no visible emphasis on policy development or advocacy efforts, particularly concerning the ethical and equitable implementation of genomics. Concerns such as genetic discrimination and equitable policy frameworks to support those with hereditary risks must be explicitly addressed. Advocacy for consumer protections, equity, and inclusion is vital to instil confidence in genomics initiatives.
- **Equity and Cultural Safety:** While the ultimate aim of personalised, equitable, and culturally safe care is clear, the graphic implies that cultural considerations are confined to Aboriginal and Torres Strait Islander populations (suggested by the outer circle design). Self-determination and cultural safety must extend to all communities, particularly other culturally and linguistically diverse (CALD) groups, to truly achieve equitable care.
- **Interpretability:** The enablers (research, funding, workforce, and models of care) and focus areas (education, prevention, and diagnosis) are visible, but the absence of narrative context leaves room for misinterpretation. Clear, consumer-centred messaging around how these components interconnect to deliver meaningful outcomes would enhance comprehension.
- **Orientation:** There may be an opportunity to have the graphic drawn in reverse with the outer ring being centred and capturing more of our community.

Q12. Are there any other comments you would like to make regarding the National Framework for Genomics in Cancer Control?

N/A

Q13. Do you consent to your survey responses being published, including any feedback, comments, or insights you provide? All data will be handled in accordance with our privacy policy. Please select 'Yes' if you agree or 'No' if you do not.

☒ Yes, and publish my name or organisation

☐ Yes, but do not publish my name or organisation

☐ No

Q14. Would you like to upload additional feedback?

Yes, have attached our Roadmap