Have your say on the draft
National Framework for Genomics in Cancer Control

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Q.1 Which group(s) do you or your organisation represent or most closely associate with? Please select all that apply.*
(Maximum selection limit: 10)

☐ 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; max character limit 500):

Q.2 Which state or territory do you reside in, or is your organisation based in?*

(Maximum selection limit: 1)

☐ South Australia
☐ Tasmania
☐ Northern Territory
☐ Australian Capital Territory
☒ National Organisation
☐ New South Wales
☐ Victoria
☐ Queensland
☐ Western Australia
☐ Other (please specify)

Q.3 Do you or your organisation represent or identify as any of the following (select all that apply):*

(Maximum selection limit: 3)

☒ 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

Q.4 Do you have any comments or feedback on strategic objective 1: prevention and early detection?

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Character limit: 1500

This strategic objective refers to establishing evidence and embedding 'evidence-based culturally safe genomic testing'. Types of evidence, benchmarks and pathways for sustained implementation can differ between settings and genomic technologies. The Framework should define the different types of 'evidence', including how they can be established, and the benchmarks required to progress to next steps of research translation.

'Culturally safe genomic testing' and 'evidence-based' can also differ between cultures/populations. Can the Framework draw on examples of how evidence has been established and what the evaluation measures for successful expansion of genomic-led cancer care were? Programs like the Beautiful Shawl project, already highlighted as an example of a culturally safe cancer program, and the implementation and evaluation of the QIMR Berghofer 'Integrated Genetic Health Care' project could be drawn upon to facilitate evaluation. The Framework should further highlight which 'other priority population groups' (Action 1.2) will be prioritised.

Promoting translational research (Action 1.3), including translational research embedded in healthcare, is critically important. This should be strengthened across genomics policy in Australia, including the refreshed National Health Genomics Policy Framework. Evolving 'HTA methodologies and processes' (Action 3.1) will be important to better support translation and streamline access for patients.

Q.5 Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials?

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Character limit: 1500

There needs to be a shift toward genomic testing at diagnosis to inform clinical management, rather than when all other avenues have been exhausted. Further evidence could be established under strategic objective 2 to support the equitable implementation of this approach.

Researchers need significant support to navigate pathways for research translation and commercialisation. Cancer Australia could address this under Actions 2.2-2.3, in collaboration with national initiatives leading in this space and government granting bodies.

A national assessment of the current clinical trials landscape would identify where expanded access is needed (Action 2.4). Clinical trials should be more flexibly designed, but still able to address regulatory and HTA requirements. Australia needs to deliver on initiatives to create a more desirable and competitive clinical trials environment. Community education should build awareness of how clinical trials lead to better outcomes for people experiencing cancer.

Framework initiatives should prioritise population groups for equitable access/participation in genomics-related clinical trials. Actions should include developing a national system for capturing data on the number of Aboriginal and Torres Strait Islander participants in clinical trials. This will reveal the extent of underrepresentation and identify barriers to inclusion. There should be requirements for inclusion of priority populations in trials, and more inclusive enrolment criteria.

Q.6 Do you have any comments or feedback on strategic objective 3: supportive care?

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Character limit: 1500

The importance of genetic counselling should be highlighted in Action 3.1, and culturally informed genetic counselling services in Action 3.2. Consider the psychosocial impacts that the mandatory upload of pathology results to My Health Record may have on people with cancer and their families.

During the Genomics Policy Roundtable series hosted by Rare Cancers Australia and Australian Genomics in 2024, wrap-around person-centred care with psychosocial support was highlighted as critically important when introducing genomics. Care for individuals who lack family/support needs to be prioritised and could be highlighted under actions for strategic objective 3.

Action 3.2 should evaluate provision of wrap-around personalised genomic cancer care for Aboriginal and Torres Strait Islander people. The Implementation Plan needs to be informed by continuing engagement work with Aboriginal and Torres Strait Islander people to determine needs for culturally appropriate care.

There is a lack of detail on how the Framework will help to minimise impacts of financial toxicity (Action 3.4). Many factors (e.g. specific diagnosis, age, living situation, referral location) can predispose individuals to financial toxicity and these should all be addressed in relation to this action. The Framework could leverage the significant pharmacogenomics investment planned under the refreshed GHFM Implementation Plan to build additional evidence for minimising adverse drug reactions in cancer patients.

Q.7 Do you have any comments or feedback on strategic objective 4: awareness and education?

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Character limit: 1500

The goal for strategic objective 4 should focus on competence (as per Action 4.1) rather than ensuring 'all health professionals are skilled…'. Focusing on health professional education/decision support, and access to genomic testing (through research or clinical care) and clinical trials will enable more equitable access to genomic-led care. Leveraging other initiatives of the Framework for awareness and education will be important – e.g. what role can the Australian Comprehensive Cancer Network (ACCN) play in the education of health professionals? Collaborating with Genomics Australia and the National Health Genomics Policy Framework will also maximise practitioner education and education consistency/reach, to further mainstream genomic testing.

Awareness campaigns (Action 4.3) need to be tailored towards different audiences (e.g. children/adolescents, different cultural populations, etc.). There is a need to establish broader public awareness of genetic factors, cancer risk, genetic testing, and genomic profiling to ensure that individuals are empowered to advocate for themselves or their family members if they ever receive diagnosis. This information can be overwhelming if an individual only becomes aware after diagnosis.

Q.8 Do you have any comments or feedback on foundational objective 1: research and data?

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Character limit: 1500

Australian Genomics supports embedding an Indigenous focus across all Framework goals and actions. Establishing an Indigenous advisory committee to oversee the application of Indigenous Data Sovereignty principles (Action 1.3), Implementation Plan development/execution, and progress towards goals/actions (including Action 1.1) will lead to better outcomes. This committee would be well placed to engage NZ, Canada, and others to learn from approaches being implemented internationally.

Management and use of genomic and health data is a critical yet complex area that has been under-resourced to date. Australian Genomics recommends a stronger focus for the Framework on data infrastructure, including integrated clinical/research infrastructure, the development of registries, and linked data with detailed clinical and treatment data. This data could then be leveraged, with informed consent of patients, for health system evaluation, HTA, development of novel treatments and other research objectives.

A national cancer data framework (Plan Action 4.2.1) aligned with the NAGIM Blueprint (QGHA) and Implementation Recommendations (Australian Genomics) would streamline data standards, harmonise data collection and quality, and improve interoperability across a federated health system. These aspects must be pillars of the national cancer data framework, and the nationally consistent data processes (Action 1.2) to achieve maximum value.

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

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Character limit: 1500

Embedding genetic counsellors into specialist clinics has many advantages as a model to support mainstreaming cancer genomic testing (Action 2.2). These advantages include equity of access, timely testing, enabling continuity of care and educating other health professionals. This approach also helps to ensure appropriate testing, effective consenting practices, and wrap-around care with long-term follow-up, all of which will be important in facilitating access to comprehensive genomic profiling and precision therapies.

As previously mentioned, the design of cancer genomics clinical trials for inclusivity of Aboriginal and Torres Strait Island peoples (Action 2.4) could be facilitated through development of a national clinical trial registry to evaluate Aboriginal and Torres Strait Islander participation in clinical trials and help improve equity of access.

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

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Character limit: 1500

Innovative models for HTA/funding need to be implemented to address the current lack of equitable access in Australia to genomic technologies and downstream treatment options available in other countries (Action 3.1).

The complexity of the Australian healthcare system and shared responsibility for its funding and delivery influence the introduction of new, equitable models of care. Patients should have access to the best genomic-led cancer care across all settings (in/outpatient, public/private), and cancer centres (regional/metro). Funding models, such as a co-funded national genomic testing program, should be explored as part of the Framework to help achieve this.

Enacting legislation to ban use of adverse predictive genetic test results in life insurance underwriting is critical to protect privacy and confidentiality, including for cancer population screening and cascade testing. This will minimise financial toxicity by empowering individuals to access testing that can inform lifestyle/health choices, without fear of genetic discrimination and financial impacts. Australian Genomics reinforced the need for a legislative ban with no limits, caps or exclusions, with particular attention to significant impacts of genetic discrimination on Aboriginal and Torres Strait Islander people in our joint consultation response with the Australian Alliance for Indigenous Genomics (ALIGN). Australian Genomics encourages the Australian Government to prioritise passing the legislation.

Q.11 Do you have any comments or feedback on the draft Framework at a Glance graphic?

Download the draft Framework at a Glance graphic here

Character limit: 1500

The graphic could highlight how development of the Framework is an action (1.5.4) under strategic objective 1 of the Plan, and that it will be linked to an Implementation Plan. Specific priority populations could also be represented.

Q.12 Are there any other comments you would like to make regarding the National Framework for Genomics in Cancer Control?

Character limit: 1500

Further detail should be provided on unique roles of the Framework within the Australian cancer genomics landscape, and how it will avoid duplication, strengthen alignment and leverage the broader genomics agenda to optimise outcomes (page 11). The National Health Genomics Policy Framework, Genomics Australia, the NACCHO Aboriginal and Torres Strait Islander Cancer Plan, and the National Agreement on Closing the Gap are all mentioned (page 11). It will be important to identify shared priorities and work to achieve them cohesively while avoiding duplication of effort, particularly with the establishment of Genomics Australia and its priorities.

Some Implementation Considerations for development of the Framework (under Plan Action 1.5.4) still need to be addressed. The Framework does not 'include the interactions between genetic and genomic testing for cancers with those for other chronic illnesses or disabilities' or 'direction on appropriate testing for older Australians, including a model of engagement for seeking consent from older Australians, their families or carers, and the role of genomic testing alongside existing population-wide screening programs with aged-based eligibility requirements'.

The Framework contextualises the importance of each objective and their actions but lacks detail on how goals and actions will be achieved. The Framework and Implementation Plan must include this detail, with measures for success to facilitate evaluation of progress.

Q.13 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.

(Maximum selection Limit: 1)

☒ Yes, and publish my name or organisation
☐ Yes, but do not publish my name or organisation
☐ No

If yes and publish my name, enter preferred name*

Australian Genomics

Q.14 Would you like to upload additional feedback?

Choose a file to upload

(Allowed File Types : PDF,DOC,DOCX,XLS,XLSX,PNG,JPG,JPEG,GIF)