Draft National framework for genomics in cancer control

We thank Cancer Australia for the opportunity to provide feedback on the National Framework for Genomics in Cancer Control. In developing this submission, we have consulted with our industry members and consumer advisory group members to ensure the feedback reflects diverse perspectives and priorities. We also wish to express our support for the feedback provided individually by our members.

The Industry Genomics Network Alliance (InGeNA) is Australia's peak body for genomics and personalised healthcare, bringing together leaders across diagnostics, therapeutics, software, data, and analytics. Our membership spans from large multinationals to innovative startups, all working collaboratively to accelerate the adoption of genomics and embed it sustainably within Australia's health system.

InGeNA works closely with a wide range of stakeholders, including our consumer advisory group, to ensure that personalised healthcare delivers tangible benefits to all Australians. We are committed to advocating for the sustainable integration of genomics into healthcare, delivering clinical and efficiency benefits that improve prevention, treatment, and quality of life.

InGeNA welcomes the opportunity to provide feedback on this consultation and reaffirms our commitment to supporting Cancer Australia in embedding genomics into clinical care to improve cancer outcomes for Australians.

1. **Focus on Clinical Implementation**: Prioritise clinical implementation over addressing evidence gaps, particularly for somatic tumour and haematological malignancy testing.
    - *Sweden*: National comprehensive genomic profiling for all solid tumours, expanding to haematological cancers.
    - *France and Germany*: Nationally-led programs scaling access to genomic profiling, demonstrating transformative outcomes.
2. **Somatic vs Germline Testing**: Distinguish somatic testing (e.g., tumour/haematological profiling) from germline testing (e.g., risk/prognostic tests). These areas require different evidence, data management, and implementation strategies, necessitating tailored approaches.
3. **Equity and Access**: Address barriers to genomic services for rural, regional, and underserved populations. Leveraging internationally proven approaches to achieve equitable care is essential.
4. **Implementation Roadmap**: Develop a clear, actionable plan with timelines, measurable goals, and sustained funding to translate genomics into clinical care.
5. **Consumer and Stakeholder Engagement**: Embed robust engagement processes with consumers, healthcare providers, and peak consumer bodies. Consumer peak bodies role is not well utilised in the framework, and recognising their roles as key change agents to build genomic literacy, consumer confidence, and system

integration. Consumer peak bodies recently engaged nationally on prevention and the role of genomics.

6. **Industry Engagement**: Industry provides the critical tools, products, and expertise for cancer genomics. A deeper partnership with industry is essential to ensure feasibility, scalability, and innovation in the mainstreaming of genomics. Current mention in the Framework (p. 19) does not adequately address the role in a collaborative manner that industry works with government and the healthcare system as well as consumer peak bodies.
7. **Predictive Data Utilisation**: Incorporate predictive data to proactively understand cancer trends and natural history, such as identifying correlations between genetic markers, cancer progression, and the onset of secondary conditions. This supports precision medicine and preventative care strategies.

We also encourage Cancer Australia to recognise the necessity of a strong partnership with industry organisations like InGeNA. With shared goals and values to improve the health and wellbeing of Australians, we are well-positioned to work closely with Cancer Australia to ensure genomics is embedded effectively in clinical care. Collaborative efforts, leveraging cross-sector expertise, will help achieve transformative outcomes in cancer genomics for the Australian population.

This Framework represents a pivotal opportunity for Australia to lead in genomics-driven cancer care. A stronger focus on clinical translation and coordinated partnerships will maximise its impact.

Do you have any comments or feedback on strategic objective 1: prevention and early detection? Download the Draft National Framework for Genomics in Cancer Control

InGeNA welcomes the focus on prevention and early detection. To maximise its impact, we recommend:

1. **Equitable Access**: Prioritise equitable access to genomic screening and testing for diverse populations, including regional, rural, and underserved communities.
2. **Data Integration**: Establish national standards for integrating genomic data with existing cancer registries to enhance prevention strategies.
3. **Education**: Invest in public and professional education
4. **Implementation Research**: Support research on large clinical studies for early detection modalities and implementing genomic-based prevention and early detection programs in real-world settings to ensure feasibility and scalability.
5. **Focus on early detection plays a key role in cancer mortality in the next 10 years**.

We note caution in using high PRS as a mechanism for prophylactic surgery. Identifying people who have gene mutations is a good start however, they can only undertake prophylactic surgery or high-risk screening if they can access it or in some cases afford it. The focus needs to be broader than simply getting people tested. There needs to be a focus on timely access to risk-reduction options and screening. It would also be beneficial to collect data on prophylactic surgeries so

uptake can be properly measured. Currently, there is no separate MBS item number for prophylactic mastectomy or oophorectomy.

Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials? Download the draft National Framework for Genomics in Cancer Control here

InGeNA supports the inclusion of genomics in improving earlier cancer diagnosis and therapeutic intervention, and clinical trials. To strengthen Objective 2, we suggest:

1. **Focus on Clinical Implementation**: Prioritise clinical implementation over addressing evidence gaps, particularly for somatic tumour and haematological malignancy testing.
2. **Comprehensive Testing**: Promote universal access to genomic testing at diagnosis to guide treatment and consider cascade testing for relatives with germline mutations.
3. **Real-World Integration**: Develop systems integrating genomic data into clinical workflows and decision-making tools for precision medicine.
4. **Clinical Trials Access**: Enhance access to genomics-driven trials ensuring trial participants selected for inclusion in are most appropriate candidates to accurately reflect the efficacy of the treatment candidate through awareness campaigns and digital trial-matching platforms, especially for rural and underserved populations.
5. **Workforce Development**: Upskill healthcare professionals in interpreting and applying genomic data.
6. **Data Sharing**: Establish national standards for ethical data sharing to foster research and maintain trust.

Implementation must include public-private partnerships, as international, with industry engagement embedded in the Framework to mainstream genomics effectively.

- *Sweden*: Standardising comprehensive genomic profiling for solid tumours, expanding to haematological cancers.
- *France and Germany*: Scaling access to genomic profiling through nationally-led programs.

A coordinated approach with defined outcomes and cross-sector collaboration is critical for success.

3. Do you have any comments or feedback on strategic objective 3: supportive care? Download the draft National Framework for Genomics in Cancer Control here

InGeNA commends the inclusion of supportive care in the Draft National Framework for Genomics in Cancer Control. To enhance Strategic Objective 3, we recommend:

1. **Personalised Support Plans**: Leverage genomic insights to tailor supportive care plans, addressing individual patients' physical, psychological, and social needs.
2. **Genomic Literacy for Care Teams**: Provide training for healthcare providers and allied health professionals enabling their effective understanding of the implications of genomics on supportive care. More care closer to home regardless of postcode
3. **Access to Psychosocial Services**: Ensure equitable access to psychosocial support services for patients and families navigating genomic testing results and implications.
4. **Support Networks**: Foster connections between patients, families, and peer support networks to share experiences with genomics-informed cancer care.
5. **Provide financial support to the advocacy patient support bodies providing patient and family care that wraps around the direct clinical care and is currently not recognised.**
6. **Genomic literacy to enable better agency and shared decision making for patients and families.**
7. **Cultural Safety**: Develop culturally safe resources for diverse populations, ensuring genomic information and care approaches are inclusive and respectful.

A focus on coordination across care settings and stakeholder input will ensure genomics is seamlessly integrated into holistic cancer care.

Q 7 **Do you have any comments or feedback on strategic objective 4: awareness and education?** Download the draft National Framework for Genomics in Cancer Control here
InGeNA strongly supports the emphasis on awareness and education. We recommend:

1. **Public Awareness Campaigns**: Develop targeted campaigns to improve understanding of genomics' role in cancer prevention, diagnosis, and treatment, with a focus on reaching diverse and underserved populations.
2. **Workforce Training**: Ensure comprehensive, ongoing education for healthcare professionals on the clinical application of genomics, including ethical considerations and communication of results.
3. **Educational Resources**: Create accessible, evidence-based materials tailored for patients and caregivers to guide informed decision-making about genomic testing.
4. **Cross-Sector Collaboration**: Partner with schools, community organisations, and media to integrate genomics education into broader health literacy initiatives.
5. **Measuring Impact**: Establish mechanisms to evaluate the effectiveness of awareness and education programs, ensuring continuous improvement and alignment with community needs.
6. **Health literacy and shared decision making should be core to the framework and across all objectives**. It helps to ensure social license and better health outcomes. Working with peak consumer bodies to also support health literacy is key as this is the network of informed consumers advocating in the health system. The framework does not recognise the role of peak consumer bodies in driving change.

A unified approach involving government, industry, and healthcare providers is essential for achieving widespread genomic literacy.

Q8 **Do you have any comments or feedback on foundational objective 1: research and data?** Download the draft National Framework for Genomics in Cancer Control here

InGeNA supports the focus on research and data as foundational to the Draft National Framework for Genomics in Cancer Control. To strengthen this objective, we recommend:

1. **Data Standardisation**: Implement national standards for genomic data collection, storage, and sharing to enable interoperability across systems and institutions.
2. **Equity in Research**: Prioritise inclusive research efforts that address underrepresented populations, ensuring genomic insights are broadly applicable.
3. **Longitudinal Data**: Invest in initiatives to link genomic data with longitudinal health records, providing deeper insights into cancer outcomes and care pathways.
4. **Collaborative Ecosystems**: Foster collaboration between academia, industry, and healthcare sectors to drive innovation and accelerate translation of genomic research into practice.
5. **Ethical Frameworks**: Ensure robust governance and ethical frameworks for genomic data use, balancing innovation with patient privacy and trust.
6. **Ensure that the goal clarifies what good looks like regarding the scale of clinical implementation and patient access.**
   Focus to be on translational research and relationship with industry and research is critical.

Q9 **Do you have any comments or feedback on foundational objective 2: workforce and models of care?** Download the draft National Framework for Genomics in Cancer Control here

InGeNA welcomes the focus on workforce and models of care as a foundational pillar. To enhance this objective, we suggest:

1. **Workforce Development**: Develop targeted training programs to build genomic literacy and competency across multidisciplinary teams, including specialists, primary care providers, and allied health professionals.
2. **Role Expansion**: to manage the complexities of genomic care delivery.
3. **Integrated Models of Care**: Design patient-centred care models that seamlessly incorporate genomics into cancer prevention, diagnosis, and treatment pathways.
4. **Collaboration Across Sectors**: Encourage collaboration between the healthcare, academic, and private sectors to support workforce scalability and sustainability.
5. **Future-Proofing**: Invest in adaptive training and systems to ensure the workforce can respond to emerging genomic technologies and their applications.
6. **Targeted upskilling of the primary care workforce needs special attention and that they recognise this as a paradigm shift in care and diagnosis.**
7. **Upskill health interpreters to help with CALD communities**. See study in Qld Genomics program.
8. **Timeliness of access to care and support is critical.**

A national strategy with measurable outcomes, funding, and continuous evaluation will ensure the workforce is equipped to meet the demands of genomics in cancer care.

Q10 **Do you have any comments or feedback on foundational objective 3: Funding, quality, and safety?** Download the draft National Framework for Genomics in Cancer Control here

InGeNA supports the foundational objective. To strengthen this objective, we recommend:

1. **Sustainable Funding Models**: Develop long-term, sustainable funding mechanisms for genomic testing, integration into care, and workforce training. This includes ensuring Medicare coverage for clinically validated genomic tests. Financial support for infrastructure for data analysis, reporting and storage.
2. **Access Equity**: Allocate funding to address disparities in access to genomic services, particularly in rural, regional, and underserved populations.
3. **Quality Standards**: Implement national benchmarks for genomic testing accuracy, laboratory practices, and clinical interpretation to maintain consistency and trust.
4. **Safety Frameworks**: Ensure genomic data privacy and security through robust policies, protecting patient information while enabling research and clinical use.
5. **Outcome Monitoring**: Establish systems to monitor the clinical and economic impact of genomic initiatives, driving accountability and continuous improvement.

A collaborative approach, underpinned by clear guidelines and stakeholder engagement including with industry, will be essential to deliver high-quality, safe, and equitable genomic care.

Q11 **Do you have any comments or feedback on the draft Framework at a Glance graphic?** Download the draft Framework at a Glance graphic here

InGeNA appreciates the concise presentation of the Framework at a Glance and offers the following suggestions for improvement:

1. Clear statement of clinical implementation focus is needed. Statement of scale of implementation to demonstrate what good looks like for Australians.
2. **Equity Emphasis**: Highlight equity as a cross-cutting theme by including a visual cue or explicit reference across all objectives.
3. **Supportive care – elaborate with care in healthcare and NFP community sector.**
4. **Call to Action**: Incorporate a clear message or tagline at the end to reinforce the purpose and encourage stakeholder engagement.
5. **Highlight awareness, health literacy and shared decision making to ensure social license about genomics and patient agency in their health decisions.**
6. **Innovation is a key element of this rapidly changing area so that patients benefit from research and industry innovations.**

A well-designed visual will enhance understanding and engagement across diverse stakeholders.

Q12

1. **Focus on Clinical Implementation**: We encourage Cancer Australia to prioritise clinical implementation over addressing evidence gaps, particularly for somatic tumour and haematological malignancy testing. International examples highlight the feasibility of rapid progress in this area:
    - **Sweden**: Implementing a standardised national comprehensive genomic profile for all solid tumours, with plans to expand to haematological cancers.
    - **France and Germany**: Establishing nationally-led structures to scale access to genomic profiling, demonstrating the potential for transformative outcomes through coordinated approaches.
2. **Somatic vs Germline Testing**: We recommend a stronger distinction between somatic testing (e.g., genomic profiling of tumours and haematological malignancies) and germline testing (e.g., risk profiling and prognostic tests). These areas require different considerations for evidence requirements, data inclusion/exclusion, storage, and utilisation. Addressing them separately would support more tailored and effective policies and implementation strategies.
3. **Equity and Access**: Ensure equitable access to genomic services by addressing barriers in rural, regional, and underserved populations. International examples underscore the value of nationally coordinated programs in achieving consistent and equitable care.
4. **Implementation Roadmap**: Provide a clear, actionable implementation plan with defined timelines, measurable goals, and sustained funding to translate genomics into clinical practice effectively.
5. **Consumer and Stakeholder Engagement**: Embed robust engagement processes with consumers, healthcare providers, and industry to align the Framework with the needs and priorities of those it serves.
6. **Industry engagement**. Industry provide the all products and instruments used in clinical and research settings for cancer. Understanding and aligning with the priorities and issues of feasibility for mainstreaming of genomics in cancer control is critical. The role of industry is mentioned once on p 19 that industry be consulted on guidance methods.
7.

This Framework represents a pivotal opportunity for Australia to lead in genomics-driven cancer care, and we encourage a stronger emphasis on clinical translation to maximise its impact.

Closing comments

Thank you for the opportunity to provide feedback. InGeNA and our members are highly collaborative and deeply committed to improving the lives of Australians through the adoption and integration of genomics into healthcare. We welcome the opportunity for

closer engagement with Cancer Australia to support the implementation of the Framework.

As a trusted partner, we are keen to work alongside Cancer Australia and other stakeholders to ensure the successful realisation of this Framework's vision. Together, we can deliver transformative outcomes that enhance the health and wellbeing of all Australians through genomics-driven cancer care.