Survey Questions

Q4. Do you have any comments or feedback on strategic objective 1: prevention and early detection? Character Limit: 1500

Action 1.1 Requires increased capacity and capability in primary care to manage the workload associated with assessment and prevention strategies for people identified with high-risk genetic profiles, including follow-up testing, surveillance and advice

Action 1.2 Requires investment to support participation of diverse Australian communities in research and address barriers to participation, including cost and time burden for people living in remote/rural areas. Training is required to upskill First Nations community leaders and health professionals to encourage local community participation.

Action 1.3 Need for a National Genomic Database, linked to cancer registries, to increase volume and depth of diverse genotype/phenotype data available for prospective cohort studies. Ethics and governance processes required to support translation of research genetic data into risk-based cancer screening and help expedite assessment of the clinical need, validity and utility of genetic tests to prioritize implementation into clinical practice.

Action 1.4 Culturally safe and appropriate genetic counselling services to be embedded in primary care to support use of genetic screening in national cancer prevention programs. Genetic test results can impact personal circumstances, including ongoing high-risk status surveillance, prophylactic procedures and fertility interventions, which can be stressful and should only undertaken with informed consent.

Q5. Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials? Character Limit: 1500

Action 2.1 Genomic sequencing technologies pose challenges not seen in genetic technologies in terms of assuring informed consent. Specific recommendations and governance will be required to ensure informed decision-making and consent is acquired in practice to enable the collection, storage and use of personal genomic data. Consideration should be given to how to manage the discovery of secondary findings (information that is not explicitly sought) or non-actionable mutations/variants.

Action 2.2 This will require HTA reform to balance evidence-based decision-making with cost-effectiveness to enable timely and equitable access to genomic-informed targeted treatments. This should aim to align and streamline HTA processes (PBC, MBS and NHRA) to ensure precision oncology companion diagnostics and therapies are reviewed and approved together and expedited approvals of multiple indications (pan tumour) based on targeted biomarkers.

Action 2.3 There should be an aim to develop a National Genomic Database that collects genomic data from research, clinical trials and clinical practice, collected by different providers to facilitate ongoing translational research.

Action 2.4 Consideration should be given to the capacity and capability of genomic testing providers to meet the needs of the health care service to ensure all Australians have equitable and timely access to genomic testing regardless of the setting.

Q6. Do you have any comments or feedback on strategic objective 3: supportive care? Character Limit: 1500

Action 3.1 Funding of psychosocial services to ensure equity of access to meet expected demand due to genomic testing. Current accessibility of psychosocial care across Australia is variable and limited in remote/rural locations. Clear defined referral pathways to help direct patients to appropriate support, based on circumstances and need for psychosocial or genetic counselling.

Action 3.2 Improve genomic literacy among community-controlled health services to help patients, families and communities navigate genomic informed cancer care and provide support for informed decision-making and consent to testing. Address barriers (travel/cost/time) to equity of access to supportive care for remote/rural communities.

Action 3.3 Requires multi-disciplinary approach with clinicians, pharmacists, nurses, and allied health playing a role in educating patients about pharmacogenomics and advice on testing costs, availability of different treatments, and supportive care.

Action 3.4 Financial toxicity should be considered to access psychosocial and psychological support for informed decision-making and consent to genomic testing. Consider the ethics of identifying patients with a mutation, with no currently available PBS-funded treatment, which could impact their decision to pay out of pocket or their inability to access therapy due to the cost.

Q7. Do you have any comments or feedback on strategic objective 4: awareness and education? Character Limit: 1500

Action 4.1 Education on genetics-informed preventive cancer control (communicating risk, test result interpretation, prevention and surveillance strategies). Professional development and accreditation should be available for all health professionals involved in genomics-informed cancer care, including nurses, psychologists and allied health.

Action 4.2 Resources to aid decision-making, referral and communication about genomic testing informed consent. Integrate recommendations on genomic testing into clinical practice guidelines (Optimal Care Pathways) and models of care to ensure national consistency in the implementation in diagnosis and treatment. Resources available for all care settings, including primary care.

Action 4.3 Increase genetic and preventive health literacy of patients to help promote use of risk-based cancer prevention and screening. Help inform public debate and policy development on the limits of the use of genomic information to inform public health. Consider the need for advice and guidance for health professionals and patients on the use of direct-to-consumer genomic/genetic tests. Campaigns should target patients in all care settings including primary and community care.

Action 4.4 No mention of other priority population needs, people with disability, including learning disabilities and implications for informed decision-making and consent to genomic testing.

Q8. Do you have any comments or feedback on foundational objective 1: research and data? Character Limit: 1500

Action 1.1 Government, healthcare providers and industry investment needed in infrastructure (biobanks, sequencing technology and data systems) and workforce capacity to ensure equity of access genomics for all Australians. Consideration of ethics and governance of sharing de-identified genomic data (linked to clinical outcomes data) with researchers and commercial entities to support translation of diagnostic and therapeutic advances into clinical practice to improve outcomes for individuals and the community.

Action 1.2 National Genomics Data Strategy to address data ownership, privacy and consent. Enable Australia-wide access to genomic data to enable coordination between Commonwealth, State and Territory health systems and sharing infrastructure and resources. Urgent need for investment in healthcare IT systems and data infrastructure to support expansion of genomic services. International collaboration and cooperation required to enable genomic data sharing to improve research translation into clinical practice, with consideration of the rights of the individual and health data privacy and governance frameworks.

Action 1.3 Indigenous researchers and community representatives involved in co-design of genomic data registries to ensure Indigenous Data sovereignty principles are applied. National Genomic Research Guidelines to define best practice for culturally appropriate engagement of Aboriginal and Torres Strait Islander peoples representation in genomic research.

Q9. Do you have any comments or feedback on foundational objective 2: workforce and models of care? Character Limit: 1500

Action 2.1 Term 'healthcare professionals' is preferable to 'clinicians' as it is inclusive of diverse range of professions involved in cancer control. Mainstreaming genomics will require cancer nurses to help inform and support patients, families and carers to facilitate access to testing. Current limited resources and education will impact workforce capacity and capability to deliver genomics-informed cancer care. Urgent need for investment in cancer nursing education in genomics and credentialling to ensure standardised best practice care for all Australians.

Action 2.2 Geneticists need to be integrated into oncology multidisciplinary team to improve capacity, accuracy and interpretation of genomics into care. Need to increase capacity by delivering training and positions for geneticists and genetic counsellors who have a role in all stages of cancer continuum, from prevention (communicating risk and screening recommendations) to treatment decision-making, and supporting emotional distress, impact on family and decision regret.

Action 2.5 Develop new models of care to ensure consistent access to high-quality genetic health services. Consider the role of primary care and community health services in genetic counselling to address the increased demand and equity of access for underserved populations, especially those in remote/rural areas.

Q10. Do you have any comments or feedback on foundational objective 3: Funding, quality, and safety? Character Limit: 1500

Action 3.1 Recognition of the limited available genomic data for small populations with specific mutations to support the evidence for approval of biomarker targeted therapies, consideration should be given to the evidentiary requirements and definition of value in HTA assessments of

genomic-informed therapies and align PBAC and MSAC processes for co-dependent technologies.

Action 3.2 National leadership in conjunction with state and territory governments is critical to achieving equity of access to genomic services and appropriate allocation of resources to ensure genetic health service delivery meets the needs of the population.

Action 3.3 Consideration should be given to the utility of genomic data sharing beyond cancer as there may be implications for the use of the data in research in other health conditions.

Action 3.4 Informed consent is important to ensure individuals understand how genomic data is collected, stored and utilised. An ethical human rights-based approach is required to ensure the rights of the individual are protected. Consideration should be given to informed consent processes and permissions (exemptions for use posthumously) to share personal genetic information which has implications for family members and guidance on how to manage the ethical implications for unactionable mutations, incidental findings and future discoveries for the individual.

Q11. Do you have any comments or feedback on the draft Framework at a Glance graphic? Character Limit: 1500

No

Q12. Are there any other comments you would like to make regarding the National Framework for Genomics in Cancer Control? Character Limit: 1500

Reference and align with National Health Genomics Policy Framework (under review) and state/territory genomics strategies is important for consistent and coordinated approach to genomics and reduce service delivery variability across Australia, which leads to inequities.

Acknowledge the needs of different priority populations, people with disability, experience disparities in cancer screening, diagnosis and treatment, likely impacting access to genomics. Strategy to address impact of learning disabilities on informed decision-making for genomic testing.

Framework has a ten-year time horizon, in a rapidly evolving space, need a plan for review of implementation with measurable outcomes informing future updates.

Framework does not address gap between supply and demand for specialist genomics services and capacity of health services. Need to increase specialist genomics workforce and adapt models of care to support access to cancer genomics services for all Australians. Foundational objective 2 requires actions around service integration, workflows and clinical pathways, professional responsibilities, scope of practice, governance, resource planning and ongoing operational requirements.

The critical role of nurses in cancer care across Australia, regardless of geographical location, population group or specialty. Nurses are first point of contact with patients, highly accessible workforce at the interface between patient, healthcare system and new technologies.