

## National Health Genomics Policy Framework Consultation July 2025

### Survey Responses (refer to each section of the [Draft Framework](#))

4. Do you support the Vision for this draft Framework and Implementation Plan?\_YES
5. Do you support the Mission for this draft Framework and Implementation Plan? YES
6. Do you support the five Guiding Principles for this draft Framework and Implementation Plan? YES
7. Do you support the four Enablers of Success for this draft Framework and Implementation Plan?  
YES
8. Do you think there is anything missing from the Vision, Mission, Guiding Principles, and/or Enablers of Success in this draft Framework and Implementation Plan? YES

*Add Enabler of Success: Provision of fit-for-purpose health technology infrastructure and assessment frameworks for timely equitable access. Recognising the fundamental importance of a coordinated and top-down approach to this key enabler. We can't embed genomic-led health without structural HTA reform to recognise the broader value chain and rapid pace of the evolving technology, or the provision of novel funding models that support timely patient access and utilisation of real-world evidence.*

9. Do you think the four Strategic Priorities will support the Vision for this draft Framework and Implementation Plan? UNSURE OR UNDECIDED

10. Do you think there are any key focus areas missing across the four Strategic Priorities? YES

If yes, how should the four Strategic Priorities be expanded or improved?

*A standalone Strategic Priority "Sustainable and Integrated Funding Models".*

*To embed genomics into health, every component of this framework: education, workforce, infrastructure, testing, data management, clinical up skilling, research etc. requires robust and predictable funding mechanisms.*

*A dedicated and forward-looking funding pillar ensures investment keeps pace with technology evolution, research updates, and emerging population needs. Purpose-driven funding drives equitable access.*

11. What information or data should be collected to monitor and evaluate the outputs and outcomes of this draft Framework and Implementation Plan?

*Data reflecting both operational progress and real-world impact, including but not limited to:*

*Volume/type tests*

*Turnaround time*

*Adoption patterns*

*Demographic/geographic accessibility data  
Out-of-pocket costs  
Distribution of funded test infrastructure  
Number/distribution trained professionals  
Mainstream genomic competency benchmarks  
Number of technologies integrated into routine care  
Average time to fund tech  
Audit reports for data security/sovereignty  
Participation rates in research or trials*

12. Do you think the Outcomes for Strategic Priority 1 in the draft Framework and Implementation Plan will support the embedding of genomics into the Australian health system, maximise health and wellbeing outcomes, and minimise duplication of effort? UNSURE OR UNDECIDED

13. Do you think the Activities for Strategic Priority 1 will achieve the specified Outcomes? NO

14. Are there any other Outcomes or Activities you think governments should consider for this Strategic Priority?

*Establish direct linkage b/w Guiding Principles, Strategic Priorities, Outcomes & Activities for meaningful/measurable results, Activities must address known access barriers incl. financial, geographic, cultural & educational. Verbs needed to reduce access inequities across public & private systems, Medicare-funded, out-of-pocket, & insurer-funded genomics. Recognise informed consent involves relationship with health workforce & link these activities accordingly. Elevate consumer protections.*

15. Do you see any risks or challenges with achieving the outcomes or implementing the activities under Strategic Priority 1? YES

*Too much emphasis on consultation, no metrics tracking implementation progress, community literacy or diversity/representation. Need language to remove risk of genetic discrimination. Need clear metrics assessing equity of access. Need stronger language supporting meaningful ways to elevate educational materials & measure awareness/traction. Consider embedding genomics into mainstream educational institutions. Risk of NFP advocacy groups overwhelmed without increased resources. Duplication risk.*

16. Do you think the Outcomes for Strategic Priority 2 in the draft Framework and Implementation Plan will support the embedding of genomics into the Australian health system, maximise health and wellbeing outcomes, and minimise duplication of effort? UNSURE OR UNDECIDED

17. Do you think the Activities for Strategic Priority 2 will achieve the specified Outcomes? NO

18. Are there any other Outcomes or Activities you think governments should consider for this Strategic Priority?

*Fit for purpose values-driven assessment/funding pathways*

*Identify & support capital & recurrent investment needs for laboratories, digital platforms, instruments, & workforce.*

*Early Value Assessment options for emerging technologies*

*Conditional reimbursement for RWE generation*

*Mission-based funding for unmet national needs*

*National test directory*

*Funded & adaptable service delivery models including telehealth, primary care, private pathology, community clinics, ACCHOs, and hospital settings*

19. Do you see any risks or challenges with achieving the outcomes or implementing the activities under Strategic Priority 2? YES

*Must elevate assessment/funding in a standalone strategic priority.*

*Address structural barriers in current HTA/reimbursement processes by employing novel mechanisms*

*Patient journey maps don't explicitly facilitate faster or more equitable access*

*Horizon scanning should partner with the industries developing the technology at scale, & sit at Federal level, not siloed within States.*

*Outputs should align with national population needs to inform strategic investment*

*No bold vision or clear metrics*

20. Do you think the Outcomes for Strategic Priority 3 in the draft Framework and Implementation Plan will support the embedding of genomics into the Australian health system maximise health and wellbeing outcomes, and minimise duplication of effort? UNSURE OR UNDECIDED

21. Do you think the Activities for Strategic Priority 3 will achieve the specified Outcomes? NO

22. Are there any other Outcomes or Activities you think governments should consider for this Strategic Priority?

*National data infrastructure roadmap & funding mechanisms incl:*

*Procurement maintenance upgrades retirement*

*Explicit framework & funding mechanisms for national data sovereignty & safety standards, management, & enforcement prioritising suitability for healthcare over research*

*National test directory, searchable & accessible to public, regularly curated, remove redundancy*

*Centrally coordinate critical data infrastructure*

*Recognise other available infrastructure more than Shariant/PanelApp*

23. Do you see any risks or challenges with achieving the outcomes or implementing the activities under Strategic Priority 3? YES

*Standards must align with international best practices for compatibility, scalability & to avoid inadvertent exclusion of global industry tools & services.*

*Embed funding mechanisms into every activity*

*No activities to measure representation of diverse population within data*

*No mechanisms defined to measure or monitor data security/safety or enforce security/safety & sovereignty principles*

*No bold statements on interoperability & system maturity requirements or defined metrics to monitor progress*

24. Do you think the Outcomes for Strategic Priority 4 in the draft Framework and Implementation Plan will support the embedding of genomics into the Australian health system, maximise health and wellbeing outcomes, and minimise duplication of effort? UNSURE OR UNDECIDED

25. Do you think the Activities for Strategic Priority 4 will achieve the specified Outcomes? UNSURE OR UNDECIDED

26. Are there any other Outcomes or Activities you think governments should consider for this Strategic Priority?

*Although in recognition that this is a Strategic Priority, specific for Aboriginal and Torres Strait Islander populations, observation that there are no other Outcomes or Activities within the existing Framework to speak to other priority populations and under-served communities named within the Framework pre-amble and Guiding Principles.*

*Including but not limited to:*

*Multi-language assets*

*Metrics & reporting on systemic equity*

*Embedding genomics in existing trusted health access points*

27. Do you see any risks or challenges with achieving the outcomes or implementing the activities under Strategic Priority 4? YES

*Community-led & co-designed activities are inherently slow & resource-intensive, & risk becoming siloed from rest-of-system activities*

*Important to define, monitor, & report on impact of the Strategic Priority Outcomes & Activities on National Closing the Gap and other relevant access & equity measures.*

28. Was the draft Framework and Implementation Plan easy to read and understand? UNSURE OR UNDECIDED

If not, how could we improve this?

*Clearer linkage of the Framework Guiding Principles & Enablers of Success to the Outcomes and subsequent Activities. Current Outcomes do not fully address Strategic Priorities, and not all Outcomes are addressed by an Activity. The whole Framework needs more verbs with bold Activities that are meaningful and measurable. The whole Framework needs to link more explicitly to other relevant Strategies i.e. National Framework for Genomics in Cancer Care. Compare to UK examples for required ambition*

29. Do you have any other feedback regarding the draft Framework and Implementation Plan?

*The focus on foundational activities, consultation & review, do not adequately acknowledge the extensive processes already conducted, risking undue duplication & ultimately slowing down meaningful action. Stronger Outcome statements needed that clarify Australia's vision for genomics in healthcare linked to the full value-chain of impact from prevention, detection, diagnosis, targeted treatment, monitoring, and prognosis. Meaningful national direction is needed to address fragmented funding processes that impact equitable access & scalability of existing infrastructure & services. Use clearer language throughout & incorporate more verbs linked to delivery of genomic-led healthcare to drive urgent action Existing assessment and funding mechanisms are a significant barrier limiting adoption of genomic technology & access to benefits. Either embed explicit funding mechanisms into every activity or ensure a detailed standalone priority creates sustainable support mechanisms. The time for consultation and more talk is well and truly over.*

### **Notes from PTA Member Advisory Panel Meeting**

#### Guiding Principles (pg9)

- Don't believe the proposed outcomes go far enough to meaningfully support these principles

#### Enablers of Success (pg11)

- Should have actions within the strategic priorities that clearly support these enablers of success.
- The strategic pillars are now too compacted and lost their focus.
- Enabler of success draws on trust, innovation, and creating the forums that facilitate dialogue and contribution of all stakeholders. No mention of the technology required.

#### Governance (pg12)

- How will this be reported to other stakeholders for transparency and accountability – unclear how they calculate the baseline and any progress from that.

#### Strategic Priority 1 – Person-, Family- and Community-Centred Approach (pg14)

- Does the role of clinical training and genetic counselling need to be explicitly called out here?
- What would a more explicit path for professional development look like? including interaction with other patient and family advocacy and support services (point also InGeNA identified)
- Only speaking to public hospital services, but in the overarching principles statement it spoke to the many different ways in which people access healthcare, how do these priorities address other touchpoints (i.e. GPs and specialist services?)
- Outcomes only relate partially to the objective – no action around increased equity of access –
- Education – urgent need for healthcare practitioner upskilling in genomics, no outcome for genetic discrimination act (no guardrails), not just relying on industry to facilitate knowledge transfer – needs to be embedded in training and education systems.

- Private health insurance as a stakeholder and lack of legislation to protect consumers.

Strategic Priority 2 – Dynamic and Sustainable Genomics Ecosystem (pg19)

- Agree with InGeNA that funding needs its own strategic priority – the assessment and funding mechanisms are a significant barrier limiting adoption and access to genomic testing in addition to:
  - Lack of infrastructure within existing pathology networks and minimal to no support for adoption of new technology
  - Minimal funding with confusing and restrictive conditions, large onus on sponsors to create application with no guarantee of success – seeking collaborative and pro-active support from government to identify testing per national priorities
  - Lack of interoperability of data across siloed health systems between state and between clinical and research
  - Lack of education in community and healthcare services
  - Lack skilled workforce and insufficient remuneration for skilled services
- Necessary infrastructure is doing a LOT of heavy lifting here – more explicit outcomes directed to this point are needed to meaningfully achieve goals
- Very soft language around supporting alternative investment and funding models at Federal level.
- Stepping stones listed in outcome 2.1 do not reflect enough action to ensure the workforce, infrastructure and services will be developed and put into action
- Outcome 2.3 needs to be a strategic priority in its own right – this is a major boundary and without adequately addressing the overarching goal of supporting equal access to all Australians will not be meaningfully impacted
- If we utilise MBS funding, we must establish an alternative assessment pathway that incorporates early value assessment for technology that addresses unmet clinical needs and allows for generation of real-world evidence
- It is likely necessary to explore alternative service delivery models to ensure diverse and flexible access options to serve all Australians, as well as explore funding options for wrap around services linked to genomic-led care plans
- Outcome 2.3 does not recognise the inherent barriers existing today in terms of access to and funding for instrumentation and other necessary infrastructure, the significant delays in funding through existing HTA pathways, the patchy coverage of existing funding across test menu (no universally accessible and easy to understand test directory) and other barriers
- Need to more clearly identify the funding pathways including early value assessment processes, mission-based approaches that “pull” in relevant technology and tools, and outcomes/value-based assessment pathways.
- Outcome 2.4 far too focused on the research aspect of appropriate data generation for HTA and fails to recognise and address that existing HTA processes are not fit for purpose for genomics, any evolution in funding or “financing” needs to consider the mechanisms for assessing “cost-effectiveness” to include the full value chain within HTA processes.

- Horizon scanning activities should be managed at a Federal level, population too small to focus on State-level capacities
- Need to have an established process to support and maintain “necessary infrastructure” – including
- How to map “patient journey, how to choose the specific case studies” and how will this facilitate faster access -
- Identifying bold new funding mechanisms, national genomic test directory, decouple diagnostic testing to drug reimbursement,
- Funding for implementation and service delivery is non-existent, roadmap for research is also insufficient, building solid evidence-base for population-based genomics interventions, funding is inadequate, dismal
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#### Strategic Priority 3 – Genomic Samples, Data and Information Management (pg27)

- Need to explicitly state that any principles and standards would adhere to global best practice to avoid inadvertently creating additional barriers when it comes to provision of tools and systems supplied from industry
- Need to explicitly identify the need to maintain data sovereignty and the process for which this will be funded, managed, and enforced
- Need to explicitly identify the mechanisms related to critical data infrastructure in terms of funding, management, and ongoing maintenance and evolution
- Need to make a call on data handling to make it more universal and actionable. UK have a good model for how to do this. Data that is generated by the healthcare system is available to the whole healthcare system. Ethical and legal commentary impacted by citizen jury, be aware of how this forum influences the policy barriers. Problematic in how this forum gained information from industry – impacts how these forums are informed and their ultimate response and asks.
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#### Strategic Priority 4 – Aboriginal and Torres Strait Islander-led Genomics (pg30)

- No reference to other underserved populations and no explicit outcomes to support representative databases and universal accessibility across other populations