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Submitted to Feedback on the draft National Health Genomics Policy Framework 2026 to 2030
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Yes, I have read and understood this privacy notice.

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Introduction

1 Are you submitting as an individual, or on behalf of an organisation?

Organisation

Introduction (continued)

2 What is your name, organisation, and email address?

Your name:

Dr Erin Evans

Organisation name:

InGeNA Ltd

Contact email:

ceo@ingena.org.au

3 What best describes you, your organisation, or the perspectives your submission represents? Select all that apply.

Industry, Other (please specify)

If other, please specify:

InGeNA engaged with industry, researchers and patient advocates for our submission

Section 1 - Vision, Mission, Guiding Principles and Enablers for Success

4 Do you support the Vision for this draft Framework and Implementation Plan?

No

5 Do you support the Mission for this draft Framework and Implementation Plan?

No

6 Do you support the five Guiding Principles for this draft Framework and Implementation Plan?

Unsure or undecided

7 Do you support the four Enablers of Success for this draft Framework and Implementation Plan?

Unsure or undecided

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

If yes, how should the Vision, Mission, Guiding Principles, and/or Enablers of Success be expanded or improved?:

Vision-bolder ambition: Transforming health for all Australians through a world-leading, universally accessible genomic healthcare system

Mission To drive widespread adoption of genomics to transform health outcomes and deliver sustainable, personalised, & preventive care for every Australian

Principles:universal, equitable, predictive outcomes with robust data infrastructure.

Enablers: unified national governance, agility, co-design & internal alignment to accelerate access & sustainability.

Section 1 - Vision, Mission, Guiding Principles and Enablers of Success (continued)

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

No

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?:

We suggest strengthening the language of priorities, proposing the updated naming and the addition of a crucial fifth priority to ensure explicit focus on funding for implementation

1. Empowering People, Families, and Communities through Genomics
2. Building a Scalable and Sustainable National Genomics Ecosystem
3. National Genomics Data & Digital Infrastructure
4. Indigenous Leadership in Genomic Research & Healthcare
5. Funding and investment to implement genomics

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

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

Collect data on measurable national targets eg CGP access rates

Track test access and utilisation through MBS and a National Genomic Test Directory

Track reimbursement process efficiency & effectiveness

Capture baseline activity data, cost-avoidance metrics, workforce development, and data interoperability (FAIR principles) adherence

Monitor implementation timeframes and deliverables and equitable access across populations

Track strategic partnerships implemented & growth of local innovation

Section 2 - Strategic Priorities

Section 2 - Strategic Priorities (continued)

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?

Yes

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?

Are there any other Outcomes or Activities you think the government should consider for this Strategic Priority?:

Formalising co-design with consumer & patient advocacy groups via a CAG

Adequately funding patient advocacy and psychosocial support services to match awareness & provide critical post-test care

CALD, rural, & rare disease populations as priority groups, ensuring equitable access & sustained long-term support beyond a broad equity lens

Boosting genomics literacy across the mainstream workforce for consistent patient experience

Use of existing education materials & focus on navigation access

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

Yes

If so, how do you think they should be addressed?:

Consistent quality experience across the whole patient healthcare journey with a genomically informed health workforce
Refocus to service access & workforce readiness
Improve patient navigation & utilise existing resources
Support patient advocacy & psychosocial services to reduce gaps in post-test care
Include mechanisms for equitable access for all priority groups (CALD, rural, rare diseases)
Include co-design & focus beyond public hospital services
Implement models of family-centred care

Section 2 - Strategic Priorities (continued)

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?

Yes

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?

Are there any other Outcomes or Activities you think the government should consider for this Strategic Priority?:

Government to reinstate funding as a strategic priority. Establish mechanisms: Genomics Innovation Fund & public-private co-investment for national access, integrating NHRA.
Implement expedited or alternative approval pathways (e.g. UK Cancer Drugs Fund) & HTA reform.
Set targets: universal CGP for cancer by 2030.
Accelerate research program transition into routine practice/MBS.
Embed formalised industry partnerships for innovation and service delivery.
Engage industry for horizon scanning

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

Yes

If so, how do you think they should be addressed?:

Commit to implement public-private partnerships & adoption of local innovation
Embed funding for genomics-based care into National Health Reform Agreement
Address Workforce skill gaps: end-to-end genomics.
Codesign & implement expedited HTA/reg pathways.
2.4.6 Implement scalable integration into mainstream clinical practice & funding schemes
Focus on translation.
Integration & funding for infrastructure.
Industry 5-10yr pipeline knowledge to co-lead horizon scanning-where AU can leapfrog

Section 2 - Strategic Priorities (continued)

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?

Yes

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?

Are there any other Outcomes or Activities you think the government should consider for this Strategic Priority?:

Embed FAIR (Findable, Accessible, Interoperable, Reusable) principles into national genomic data infrastructure and management.
Establish a National Genomic Test Directory (NTD) within five years to standardise testing and streamline access.
Elevate genomic data security and sovereignty to a national interest with enforceable standards and accreditation mechanisms

Ensure funding for scalable, secure genomic information platforms.

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

Yes

If so, how do you think they should be addressed?:

Embed FAIR (Findable, Accessible, Interoperable, Reusable) principles for data scalability & reuse

Mechanisms for industry to demonstrate compliance needed

Ensure reuse: research & clinical domains

Absence of a National Genomic Test Directory is a gap to harmonising access & funding. Priority to deliver this

Outdated legal/reg frameworks and fragmented, siloed data infrastructure impede secure & interoperable data sharing

Provide funding for scalable, national data platforms for implementation

Section 2 - Strategic Priorities (continued)

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?

Yes

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?

Are there any other Outcomes or Activities you think the government should consider for this Strategic Priority?:

Governments should ensure dedicated funding & explicit power-sharing frameworks for genuine co-design with Aboriginal and Torres Strait Islander people, as resource-intensive co-design isn't adequately detailed.

Acknowledge & address structural challenges in clinical trials for Indigenous populations, ensuring culturally safe research R&D of specific Indigenous reference genomes.

Furthermore, a commitment to sustained long-term support infrastructure beyond initial testing is vital

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

Yes

If so, how do you think they should be addressed?:

Risks for Strategic Priority 4 include the lack of dedicated funding and explicit power-sharing frameworks for genuine co-design with Aboriginal and Torres Strait Islander people.

Ensure this does not delay individual access.

Challenges also involve structural barriers in clinical trials for Indigenous populations, and the need for culturally safe research and specific Indigenous reference genomes.

A major gap is commitment to sustained long-term support infrastructure beyond initial testing

Section 3 - Closing Questions

28 Was the draft Framework and Implementation Plan easy to read and understand?

No

If not, how could we improve this?:

Lacks a national stocktake or strategic gap analysis for future planning, making its direction unclear. Actions are too foundational and don't reflect current activity

Actions: have a delivery & implementation focus

Integration with key stakeholder contributions: industry, patient groups & academia to enable scale & co-ordination

Desired outcomes & national actions need to align

Implementation details (timeframes, responsibilities, deliverables) are needed for accountability & clarity

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

Do you have any other feedback regarding the Draft Framework and Implementation Plan?:

InGeNA supports Genomics Australia & offers this constructive feedback to strengthen the Framework's impact.

Greater clarity is needed on which activities and outcomes will drive change, underpinned by a detailed vision for genomics across the care continuum

5-10y. Industry requires clear priorities & timelines to support planning and future investment, including public-private partnerships.

The Framework must prioritise innovation, transformation & implementation, not remain in a research- translation phase. Genomics is already in routine use & requires a coordinated, scalable national approach. Measurable targets are essential: universal CGP access, a National Test Directory, infrastructure funding & FAIR-aligned federated data systems by 2030. Expedited approval and funding pathways must be created. Proactive industry collaboration and alignment with global standards will ensure impact, avoid duplication & support sustainable scale. Australia must seize this opportunity to leapfrog.