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Submitted to Feedback on the draft National Health Genomics Policy Framework 2026 to 2030
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Please confirm you have read and understand this privacy notice. You must confirm to take part in this consultation process.

Yes, I have read and understood this privacy notice.

Disclosure to Overseas Recipients

Do you consent to your personal information being disclosed to overseas recipients? You must consent to take part in this consultation process.

Yes, I consent to any personal information I provide as part of this consultation process being disclosed to overseas recipients, and:

Publication

Do you consent to the publication of your response to take part in this consultation process? You do not need to consent to the publication of your response to take part in this consultation process.

Yes, I consent to my response being published on the department's website and/or the department's Consultation Hub website, including any personal information I provide.

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:
LINEAGE Research Team

Organisation name:
The LINEAGE Study

Contact email:
lineage.study@sydney.edu.au

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

Research, Other (please specify)

If other, please specify:
MRFF-funded research team, whose work focuses on ethical, legal and social issues in genomic data governance

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

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

Unsure or undecided

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

Unsure or undecided

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?

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

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

MISSION: 'ethical' should be 'ethically defensible' ('ethical' not binary)
PRINCIPLES: need to be uniformly phrased and not include tautological definitions (eg equity). Consider expanding prevention to 'meeting needs'. Consider adding 'sustainability' principle (care where needed, environmental impact, data storage). Need information on ranking of principles if they conflict. P3 should be 'socially acceptable' not 'responsible'
ENABLERS: speak of trustworthiness, not trust. Add more specificity

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?:

The Priorities should be expanded to focus more explicitly on underserved groups. This includes minority populations other than Aboriginal and Torres Strait Islander Peoples, patients with a symptomatic but undiagnosed condition and diagnosed patients who cannot access therapy.

More information could also be provided to show how the Principles flow through to the Strategic Priorities.

More detail about outcomes/deliverables/endpoints is needed.

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?:

For Strategic Priority 3, it will be important to understand how genomic data can or should flow, and also how it is currently flowing/moving (or not). It will also be important to leverage existing research and its outputs that touch on this question.

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?

Unsure or undecided

13 Do you think the Activities for Strategic Priority 1 will achieve the specified Outcomes?

Unsure or undecided

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?:

The preamble to SP1 mentions ethical, legal and social implications but these do not flow to Activities. Suggest drawing on the sector to establish key gaps, against substantial existing research.

O1.1 2nd point: Making informed choices is more complex than mere data visibility. Some people may need significant ongoing support
O1.1 5th point: should also mention avoiding harm
O1.2 This could instead be written with a strengths-based approach rather than using deficit language

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?:

A1.1.3 The LINEAGE Project is already working on clinical consent and how this may enable consent for research/secondary use. We would be pleased to share our findings with the Department

A1.1.6 The sector has raised significant concerns about automatic upload of results to MHR for all tests. LINEAGE shares these concerns and urges the Department to work with peak bodies such as HGSA to achieve an ethically defensible outcome that accounts for the complex implications of some genomic results

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?

Unsure or undecided

17 Do you think the Activities for Strategic Priority 2 will achieve the specified Outcomes?

Unsure or undecided

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?:

Activity needed to map existing onshore sequencing capability and whether/how this can meet future demand.
Activity needed to map existing storage capability
Activity needed to articulate and enable future sequencing and storage demand, and clinical demand
Activity needed to better understand who funds what provision
O2.3 title should reflect emphasis on ethics throughout

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?:

What constitutes equitable access could be specified in greater detail.
A2.1.4 The Department is encouraged to leverage existing statements of best practice and other professional guidelines, such as those developed by HGSA
A2.2.2 It is not clear what is meant by 'ethical model'
A2.4.2 investment should be beyond research
O2.4 second dot point (diversity): this should also be reflected in governance. LINEAGE is directly addressing diversity in governance in its work

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?

No

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?:

Outcome 3.1 should also include 'clear', and references to ethical norms
Activity: better understand current Australian regulation and where reform is needed. LINEAGE is developing this, among other activities (e.g. work on trust, privacy etc). We would be pleased to share our findings
Activity: build relationships with key actors to leverage knowledge and expertise on ethical genomic data governance. LINEAGE is well placed for this and will deliver its governance framework in 2027

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?:

3.1.1 This has been completed, eg NAGIM. LINEAGE is currently working on legal and regulatory aspects and we are happy to offer our expertise to e.g. curate existing research outcomes and legal status quo
3.1.2 & 3.1.3 These activities overlap with the LINEAGE project to develop a framework for ethical governance of genomic data (to be delivered in 2027). See: https://doi.org/10.1038/s41525-025-00492-6 We would be delighted to engage to explore how our framework can help achieve these activities

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?

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?

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

LINEAGE strongly supports this Strategic Priority. We have multiple investigators and researchers in our project who are Aboriginal or Torres Strait Islander and are embedding research activities in this space across our project.

LINEAGE also strongly supports other culturally, ethnically and linguistically diverse groups, as well as those living with a genetic condition, being identified more specifically as priority populations within the Framework.

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

Unsure or undecided

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

LINEAGE strongly supports groups such as ALIGN having leadership in this space and being allocated resources and support to continue throughout the life of this Policy Framework.

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?:

Achievements of the 2018-21 Framework could be highlighted, as well as detail on how this new iteration will build on it.
The summary points for the 4 SPs do not always match to their expanded descriptions (e.g. points missed or inconsistent).
It is unclear what content is part of the Framework c.f. Implementation Plan. We would welcome the opportunity to provide feedback on a more detailed Implementation Plan.
The role that Genomics Australia will play could be clarified.

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?:

The Activities in the framework could be more specific and go beyond consultation, mapping etc. Sector engagement will be able to leverage many useful existing resources.

LINEAGE supports emphases on concepts such as trust/trustworthiness. At present, the role that research on ethical, legal and social implications of genomics is specified only vaguely in the framework, and the binary 'ethical' is used. Suggest more specific activities to collate existing ELSI research relevant to the Framework. LINEAGE has undertaken activities such as systematic reviews and scoping reviews and would be pleased to make relevant publications and white papers available.

Strategic Priority 3 could also focus on data reduction or disposal, in line with the proposed Principle of sustainability, to encourage pre-emptive thinking about what data to generate and store.

The 2018-21 Framework identified barriers and LINEAGE would endorse their inclusion here too.