



National Health Genomics Policy Framework and Implementation Plan 2026-2030 (Consultation Draft)

Online Survey Questions to support organisations collating feedback

About this document

This document is a static version of the National Health Genomics Policy Framework and Implementation Plan 2026-2030 online survey for public consultation. It contains the same information and questions included in the online survey on the Australian Government Department Of Health, Disability and Ageing Consultation Hub.

It is to be used to support organisations to collate input where multiple members will inform the organisation's response. In this circumstance, a contact person should submit the consolidated input on behalf of their organisation via the online survey.

This document is **not** to be submitted to the department via email.

All submissions are to be made via the online survey on Consultation Hub.

Online Survey — Page 1

Privacy Notice

Your personal information is protected by law, including the Privacy Act 1988 and the Australian Privacy Principles (APPs).

Who is collecting your personal information?

Your personal information is being collected by the Department of Health, Disability and Ageing (the department/ we).

What information is being collected?

If you choose to respond to this consultation process, we may collect personal information about you.

This may include your name and email address, the organisation you work for or otherwise represent, and how the issues, interests and perspectives you and/or the organisation you work for or otherwise represent inform your response to this consultation process.

You will also be asked to provide your views and opinions about the draft National Health Genomics Policy Framework 2026 – 2030 (draft Framework and Implementation Plan).

Why does the department collect your personal information?

We collect your personal information for the primary purpose of understanding the perspectives you are bringing to this public consultation process when you provide feedback on the draft Framework and Implementation Plan. Your input will help refine the draft Framework and Implementation Plan ahead of its finalisation. Your input will also inform the development of a summary of the findings gleaned from this public consultation process.

We may use your personal information to contact you about your submission, to obtain further information from you or to inform you about the outcomes of this consultation process.

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What would happen if the department did not collect your personal information?

You may provide an anonymous submission.

If you do not or are unable to provide your personal information, the department may be unable to fully consider the context and relevance of your feedback and take it into account when finalising the Framework and Implementation Plan.

If you do not or are unable to provide your personal information, the department will be unable to contact you about your submission, the consultation process, or other related policy matters.

Who will the department disclose your personal information to?

If you provide your personal information, we will disclose it to Allen and Clarke Consulting Pty Ltd (Allen & Clarke), a consultancy firm which has been engaged by the Australian Government Department of Health, Disability and Ageing to support this consultation process.

If you provide your personal information, we may disclose it to state or territory government employees, and Professor Alex Brown, Professor of Indigenous Genomics at the Telethon Kids Institute and The Australian National University, who are involved in the development of the draft Framework and Implementation Plan.

Access to and correction of your personal information

The department's privacy policy contains information about how you may access and seek correction of your personal information.

Privacy complaints

The department's privacy policy contains information about how you may complain about a breach of the Australian Privacy Principles or the Australian Government Agencies Privacy Code and how the department will deal with complaints.

Overseas disclosure of your personal information

If you provide your personal information, we will disclose it to employees of Allen & Clarke, some of whom are based in New Zealand.

If you consent to the publication of your response to this consultation process, we may publish all or part of your response on the department's website and/or the department's Consultation Hub website — this may involve disclosure to overseas recipients.

You will be given the opportunity to consent or not consent to the publication of your response on Page 3 of this survey.

Further information

You can read the department's privacy policy on the [department's website](#). You can obtain a copy of the APP privacy policy by contacting the department using the contact details set out at the end of this notice.

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Consent

We do not require you to submit any sensitive information as part of this consultation. If you choose to provide sensitive information to us, you consent to the Department of Health, Disability and Ageing collecting that information about you for the purposes indicated above.

If you are providing the department with personal information about another individual, unless you are authorised to consent on their behalf, you will need to inform that individual of the contents of this notice, and obtain their consent to the department collecting their personal information.

Contact details

If you wish to contact the department about a privacy-related matter, including questions about this notice, please contact the department's Privacy Officer by one of the following methods:

- **Post**
Privacy Officer
Department of Health, Disability and Ageing
23 Furzer Street
WODEN ACT 2606
- **Email**
privacy@health.gov.au
- **Telephone**
02 6289 1555

Question — Privacy notice (unnumbered)

Please confirm you have read and understand this privacy notice. You must confirm to take part in this consultation process.

Response — required

☒ Yes, I have read and understood this privacy notice.

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Disclosure to Overseas Recipients

The department is seeking your consent to disclose your personal information to Allen and Clarke Consulting Pty Ltd (Allen & Clarke), a consultancy firm which has been engaged by the Australian Government Department of Health, Disability and Ageing to support this consultation process.

If you provide your personal information as part of this consultation process, we will disclose it to employees of Allen & Clarke, some of whom are based in New Zealand.

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Ordinarily, where the department discloses personal information to an overseas recipient, Australian Privacy Principle (APP) 8.1 requires the department to take reasonable steps to ensure that overseas recipients do not breach the APPs. However, if you agree to take part in this consultation, APP 8.1 will not apply to this disclosure and the department will not be accountable under the Privacy Act for any breach of the APPs by the overseas recipient, and you will not be able to seek redress under the Privacy Act.

Question — Consent to disclosure to overseas recipients (unnumbered)

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

Response — required

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

- understand that Australian Privacy Principle (APP) 8.1 requires the department to take reasonable steps to ensure that any overseas recipients to whom personal information is disclosed do not breach the APPs in relation to my personal information.
- acknowledge that I have been expressly informed that if I consent to the overseas disclosure of my personal information APP 8.1 will not apply to the disclosure and after being advised of this, I consent to the disclosure
- understand that the department will not be accountable under the *Privacy Act 1988* (Cth) for any breach of the Australian Privacy Principles by an overseas recipient and I will not be able to seek redress under that Act
- have obtained the consent of any other individuals whose personal information you have provided (including information about sole trader organisations)

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Publication

The department is seeking your consent to publish your consultation response on the department's website and/or the department's Consultation Hub website. If you consent to publish your response, it will include any personal information you choose to provide as part of this consultation process.

If you consent to publish your consultation response it could be accessed by any person, including a person located overseas. The purpose of publishing consultation responses is to support transparency.

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Ordinarily, where the department discloses personal information to an overseas recipient, Australian Privacy Principle (APP) 8.1 requires the department to take reasonable steps to ensure that overseas recipients do not breach the APPs. However, if you provide consent to the publication of a response that includes your personal information, APP 8.1 will not apply to this disclosure and the department will not be accountable under the Privacy Act for any breach of the APPs by the overseas recipient, and you will not be able to seek redress under the Privacy Act.

Question — Consent to publication (unnumbered)

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.

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, and:

- understand that Australian Privacy Principle (APP) 8.1 requires the department to take reasonable steps to ensure that any overseas recipients to whom personal information is disclosed do not breach the APPs in relation to my personal information.
- acknowledge that I have been expressly informed that if I consent to the publication of my consultation response and it includes personal information APP 8.1 will not apply to the publication
- understand that the department will not be accountable under the Privacy Act 1988 (Cth) for any breach of the Australian Privacy Principles by an overseas recipient and I will not be able to seek redress under that Act
- understand that copyright in the content of my submission will vest in the Commonwealth of Australia
- understand that the department has complete discretion as to whether my submission, in full or part, will be published
- have obtained the consent of any other individuals whose personal information I have provided (including information about sole trader organisations)

Response — required

☒ 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.

☐ No, I do not consent to my response being published.

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Introduction

Question 1

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

Response — required

- ☐ Individual
- ☒ Organisation

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Introduction (continued)

Question 2

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

Response — optional

Your Name: Sue Gedeon
Organisation Name: The Royal Australian College of General Practitioners
Contact Email: sue.gedeon@racgp.org.au

Question 3

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

Response — required

- ☐ Australian Government
- ☐ State/territory government
- ☐ Clinical
- ☐ Industry
- ☐ Research
- ☐ Aboriginal and/or Torres Strait Islander
- ☐ International
- ☐ Consumer advocacy
- ☐ Member of the public
- ☐ Prefer not to say
- ☒ Other (please specify)

If other, please specify

Member organisation

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

This section contains overarching questions regarding the Vision, Mission, Guiding Principles, Enablers for Success in the Draft Framework and Implementation Plan.

We have included short excerpts from these sections of the Draft Framework and Implementation Plan. You are encouraged to read the document in full before completing the survey.

The following section will provide an opportunity to comment on the Strategic Priorities, and their associated Outcomes and Activities.

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Question 4

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

Vision: All people who access health care in Australia benefit from appropriately embedded genomics within the health system.

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 5

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

Mission: To establish and/or maintain processes that support person- and family-centred, culturally safe, efficient, effective, ethical, and equitable implementation of genomics-informed health care and research in Australia.

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 6

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

Guiding Principles:

1. Equity
2. Empower individuals and communities
3. Evidence-based and socially accepted
4. Prevention-focused
5. Whole-of-system focused

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

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Question 7

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

Enablers of Success:

1. Collaborative and culturally appropriate governance, leadership, information-sharing and, where necessary, coordination across Australian governments
2. Flexibility
3. Individual, community and stakeholder engagement and partnerships
4. International engagement and partnerships

Response — optional

- ☒ Yes

☐ No

☐ Unsure or undecided

Question 8

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?

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Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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

(500 character limit)

RACGP response:

Shared decision making is highlighted as part of the Strategic Priority 1. This should be included within the Mission. It is a core part of considering genetic testing and in supporting person- and family-centred health care.

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Section 1 — Vision, Mission, Guiding Principles and Enablers for Success (continued)

Question 9

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

Vision: All people who access health care in Australia benefit from appropriately embedded genomics within the health system.

Strategic Priorities:

Strategic Priority 1 — Person-, Family- and Community-Centred Approach

Strategic Priority 2 — Dynamic and Sustainable Genomics Ecosystem

Strategic Priority 3 — Genomic Samples, Data and Information Management

Strategic Priority 4 — Aboriginal and Torres Strait Islander-led Genomics

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

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Question 10

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

Response — optional

☐ Yes

☒ No

☐ Unsure or undecided

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

(500 character limit)

Click or tap here to enter text.

Question 11

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

Response — optional

(500 character limit)

Click or tap here to enter text.

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Section 2 - Strategic Priorities

This section provides an opportunity to comment on each of the Strategic Priorities, and their associated Outcomes and Activities.

The four Strategic Priorities in the new Draft Framework and Implementation Plan are:

- Strategic Priority 1 — Person-, Family- and Community-Centred Approach
- Strategic Priority 2 — Dynamic and Sustainable Genomics Ecosystem
- Strategic Priority 3 — Genomic Samples, Data and Information Management
- Strategic Priority 4 — Aboriginal and Torres Strait Islander-led Genomics

In the next section, you will have the opportunity to provide any other feedback on the Draft Framework and Implementation Plan.

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Section 2 - Strategic Priorities (continued)

Strategic Priority 1 — Person-, Family- and Community-Centred Approach

Question 12

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?

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 13

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

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 14

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

Response — optional

(500 character limit)

RACGP response:

Outcome 1.2 - As part of improving public genomics knowledge, the RACGP would support the development of a national online databank of living resources (updated as new evidence emerges) for both health professionals and consumers. GPs should be on the panel for the development of any resources, as GPs will often undertake shared decision making with patients regarding genetic testing.

Public genomic knowledge should include harms, risks, costs and limitations associated with genomic testing. It should also include information on identifying scams.

Question 15

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

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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

(500 character limit)

RACGP response:

Direct-to-consumer tests - The RACGP has concerns about commercial, direct-to-consumer tests being offered to consumers without formal counselling, which can have important and lifelong implications for people regarding issues such as life insurance and reproductive decisions.

Therapeutic Goods Administration (TGA) reviews – Each genetic test should be thoroughly reviewed by the TGA to ensure accuracy.

Access to genetic counsellors – The low number of genetic counsellors presents an ongoing challenge. In addition, there is generally low access to genetic counsellors, particularly through the public system, and for people in rural and remote areas of Australia.

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Section 2 - Strategic Priorities (continued)

Strategic Priority 2 — Dynamic and Sustainable Genomics Ecosystem

Question 16

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?

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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Question 17

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

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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Question 18

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

Response — optional

(500 character limit)

RACGP response:

Outcome 2.2 - guidelines and educational materials should be government funded. GP-facing guidelines and education should have strong GP input. The RACGP produces two guidelines with genomic information – Genomics in general practice, and Guidelines for preventive activities in general practice (the Red book).

Outcome 2.3 - Detailed genomic testing as a 'fishing exercise' for potential medical conditions represents low value care. De-facto screening programs should be avoided without sufficient assessment of the effectiveness, including health economic analysis.

Question 19

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

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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

(500 character limit)

RACGP response:

Concerns about potential impacts to health and life insurance continues to be a barrier to effective genomics in healthcare. Ongoing management of this risk should be a priority, with decisions made as to how much risk is shared broadly by society, and how much can be used to determine who to insure, and at what premium.

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Section 2 - Strategic Priorities (continued)

Strategic Priority 3 — Genomic Samples, Data and Information Management

Question 20

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?

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 21

21. Do you think the Activities for Strategic Priority 3 will achieve the specified Outcomes?

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

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Question 22

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

Response — optional

(500 character limit)

RACGP response:

Data infrastructure should be designed so that genomic testing does not have to be repeated if there are difficulties accessing the original data. Ideally, genomic data should sit securely associated with My Health Record for life-long future access across healthcare system. Some of this detail has been picked up in Sections 1.1.5 and 1.1.6 but should also be explicitly stated here.

Ideally, integrating genomic data into medical software will support better quality improvement and guide appropriate prescribing and clinical decisions.

Question 23

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

Response — optional

☐ Yes

☒ No

☐ Unsure or undecided

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

(500 character limit)

Click or tap here to enter text.

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Section 2 - Strategic Priorities (continued)

Strategic Priority 4 — Aboriginal and Torres Strait Islander-led Genomics

Please be reminded that strengths-based, constructive and respectful feedback is encouraged. Please ensure all responses are free from discriminatory and racist language. We may exclude inappropriate responses from analysis.

Question 24

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?

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

Question 25

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

Response — optional

- ☒ Yes
- ☐ No
- ☐ Unsure or undecided

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Question 26

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

Response — optional

(500 character limit)

Click or tap here to enter text.

Question 27

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

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

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

(500 character limit)

RACGP response:

There is a real risk that with geographic and especially financial barriers to access expertise, testing and resulting medication could worsen outcomes, so an understanding of this will be crucial. In addition, an understanding of multimorbidity is essential as it interferes with evidence of effectiveness for personalised medicine or other genomics. Multimorbidity is complex and it will require time, energy, and financial resources to address the challenges this will present for participation.

It should be stated clearly that race is a social, not a genetic construct. Genomics carries the risk, even if unintended, of reinforcing racialised assumptions, such as the notion that “this medicine doesn’t work in Aboriginal people” or other culturally defined groups. There is a need for clarity to avoid these misconceptions among both the public and health professionals.

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Section 3 - Closing Questions

Question 28

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

Response — optional

☒ Yes

☐ No

☐ Unsure or undecided

If not, how could we improve this?

(500 character limit)

Click or tap here to enter text.

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Question 29

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

Response — optional

(1000 character limit)

RACGP response:

The RACGP is pleased to see that the Australian Alliance for Indigenous Genomics (ALIGN) and the National Aboriginal Community Controlled Health Organisation (NACCHO) are advising on this and it is important that the framework and implementation plan include specific considerations for Aboriginal and Torres Strait Islander people. The [Lowitja Institute](#) would also be well placed to include in the framework and implantation plan.

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Almost done...

You are about to submit your response. By clicking 'Submit Response' you give us permission to analyse and include your response in our results. After you click Submit, you will no longer be able to go back and change any of your answers.

Question — PDF Copy of Response (unnumbered)

If you provide an email address you will be sent a receipt and a link to a PDF copy of your response.

Response — optional

Email address: Click or tap here to enter text.