

A NATIONAL CLINICAL GENOMIC CONSENT PROCESS

Development of standardised consent materials for clinical genomic testing in Australia

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Project Description		2
Appendix 1	The National Clinical Genomic Consent Form (V15.3)	9
Appendix 2	Supporting Material to accompany the consent form (V11.2)	11
Appendix 3	Consultation Document	16
Appendix 4	Consultation List	22
References		24

A National Clinical Genomic Consent Process

Summary

Challenge: currently in Australia, there is no single, national approach to obtaining patient consent to undertake genetic or genomic testing. Standards and practices are fragmented, and consent forms differ not only between states, but also between genetic service providers. This creates inconsistency in the experience, outcomes and management of patients across Australia, and is a barrier to the flow of health information between jurisdictions.

In response to this need, in 2017 Australian Genomics embarked on a project to develop a clinical genomics consent form that can be adopted nationally, for use across all genetic conditions. The working group (see 'Investigators, above) undertook a systematic review of existing consent forms, developed guidelines for content of consent materials, and drafted a form with supporting information. Professional and public consultation was undertaken against these materials. The finalised National Clinical Genomic Consent Form and Supporting Information will now be piloted in different jurisdictions. The evaluation of the pilot will permit finalisation of the materials, for broad national rollout mid-2019. These will be living documents, undergoing ongoing assessment and refinement to retain currency and reflect regulatory evolution as genomics is mainstreamed throughout the Australian healthcare system.

This report details the process and outcomes of this project.

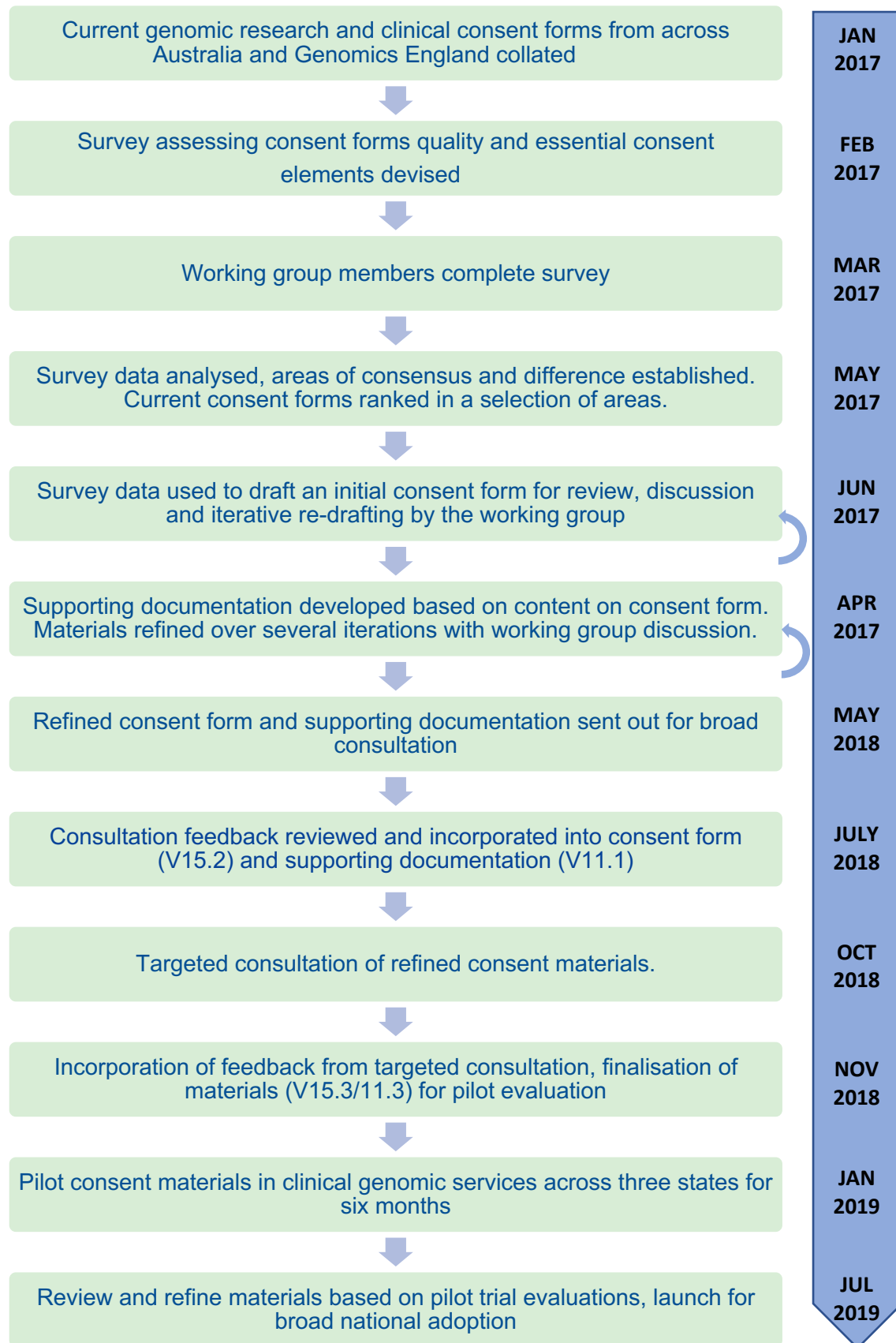
Project aims and methodology:

- 1. To review existing consent materials**
 - (i) Systematically evaluate forms currently in use in Australia, with representative examples from different geographic jurisdictions
 - (ii) Identify characteristics (good and bad) to inform the development of recommendations on content of consent materials.
- 2. To develop recommendations and guidelines around genomic consent materials**
 - (i) Determine mandatory content and information
 - (ii) Describe key features of structure, voice and delivery of the consent materials
- 3. To draft consent materials based upon the recommendations developed in (2)**
 - (i) Prepare a consent form
 - (ii) Prepare supporting information
- 4. Undertake a broad consultation on the materials**, inviting comment and input from the Australian public and professionals
 - (i) Develop a consultation form, to support standardised and systematic evaluation of the materials developed
 - (ii) Request / invite review from the Australian public and professional groups / individuals
 - (iii) Assimilate and evaluate responses
- 5. Re-draft consent materials based upon the consultation in (4)**
- 6. Undertake a trial roll-out of the consent materials** in different states
 - (i) Pilot the use of the materials, and evaluate the experiences of health professionals and patients to the materials
 - (ii) Based on a six-month trial, the materials will be reviewed and modified if necessary.

The Consent Form and Supporting Information Material are provided in the appendices.

Project overview

Figure 1. Process Summary



Project Outcomes

1. Review and evaluation of existing consent materials

- There is **no common national stance on management of issues** relating to genetic/genomic consent process:
 - Return of actionable and non-actionable disease-causing variants;
 - Incidental findings (which inform genetic risk for conditions not related to the purpose of the test: e.g. a BRCA1 mutation identified in a child being sequenced for epilepsy);
 - Analysis and gene lists;
 - Further use of samples & genomic data in research & whether re-contact is required / best-practice;
 - Storage and use of the samples by the diagnostic laboratory;
 - Data sharing;
 - Risks of genomic testing; and
 - Implications for relatives and insurance.
- This lack of national consistency may be a **barrier to the flow of health information** across states or jurisdictional borders as families are dispersed across the country.
- A **landscape analysis** and evaluation of genomic testing consent forms from different states permitted the group to 'cherry pick' the best elements of each:
 - SA Pathology (clinical)
 - Melbourne Genomics Health Alliance (clinical and research)
 - New South Wales Health (clinical)
 - The University of Western Australia (research)
 - PathWest (clinical)
 - Genomics England (research)
- The **barriers to genomic clinical consent** were discussed, and the **essential elements of a consent form** were determined.
- The **legal, ethical and social issues** relevant to the project were discussed. Balancing the need to convey concepts adequately to support informed consent, without overburdening the reader, must be a deliberate and carefully considered process. The principal of autonomy in the context of consent, and the information provided, was also explored.

2. Guidelines and Recommendations

1/ **Brevity** - The National Clinical Genomic Consent form must be in plain language, and brief. While accompanying information material can support the consent process, the consent form itself must be **no longer than one double-sided page**.

2/ **The patient voice** – The development of consent forms must engage the target audience: the patient. Australian Genomics consulted our Community Advisory Group, patient community and patient advocacy groups from around Australia in development of these materials.

3/ **Review** - Given the changing landscape around key issues associated with genomic testing, it is expected that these documents will need to be reviewed on an annual basis.

4/ **Specialised consent forms** – Australian Genomics will seek broad input on the demand for specialised consent forms (eg paediatric testing). We will develop these variations on the

national clinical genomic consent form with specialised input from the involved clinical specialists and patient groups.

“It will be easier to get consensus about consent for return of incidental findings when we have achieved consensus on what the definition of clinically actionable findings should be for the Australian population.”

3. Drafting the National Clinical Genomic Consent Materials

The Clinical Genomic Consent form and Supporting Information Material were drafted based upon extensive review and discussion of example materials in use, and aligned with the agreed Guidelines and Recommendations for structure and content.

These materials underwent iterative development and refinement over an 11-month period amongst working group members.

4. Consultation Process

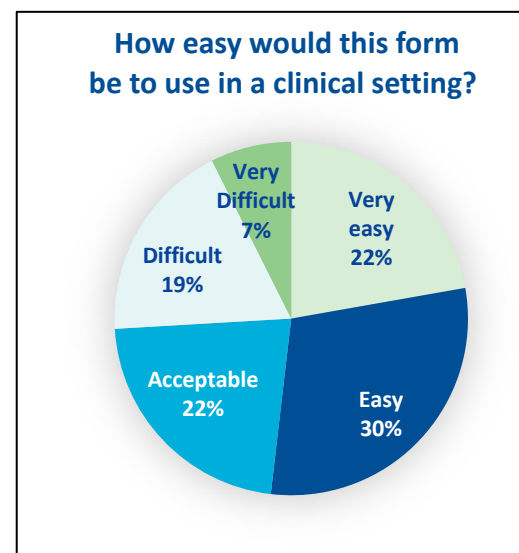
The working group agreed that the National Clinical Genomic Consent form agnostic of testing purpose (V15.1) was ready for broad consultation in May 2018. A consultation framework was developed to support the collection of standardised, comprehensive feedback (Appendix 3).

In the initial round of consultation, invitations were sent to 65 individuals and organisations (Appendix 4). The documents were also made available to the public on the Australian Genomics website. Responses were submitted by 42 individuals and organisations, including Committees of the Human Genetics Society of Australasia; Commonwealth and State Departments of Health; Clinical Geneticists; Genetic Counsellors; Research Institutions; Community Advisory Groups; Genomic Alliances; and Medical Specialist Colleges.

Over 80% of respondents found all elements in consent form and supporting documentation very good, good or acceptable.

Seventy-four per cent of respondents believed that it would be at least acceptably easy to implement the consent form in the clinic.

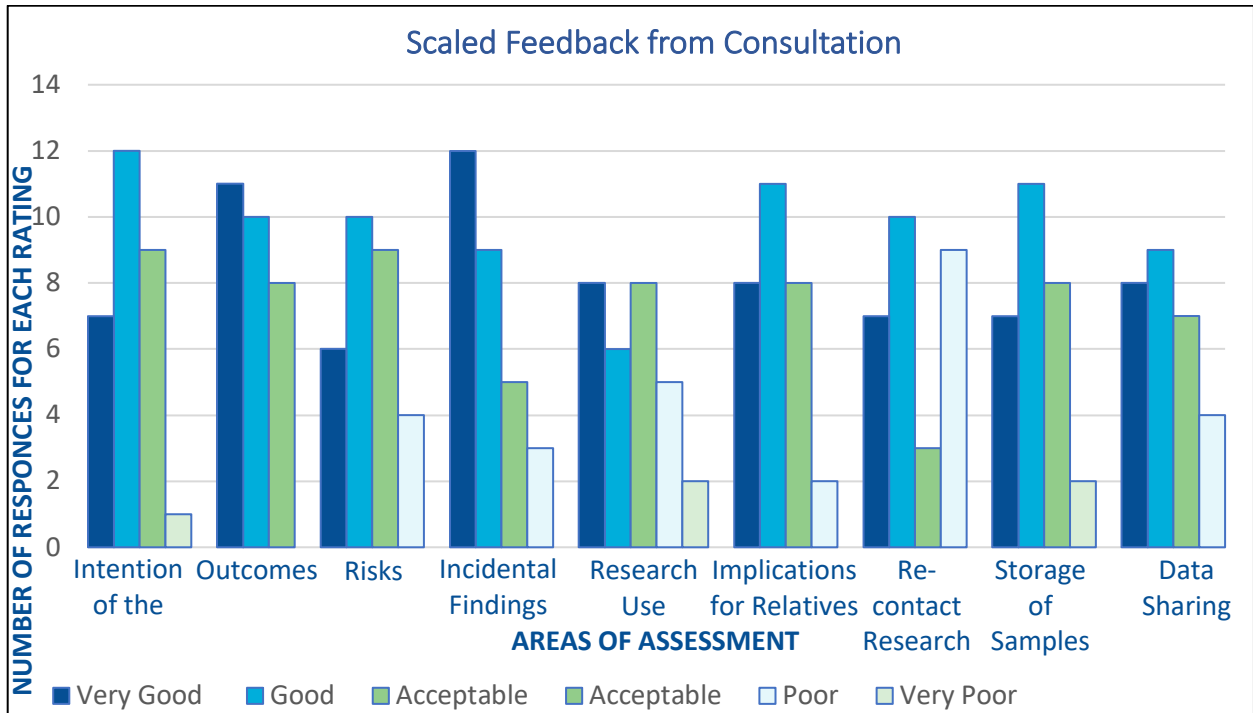
Inclusion of consent for research: The ‘re-contact for future studies’ and ‘use of sample for research’, seemed to be a key point of differentiation in perceived acceptance of the form: more as a philosophical segregator of the community consulted, rather than the structure of these specific materials.



Some groups remain convinced that an option for research should not be incorporated into clinical genomic consent forms, despite strong support from the majority of the genomics community who provided feedback.

There were major recurring themes from the consultation feedback, which are addressed in the table below:

Major Recurring Themes	Specific Feedback	How they have been addressed
Need for parent/guardian (P/G) consent and broader consent for other testing processes	<ul style="list-style-type: none"> • P/G consent form needed or change wording of current form • Predictive testing, segregation, carrier testing etc. not covered 	<ul style="list-style-type: none"> • P/G consent form will be developed as next phase of work • This form is for genomic testing specifically. Other types of testing will use genetic testing consents.
My Health Record (MyHR)	<ul style="list-style-type: none"> • MyHR is not mentioned on the consent form 	<ul style="list-style-type: none"> • Advice was sought from the Digital Health Agency on management of MyHR information on a national document, given differences in state policy around genomic reports in MyHR. • Check box inserted, per their recommendations
Risks	<ul style="list-style-type: none"> • Risks are not well defined • Some risks are understated where as others are overstated 	<ul style="list-style-type: none"> • Wording to be changed to better define risks of genomic testing
Anonymous versus coding data sharing for clinical and research purposes	<ul style="list-style-type: none"> • Confusion between what data will be shared anonymously versus coded • Confusion regarding what data will be shared for research • Concern with the terminology 	<ul style="list-style-type: none"> • Data sharing and research section has been re-worded for clarity • Descriptions for anonymous and coded data simplified, and accompanied with a figure
Use of results for the healthcare of family members	<ul style="list-style-type: none"> • Optional sharing of results for the healthcare of family members should be removed 	<ul style="list-style-type: none"> • Familial sharing option will remain on the consent form, with the understanding that majority of individuals will select 'Yes'. However in rare cases 'No' must be an option, given jurisdictional differences in management.



“...consider how clinicians undertake a process of consent; and to use the form as a way to summarise that process.”

5. Incorporation of consultation outcomes, and secondary targeted consultation.

After aggregation and analysis of the consultation data, the working group convened a face-to-face meeting to discuss and resolve conflicts or discrepancies in the responses, and agreed to content for amendment and inclusion.

A secondary consultation was undertaken with many Patient Advocacy Groups, the National Aboriginal and Torres Strait Islander Health Standing Committee and the Regulatory and Ethics Workstream of the Global Alliance for Genomics and Health (GA4GH) (Appendix 3).

The responses of this consultation informed further refinement of the materials, and they were approved for release and evaluation in clinical practice.

The resulting National Clinical Genomic Consent Form and Supporting Information Material are provided in the appendices.

6. Trial use and evaluation

The developed Clinical Genomic Consent Materials will undergo a six-month pilot in three jurisdictions, January – June 2019. Structured evaluations will be conducted as to the general ease of use of the materials, the adequacy and completeness of the information included, the simplicity and clarity of the language, and the degree to which the materials support the consent process for health professionals in the genomics community. Patient opinion on the materials will also be sought. At the end of this trial the outcomes of the evaluations will inform further refinement and improvement of the materials.

We will continue to undertake a process of review and harmonisation where appropriate with new jurisdictional forms (for example the revised NSW Health genetic consent form), and will commence a process of development of specialised Genomic consent forms for different use cases (such as paediatric; mature minor; plain language; and materials for CALD communities).

Australian Genomics envisages that the National Clinical Genomic Consent Form and Supplementary material will be living documents, and we would recommend a process of structured annual review.

7. Conclusions

The development of a National Clinical Consent form is challenging. There is jurisdictional variation in policies and procedures in clinical care; there are limitations in the resourcing, flexibility and infrastructure in some genetic laboratories and services; and there is inconsistency in use of terminology across Australian genomic practice.

The development and consultation process of these clinical genomic consent materials was a resource-intensive, lengthy process, but an extremely valuable one.

There is a significant amount of information to digest when consenting to a genomic test: consent should be considered as a process, and the consent form and supporting documentation aims to better support this process.

Development of the National Clinical Genomic Consent Materials has identified several key areas that will need to be targeted in support of mainstreaming genomics in a standardised fashion across the Australian healthcare system:

- Seek consensus on what the definition of clinically actionable findings should be for the Australian population;
- Develop common policies around management of incidental / secondary findings;
- Harmonise approaches to release of results to family members, for the benefit their healthcare;
- Consultation on the relative benefits and risks of including consent for research as part of a clinical consent process – and a calculation as to the impact this has on patients and families tested;
- Seeking jurisdictional input and agreement on approaches to identified challenges and differences would make significant gains toward equitable application of genomic testing across Australia.

Australian Genomics looks forward to addressing these issues in partnership with State and Commonwealth Departments of Health, particularly the Project Reference Group on Health Genomics; our colleagues at the Human Genetics Society of Australasia and the Royal College of Pathologists Australasia; and patient communities.

Australian Genomics acknowledges the considerable in-kind investment in time and effort of the expert members of the National Clinical Genomic Consent working group.

APPENDIX 1 – NATIONAL CLINICAL GENOMIC CONSENT FORM

Affix identifier information here

Clinical Consent Form for Genomic Testing

It is my choice to have genomic testing. I can say yes or no to the options on this form.

I, _____ (patient and/or parent/guardian names), understand that my DNA will be tested by panel/exome/genome to look for changes in genes

that may be associated with _____

About the Test

- Genomic testing is done on DNA from my blood, saliva or tissue.
- Genomic test results are based on current knowledge, which may change in the future.
- I can choose not to be told about the results.

Potential Outcomes

I understand that:

- This test may find a cause for the condition(s).
- This test may not find a cause for the condition(s).
- The result may be of '*unknown significance*', which means it cannot be understood today.
- There is a chance that genomic testing could find other medical conditions (incidental findings).
- This test will not predict all future health problems.
- Genomic testing may identify unexpected family relationships.
- Further testing or information sharing may be needed to finalise the result.

Results

I understand that:

- I will be told the results by a health professional.
- Results may have implications for the health/genetic risks of my family members.
- Results from these tests may affect my ability to obtain some types of insurance.
- The results will be available to health professionals involved in my care.
- Results are confidential and may not be released without my consent, unless allowed by law.

I provide consent for:

- Results of this testing may be used for the healthcare of my family members
 Yes **No**
- In the event of my death, my results can be released to:

Name

Contact

Laboratory Sample and Data Storage

I understand that:

- Sometimes a second DNA sample is needed.
- The **sample, genomic results and test report** will be handled according to guidelines.
- I request my sample(s) be destroyed after the required storage time: **Yes** **No**

Data and Sample Sharing

I understand that:

- The **identified** sample, genomic results and test report will only be used by those involved in my care, unless required or allowed by law.
- The **de-identified** sample, genomic data and related health information may be shared and stored to help advance scientific knowledge.

Research

I also provide consent to:

- Sharing the sample, genomic data and related health information for ethically approved research into the same or a related condition, where it remains possible to re-identify me. This allows information to be returned to me where appropriate, but participation may not have direct benefits to me or my family.
 Yes **No**
- Being contacted about other kinds of genomic research in the future. If interested in taking part, I would be asked to sign a separate consent form.
 Yes **No**

I have had enough time to consider the information in this consent form and have:

- Had genomic testing explained to me by a health professional.
- Been given written information about genomic testing.
- Been able to ask questions until I am satisfied with the answers.
- Been offered a copy of this consent form.

I provide consent to have genomic testing as summarised in this form.

Do not send reports to My Health Record

Signature _____ Date _____

Print Name _____

Date of Birth _____

Address _____

Health Professional Signature _____ Date _____

Health Professional Print Name _____

V11.2 30NOV2018

About this information sheet

This information sheet explains genomic testing. It has been designed to accompany the clinical consent form for genomic testing that your health professional will discuss with you. The clinical consent form needs to be signed before genomic testing is started. Having genomic testing is optional. *It is your choice whether to have this test.*

Questions to ask your doctor/genetic counsellor

Once you have read this form, you may wish to ask your doctor/genetic counsellor these questions:

- What is the chance that the genomic test will identify the cause of my/my child's condition?
- How long will it take to get a result?
- Who will give me the result and how?
- Where will my genomic test be performed?
- What is the cost to me (if any) of my genomic test?
- What (if any) are the implications for other members of my family if I have this test?
- What is the chance of this test finding something that is unrelated to my/my child's current health condition?

Potential outcomes of genomic testing

Your doctor or genetic counsellor will discuss the outcomes of genomic testing including:

- Finding a variant that is the cause of the condition.
- Finding a variant of unknown significance (VUS). The effect of VUS is unknown. Sometimes testing in other family members for the VUS may help to understand if it could be the cause of a condition. The understanding of VUS may change over time.
- No gene variants found that could explain a genetic condition. Reasons for this include:
 - the variant causing the condition cannot be found by the test;
 - the gene causing the condition was not tested;
 - the gene causing the condition is not yet known.
- Future testing may help clarify this, but the timing for this is unknown.

Potential benefits of genomic testing

Some people wish to have genomic testing to find a genetic diagnosis to help them understand their or their child's condition. A genetic diagnosis can also sometimes help families to access support and services that they need, and to plan for the future. A genetic diagnosis may also help health professionals manage a condition.

A genetic diagnosis may provide families with information about the chance of having another child with the same condition. Sometimes, the genomic test result in one person may also be important for the care of their relatives.

Genomic testing can lead to a diagnosis in 30-50% of people with rare genetic conditions. If a diagnosis doesn't happen today, the genomic test result could be looked at in the future as our understanding improves.

It is important to remember that genomic testing is not a general health test and will not identify *all* gene changes that could contribute to health problems that may develop in the future.

Potential risks of genomic testing

Incidental findings

In genomic testing, we are looking at many genes all at once and so there is a small chance they might see a variant in a gene that is not related to your health condition. This is called an incidental finding. It is a variant in a gene not related to the reason for doing the genomic test, but could be important to know about for your health. If your doctor determines that these incidental findings have important consequences for you or other family members, they will raise it with you. If medical follow up is required as a result of an incidental finding, your doctor or genetic counsellor will assist you by making appropriate referrals, if necessary. Your doctor or genetic counsellor will be able to give you some examples of incidental findings.

Insurance

In Australia, genomic testing will not alter your ability to get health insurance or your health insurance premiums. Genomic testing in you or your child could affect how easy it is for you or other family members to get income protection, travel or life insurance; or the price of your premium. An existing diagnosis may already affect your ability to obtain these kinds of insurance. Industry regulation prevents insurers from asking relatives for your genetic test results, and you cannot be requested to have a test by an insurer. Your healthcare provider will not provide your results to an insurance provider without your permission.

Further details can be found at: <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/FactSheet23A>.

Withdrawal from testing

You can change your mind about having genomic testing or being told the results. You can cancel the test at any time before the laboratory finishes the test. You can also choose not to be told the result after the test is finished, but the test result will be placed in your medical record.

Sharing results to help family members

Genetic services will not usually contact your relatives. However, your relatives may be referred to genetic services to arrange testing for themselves or their children when you tell them, or, when they find out there is a genetic condition in the family. With your permission, your test results may be released to another genetics service to help with the care of other family members. As genetic changes are unique in families, it is helpful for genetic services to be able to share information (for example – exactly what genetic change is present in a family), so that the correct testing can be offered to others in the family who may be at risk. All efforts will be made to ensure that your identity is not revealed to those family members unless you wish to provide that information.

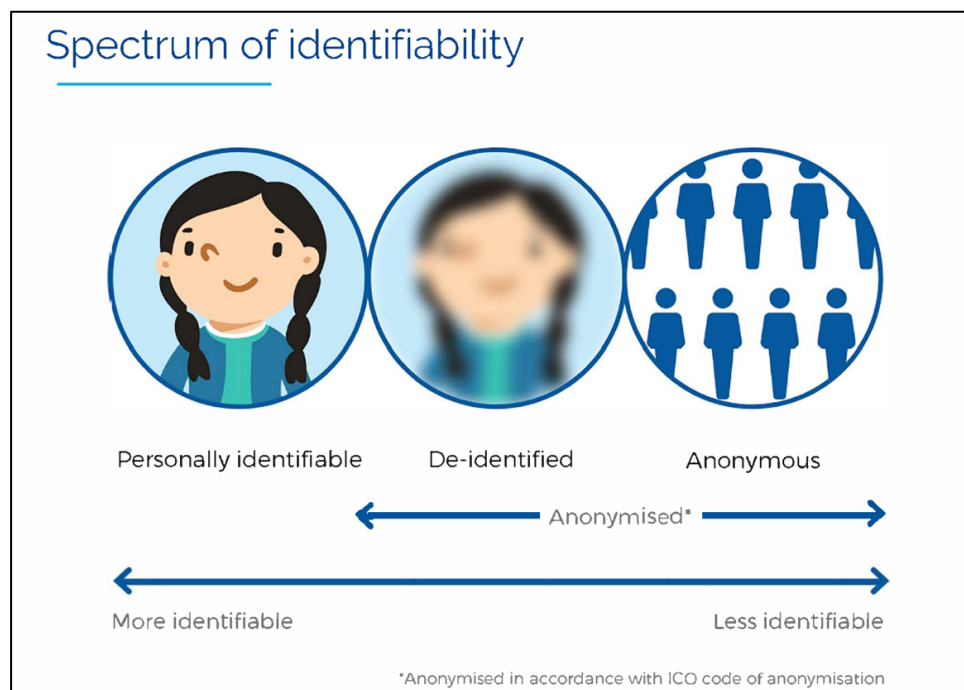
Data and Sample Sharing

Your identified results and genomic data from the test will be stored in secure, access controlled databases that meet Australian/international security standards and laboratory guidelines.

Your identified results and genomic data, your identified sample, or the fact that you have had genomic testing, will not be used or disclosed outside of your care without your consent, unless required or allowed by law. The health professionals involved in your care may order further testing of your sample or share your genomic data with each other to help work out what your test results mean.

Providing consent for genomic testing also allows for the sharing of your sample, genomic data and related health information to advance scientific knowledge. Your information will be shared in a way that keeps you anonymous. This may include sharing with large databases to help improve understanding of gene variants and related conditions by comparing your results to those from other people.

Your information and sample will only be shared when safeguards are in place to help protect your privacy. Personal identifiers will be removed (including your name, date of birth, and address) and stringent security measures will help prevent unauthorised access or misuse. Sharing will also involve only the least information necessary. These safeguards make it difficult to know whether the information is about you or other people; however, there is always a very small chance that you might be re-identified. Given that the potential to identify you is significantly reduced, you are unlikely to directly benefit from this sharing.

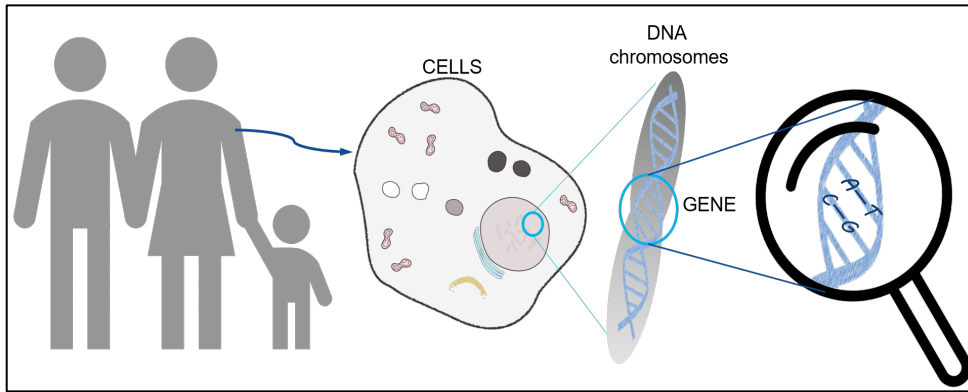


You can also provide consent to sharing for research into the **same or related condition** in a way that may be linked back to you. In this context, the identifiers described above can be removed from your information or sample, and replaced by a code. If there are findings from this research that have implications for your future clinical care, it may be possible to re-identify you, so that your results can be returned. However, participating in research does not guarantee direct benefits to you.

All researchers must respect the relevant laws (including privacy and security requirements) and ethical guidelines for biomedical and health research. Sharing in this context will only happen for projects approved by a human research ethics committee. You can choose not to provide consent to this sharing.

About the test – What is Genomic testing?

Our bodies are made up of billions of cells. In most of our cells we have a complete copy of our genetic information (genome). We all have about 20,000 genes in our genomes. Our genes are made of DNA and contain the instructions for growth and development of the body. Until recently, doctors and scientists were only able to test one gene at a time. Genomic technology allows us to test all of our genes at once (genomic testing).

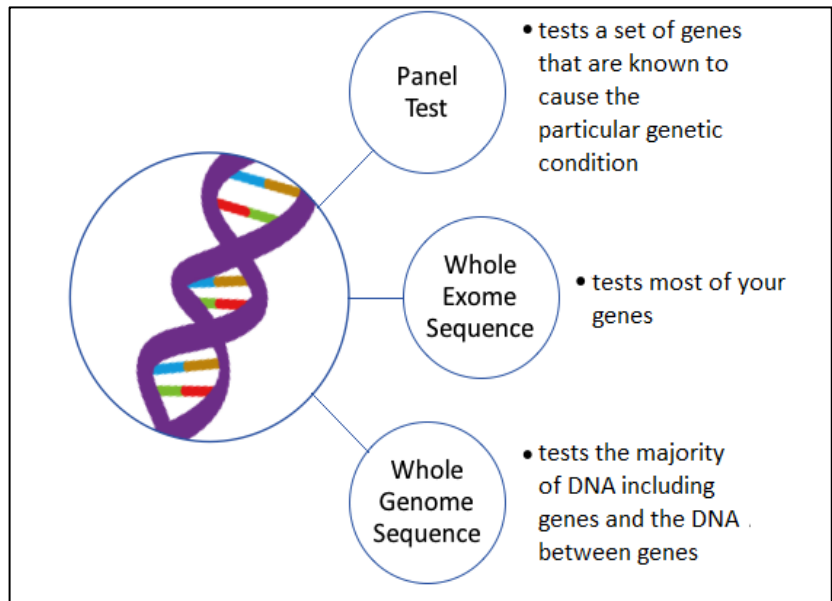


DNA can be taken from your body cells to identify changes that contribute to or cause disease.

Types of genomic testing

Most genomic testing uses DNA that comes from a blood, tissue, saliva, or mouth swab sample. There are three main types of genomic testing:

Types of genomic tests



What are genetic variants?

Each person's genome contains many genetic differences (variants). Most of these are harmless and do not change how the gene works in the body. Genomic testing is done to find gene variants that *do* change how a gene works and therefore cause genetic conditions.

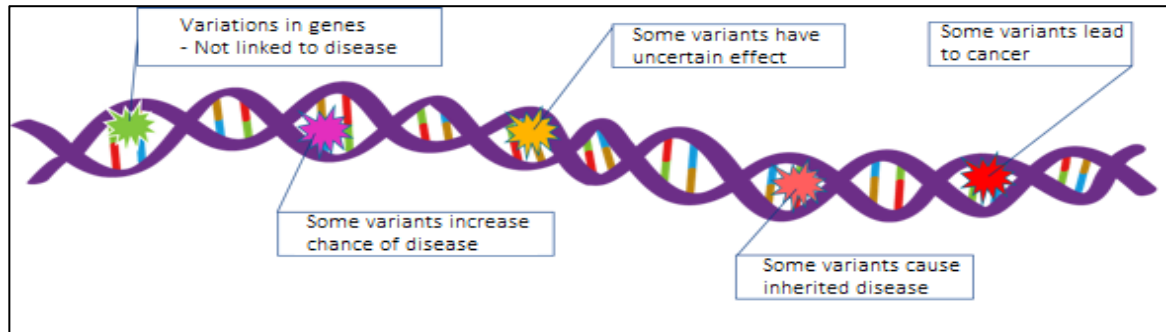
Example:

Think of a gene as like a sentence in an instruction manual and consider the following sentence

MUM CUT THE HOT DOG

MOM CUT THE HOT DOG	Some spelling changes look different but <i>don't</i> change the meaning of the sentence. Therefore, the gene still works.
MXM CUT THE HOT DOG	Other spelling changes look different and <i>do</i> change the meaning. Therefore, the gene doesn't work.
MEM CUT THE HOT DOG	Other spelling changes look different but we do not know if the meaning changes. Therefore, we are uncertain what the effect on the gene might be.

Different types of DNA variations have different effects on the genetic code and body functions.



Questions?

This information sheet provides general information about genomic testing. It supports the information you should receive from a medical specialist or genetic counsellor. If you have any questions about the test or any of the information in this sheet, please contact your doctor or genetic counsellor.

APPENDIX 3

National Clinical Consent Form for Genomic Testing and Supporting Information

Consultation document

1. How would rate the consent form and the supporting documentation regarding:
(please mark with an x)

	Very Good	Good	Acceptable	Poor	Very Poor
Intention of the test					
The outcomes of the testing					
The risks of genomic testing					
Incidental findings					
Use of samples in research					
Implications for relatives					
Re-contact for further studies					
Storage of samples					
Data sharing					

2. What do you like about this form and supporting documentation?

3. What would you change about this form and supporting documentation?

4. How easy would this form be to use in a clinical setting?

(please mark with an x)

Very Easy	Easy	Acceptable	Difficult	Very Difficult

5. What can we do to help ensure uptake in your state or institution?

6. Do you have any further comments on this form and supporting documentation?

OPTIONAL FURTHER QUESTIONS:

7. The intention of the test:

a. Do you agree with the content regarding intention? Yes No

b. If you selected 'No' or 'Undecided', what were your reasons why?

c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

d. Is there any further information regarding the intention of the test that you think should be included in the consent form or supporting documentation? Please describe these below.

8. The outcomes of the testing:

a. Do you agree with the content regarding outcomes of the testing? Yes No

b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding the outcomes of the testing that you think should be included in the consent form or supporting documentation? Please describe these below.

9. Risks of genomic testing:

- a. Do you agree with the content regarding risks of genomic testing? Yes No

- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding the risks of genomic testing that you think should be included in the consent form or supporting documentation? Please describe these below.

10. Incidental findings:

- a. Do you agree with the content regarding incidental findings? Yes No

- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding incidental findings that you think should be included in the consent form or supporting documentation? Please describe these below.

11. Use of samples in research:

- a. Do you agree with the content regarding use of samples in research? Yes No

- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding the use of samples in research that you think should be included in the consent form or supporting documentation? Please describe these below.

12. Implications for relatives:

- a. Do you agree with the content regarding implications for relatives? Yes No

- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding the implications for relatives that you think should be included in the consent form or supporting documentation? Please describe these below.

13. Re-contact for further studies:

- a. Do you agree with the content regarding re-contact for further studies? Yes No
- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding re-contact for further studies that you think should be included in the consent form or supporting documentation? Please describe these below.

14. Storage of samples:

- a. Do you agree with the content regarding the storage of samples? Yes No
- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how this section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding the storage of samples that you think should be included in the consent form or supporting documentation? Please describe these below.

15. Data sharing:

- a. Do you agree with the content regarding data sharing? Yes No

- b. If you selected 'No' or 'Undecided', what were your reasons why?

- c. Do you have any suggestions for how section in either the consent form or the supporting documentation, could be better expressed?

- d. Is there any further information regarding data sharing that you think should be included in the consent form or supporting documentation? Please describe these below.

APPENDIX 4

LIST OF INDIVIDUALS / ORGANISATIONS APPROACHED IN THE CONSULTATION PROCESS

Broad Consultation - May 2018		
	Name	Organisation
1	Vanessa Clements	Department of Health (NSW)
2	Eva Pilowsky	Department of Health (NSW)
3	Paul Fennessy	Department of Health and Human Services (Vic)
4	Shane Porter/ Moira Campbell	Department of Health
5	Edwina Middleton	Department of Health (NSW)
6	Sally Howard	Department of Health (NSW)
7	Keith McNeil	Queensland Health
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11	Dr Michael Gannon	Australian Medical Association
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13	Mr John Batten	ROYAL AUSTRALASIAN COLLEGE OF SURGEONS
14	Professor Steve Robson	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
15	Dr Catherine Yelland	The Royal Australasian College of Physicians
16	Dr Michael Buckley	Human Genetics Society of Australasia
17	Kevin Forsyth	Academy of Child and Adolescent Health
18	Ivan Macciocca	Australasian Society of Genetic Counsellors
19	A/Prof Michael Gabbett	Australasian Association of Clinical Geneticists
20	Kate Dunlop	Centre of Genetic Education
21	Australian Genomics Community Advisory Group	Australian Genomics
22	Melbourne Genomics Community Advisory Group	Melbourne Genomics
23	Queensland Genomics Community Advisory Group	Queensland Genomics
24	Monica Ferrie	Genetic Support Network of Victoria
25	Amanda Samanek	Genetic and Rare Disease Network (WA)
26	Steffani-Jade McDonagh	Genetic Alliance Australia (NSW)
27	Nicole Millis	Rare voices Australia
28	Julia Overton, Chief Executive	Health consumer Alliance (SA)
29	Norah Grewal	Research Associate in Law and Ethics
30	Emma Tudini	QIMR Berghofer
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35	Mathew Wallis	Austin Hospital, Clinical Genetics Service
36	Matthew Hunter	Monash Medical Centre Genetics Clinic
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39	Melissa Gratz	Mercy Women Genetics service
40	Susan Fawcett	Royal Women's Hospital
41	Paul James	Peter Mac familial cancer
42	Monash Health Familial Cancer Centre	Monash Health Familial Cancer Centre
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49	Dr Felicity Collins	Royal Prince Alfred: General Genetics
50	Dr Michel Tchan	Westmead Adult Hospital: General Genetics
51	Dr Judy Kirk	Westmead Adult Hospital: Cancer Genetics
52	Dr Linda Goodwin	Nepean Hospital
53	Dr Alison Colley	Liverpool Hospital: General Genetics
54	Dr Annabelle Goodwin	Liverpool Hospital: Cancer Genetics / Royal Prince Alfred: Cancer Genetics
55	Dr David Mowat	Sydney Children's Hospital Randwick
56	Dr Kathy Tucker	Prince of Wales Cancer Service
57	Dr Kathy Wu	St Vincent's Genomic Centre
58	Bronwyn Burgess	Hunter Genetics
59	Julie White	Genetic Helath QLD
60	Karin Kassahn	SAPathology
61	Chris Barnett	SAPathology
62	Eric Haan	SAPathology
63	Nicola Poplawski	SAPathology
64	Skye Jakobi	Department of Health (SA)
Targeted Consultation - October 2018		
65	Adrian Thorogood	Global Alliance regulatory ethics working group (REWG)
66	National Aboriginal and Torres Strait Islander Health Standing Committee	National Aboriginal and Torres Strait Islander Health Standing Committee
67	Tara Morrison	HCU Network Australia
68	Megan Donnell	Sanfilippo Children's foundation
69	Bronwyn Byrne	Leukodystrophy Australia
70	Adam Walczak	CanTeen
71	Deidre Gorrie	Cystic Fibrosis Victoria
72	Glenda Colburn	Lung Foundation Australia
73	Jan Mumford	GAA
74	Kate Vines	Rare Cancers Australia
75	Paul Bennett	CanTeen
76	Rebecca Davis	AMDF
77	Amanda Samanek	GARDN
78	Christine Walker	CIA
79	Kathy Wells	BCNA
80	Monica Ferrie	GSNV
81	Nicole Millis	RVA
82	Shannyn Floyd	KHA
83	Steve Roach	Myeloma
84	Sharon Gavioli	lungfoundation
85	Snezana Djordjevic	lukemia Foundation
86	Cindy Van Rooy	CFV

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