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The OurDNA health survey

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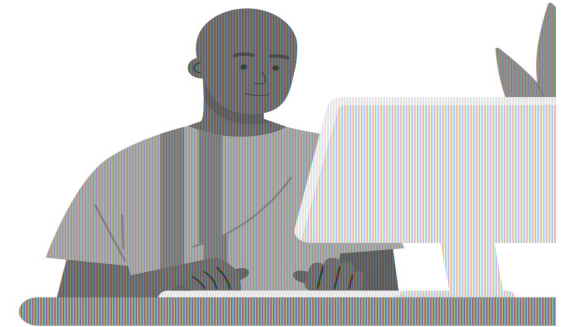


OurDNA

Many Australian communities are currently underrepresented in the resources doctors and researchers use to identify and diagnose different health conditions.

OurDNA is building **genetic resources** that include these multicultural communities, enabling future generations to benefit from any advancements in medical research.

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The health survey

We want to make sure that the resources we're building will improve medical research and help with health conditions that are common to communities, such as diabetes, cancer and heart disease.

Giving a blood sample to create better genetic resources is **very helpful** for doctors and researchers.

However, the genetic resources are even more powerful if they include **genetic information AND health information.**

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CCGTACCGAGGA
TAAAGGCTTATC
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Health information in medical research

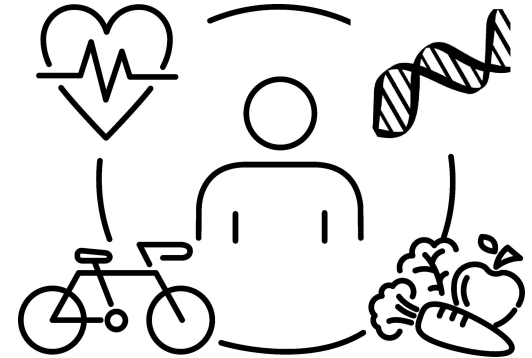
Your health is affected by changes in your DNA, but also by your environment, and the way you live.

Knowing more about

- a person's health
- the way they live
- their health history

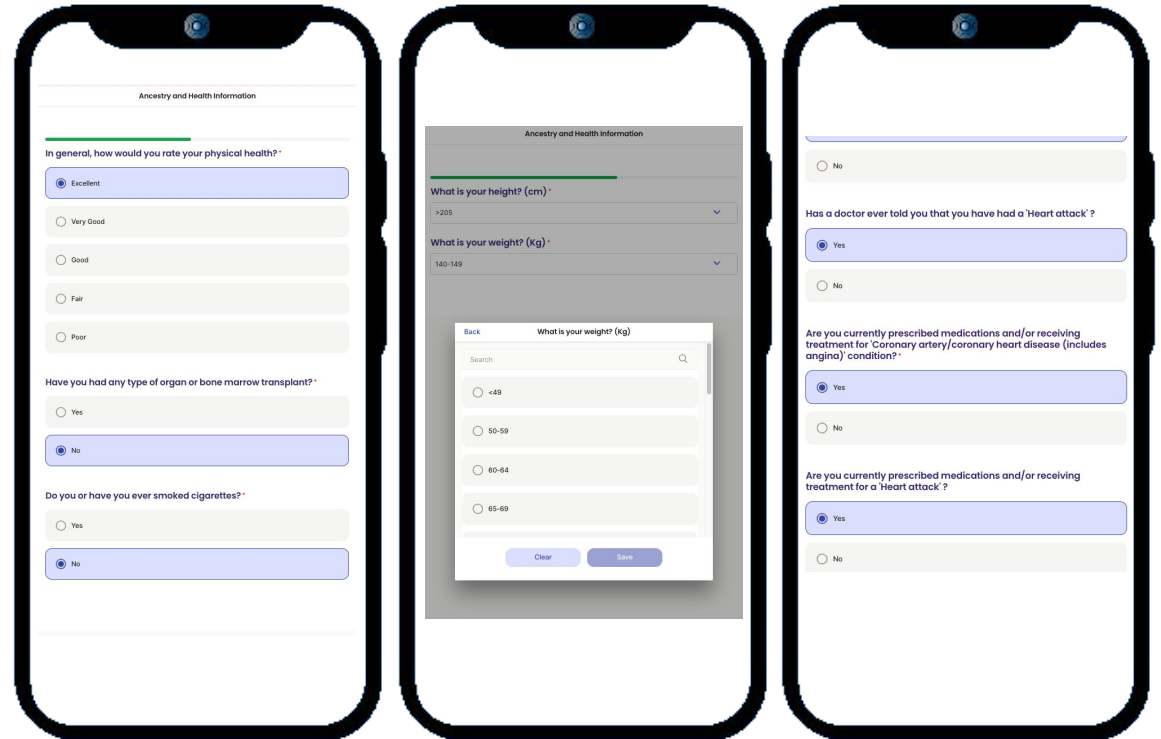
can help doctors and researchers to

- identify which changes in that person's DNA are the most important to study
- make clearer connections between health conditions and changes in DNA



How will the survey look?

The health survey is part of the step-by-step consent app, part of the section titled 'Ancestry and health information'.



The image displays three smartphone screens showing the 'Ancestry and Health Information' survey interface. The first screen shows the main survey questions with radio button options. The second screen shows a modal for selecting weight in kilograms. The third screen shows the continuation of the survey questions.

Screen 1: Ancestry and Health Information

In general, how would you rate your physical health?*

- Excellent
- Very Good
- Good
- Fair
- Poor

Have you had any type of organ or bone marrow transplant?*

- Yes
- No

Do you or have you ever smoked cigarettes?*

- Yes
- No

Screen 2: Ancestry and Health Information

What is your height? (cm)*

>205

What is your weight? (kg)*

140-149

Back What is your weight? (kg)

Search

- <49
- 50-59
- 60-64
- 65-69

Clear Save

Screen 3: Ancestry and Health Information

Has a doctor ever told you that you have had a 'heart attack' ?

- No
- Yes

Are you currently prescribed medications and/or receiving treatment for 'Coronary artery/coronary heart disease (includes angina)' condition?*

- Yes
- No

Are you currently prescribed medications and/or receiving treatment for a 'heart attack' ?

- Yes
- No

Which questions are in the health survey?

1. General physical health
2. Height (range)
3. Weight (range)
4. Smoking status
5. Organ or bone marrow transplant
6. Cancer:
 - Blood cancer
 - Other cancer
7. Other conditions
8. Prescribed medications or treatment for cancer
9. Long Term side effects following COVID

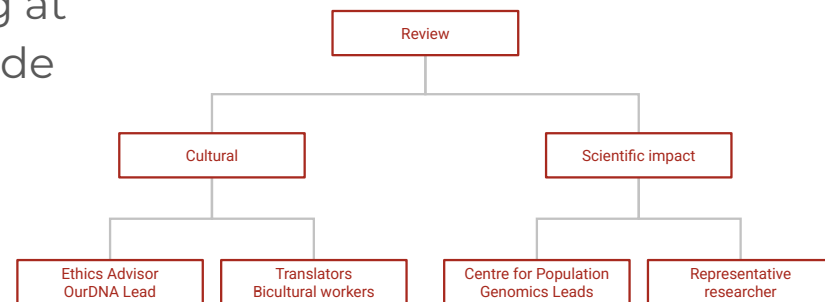
Coronary artery disease / coronary heart disease (includes angina)
Heart attack
Stroke
Crohn's disease
Ulcerative colitis
Type 1 diabetes
Type 2 diabetes
Asthma
Multiple sclerosis (MS)
Rheumatoid arthritis (RA)
Systemic lupus
Macular degeneration
Skin condition (e.g. eczema, psoriasis)
High blood pressure
High cholesterol
Sickle cell anaemia
OR
None of the above

Whether the health condition was diagnosed (by a doctor)

Whether the participant has prescribed medications or treatment

How was the survey developed?

The health survey was developed by looking at other surveys for genetic resources worldwide and has been reviewed by community members, scientists, and the OurDNA team for: length, cultural appropriateness, scientific impact, and ability to translate



What changed during review?

- More accessible and culturally sensitive language
- Overall length reduced
- Focused on most relevant health conditions
- Removed nonessential questions that may be perceived as intrusive

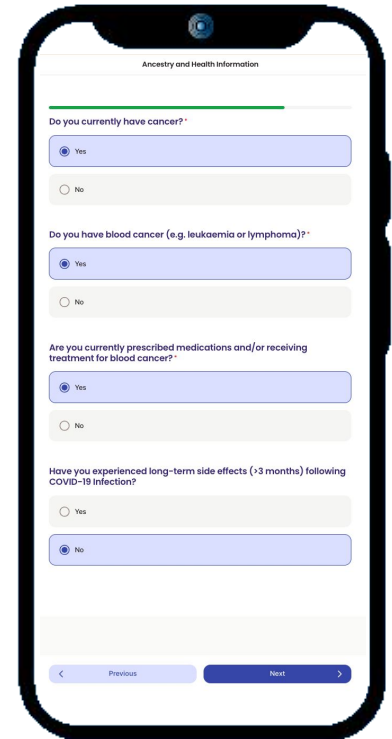
How will the survey be rolled out?

The survey is now live for all future participants

Notification and phone calls for existing participants (led by recruitment team after the script and materials have been approved by the Human Research Ethics Committee)

In which languages (so far)?

Tagalog, Vietnamese, Arabic



Ancestry and Health Information

Do you currently have cancer?*

Yes

No

Do you have blood cancer (e.g. leukaemia or lymphoma)?*

Yes

No

Are you currently prescribed medications and/or receiving treatment for blood cancer?*

Yes

No

Have you experienced long-term side effects (>3 months) following COVID-19 infection?

Yes

No

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Piloting the survey

We will be starting to use the health survey in the step-by-step consent process in upcoming events.



For the first months, we'll be asking you to note whether

- Anyone **stopped the consent process** at or because of the health survey
- **You receive feedback** from participants about the survey or any of the questions
- You **observed any discussion** about, or challenges with, specific sections of the survey

The OurDNA community engagement and recruitment team members will be keeping track of any of these situations – please do let them know.

<https://cpg-populationanalysis.atlassian.net/wiki/x/UAC9LQ>

Why are particular questions used in the survey?

The information participants provide in the survey can help researchers and doctors to make sense of their DNA information.

The next few slides pick out some of the questions and talk about why they are included in the survey.

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Survey questions: health, height & weight

In general, how would you rate your physical health?

- a. Excellent
- b. Very Good
- c. Good
- d. Fair
- e. Poor

What is your height? (cm) (in ranges of 5 or 10 cm)

What is your weight? (Kg) (in ranges of 5 or 10 kg)

Why do we ask these questions?

Your general health or your height and weight can help doctors and researchers work out how much different DNA changes are responsible for different health conditions.

Survey questions: smoking

**Do you or have you ever smoked
cigarettes?**

- a. Yes
- b. No

**Why do we ask these
questions?**

The way you live, such as smoking, can also help doctors and researchers understand which DNA changes could relate to smoking or other factors in your environment and which changes relate to common health conditions.

Survey questions: transplants & cancer

Have you had any type of organ or bone marrow transplant?

- a. Yes
- b. No

Do you currently have cancer?

Yes No

[if yes] Do you have blood cancer (e.g. leukaemia or lymphoma)?

Why do we ask these questions?

Your medical history, such as an organ or bone marrow transplant, or if you've had cancer, to help researchers to recognise changes in your DNA related to your transplant or cancer, not another health condition.

Survey questions: conditions

Do you currently have or have you ever had any of the following conditions?

Health conditions (Yes/No)

Coronary artery disease / coronary heart disease (includes angina)

Heart attack

Stroke

Crohn's disease

Ulcerative colitis

Type 1 diabetes

Type 2 diabetes

Asthma

Multiple sclerosis (MS)

Rheumatoid arthritis (RA)

Systemic lupus

Macular degeneration

Skin condition (e.g., eczema, psoriasis)

High blood pressure

High cholesterol

Sickle cell anaemia

None of the above

Have you experienced long-term side effects (more than 3 months) following COVID-19 Infection?

Why do we ask these questions?

Knowing health conditions you have or have had, including any of the 15 health conditions or [long] COVID-19 can help doctors and researchers work out if changes in your DNA are connected with/relate to those conditions.

Please note that the COVID question should focus on long term side effects of the infection itself, not vaccine-related concerns.

The conditions were chosen based on a literature review of:

- How much genetics is expected to contribute to the condition
- What is already known about DNA changes that cause or increase the risk of the condition
- How common the condition is in the communities OurDNA is working with
- How likely it is that data from OurDNA could assist with research into this condition

Survey questions: doctors and prescribed medications

Has a doctor ever told you that you have this condition?

Are you currently prescribed medications and/or receiving treatment for this condition / cancer?

Why do we ask these questions?

Your medications and the conditions your doctor has told you about can help researchers to confirm whether your DNA changes relate to health conditions you may have.

FAQs

WEBSITE FAQ: Why is OurDNA asking for my health information?

OurDNA is asking participants to complete a short set of questions to help us understand some things about your health and if you've previously had, or currently have, certain health conditions.

This information will help doctors and researchers to study health conditions that may be common in your community, and make the relationship between changes in DNA and these common conditions clearer. This will help researchers to create better tools to predict, identify and treat conditions, such as diabetes and heart disease.

How do I answer if...

...A person says that their friend didn't have to / they didn't expect to have to answer these types of questions?

These questions are (now) not optional if you take part in OurDNA.

Please explain that we want to make sure that the resources we're building will improve medical research and healthcare now and in the future. Genetic resources are more powerful if they include genetic AND health information.

We have introduced the health survey to make sure that the OurDNA data can be best used for future research. Having resources that represent communities can help doctors and researchers make more accurate diagnoses, and eventually help predict, treat and even prevent health conditions. Answers to the questions asked in the survey will help make medical research and healthcare better for everyone.

However, ultimately, it is each person's choice whether or not to take part in OurDNA.

FAQs

How do I answer if...

...A person does not know if they have one of the conditions on the list?

If a person does not know if they have, or have had a condition, suggest to them to select **no**. If they do mark yes, they will then be asked whether a doctor has told them that they have the condition and if they are taking prescribed medication for the condition. If they are unsure about either option, they are better to say No at the beginning.

When in doubt, or the person doesn't recognise the name of a condition, suggest they say **no**.

...A person has a condition similar to the ones on the list, but not quite the same...

eg. macular degeneration (an eye disease)

Shortsighted, long sighted or astigmatism? No. Retinal disease? Yes.

eg. coronary heart disease

Surgery or a stent for heart condition? Yes.

eg. diabetes

Pre-diabetes? No.

eg. ulcerative colitis or Crohn's disease

Irritable bowel or coeliac disease? No.

eg. systemic lupus

Rashes? No, unless told by a doctor that it is lupus-related and immunosuppressants or anti-inflammatories are in use...

FAQs

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How do I answer if...

...A person would like to discuss the conditions in a more private place?

If possible at the venue, it would be great to have a more private location for people to discuss and/or answer the questions. Please do assure people that any information they give will be stored separately and shared with other researchers without personal details (such as their name and address).



**What other questions do you have?
Send us an email!**