The Fiji Heart Study, is a research project dedicated to understanding genetic factors linked to heart health and disease among Peoples of Fiji living in Aotearoa NZ

Genetics Information booklet for the Fiji Heart Study

Contents

Why is this research important?

- Heart attacks or angina can happen when a blood vessel in the heart wall becomes narrowed or blocked.
- Genetic or inherited factors that can cause or prevent heart attacks/angina have never been studied in Peoples of Fiji.
- A better understanding of these inherited factors can help to develop tools for earlier diagnosis and prevention of heart attacks in our community and to develop medicines that are better designed for us, with fewer side effects.

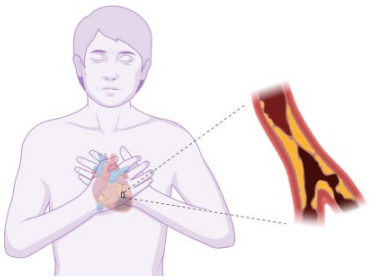


Figure 1. Diagram of blockage in major coronary arteries, which can cause a heart attack. Created in https://BioRender.com

Important definitions for this genetic study:

Coronary artery disease: Coronary artery disease is when the blood vessels that supply blood to the heart get clogged or narrowed, making it harder for blood to reach the heart.

Genetic/genomic research: a type of health research that studies how a person's genetic information affects their health and potentially also the health of their family.

DNA: is any genetic information in your body that allows it to develop, grow and function. It can be found in all parts of your body, including your blood and saliva. Everyone's DNA is unique, except for identical twins. You share parts of your DNA with your blood relatives, like your parents, grandparents, siblings, and children. People from the same ancestry also have some similar genetic information.

Genome: This is information about all the DNA in your body, like the complete instruction manual for your body. It helps us understand how the human body works and how it might be affected by diseases.

Genes: small sections of DNA, that provide specific instructions to carry out a specific task.

Genetic factors or variants: changes within a gene sequence are called genetic variants. These changes make each of us unique. Most of the time, they don't affect us at all. But sometimes, they can cause health problems or increase the risk of developing disease in the future.

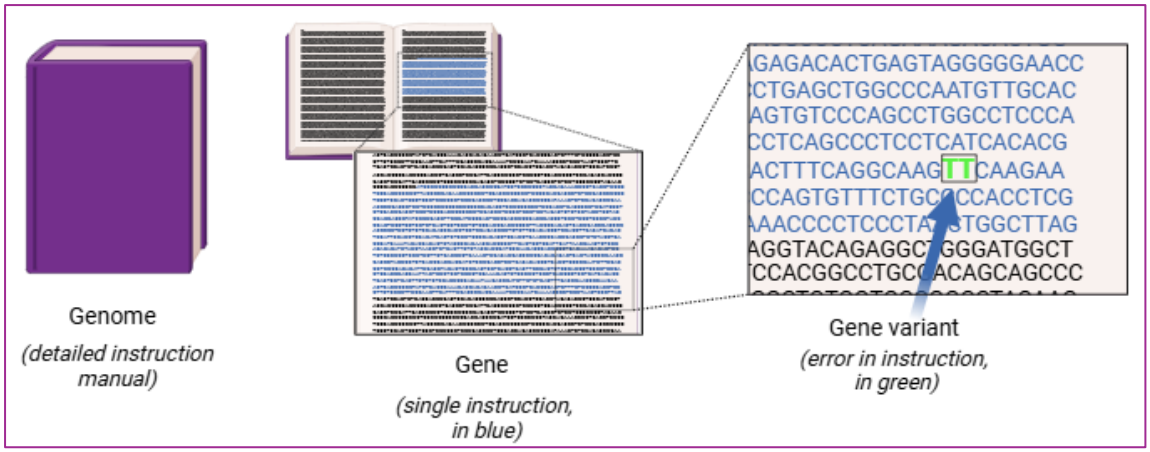


Figure 2. Zooming in from genome to gene variant using analogy of an instruction manual. Created in https://BioRender.com

How will your blood sample be used in this study?

In this study, your blood will be used to extract DNA and RNA for genetic analysis and to analyse biomarkers derived from your blood.

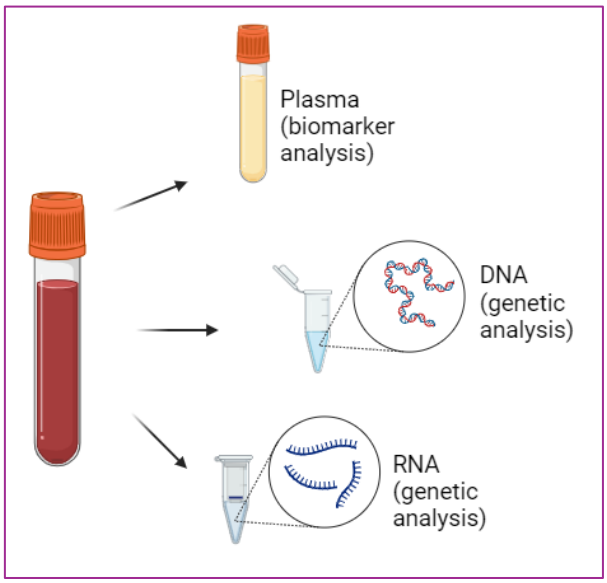


Figure 3. Examples of molecules we may study from your blood sample. Created in https://BioRender.com

How is genetic data used in NZ healthcare?

Genetic and/or genomic information is already being used in healthcare in Aotearoa | New Zealand. For example

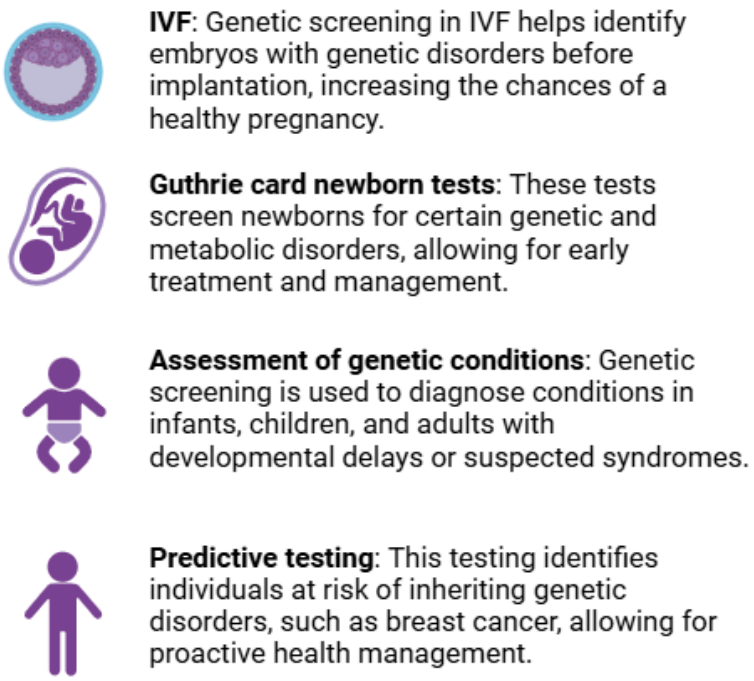


Figure 4. Use of Genetic information in NZ healthcare. Created in https://BioRender.com

Risk factors in heart disease

For most people, there are many different factors that can affect our risk of developing heart disease. We list 2 main types: those we have some control over (e.g. diet and lifestyle), and those we don't (e.g. genetics).

Diet and lifestyle

Some positive diet and lifestyle choices that can help protect against coronary artery disease (CAD) include:

- Healthy food: Eating a balanced diet rich in fruits, vegetables, whole grains, lean proteins, and healthy fats can support heart health.
- Regular exercise: Engaging in regular physical activity, such as walking, jogging, or cycling, helps maintain a healthy weight, lowers blood pressure, and improves cholesterol levels.
- Healthy weight: Keeping a healthy weight reduces the strain on your heart and lowers the risk of developing conditions like high blood pressure and diabetes.
- Avoiding tobacco: Not smoking or using tobacco products helps keep your arteries healthy and reduces the risk of plaque buildup.
- Moderate alcohol: Drinking alcohol in moderation, if at all, can help maintain healthy blood pressure and prevent heart damage.
- Managing stress: Finding healthy ways to manage stress, such as through meditation, yoga, or hobbies, can help keep your heart healthy.
- Sleep: Ensuring you get enough good-quality sleep each night supports overall heart health and helps regulate blood pressure, weight, and blood sugar levels.

Genetic risk factors

Certain genetic factors or genetic variants can increase a person's risk of getting heart disease. For some people it takes single variant in a **single gene (monogenic**) to cause early risk of a heart attack. These genetic variants are usually rare. Diseases caused by a single gene variant are often called familial or inherited because they can be passed from parent to child. In Australia, genetic testing for these single-gene variants is available for some diseases.

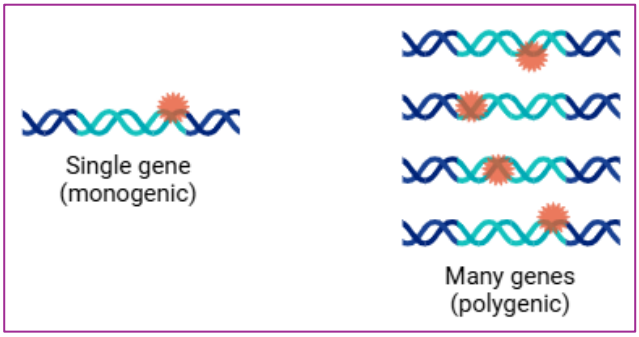


Figure 5. Monogenic versus polygenic risk factors for heart disease. Created in https://BioRender.com

For other people, it could be the cumulative effect of many variants on **many different genes (polygenic)** that increases their risk for developing heart disease. We are still learning about how different genetic variants affect diseases, so doctors don't use this information in their guidelines yet. Also, most of what we know comes from studying people of European ancestry. For example, about 86% of genetic data is from people with European backgrounds, while less than 4 % is from people with South Asian or African ancestry.

What genetic services are available through our healthcare system in NZ?

Genetic Health Service NZ is a national service that helps diagnose and support people with genetic conditions. It operates through regional hubs and outreach clinics to provide accessible genetic services across New Zealand. Services are provided by a team of specialist clinical geneticists and genetic counsellors.

A clinical geneticist is a medical doctor who specializes in diagnosing and managing patients with genetic disorders. They use their expertise in genetics and medicine to understand how genetic conditions affect health and to develop treatment plans.

A genetic counsellor is a healthcare professional with specialized training in medical genetics and counselling. They help individuals and families understand their genetic risks, interpret genetic test results, and make informed decisions about their health and future.

You can find out more at https://www.tewhatuora.govt.nz/health-services-and-programmes/genetic-health-service-nz/about

What kind of genetic results can I expect from participating in the Fiji Heart Study?

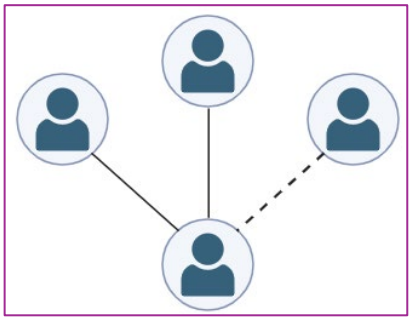
Our study is for research only, so we cannot give you a confirmed genetic diagnosis. However, if we find any important and actionable genetic findings that are related to your coronary artery disease (primary outcomes of this research) and can help manage your health, we will inform your doctor. Your doctor will discuss your options with you and, with your permission, refer you to Genetic Health Service NZ for a confirmed diagnosis and support, including genetic counselling.

You also have the option to consent to receiving what we call secondary or incidental findings (i.e. findings that are unrelated to the primary outcomes of this research). While, secondary or incidental findings will not be specifically sought, there is a small chance they are discovered in our analysis.

Incidental finding example: A person has a genomic test for heart disease, and the test finds they are a carrier of a gene variant that causes breast cancer (BRCA2). Although breast cancer is a genetic condition, it is not related to heart disease. Finding out the person is a carrier for BRCA2 was an incidental finding.

Important issues to think about when considering referral to Genetic Health Service NZ

1. You and your whānau/family may hold cultural, spiritual or religious beliefs regarding the handling, use and disposal of human samples, especially for genetic research. These should be discussed with your whānau as appropriate.



2. Genetic testing can sometimes reveal surprising family relationships, for example when an individual's parent is shown not to be their biological parent. This doesn't happen often, but if you think it might be a possibility, you may wish to talk to a health professional before testing.
3. Genomic test results do not affect existing insurance cover. If you join the Fiji Heart Study, we will never share your genetic

results with your insurance provider, as our research cannot provide clinically verified diagnostics. If you already have medical records relating to your heart condition and/or obtain a clinically verified genetic diagnosis through NZ Genetic Health Services, you may have to declare this when you update or take out a new policy and this may affect the cost and/or how easy it is to get new insurance (such as health, travel or life) in the future. Your healthcare provider will not share your results with an insurance company without your permission.

How are my data, privacy and confidentiality protected?

All research in Aotearoa New Zealand is reviewed by an independent group of people called the Health and Disability Ethics Committees (HDECs). HDECs are Ministerial committees (established under section 87 of the Pae Ora Act 2022) in New Zealand that review health and disability research to ensure it meets high ethical standards. The HDECs follow established guidelines to ensure that research benefits participants and ensure that studies are conducted ethically and responsibly.

The Fiji Heart Study has also been approved by the Community Advisory Group and interim Research Advisory Group-Māori to ensure cultural safety and oversight of the study.

As part of this approval, we have taken steps to make sure that participant data is stored securely in University of Otago facilities and/or data centres. Any personal or identifiable information, (such as your contact details and National Health Index (NHI) number) will be kept separate from health and genetic information, to maintain your confidentiality and privacy. This means that your data is "de-identified". All data is kept on secure, password-protected servers and access restricted to only authorised researchers.

All data generated will adhere to the Fiji Heart Study data management plan, ensuring that your data remains confidential and is used only with your permission. Any use of your samples and data will abide by the Privacy Act 2020, the Health Information Privacy Code 2020 and the University of Otago Privacy Policy.