

PARTICIPANT INFORMATION SHEET

(For young children)

Short title: CHAANZ and NZ Heart Registries
Study title: Congenital and Paediatric Heart Disease Registry
Coordinating Centre: Congenital Heart Alliance of Australia and New Zealand (CHAANZ)
Locality: Te Toka Tumai Auckland, Starship Child Health
Ethics committee ref.: 2023 FULL 12788
Chief investigator: Professor David Celermajer
Principal Investigator: Dr Clare O'Donnell

We are inviting you to help us learn more about heart conditions.

Please read this information with your parents/family/whānau/‘Aiga and ask them any questions you have. You can also ask us if there is anything that is not clear or if you want to know more. It is up to you if you want to take part and you can take time to decide.



What is the Congenital and Paediatric Heart Disease Registry?

This is a collection of information, called a Registry, about children and young people with heart problems in Aotearoa New Zealand and Australia. This will help us to understand heart problems better, how they change as you get older, and how best to treat them. We will also learn how many people have heart problems.

Do I have to be involved?

You don't have to take part if you don't want to. You and your parents and whānau should talk about it. It is up to you if you want to take part, and you can say no even if your parent or carer says you can. If together you decide not to take part, that's OK, it won't affect the care you receive.

What will happen if I take part in the study?

We will include your health information in the Registry, unless you and your whānau tell us you don't want to be involved. You don't have to do anything extra to be involved, there are no extra tests or appointments. We collect information like your name, age, ethnicity (e.g. Māori, Pākehā, Samoan), and information about your heart health from your hospital records. If you were born with this condition, we will send your information to the Registry in Australia. If your heart condition started after you were born, it will be saved here at Starship.

Will taking part help me?

Taking part in this study will not affect any part of your hospital care. Taking part will help us to learn new information about heart problems like yours. This might help you or children like you in the future.

Will anyone know if I take part in the Registry?

Your family, your heart doctor, and a small number of people from the Registry team will know you are taking part. You can talk to anyone you want about the project. You can ask any questions you have. But we won't tell anyone else you are taking part. When you are around 16-18 years old, we will check if you still want your information in the Registry.

Who will answer my questions about the Registry?

If you want to know more, ask your family/whānau/carer as they have some papers with more information about it. Or you can ask the doctor or nurse lots of questions.

What if there is a problem or something goes wrong?

Tell us if you think there is a problem and we will try and sort it out straight away. You or your parents/whānau/carer can contact the nurse or doctor looking after you.



Thank you!

Additional study information and opt-out form accessed here:

<https://www.chaanz.org.au/participant-information-nz>

