

# Patient Self-Screening for Familial Hypercholesterolemia

## Participant Information Sheet

### What is the project about?

Familial hypercholesterolemia is an inherited condition that can cause early heart disease. It affects 1 in 250 people, but 90% of cases are not detected. If detected and treated early, patients can have a normal life expectancy. This study will help General Practitioners (GP) to detect the condition early so that treatment can be commenced, and heart disease prevented.

### Who is leading the project?

This research is being done through the School of Medicine at the University of Notre Dame. The researchers involved are Dr. Stephanie Eid, Dr. Katrina Giskes, Dr. Margot Woods, Associate Professor Charlotte Hespe, Donna Jeong and Luke Jennings.

### What will I be asked to do?

You will be asked to complete a short questionnaire on your mobile phone while you are waiting for your GP appointment. This will take about 5 minutes to complete. The questionnaire asks about your health and family history of heart and circulatory diseases. Your answers will go to your GP if you choose to provide your details. If you are at high risk of familial hypercholesterolemia, your GP may arrange some blood tests to further investigate, and these will be bulk billed.

A very small number of patients who partake in the study will also be contacted by phone to participate in a short interview about their experience of completing the questionnaire. This will provide some feedback about ways the screening can be improved or simplified. This will take about 15 minutes and will be recorded.

### Are there any risks associated with participating in this project?

Your participation is voluntary and there will be no harms or implications to you if you do/do not participate. Your decision to participate/not participate will not bear any influence on the quality of your care by your GP and will not influence your current or future relationship with any practitioners in the practice, or with the medical practice.

Your GP will discuss your results with you. If you are at high risk of familial hypercholesterolemia, your GP may arrange some blood tests. If indicated, your GP may also discuss treatment options with you. If you find that you are experiencing difficult feelings or becoming distressed, we can arrange for you to access support from a counselor.

**What are the benefits of participating?**

Participating may have several benefits:

- Your responses will improve your medical record information. This is important information that will guide your current and future medical care.
- Your risk of familial hypercholesterolemia will be assessed, and if you are at high risk, early treatments may be started and these may prevent heart and circulatory problems later in your life.
- Your participation may improve patient care, especially for the detection of this condition.

**Are there any costs involved?**

Participation in this study will not cost you anything, nor will you be paid.

**What if I change my mind?**

Your participation is completely voluntary, and you are free to withdraw at any time without giving a reason and without any impact on your care.

**How will you keep my information private and confidential?**

All aspects of the study, including results, will be confidential and only the researchers will have access to information on participants, except as required by law. Once the study is complete, the data will be stored securely as per the University of Notre Dame policy for research data management. A report of this study may be submitted for publication, but individual participants will not be identified.

**Will I be able to find out the results of the project?**

If you provide your personal information, your responses will be forwarded to your GP. You can also choose to have your responses emailed to yourself. Once we have analysed the information from this study, we aim to submit a report for publication. You can contact us if you wish to receive feedback of the study results.

**Who do I contact if I have questions about the project?**

Please feel free to contact Dr. Stephanie Eid on [stephanie.eid1@nd.edu.au](mailto:stephanie.eid1@nd.edu.au).

If you have personal or specific health-related questions, please discuss these with your GP.

**What if I have a concern or complaint?**

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (reference number 2021-165S). If you have a concern or complaint regarding the ethical conduct of this research project or would like to speak to an independent person, please contact the Research Ethics Officer at (+61 8) 9433 0943 or [research.ethics@nd.edu.au](mailto:research.ethics@nd.edu.au). Any complaint or concern will be treated in confidence.

**Thank you for your time.**

**Kind Regards,  
Dr. Stephanie Eid  
(General Practitioner and Lead Researcher)**