

## What does participation involve?

Participation involves providing your contact details and answering a questionnaire. Participants will answer questions about their disease diagnosis and may be asked to donate a saliva sample.

We will extract DNA from your saliva sample to investigate genetic factors that increase PD risk and/or influence disease prognosis and treatment response. For instance, we will compare DNA from people with PD against a control group who do not have this condition, or compare DNA of PD patients who experience a particular side effect against those who do not.

Participation also involves consenting to storage of your questionnaire and genetic information in a secure data repository for future use. This information may be stored indefinitely and pooled together with similar data from other participants. To see how your privacy is protected, please read Section 8 - 'Is it confidential?'

Before you participate, though, we need your consent. The consent form is located on the following page. When consent is given, we will begin the process of collecting your DNA sample. This will involve you providing a sample of saliva into a specialised collection container which we will send to you. You will be asked to return this sample via Australia Post to our laboratory, at no cost to you.

## Do I have to give a DNA sample?

To participate in this study, you may be asked to provide a saliva sample, as explained in the paragraph above. Providing a sample can be done in your own home.

## What is in it for me?

While this study is unlikely to be of any immediate and specific benefit to you, extensive research is required to find answers to the questions we are investigating. Future medical or scientific discoveries may come from the research in which you participate, and, in turn, help improve the available treatments and outcomes for people with PD. Many participants value the unique contribution that they can make to research.

Due to the specific sample design of the study, we will not be able to provide any individualised analytical feedback to participants about their health condition, biological sample, or DNA. However, researchers will be providing everyone who participates with a newsletter. In this newsletter we will give you information about the progress and outcomes of this study, as well as that of several other studies. Our research team values the time and effort that you give to research.

## Are there any risks?

Researchers acknowledge that being invited into this research study may be a sensitive issue for you and may, therefore, cause you some discomfort. We would like to restate that we currently do not have any information about you.

You may feel that some of the questions we ask in the questionnaire are stressful or upsetting. If you do not wish to answer a question, you can skip it and go to the next question, or you may stop immediately.

If you have any questions or concerns about this research study, you may telephone the Project Coordinator, Richard Parker on 07-3362-0297. You may also use our free call number: 1800-257-179. If you have any concerns or complaints regarding the conduct of this study, you may contact the

## Will I be contacted again about this study?

We plan to extend this study and may seek to re-contact some of the participants in the current study.

Choosing to participate in the current study does not mean that you will necessarily be re-contacted. If we do contact you about a follow-up study, you can of course choose not to participate, and it will not impact your participation in the current study in any way.

## Is it confidential?

Yes. All information and data collected for the study remains confidential in accordance with The Australian National Health and Medical Research Council (NHMRC) Human Research guidelines and the Australian Privacy Act.

Your personal details, questionnaire data, biological sample and genetic data will all be stored separately. Your individual questionnaire, biological sample and genetic data files will have a number assigned to it, not your name. Your name and personal details will continue to be stored on file at QIMR Berghofer but will be stored separately from, and not linked with, your questionnaire information, biological sample and genetic data. The only link between your data and your personal details is your participant identification number (meaning your sample is potentially re-identifiable). Linking both your personal details and data file using this number is severely restricted to members of the QIMR Berghofer research team.

Results of this research study may be presented in scientific papers in medical literature, or in public talks, but your identity will not be revealed. The data collected as part of this study will be combined at analysis with the data from many other people, and as such there will be no way of identifying you as a participant.

In accordance with relevant Australian privacy and other laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

By confirming your consent online, you consent to the research team collecting and using personal, questionnaire and genetic information about you as described for the research study.

## What will happen to information about me?

The researchers will store your personal, questionnaire and genetic information indefinitely at QIMR Berghofer Medical Research Institute. The reason why we need to store this information indefinitely is because it will continue to be valuable to researchers many years into the future, and may be considered for use in future, related projects. Before any future work proceeds it will be subject to approval by the relevant ethics committees.

## What will happen to my biological and DNA samples?

**This Study:** We will use your biological (saliva) sample to extract one or more samples of DNA. The research team will then look for differences and similarities between participants' DNA samples. This information can help us understand why some people have a certain condition such as Dementia and some people do not. The research team will also investigate why some people have differing caregiver experiences.

Your biological sample and samples of your DNA will be stored securely at QIMR Berghofer Medical Research Institute along with samples from many other people. They will be re-identifiable, which means that they will be stored with a barcode label and can be identified as yours even though your personal details are stored separately. Linking your personal details with your biological sample or DNA using the barcode is restricted only to members of the QIMR Berghofer research team.

We may decide to send part of your biological sample and/or a sample of your DNA to another laboratory (which may be overseas) for processing or analysis. If this occurs, your part sample will only be labelled with a number and transported along with samples from many other people. No information identifying you will be sent to or accessible by the other laboratory. Any sample remaining after processing or analysis by the other laboratory will be returned to QIMR Berghofer Medical Research Institute for indefinite storage.

**Future Studies:** We would like to store your biological and/or DNA samples for a long time for use in future research studies that may or may not be related to this study. There is no direct benefit to you from the storage of your biological and/or DNA samples. In the future, other doctors and scientists at this and other medical and research centres may use your samples to learn about many different diseases and conditions. Their goal is to improve health outcomes and develop new treatments. The purpose of storing these types of samples is to answer questions in the future, so we expect to keep your samples for a long time.

## Who are the researchers?

- Dr Miguel Renteria, QIMR Berghofer Medical Research Institute.
- Dr Penelope Lind, QIMR Berghofer Medical Research Institute.
- Prof Nick Martin, QIMR Berghofer Medical Research Institute.

## What if I don't want to participate or what if I change my mind later and want to withdraw from the study?

Participation is voluntary, and you can choose not to participate. If you do choose to participate you can withdraw from the study at any time, at any stage, or for any reason for some, part, or all of the research. You can withdraw your consent by contacting the Project Coordinator by phone 1800 257 179 (free call) or email [parkinsonsgenetics@qimrberghofer.edu.au](mailto:parkinsonsgenetics@qimrberghofer.edu.au).

## What if I have questions?

You can call or email us. Our Free call number is 1800 257 179. Our email address is [parkinsonsgenetics@qimrberghofer.edu.au](mailto:parkinsonsgenetics@qimrberghofer.edu.au). We are happy to answer any questions you have before you agree to participate and also at any time throughout the study.

**I have read this information sheet and have understood it.**

**Yes - proceed to consent page**

**No - I choose not to participate / I am not eligible**





**QIMR Berghofer**  
Medical Research Institute

