Transforming Parkinson's Care in Africa (TraPCAf)

Participant Information Sheet:

GP2 – Global Parkinson's Genetics Program

Introduction

You have been invited to take part in the Transforming of Parkinson's Care in Africa (TraPCAf) study, the details of which are on the information sheet that you have been given.

The TraPCAf team are collaborating with researchers from around the world through the Global Parkinson's Genetics Program (GP2) to study the genetics of Parkinson's disease. GP2 includes people with and without Parkinson's disease. You can find more information about GP2 and the researchers leading the program at www.gp2.org. GP2 is funded by the Aligning Science Across Parkinson's (ASAP) initiative and The Michael J. Fox Foundation for Parkinson's Research.

What will happen to me if I take part?

If you choose to participate in the GP2 study as well as the TraPCAf study, you will be asked to provide a small sample (less than a tablespoon) of blood, which will be taken like a normal blood test by the researchers. We will also ask you to provide a sample of saliva, which you can do by spitting into a pot.

Do I have to take part?

Your participation in this study is voluntary. The decision about whether or not to participate is completely up to you. If you choose not to participate in the study, your choice will not affect your medical care.

What are the benefits in my taking part?

GP2 will not provide payment for participation. You will be contributing to wider knowledge about how and why people get Parkinson's disease and possibly ways to prevent people developing the disease in the future.

Definition of the research data – genomic and personal data

Your sample will be used to generate genomic data. Genes are the basic 'instruction book' for the cells that make up our bodies. Genes are made out of DNA, and all of the DNA in each cell is called the genome. Although our DNA is very similar to each other, your genomic data is entirely unique.

Data coding (or pseudonymisation)

Information that directly identifies you, such as your name, will be replaced with a 'code' or 'ID number'. Your name and other identifying information will not be shared with other researchers.

Future use

Your samples and data will be used to learn about the genetic differences between people with and without Parkinson's disease. They may also be used in additional research studies involving Parkinson's disease, other neurological conditions, other types of disorders, or other biomedical research studies. These additional studies may involve the development of cures, therapies and products and services for the benefit of patients.

International sharing

This research may be conducted anywhere in the world; the researchers studying your samples and data may be located outside your country. These projects can also take place in universities, hospitals, non-profit groups, for-profit companies, or government laboratories.

Commercial/non-academic use

Your sample and data are a gift for research. The future research projects may take place in universities, hospitals, non-profit groups, for-profit companies, or government laboratories. Some of the research done with your information may one day lead to new software, tests, drugs, or other commercial products. If this happens, you will not receive any of the profits from these new products.

Managed access (and unrestricted access for aggregate data)

Your coded data will be stored on a secured data platform. Information in this data platform can only be accessed and used by researchers who have been granted formal approval to access data and who have signed agreements to protect the confidentiality of the information. The access agreements also require researchers to respect the laws and ethical guidelines for scientific research. Your coded data may also be combined with data from many thousands of other people in large-scale analyses. A summary of this data may be made public (openly accessible) to anyone without restriction, although you will never be identifiable.

Storage on cloud servers

Your coded data will be stored on one or more data platforms coordinated by multiple institutions that can be used by researchers around the world. These researchers may be conducting their own projects or may be working on projects coordinated by the sponsors. The data platform may be hosted on commercial cloud servers. The cloud refers to software and services that run on the Internet, instead of on a specific computer. These cloud servers meet international security and safety standards.

Limit to duration of storage

Preferred: Your coded samples and/or data will be stored indefinitely or until they are withdrawn or no longer useful for current or future research.

If indefinite storage is not allowed: Your coded samples and/or data may be stored and used for research for 30 (thirty) years.

The limits are determined by country-level ethical approval boards.

Data withdrawal

You may withdraw consent for research use of your samples and data at any time. If you choose to withdraw, your samples will be destroyed, and your data will be removed from the data platform. However, it may not be possible to retrieve data that has already been distributed for research use or combined with other data in larger analyses.

Request consent to contact you for future research

With your permission, we may re-contact you to invite you to provide additional data or to be involved in new research projects.

Lack of benefit to you personally and risk of re-identification

You will not benefit personally from sharing your data. Participating in the study may help researchers in many areas of scientific research, such as health and genetics.

Your information will be coded, which means it will not be connected to any information that directly identifies you, such as your name, address, and contact information. However, it is very difficult to make genetic information completely anonymous. There is a risk that people that have your information could try to connect it to your identity by combining it with other personal information about you, through a process called re-identification. Also, in the future, new technologies could be developed that make it easier to connect your genetic information to your identity. The risks related to re-identification are difficult to predict at this time.

Because genetic information is shared among people who are biologically related to you, it is possible that information about your family members could also be revealed.

There is always a risk that information from genetic studies might be used to make certain statements or conclusions about groups or communities. In some cases, this can lead to discrimination against individuals, families, groups or communities.

Where can I get more information?

If you have any questions about the information provided to you, please contact the research team:

Contact name:

Phone number:

Local ethics authority: