You are being invited to take part in a large national research study called the Parkinson's Disease DNA Bank. This is an additional part of the PD MED, PD REHAB, PD SURG and PD COMM studies, one of which you have already agreed to take part in. You do not have to take part in the Parkinson's Disease DNA Bank. If you choose not to, you do not have to give a reason and this will not affect the standard of care that you receive. Before you decide, it is important for you to understand why the study is being done and what it involves. Please take time to read the following information carefully and discuss it with your family, friends or your GP if you wish.

What is the Parkinson's Disease DNA Bank?
This is a collection of blood samples from patients with Parkinson's disease and their carers who have already agreed to help by joining the PD MED, PD REHAB, PD SURG or PD COMM Trials. DNA is the material in our genes that determines our genetic makeup. It can be extracted from a small blood sample. The DNA will be kept securely in the Molecular Neurology Laboratory in the University of Birmingham in the UK. The samples will be kept indefinitely. Small amounts of everyone's sample will be sent to other laboratories to perform medical research. This research will look at DNA sequences in many different genes to see which are important in causing Parkinson's disease and the complications of its treatment. Other genetic research may become possible on the samples in the future. Before any of the DNA Bank samples are released to other researchers, all research projects will be approved by a management committee after considering the scientific merit of the project and its ethics. The proposed research work will also undergo evaluation by an independent medical ethics committee. Research requests to work on these samples may come from individual researchers, groups or commercial organisations. It may be necessary to use information from your medical records for the study but this will be done in the strictest of confidence by responsible people from the Parkinson's Disease DNA Bank study team or from other organisations involved in the research.

Why have I been invited?
As someone who has agreed to help with the PD MED, PD REHAB, PD SURG or PD COMM Trials, you are eligible to join this additional study if you choose to do so.

Are there any medical risks in taking part in this study?
Taking the blood sample may be a little painful and may result in short-lived bruising.

Are there any benefits for me from taking part in the study?
Not directly. These samples will allow new research into Parkinson's disease which would otherwise not have been possible. From the legal point of view, this sample will be taken as a gift. You will not have any legal right to share any profits that might arise from research using the sample.
Do I have to take part in the study?
No, you do not have to take part in the study, or give a reason if you choose not to. Before deciding, you should read this leaflet carefully and ask your doctor questions if there are things that you do not understand. If you do decide to take part, we will ask you to sign a consent form indicating that you understand what the study involves. Your hospital doctor will then enter you into the study.

Can I withdraw from the study?
Yes, you can decide to withdraw from the study at any time. Signing the consent form does not commit you to joining the study and withdrawal will not affect the standard of care that you receive in the future. If you withdraw from the study, the stored sample will be destroyed along with any information we have collected.

Will participation in the study affect my legal rights?
No. Whether or not you take part, you will retain the same legal rights as any other patient treated by the NHS. There are no special arrangements for compensation in the very unlikely event of a mishap as a result of taking part in the study.
All information collected in the study will remain strictly confidential in the same way as your other medical records. The information will be put into a computer and analysed, but you will not be identified when the results are reported.

What will happen to the results of the study?
Both the samples and any information about you will be kept confidential at all times. The overall results of the research will be publicised in the medical press and elsewhere. Individuals taking part will not be identified in the results.
We will not automatically provide you with your own results because individual genetic test results may have no useful value to you. However, if you want the result of a particular genetic test, you may apply for this to the specialist who normally cares for you. In order to provide the required genetic counselling to understand the result concerned, your specialist will refer you to your local clinical genetics department. The consultant clinical geneticist will then apply to the University of Birmingham who will arrange via the PD GEN Management Committee and any research laboratory involved in the work for the result to be passed back to you in appropriate terms. The standard fee operating at the time will be payable for this service.

Who is organising and funding the study?
The central study organiser is the University of Birmingham Clinical Trials Unit, which has experience of running very large trials. The study was initially funded by the Medical Research Council. Subsequently we have obtained funding from Parkinson’s UK, the National Institute for Health Research (NIHR), University Hospitals Birmingham Charities and the Midlands Neurosciences Teaching and Research Fund. The doctors involved are not being paid for recruiting patients into the study. The study has also been reviewed by regional and local research ethics committees.

Do you have any other questions?
We hope that you will choose to take part in the Parkinson’s Disease DNA Bank. If you still have questions about the study now or later feel free to ask your hospital doctor or nurse. Their names and telephone numbers are given at the front of the sheet. If you would prefer to delay your decision, perhaps to discuss with friends or relatives, then you can make an appointment to come back later. But, please remember to keep this information sheet in a safe place and write the names and telephone numbers in your diary or address book.

Thank you for taking the time to consider taking part in this study.

What if my first language is not English?
If your first language is not English, we will obtain an interpreter so that the study can be fully explained to you.

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