HUMAN BIOMATERIALS RESOURCE CENTRE
Information Sheet for Patients with Neurodegenerative Disorders

Introduction

- The Human Biomaterials Resource Centre (HBRC) is a 'tissue bank' (also called a 'biobank' or 'bioresource'). It collects and stores human samples in a secure environment for ethically approved biomedical research. Scientists need human samples to find out how diseases start, and to find new ways of diagnosing and treating illnesses.
- This information sheet explains what happens when a sample is donated to the HBRC. Please take time to read it carefully and ask if anything is not clear. If you have any questions at a later date, please contact us using the details at the bottom of this sheet.

Why are we inviting you?

- You have been diagnosed as having a form of what is called a 'neurodegenerative disorder'. There are many different types of neurodegenerative disorders, such as Alzheimer's disease and Parkinson's disease. These diseases affect a large number of people in the UK and as the population as a whole ages, they will become more common. Although we can treat some symptoms in some of these diseases, as yet there are no truly effective treatments as we do not understand what causes them.
- Scientists need lots of samples to carry out biomedical research. We may ask many people to give us samples, in order to make sure we have enough for research now, and in the future.

What are we asking you to do?

- We are inviting you to donate blood, urine, or saliva samples to the HBRC.
- Sometimes blood and urine will be collected anyway as part of your routine care, and so we will just ask for a little bit extra. Sometimes we may ask you to donate specially for research. In this case, when you come for your hospital visit, we would like you to allow staff to take a small sample of blood (30ml, which is the equivalent to about 6 teaspoons) and/or collect a small amount of urine and/or saliva.
- Sometimes research projects require serial blood or urine samples, or for samples to be taken at a certain time point, so that the progress of disease can be monitored. In these instances, we may ask to collect samples on more than one occasion.
- You will not be asked to donate samples if your doctor thinks this is not right for you. Very occasionally, we would also like to receive other fluids, but **ONLY** if they are being taken as part of your routine care and there is enough left over after any diagnostic tests.
- We would also like permission to access your health records. This is because information about your medical conditions and treatments (now, and in the longer term) is scientifically useful in research. This includes long-term follow up information held by, for example, the Office of National Statistics.
- We will ask for your permission using a consent form. You will be given a copy to keep. Please also keep this information sheet to remind you of what you were asked to do, and why.

What will happen if you agree?

- When your sample arrives at the HBRC, a member of staff will assign it a unique sample code. The link between the sample code and your identity will be retained securely within the NHS.
- Samples may be released straightaway to an approved research project, or stored in the HBRC until required.
- Samples may be released for genetic studies, but only to research projects aimed at providing clues to the nature of disease, or if it is already known that genes are important.
- Samples may also be used to support ethically approved biomedical research which uses animals, but only when this is absolutely necessary and experiments cannot be performed in any other way. Animal models can be invaluable for increasing our understanding of disease and advancing treatments.
- Sometimes scientists need to grow cells in a culture dish for a long time and again, this type of approach can be invaluable for biomedical research.
- All information about you will remain confidential and will be stored in accordance with the UK Data Protection Act 2018.
- No information will ever be released to an insurance company, used to sell you anything, or given to other organisations except for the purposes of biomedical research.
- Scientists receiving your samples will **NOT** be provided with any personal information such as your name, address or phone number. The information received will relate to your disease, treatment and medical history only and **NOT** your identity.
- Your samples and associated information from your health records will be used mainly by local scientists, but they may also be made available to scientists outside of Birmingham, elsewhere in the UK or overseas. Scientists

may work in universities, hospitals or private/commercial companies that carry out biomedical research. Commercial collaborations are vital for the development of suitable drugs and treatments.

- You will not receive any personal financial reward for your donation, and the samples you have gifted will never be ‘sold’ for profit. However, we will ask scientists to cover some of the costs incurred in sample collection and storage.
- Participation in the HBRC is ‘enduring’, i.e. we can request donations from you until you withdraw. This does **NOT** mean that you must donate at every hospital visit – just that there is no need for you to re-consent every visit.

Do you have to agree?

NOT AT ALL. It is entirely up to you. You do not have to donate a sample or give a reason for choosing not to. Your decision will not affect your care or treatment in any way, now or in the future.

What happens if you change your mind?

- You can change your mind at any time by contacting your hospital doctor or the HBRC directly (details below). You do not have to give a reason why.
- If you tell us you have changed your mind, this will not affect your care or treatment in any way, now or in the future. All samples held in the HBRC will be destroyed in the way human samples are normally destroyed by hospitals. Similarly, any information we store about you will be deleted (apart from records allowing us to trace your samples’ history). We will contact any research groups and ensure that any unused samples and associated information are destroyed.
- If you change your mind after a long period of time, the samples and associated information may already have been used. Unfortunately, we cannot recall samples or associated information from scientists if this is the case.

What are the benefits to you?

It is unlikely that there will be any direct benefit to you, since it takes many years for research to produce advances in the way diseases are diagnosed, treated, or prevented. You can benefit from the knowledge that research will make faster progress if more human samples are studied, and you are personally contributing to this.

What are the risks to you?

As far as we know there are **NO** increased risks to your health associated with donating samples to the HBRC. Samples will only be collected when it is safe to do so during your routine hospital visits. Your identity will remain confidential, and when we provide samples to scientists, they will be obliged to use the samples only for the research declared in their ethical approval. They will be bound by a strict agreement to ensure this.

Can you find out the results?

- The development of reliable new clinical tests takes many years, so the HBRC will not routinely report individual research results. You can find out more generally about the types of research projects using your samples by contacting us using the details below. You can also ask to visit us the same way.
- If a research project using your samples generates clinically important information, then your doctor, or another member of your healthcare team, will contact you about this. They may wish to discuss how the information could guide treatment for your current condition or for other conditions (possibly hereditary) which may affect you and your family.

What happens if you lose capacity?

- We would like to be clear about what we should do if your illness causes you to develop incapacity at some point in the future. You can give consent now to continue donating samples to the HBRC, although this consent will depend on individual circumstances at the time.
- Alternatively, you can indicate that we should stop collecting samples altogether. We would still like to use the existing samples and data that we have already collected, but again, if you prefer, those samples and any data will be destroyed.
- Another option is for you to delegate the decision entirely to a ‘consultee’ who will advise on your behalf at a later date. You may wish to identify someone now who could do this, although it may not be possible for this person to fulfil their role at the time.
- It is important that you make your wishes clear on the consent form. We will seek further advice from a consultee about your wishes, as soon as we are made aware of your loss of capacity.

Our contact details

The General Manager, Human Biomaterials Resource Centre, College of Medicine and Health, University of Birmingham, Edgbaston, Birmingham B15 2TT (07584 312396; hbrc-tissuebank@contacts.bham.ac.uk).

If you have a concern or complaint about the HBRC, please contact the Research Ethics Governance & Integrity Team, College of Medicine and Health, University of Birmingham, Birmingham B15 2TT (researchgovernance@contacts.bham.ac.uk).