

NBTR - Blood & Cerebrospinal fluid (CSF) samples

It can be very helpful to researchers if participants are prepared to give small blood and/or CSF samples which can be linked later with the donated brain tissue. This is to see whether there may be changes present during life which might help predict who may later develop dementia or other diseases. These changes are known as biomarkers. Samples would be purely for research purposes and would not be able to tell us whether you personally are at risk of developing problems. It would be completely voluntary and your decision would not affect your participation as a tissue donor.

What would blood sampling involve?

It would usually involve coming to one of our clinics where trained staff would complete a separate consent form with you and take a sample of less than 20ml of blood (four teaspoons). As with any blood sampling there is a possible risk of mild discomfort when the sample is taken and that there may be some tenderness or bruising afterwards. It is better if the sample can be taken in the clinic because it can then be processed straightaway. If you come to a clinic we will provide a taxi (or reimburse you for any travelling expenses). If you are unable or do not wish to travel to a clinic, we may be able to arrange for the sample to be taken during a home visit.

What would CSF sampling involve?

A procedure known as lumbar puncture or spinal tap is used to obtain a sample of Cerebrospinal Fluid (CSF). This fluid cushions your brain and spinal cord, and contains important bodily proteins and salts similar to blood. Because it has direct contact with the brain, it can give doctors and researchers important information about what is happening in the brain.

This procedure would only be done in the clinic. After completion of the consent form, you would be asked to lie down comfortably on one

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Information about
donation of additional
samples

side, and a trained health professional would take a sample of CSF (approximately 20mls or four teaspoons) through a small needle which is placed in the lower back. The way the sample is collected is similar to how anaesthetists give pregnant women epidurals during labour. It involves lying on one side, curled up. The skin of the lower back is numbed with local anaesthetic and then a very fine needle is introduced to obtain the sample. A lumbar puncture may cause some localised pain in the lower back where the needle enters the skin. Sometimes following the procedure patients complain of a headache and may feel a bit sick. Serious complications following a lumbar puncture are extremely rare.

The whole lumbar puncture will only take about 30 minutes but you will be advised to rest for an hour or so afterwards before you go home.

We will provide taxi transport for you to get to and from the clinic.

Do I have to give both types of sample?

No, it is completely optional. The type and number of samples you give is entirely up to you.

Where and how will they be stored?

Samples will be stored in exactly the same way as brain and spinal cord samples in secure purpose built facilities. They are subject to exactly the same degree of care and attention.

What about my preferences?

You will be asked about any preferences or restrictions on your consent. For instance, if you prefer that your samples are not used for genetic projects, by commercial organisations, in projects involving animals or sent out of the UK then these preferences will be recorded and we will abide by them.