

Feedback – Dr. Cathie Sudlow

Hello, my name is Cathie Sudlow. I am UK Biobank's Chief Scientist and I'm also a Consultant Neurologist. I see patients with a range of neurological disorders, particularly stroke and mini stroke, in my clinic at the Western General Hospital in Edinburgh.

You have taken part in UK Biobank on the understanding that you will not receive any results from the assessment visit other than the few simple measures, such as blood pressure, that you were given immediately after your visit. Neither will you receive feedback on the results of analyses carried out on your samples or data. However, you will be informed of advances that come out of research using UK Biobank. Indeed your data and your samples are supporting pioneering research which may benefit you and your loved ones in years to come.

In the same way, participants attending this imaging assessment, for which we are now recruiting, will receive the results of the same few simple measures at the end of their visit but otherwise they will not receive routine feedback of any pictures or results from the imaging scans.

It is important to remember that this assessment is not a health check, and it is not a replacement for any clinical appointment. The scans being performed are not intended for diagnostic use and are not designed to identify any particular abnormalities. Instead, the images will be stored for future research use.

Staff conducting the scans will look at the images to ensure their technical quality is good, rather than to identify particular clinical problems. The scans will not be routinely reviewed by specialists or other doctors.

However, imaging scans like these do show abnormalities from time to time, most of which are no cause for concern. If the technician happens to notice something unusual in your scan, that they think may be potentially serious, they will refer the image to a specialist doctor. In the unlikely event that a potentially serious abnormality is confirmed to be present on one of your scans, we will write to you and your GP within about two weeks of your visit, so that your GP can make arrangements for further investigation, if required. The finding may, of course, be something you are already aware of and it may still, on further investigation, turn out not to be serious after all. It is also important to recognise that feedback like this may affect your life in other ways. For instance, it may cause worry or affect your ability to obtain some types of insurance.

Scientists know very little about the impact on participants and the health service of reporting such 'incidental' findings. We should therefore like to take this unique opportunity to find out how this information affects you, your GP and other health services. For this reason, should we write to you about a possible abnormality, we will contact you and your GP again about one month and six months later to find out what, if anything, happened. This will be important in designing and carrying out other studies by other scientists in the future and will, in itself, be another major health finding to come out of UK Biobank.

Please do remember that our scans are for research purposes only. They will not be checked in the same way as a scan requested by your doctor. You should not rely on the absence of feedback from us as reassurance about your health. For these reason, it is always sensible to talk to your GP about any health worries you might have.

The health research community and doctors, like me, who see patients every week, are very grateful to you for helping UK Biobank so far. If you feel able to join us for this imaging assessment, we should be delighted to see you. Meantime, if you have any questions please do not hesitate to contact us via this website or by calling the Participant Resource Centre number on this page. Thank you.