

BUCNI Data Protection guidelines

Scan data is considered 'special category personal data'. Unless there is a good reason otherwise, the legal basis for processing, in line with UCL guidelines, is under Article 9(2)(j), where the processing is necessary for archiving purposes in the public and scientific research purposes. This legal basis must be stated to the participant in the information sheet. This is appropriate given the Birkbeck/UCL Centre for NeuroImaging's (BUCNI) procedures which follow these principles:

- ◆ *Using 'technical and organizational measures' to ensure data minimisation, e.g. pseudonymisation;*
- ◆ *Using anonymised data where possible;*
- ◆ *Not processing in ways that are likely to cause substantial damage or distress to individuals;*
- ◆ *Having the assurance that research ethics committee approval is in place where needed.*

The BUCNI data pipeline is as follows:

1) On the scanner registration, there are multiple fields that are potentially identifiable. We use the following conventions to prevent identification by non-lab or BUCNI staff.

1. Participant first name and last name fields. For GDPR compliance, we use the exact date and time of the scan in the YYMMDDHHMMSS format as last name. (First name is no longer needed).
2. The Patient ID field refers to the BUCNI log entry. This is in the format of B000XXXX, and is simply assigned in order of participant. The paper log book contains only a YYMMDD Initials as well as scan details, and stays within the locked scanner suite.
3. Patient DOB is always set to January 1 1980.
4. Height and weight are set to individual's actual measurements.

2) Siemens format data are sent to a remote server (the 'Leonardo' or a different DICOM server). These are saved to a different disk with a directory name of YYMMDD + first and last name initials. These data are then sent to a different server within the BUCNI local network.

3) On this server (buc02), data are saved locally to a backup as well as to two DVD disks currently (kept behind two locked doors with restricted access).

4) Data are then taken by each investigator group via encrypted hard disk, encrypted memory stick, or secure file transfer.

The scanner and 'Leonardo' computers are completely separate from outside network access, and the buc02 server has a highly restrictive firewall.

The BUCNI screening form includes four questions with particular relevance to data protection:

1. May we contact you and help you liaise with your G.P. if we notice something unusual in the scan? (yes/no)
2. Would you like to be informed yourself if something unusual was found in your brain scan? (yes/no)
3. I acknowledge that these scans are not optimized for detection of clinical abnormalities (tick box)

In the case that the answer to question 2 is 'no', the participant should not be scanned as it puts the individual and BUCNI in an ethically compromised position in the case there is an incidental finding.