

Appendix

Brain Health Clinic Privacy Notice

Data protection

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly.

We will be using information from you and your medical records in order to undertake this research and will use the minimum personally-identifiable information possible.

How we use your data

We will use your data to:

- enable the NHS to provide you with clinical assessment services
- register you as a member of the Brain Health Clinic Research Database (if you agree to this)

The processing of this information is necessary for the University to undertake a public task as defined under Article 6(1)(e) of the Act, i.e. the processing is necessary for the University to perform a task in the public interest or for its official functions, and the task or function has a clear basis in law.

We will only use your data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another related reason and that reason is compatible with the original purpose. If we need to use your data for an unrelated purpose, we will seek your consent to use it for that new purpose.

Authorised magnetic resonance imaging (MRI) scanning centre personnel at Oxford Centre for Integrative Neuroimaging (OxIN) and the research team will have access to the MRI imaging data. MRI imaging data is assigned a unique ID as it is collected, and stored in a secure database on University managed IT systems. Due to the nature of the MRI images, they remain potentially identifiable, even after we destroy your personal details. Imaging

data will be stored on archive tapes at the MRI location and kept indefinitely, for quality control, and to facilitate further use of the scans where permission has been given.

If you agree to your details being held to be contacted regarding future research, we will retain a copy of your consent form securely until such time as your details are removed from our database. We will keep the consent form and your details separate from one another and any research data.

Retaining your data

We will only retain your data for as long as we need it to meet our purposes, including any relating to legal, accounting, or reporting requirements.

If you agreed to join the Research Database, you can withdraw your data in three ways:

1. No further contact: The BHC will no longer contact you (if you agreed to be re-contacted about the follow-up or future research studies), but would have permission to retain and use samples and information previously provided and obtain and use further information from health records.
2. No further access: The BHC will no longer contact you (if you agreed to be re-contacted about the follow-up or future research studies), the BHC would remove all your personal data from our database and would no longer obtain information from health records in the future, but has permission to use samples and information previously provided.
3. No further storage of DNA samples: The BHC will destroy your DNA sample (if you agreed to provide a saliva sample)

Security

Your data will be held securely in accordance with the University's policies and procedures. Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at

Where we store and use your data

We store and use your data in a secure NHS data-centre and on University premises, in both manual and electronic forms. To minimise risks of data breaches, your data will not be stored or used in an identifiable form for longer than is necessary.

Electronic data may be transferred to, and stored at, a destination outside of the UK and the European Economic Area ("EEA"), for example, when a researcher is based overseas. There is the potential that such countries might not offer the same level of protection of privacy as that demanded by law in the UK. To minimise this risk and ensure that any such transfer of information abroad will not compromise confidentiality,

Such transfers will only take place if one of the following applies:

- the country receiving the data is considered by to provide an adequate level of data protection;
- the organisation receiving the data is covered by an arrangement recognised as providing an adequate standard of data protection
- the transfer is governed by approved contractual clauses;
- the transfer has your consent;
- the transfer is necessary for the performance of a contract with another person, which is in your interests.

Your rights.

Your rights under the General Data Protection Regulation

Under UK General Data Protection Regulation (GDPR), and the associate Data Protection Act of 2018, you have the following rights in relation to the information that we hold about you (your 'personal data').

- **The right to request access to your data** (commonly known as a "subject access request"). This enables you to receive a copy of your data and to check that we are lawfully processing it.
- **The right to request correction of your data.** This enables you to ask us to correct any incomplete or inaccurate information we hold about you.

- **The right to request erasure of your data.** This enables you to ask us to delete or remove your data in certain circumstances for example, if you consider that there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your data where you have exercised your right to object to processing (see below).
- **The right to object to the processing** of your data, where we are processing it to meet our public tasks or legitimate interests (or the legitimate interests of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your data for direct marketing purposes.
- **The right to request that the processing of your data is restricted.** This enables you to ask us to suspend the processing of your data, for example, if you want us to establish its accuracy or the reason for processing it.
- **Request the transfer of your data to another party**

Contact

If you wish to raise any queries or concerns about our use of your data, please contact us at:

The Brain Health Clinic,
Oxford Centre for Human Brain Activity (OHBA)
University Department of Psychiatry
Warneford Hospital
Oxford OX3 7JX
UK