



What is the Global Epidemiology and Outcomes following Traumatic Brain Injury (GEO-TBI) registry?

The GEO-TBI is an international database for recording the occurrence of all traumatic brain injuries and their outcomes to provide reliable data on the incidence of such injuries. The GEO-TBI registry was established in 2017 across the UK, and it is an international collaboration aimed to drive the development and research of neurotrauma management. You have been contacted as you have recently sustained a traumatic brain injury.

What are the benefits of the GEO-TBI registry?

- It provides accurate independent information to patients, carers, healthcare regulators and head injury management professionals about the frequency and outcomes after traumatic brain injury.
- It enables the identification of best practices and encourages professionals to develop their practices towards a global standard.
- It helps medical professionals and researchers to identify patient groups for further study and/or in unmet need for treatment.
- It helps give up-to-date information on the changing worldwide trends of traumatic brain injury occurrence.

Who will have access to my information?

Your treating team will record basic demographic information such as your name, date of birth and NHS number to reliably identify your record for future research purposes. We will collect data on the time and type of injury you had, details of the possible operations, and short-term outcome data.

Data will be kept confidential at all times. Your personal data will only be accessible to your local team. Authorised persons working for the GEO-TBI registry will have access to your data in anonymised form for data registry-wide analysis, from which you can not be identified.

Is my information safe?

Keeping your information safe is of the highest importance. All those involved in the GEO-TBI comply with the requirements of the Data Protection Act 2018 the General Data Protection Regulation (GDPR) and NHS Act 2006. Only your medical team will have access to your identifiable information. All personal information is securely stored in encrypted form, and there are strict procedures in place to ensure only those authorised will be able to view your records. Your personal information will not be shared or passed onto any third party unless required by law.

What if I have further questions about the GEO-TBI registry?

Your treating team should be able to provide you with information about the registry. If you would like to find out more information, you can contact us via e-mail at geotbi@orion.net or write to The GEO-TBI, Orion MedTech CIC, Heron Suite, Middle Court, Copley Hill Business Park, Cambridge, CB22 3GN.

Permission

I **understand** that my information will be stored on the ORION database for the purpose of participating in the GEO-TBI registry.

I **agree** for my NHS number or equivalent identifier to be used for linking my data to other data sources for research around the quality and efficacy of my treatment Yes No

I would like to be **informed** about future relevant research that I may be eligible for Yes No

Signed:..... Date:.....

Name:.....

*If signing on behalf of a child or young person by a person with **parental responsibility**:*

Relationship to patient: