



General Data Protection Regulation (GDPR)

The Transfusion Medicine Epidemiology Review (TMER)

How we use your information

Updated 3rd October 2018

Reviewed 18th June 2020

Updated 10th August 2020

The Transfusion Medicine Epidemiology Review (TMER) is a collaborative public health surveillance project between the UK National CJD Research & Surveillance Unit (NCJDRSU), NHS Blood and Transplant (NHSBT) and the remaining UK Blood Services. The main purpose is to investigate evidence that Creutzfeldt-Jakob disease (CJD) and variant Creutzfeldt-Jakob disease (vCJD) may be transmitted via blood and help prevent disease spread. We share the minimum amount of personally identifiable information on CJD cases that is necessary, with the UK Blood services, who then use this to check against their records and identify individuals who have received or donated blood components from/to cases of CJD. Recipient and donor details (name, date of birth, address, NHS number, study number) are also shared with NHS Digital services in order to flag recipients and donors for the purpose of obtaining details on date, location and cause of death when a recipient or donor dies. Data are not always available for every field requested but, as a minimum, name and date of birth are a mandatory requirement.

The nature of this non-research project means we use personal identifiable information about individuals without their explicit consent. We have special permission to do this under Section 251 of the NHS Act 2006 and Health Service (Control of Patient Information) Regulations 2002 for England and Wales, and from the Public Benefit and Privacy Panel (PBPP) for Health and Social Care for Scotland.

We know how important it is to protect the privacy of individuals we hold personal identifying information on and as such we will:

- only ask for what we need
- make sure nobody has access to it who shouldn't
- only keep it for as long as we need to
- not make it available for commercial use (such as marketing)
- only use this information as the law allows
- carefully protect this information at all times
- provide training to staff who need to use personal identifying data to do their job
- only share this information as the law allows

- respond appropriately if personal information is not used or protected properly

Our staff are trained to treat personal information in the strictest confidence, in compliance with the General Data Protection Regulation (GDPR) and the NHS Caldicott principles and have a duty to maintain confidentiality. They undergo relevant Information Governance (IG) training and will only be allowed to deal with personal information if their IG training certificates are kept up to date. Any deliberate or negligent breaches of this policy are disciplinary offences.

Contact for further information

The NCJDRSU is the data controller under this privacy notice. If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at <https://ico.org.uk/>.

Data Protection Officer contact information:

Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL

Email: dpo@ed.ac.uk

General information about the legal basis of processing personal identifiable information by the NCJDRSU, including your rights, is available at http://www.cjd.ed.ac.uk/privacy_notice