IRAS: 210735 CRYOSTAT-2 Early cryoprecipitate in trauma
Privacy notice for clinical trial website

Queen Mary University of London (QMUL) is the Sponsor for this clinical trial which is based in the United Kingdom and has delegated overall management of this study to the Clinical Trials Unit at NHS Blood & Transplant, and will act as joint data controllers. This means that we are responsible for looking after your information and using it properly.

Your information will only be used by researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research**.**

We will be using information from you and your medical records in order to undertake this trial.

As publicly-funded organisations, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.

With your signed consent, we will keep identifiable information about you for 2 years after the study has finished to allow us to complete analysis of the data that we have collected. After this time your identifiable information will be deleted.

To safeguard your rights, we will use the minimum amount of personally-identifiable information possible.

The personally-identifiable information we will collect are: Name, date of birth, sex, NHS number (or CHI number if you live in Scotland) and postcode. This data is shared with NHS Digital so that we can check on your survival status one year after your injury. For some patients, we will also access information collected by the Trauma Audit & Research Network (TARN, hosted by the University of Manchester) about how you feel about your health six months after your injury. By accessing existing TARN data, it means that we do not need to ask you for the same information twice. NHS Blood & Transplant will have contracts with NHS Digital and The University of Manchester that will ensure the security and integrity of your data at all times. This data will only be shared for this purpose and deleted at the end of the study. It will not be shared with any other organisation or published.

NHS Blood & Transplant will have special permission in place to collect personally identifiable data from those participants who take part in the study but have not signed a consent form (e.g. due to the nature of their injury, or who were discharged prior to consent being taken by the research team for any reason). If you did not sign a consent form and you do not wish for your identifiable data to be used, you can contact us on 01223 588720 or via email cryostat2@nhsbt.nhs.uk

You have the right to access, correct or complete the information you have given us. You also have the right to withdraw from the trial at any time and request that your data be deleted (“right to be forgotten”). If you wish to withdraw, please arrange to speak with the doctor or nurse listed at the bottom of your patient information sheet. After the trial has been completed, we will provide QMUL with an anonymised data set produced by the research. This information will not identify you and cannot be combined with other information in a way that could identify you.

You can find out more about how we use your information in research at https://www.hra.nhs.uk/information-about-patients/ or by contacting the Trial Manager by email at cryostat2@nhsbt.nhs.uk

Under GDPR, all NHS organisations are legally required to appoint a Data Protection Officer (DPO). The DPO for NHS Blood & Transplant is Aaron Powell, the Chief Digital Officer, who is responsible for ensuring that all practices and processes within NHS Blood & Transplant are designed to support people’s privacy and data rights. You can contact the DPO by email at dpofficer@nhsbt.nhs.uk

You can also look at the website of the Information Commissioner (https://ico.org.uk/) for more information on the new GDPR legislation and you have the right to speak to them if you are worried that your data is not being appropriately protected or processed.