

Addendum to the Information Sheet for GDPR Transparency

The UK Paediatric ITP Registry

IRAS Number: 14145

Manchester University NHS Foundation Trust is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The sponsor will keep identifiable information about you from this study for up to 5 years after the study has finished.

Your rights to access, change or move you information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at <https://research.cmft.nhs.uk/getting-involved/gdpr-and-research>.

Manchester University NHS Foundation Trust and your hospital will collect information from you and your medical records for this research study in accordance with our instructions.

Manchester University NHS Foundation Trust and your hospital will use your initials, gender, DOB, postcode and email address (if you choose to provide it) to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Manchester University NHS Foundation Trust and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your Hospital will pass these details to Manchester University NHS Foundation Trust along with the information collected from you and your medical records. The only people in Manchester University NHS Foundation Trust who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, DOB or contact details.

Your hospital will keep identifiable information about you from this study for 5 years after the study has finished/until 2031.