The laws about how personal data can be used have recently changed. You are being given this leaflet as you are a PIROUETTE participant and we need to explain to you what this means for the data you are contributing.

Please take the time to read this leaflet – you can ask your PIROUETTE researcher if you have any questions.

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).

**CTRC**
Our Data Protection Officer is Victoria Heath and you can contact them at LegalServices@liverpool.ac.uk.

**MFT**
Our Data Protection Officer is MFT Data Protection Officer and you can contact them at dpo@mft.nhs.uk or alternatively, information.governance@mft.nhs.uk.
Manchester University NHS Foundation Trust (MFT) is the sponsor for this study based in the United Kingdom; they have delegated the day-to-day management of the study to the University of Liverpool Clinical Trials Research Centre (CTRC), which is part of the University of Liverpool. We will be using information from you and your medical records in order to undertake this study and will act as the data controllers for this study. This means that we are responsible for looking after your information and using it properly.

MFT and CTRC will keep identifiable information about you for 15 years after the end of the trial.

Your rights to access, change or move your 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 but we will not use it in any further analyses.

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

You can find out more about how we use your information in the “How we use your information” section on the study website here: http://www.pirouette-trial.uk/.

Your NHS Hospital will collect information from you and your medical records for this research study in accordance with our instructions.

Your NHS Hospital will use your name, NHS number and contact details 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 MFT, CTRC and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your NHS Hospital will pass these details to MFT along with the information collected from you and your medical records. The only people in MFT who will have access to information that identifies you will be people who need to contact you to arrange follow-ups/assessments as part of the trial or 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, NHS number or contact details.

Your NHS Hospital will keep identifiable information about you from this study for 15 years after the end of the trial.

Additional information:

Manchester University NHS Foundation Trust (MFT) and the University of Liverpool Clinical Trials Research Centre (CTRC) take great care to abide by our legal and moral obligations when handling your personal and healthcare data. Due to changes introduced in the EU General Data Protection Regulation (GDPR), we would like to provide you with information on the lawful basis on which we are processing your data. The lawful basis for the processing of your personal data for the research study which you have participated in is a “task in the public interest”.

As a university (CTRC) and NHS organisation (MFT) we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, 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. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.