



PCTU research privacy notice

What is a privacy notice?

This privacy notice explains generally how The Pragmatic Clinical Trials Unit (PCTU) at Queen Mary University of London (QMUL) processes personal data of individuals collected as part of the research that we undertake.

What is personal data?

Personal data is data about people from which it is possible to identify those people (either directly, for example through their name, or indirectly, through for example, postcode, NHS number and other information). The U.K. General Data Protection Regulation (UK GDPR) is a law which sets out the key principles, rights and obligations for processing of personal data.

How do we use your personal data?

As part of a publicly-funded organisation, the PCTU uses personal data to undertake research that serves the public interest.

The legal basis for processing personal data is to perform a task carried out in the public interest (please refer to articles 6(1)(e) and 9(2)(j) of the UK GDPR).

Who is responsible for your data?

Each PCTU study is sponsored by a University or an NHS organisation. This organisation oversees the trial, including making decisions about what data will be collected and how the data will be managed and used.

Under the UK GDPR, the sponsoring organisation is the Data Controller for each study. Details about the organisation sponsoring a study you are involved in will be available in the patient information sheet for that study. Participants will also receive the sponsor's contact details so that they know how to get in touch to raise any concerns regarding their personal data.

Each organisation will have its own privacy notice. Many of PCTU's studies are sponsored by QMUL. Please see Privacy-Notice-for-Research-Participants.pdf for QMUL's privacy notice.

How long do we keep your data for?

All personal data is kept in line with QMUL's Records Retention Policy.

What are your rights regarding your data?

Under the the UK GDPR, data subjects have certain rights over how their data is processed, including the right to know what information is processed and how.

However, a number of those rights are limited when the data is being used for research purposes, including the right to access personal data, to restrict or object to the data processing and to correct inaccurate data. This is because records need to be managed in a specific way to ensure that research is accurate and reliable.

What should you do if you have a query or concern?

If you would like to make a request relating to your personal data, you should contact QMUL's Data Protection Officer at data-protection@qmul.ac.uk and requests will be considered on a case by case basis. Additionally if you wish to contact the PCTU with any query please email pctu-enquiries@qmul.ac.uk.

You can refer to our QMUL's central research privacy notice for more information, including on your rights, which can found at Privacy-Notice-for-Research-Participants.pdf.