

FITNET-NHS Trial: GDPR statement about personal data

Handling of data

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

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](#).

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).

Our Data Protection Officer is Henry Stuart and you can contact him at:
data-protection@bristol.ac.uk.

Personally-identifiable information

The Bath Royal United 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 University of Bristol and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The Bath Royal United Hospital will pass these details to the University of Bristol along with the information collected from you and your medical records. The only people in the University of Bristol who will have access to information that identifies you will be people who need to contact you to gather research information 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 and contact details. The Bath Royal United Hospital will keep identifiable information about you from this study for 5 years after the study has finished (until 2026).

Data collection from GP and hospital records

The University of Bristol will collect information about you for this research study from NHS Digital and GP surgeries. This information will include your name, NHS number and contact details and health information, which is regarded as a special category of information. We will use this information to collect data on the number of hospital admissions and health services used as well as to find out at what age you or your child was first diagnosed with CFS/ME, and how long has it been since you or your child was first diagnosed by your GP and then referred to the trial

Future research

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

If you have any questions for the trial team, please contact us on: fitnet-nhs@bristol.ac.uk