Birmingham and Solihull Mental Health NHS Foundation Trust
Research Privacy Notice

Background

All NHS organisations are expected to participate and support health and care research.

The Health Research Authority (HRA) set standards for NHS organisations to make sure they protect your privacy and comply with the law when they are involved in research.

HRA research ethics committees review research studies to make sure that the data used about you is in the public interest, and meets ethical standards.

Health and care research may be exploring prevention, diagnosis, or treatment of disease, which includes health and social factors in any disease area.

Research may be sponsored by companies developing new medicines or medical devices, NHS organisations, universities, or medical research charities. The research sponsor decides what information will be collected for the study and how it will be used.

Health and care research should serve the public interest, which means that research sponsors must demonstrate that their research serves the interests of society. They do this by following the UK Policy Framework for Health and Social Care Research. They also have to have a legal basis for any use of personally identifiable information.

For Birmingham and Solihull Mental Health NHS Foundation Trust, research is a core component of our activity and is key to making advancements in patient care.

Clinical research is an essential requirement to improve knowledge and understanding of which treatments work best and Birmingham and Solihull Mental Health NHS Foundation Trust strive to ensure that our patients are identified and offered early participation in suitable research as part of their treatment and care choice.

The research we undertake helps to answer important questions about which methods of diagnosis and treatments have the most beneficial outcomes for patients, in terms of caring, controlling or preventing disease.

Patient involvement in clinical research is vital. New and better treatments for many diseases wound not have been possible without research.

Research is the only way we can continue to improve prevention and treatment of diseases and patient care.

Birmingham & Solihull Mental Health Foundation Trust privacy notice for Research

This privacy notice tells you what to expect us to do with your personal information when it is used for research purposes.

You can find more detailed information about how we use your personal information for general purposes via the following:

- The Trust's general Privacy Notice can be found here: https://www.bsmhft.nhs.uk/wp-content/uploads/2023/08/Service-users-privacy-notice.pdf

Our contact details:

Name: Birmingham and Solihull Mental Health NHS Foundation Trust

Address: Uffculme Centre, 52 Queensbridge Road, Birmingham, B13 8QY

General phone number: 0121 301 3950

General inquiries email address: https://www.bsmhft.nhs.uk/contact-us/

Website: https://www.bsmhft.nhs.uk/

We are the controller for your information (a controller decides on why and how information is used and shared).

Our Data Protection Officer is the Head of Information Governance and is responsible for monitoring our compliance with data protection requirements. You can contact them with queries or concerns relating to the use of your personal data at:

Head of Information Governance/Data Protection Officer Information Governance Team
Birmingham and Solihull Mental Health NHS Foundation Trust
Uffculme Centre, 52 Queensbridge Road, Birmingham, B13 8QY
Email: bsmhft.informationgovernance@nhs.net

How do we get information and why do we have it?

In clinical trials, the researchers are collecting data that will tell them whether one treatment is better or worse than other. The information they collect will show how safe a treatment is, or whether it is making a difference to your health.

Different people can respond differently to a treatment. By collecting information from lots of people, researchers can use statistics to work out what effect a treatment is having.

Other types of research will collect data from lots of health records to look for patterns. It might be looking to see if any problems happen more in patients taking a medicine. Or to see if people who have screening tests are more likely to stay healthier.

Some research will use blood tests or samples along with information about the patient's health. Researchers may be looking at changes in cells or chemicals due to a disease.

All research should only use the patient data that it really needs to do the research. The type data collected during a research study will be described to you in a participant information sheet.

When you agree to take part in a research study, the sponsor will collect the minimum personally-identifiable information needed for the purposes of the research project.

Information about you will be used in the ways needed to conduct and analyse the research study. NHS organisations may keep a copy of the information collected about you.

Depending on the needs of the study, the information that is passed to the research sponsor may include personal data that could identify you. You can find out more about the use of patient information for the study you are taking part in from the research team or the study sponsor.

You can find out who the study sponsor is from the information you were given when you agreed to take part in the study.

For some research studies, you may be asked to provide information about your health to the research team, for example in a questionnaire. Sometimes information about you will be collected for research at the same time as for your clinical care, for example when a blood test is taken.

In other cases, information may be copied from your health records. Information from your health records may be linked to information from other places such as central NHS records, or information about you collected by other organisations. You will be told about this when you agree to take part in the study.

What information do we collect?

If you take part in some types of research, like clinical trials, some of the research team will need to know your name and contact details so they can contact you about your research appointments, or to send you questionnaires.

Researchers must always make sure that as few people as possible can see this sort of information that can show who you are.

In lots of research, most of the research team will not need to know your name. In these cases, someone will remove your name from the research data and replace it with a code number. This is called coded data, or the technical term is pseudonymised data. For example, your blood test might be labelled with your code number instead of your name. It can be matched up with the rest of the data relating to you by the code number.

In other research, only the doctor copying the data from your health records will know your name. They will replace your name with a code number. They will also make sure that any other information that could show who you are is removed. For example, instead of using your date of birth they will give the research team your age. When there is no information that could show who you are, this is called anonymous data.

Who do we share information with?

Sometimes your own doctor or care team will be involved in doing a research study. Often, they will be part of a bigger research team. This may involve other hospitals, or universities or companies developing new treatments. Sometimes parts of the research team will be in other countries.

You can ask about where your data will go. You can also check whether the data they get will include information that could show who you are. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements.

What is our lawful basis for using information?

Personal information

Under the UK General Data Protection Regulation (UK GDPR), the lawful basis we rely on for using personal information is:

(a) We have your consent - this must be freely given, specific, informed and unambiguous.

(e) We need it to perform a public task - a public body, such as an NHS organisation or Care Quality Commission (CQC) registered social care organisation, is required to undertake particular activities by law. See this list for the most likely laws that apply when using and sharing information in health and care.

More sensitive data

(j) For Archiving, research and statistics (with a basis in law). See this list for the most likely laws that apply when using and sharing information in health and care.

Common law duty of confidentiality

In our use of health and care information, we satisfy the common law duty of confidentiality because:

- you have provided us with your consent (we have taken it as implied to provide you with care, or you have given it explicitly for other uses)
- for specific individual cases, we have assessed that the public interest to share the data overrides the public interest served by protecting the duty of confidentiality (for example sharing information with the police to support the detection or prevention of serious crime). This will always be considered on a case by case basis, with careful assessment of whether it is appropriate to share the particular information, balanced against the public interest in maintaining a confidential health service
- A statutory authority or gateway (legal power) has expressly set aside the common law duty of confidentiality for any particular processing
- Confidential patient information that has undergone pseudonymisation
- Confidential patient information that has undergone effective anonymisation

What happens to my research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data for several years (a legal requirement for clinical trials), in case the researchers or government regulators need to check it. You can ask about who will keep it, whether it includes your name, and how long they will keep it.

Usually your hospital or GP where you are taking part in the study will keep a copy of the research data along with your name. The organisation running the research will usually only keep a coded copy of your research data, without your name included. This is kept so the results can be checked.

If you agree to take part in a research study, you may get the choice to give your research data from this study for future research. Sometimes this future research may use research data that has had your name and NHS number removed (this would make the data anonymous so other future researchers won't be able to contact you). Or it may use research data that could show who you are (in which case future researchers maybe able to contact you).

You will be told what options there are. You will get details if your research data will be joined up with other information about you or your health, such as from your GP or social services.

On rare occasions NHS organisations may provide researchers with confidential patient information from your health records when we are not able to seek your agreement to take part in the study, for example because the number of patients involved is too large or the NHS organisation no longer has your contact details. Researchers must have special approval before they can do this.

Any information that could show who you are will be held safely with strict limits on who can access it.

Researchers may not be able to specify all the possible future uses of the information they keep. It could include providing the information to other researchers from NHS organisations, universities or companies developing new treatments or care. Wherever this happens it will be done under strict legal agreements.

The information about you will be depersonalised (either pseudonymised or anonymised) wherever possible so that you cannot be identified. 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.

What are your data protection rights?

Under data protection law, you have rights including:

Your right of access - You have the right to ask us for copies of your personal information (known as a subject access request).

Your right to rectification - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

Your right to erasure - You have the right to ask us to erase your personal information in certain circumstances.

Your right to restriction of processing - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

Your right to object to processing - You have the right to object to the processing of your personal information in certain circumstances.

Your right to data portability - You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact us at bsmhft.informationrequests@nhs.net if you wish to make a request.

National data opt-out

You will have a choice about taking part in a clinical trial testing a treatment. If you choose not to take part, that is fine.

In most cases you will also have a choice about your patient data being used for other types of research. There are two cases where this might not happen:

1. When the research is using anonymous information. Because it's anonymous, the research team don't know whose data it is and can't ask you.
2. When it would not be possible for the research team to ask everyone. This would usually be because of the number of people who would have to be contacted. Sometimes it will be because the research could be biased if some people chose not to agree. In this case a special NHS group will check that the reasons are valid. You can opt-out of your data being used for this sort of research. In England you can register your choice to opt out via the NHS website. If you do choose to opt out you can still agree to take part in any research study you want to, without affecting your ability to opt out of other research. You can also change your choice about opting out at any time.

How do I complain?

If you have any concerns about our use of your personal information, you can make a complaint to us at:
bsmhft.customerrelations@nhs.net

Telephone: 0800 953 0045 Text: 07985 883509

Customer Relations Team – PALS service
Birmingham and Solihull Mental Health NHS Foundation Trust
The Barberry Centre
25 Vincent Drive
Birmingham
West Midlands
B15 2FG.

Following this, if you are still unhappy with how we have used your data, you can then complain to the ICO.

The ICO's address is:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline number: 0303 123 1113

ICO website: https://www.ico.org.uk

Date of last review: 23rd November 2023