

General Data Protection Regulation 2018 - Additional information for Patients, Carers and Service Users in relation to research

What does this document mean to you?

Common Law and the General Data Protection Regulation 2018 governs how we take care of your information which we hold about you. We have an obligation to let you know how we will take care of the information about you and what we will use it for.

Chelsea and Westminster Hospital NHS Foundation Trust (the Trust) collects a lot of data and information about you, the patient, to ensure that you get the best care possible. A privacy notice is available on the Trust's website <http://www.chelwest.nhs.uk/about-us/organisation/foi/how-we-use-your-information> which explains how and why we collect information about you what we do with it and your rights under data protection law.

The Trust's privacy notice provides a general overview and the information below provides additional information in relation to research.

General information in relation to research – a summary

- All NHS organisations (including Health & Social Care in Northern Ireland) are expected to participate and support health and care research.
- 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. The Trust does this by following the UK Policy Framework for Health and Social Care Research.
- Common Law and the General Data Protection Regulation 2018 governs how the Trust takes care of your information which we hold about you.
- As an NHS organisation the Trust uses personally-identifiable information to conduct research to improve health, care and services.
- As a publicly-funded organisation, the Trust has 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, the Trust uses your data in the ways needed to conduct and analyse the research study.
- To safeguard your rights, the Trust will use the minimum personally-identifiable information possible.
- You are free to withdraw from a research study at any time.
- Your rights to access, change or move your information are limited, as the Trust need to manage your information in specific ways in order for the research to be reliable and accurate.

Patient information and health and care research

All NHS organisations, such as the Trust, are expected to participate and support health and care research. The Health Research Authority and government departments in Northern Ireland, Scotland and Wales set standards for NHS organisations to make sure they protect your privacy and comply with the law when they are involved in research.

The Health Research Authority's research ethics committees review research studies to make sure that the research uses of data about you are in the public interest, and meet ethical standards. More information available <https://www.hra.nhs.uk/about-us/what-we-do/how-we-regulate-health-and-social-care-research/>

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.

The Trust acts as research sponsor for some studies.

Health and care research serves the public interest, which means that research sponsors have to demonstrate that their research serves the interests of society as a whole. The Trust does this by following the UK Policy Framework for Health and Social Care Research, more information available <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/> The Trust also has to have a legal basis for any use of personally-identifiable information.

How patient information may be used for research

When you agree to take part in a research study, the sponsor (which may or may not be the Trust depending on which research study) 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. The Trust 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.

If you are a research participant then some of your rights may not apply

The General Data Protection Regulation incorporates a range of exemptions from data subject rights for health research, to take account of particular aspects of research. These exemptions need to be balanced with what is fair to participants.

The following data subject rights may be limited:

- The right to erasure
- The right to access by the data subject
- The right to rectification
- The right to restrict processing
- The right to object to processing

The following data subject right is not applicable to research under legitimate interests or public interest:

- The right to data portability

In general these exemptions are similar to those under previous legislation, and mean that normally there will be no right for you, as a research participant, to access your data, rectify it or have your data erased.

Keeping information for future research

Information about you that is collected during a research study may be kept securely to be used in future research in any disease area, including research looking at social and economic factors affecting health. This may include combining it with information about you held by other health or government organisations such as NHS Digital, more information available; via <https://digital.nhs.uk/services/nhs-number>

Usually the information is combined together by matching information that has the same NHS number (more information available via <https://digital.nhs.uk/services/nhs-number>) Doing this makes maximum use of the information you have provided and allows researchers to discover more.

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 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.

On rare occasions the Trust 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 Trust no longer has your contact details. Researchers must have special approval before they can do this.

Your choices about health and care research

If you are asked about taking part in research, usually someone in the care team looking after you will contact you. People in your care team may look at your health records to check whether you are suitable to take part in a research study, before asking you whether you are interested or sending you a letter on behalf of the researcher.

You may have the opportunity to sign up to a register to hear about suitable research studies that you could take part in. If you agree to this, then research nurses, researchers or administrative staff authorised by the organisation may look at your health records to see if you are suitable for any research studies.

It's important for you to be aware that if you are taking part in research, or information about you is used for research, your rights to access, change or move information about you are limited. This is because researchers need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from a study, the sponsor will keep the information about you that it has already obtained. They may also keep information from research indefinitely.

If you would like to find out more about why and how patient data is used in research, please visit the Understanding Patient Data website, available via <https://understandingpatientdata.org.uk/what-you-need-know>

In England you can register your choice to opt out via the National Data Opt-out Programme, more information available via <https://digital.nhs.uk/services/national-data-opt-out-programme>

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.

If you have a concern or would like further information

If you wish to raise a complaint on how we have handled your personal data, you should raise your concern with us in the first instance via an email to our Data Protection Officer via information.governance@chelwest.nhs.uk

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 directly to the Information Commissioner's Office via <https://ico.org.uk/concerns/>