

General Data Protection Regulation and Research - Privacy Notice

Version : 4

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Approved by: Head of Information Governance and

Head of Research Governance (based on guidance from HRA)

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The General Data Protection Regulation (GDPR) comes into force on 25th May 2018 which is designed to enable individuals to better control their personal data. The Health Research Authority (HRA) has published guidance about research and the general use of patient information which can be found at [HRA patient information](#).

As a NHS organisation 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. In any case all research, using identifiable or non-identifiable data, would have to go through a governance process and may require approval by a Research Ethics Committee.

As a research hospital, GOSH is at the forefront of using innovative technologies in the clinical treatment of patients and in support of pioneering research to find cures of complex and rare conditions. We have set-up the Digital Research Environment (DRE), which is a research and innovation platform within GOSH. The DRE provides routinely collected clinical and other data for use in approved research studies or clinical audits to improve patient health, care and services. Only de-identified/anonymised data are made available to researchers via the DRE. Any published research results will only include de-identified/anonymised data.

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 be used for the purpose of health and social care research, or to contact you about future opportunities to participate in research.

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.

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 can be contacted at your.data@gosh.nhs.uk