

PIONEER within UHB PRIVACY NOTICE

Who are University Hospitals Birmingham NHS Foundation Trust?

University Hospitals Birmingham NHS Foundation Trust (UHB) is recognised as one of the leading research-active Trusts in Europe. Across our hospital and community sites, UHB employs more than 20,000 staff and run the largest single-site hospital in the country.

The Trust has centres of excellence for a number of services, hosts the Institute of Translational Medicine, and leads the West Midlands Genomic Medicine Centre.

UHB researchers, many of whom are world leaders in their field, are engaged in a broad range of research activity. For more information about the research UHB does, please visit our website: <https://www.research.uhb.nhs.uk/about-us/our-research/>

As a leading research-active Trust, UHB is committed to protecting the privacy and security of your personal information. UHB are registered with the Information Commissioner's Office (ICO) to process personal and special category information under the following registration number: Z5568104.

UHB and PIONEER's research follows the UK policy framework for health and social care research: <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>.

What is PIONEER?

The PIONEER programme is a Health Data Research UK affiliated research database, that safely and securely collects and stores health data from patients with an unplanned illness or symptoms. The PIONEER programme aims to understand the symptoms and diseases people come to hospital with, whether they had been to hospital or other healthcare providers before with the same problems, the time it took to make a diagnosis, the care they received and the consequences of that diagnosis. The ultimate aim of the PIONEER programme is to improve the way the NHS provides care to people when they are suddenly unwell or have an unexpected flare up in their symptoms.

PIONEER will include electronic health records for patients from a number of healthcare providers, as listed in our partners section of the website. This includes the four hospitals within University Hospitals Birmingham NHS Foundation Trust and the West Midlands Ambulance Service. In the future, PIONEER will expand to include patient data from other hospitals and health care settings and providers.

The PIONEER protocol (which explains more about the project and how it operates), can be found on the PIONEER website (www.pioneerdatahub.co.uk) and this also includes a short video about PIONEER.

UHB is the Data Controller for PIONEER, and UHB controls all health data processes for PIONEER. This is done in accordance with national data health data law and polices, in accordance with the

HRA and ethically approved and CAG supported protocol, providing a legal basis for confidential patient information to be shared without consent under common law duty of confidentiality.

We are working together with data scientists from the University of Birmingham to curate and analyse your data to tell us how to provide the most effective healthcare for patients when they are suddenly unwell or seek unplanned health care or advice.

We have partnered with Microsoft and ENSONO who have provided a UK cloud-based system for us to manage and process this data. Microsoft and ENSONO do not have access to the data within this system.

At no point will any of your identifiable data be accessible to anyone outside of the NHS, specifically University Hospitals Birmingham Hospitals NHS Foundation Trust or your local health care provider.

PIONEER and the PIONEER protocol has been approved by the Health Research Authority's East Midland's Derby Research Ethics Committee (reference: 20/EM/0158). This committee is an independent group who review research taking place in the UK from an ethical viewpoint, protecting patients and the public while promoting good ethical research.

Also, PIONEER has been approved by the Health Research Authority, as advised by the Confidentiality Advisory Group (CAG), providing a legal basis for confidential patient information to be shared without consent under the common law duty of confidentiality. The CAG is an independent body which provides expert advice on the use of confidential patient information to protect and promote the interests of patients and the public, while at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. Please see the CAG website for further details - <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/>. The CAG registration number is 20/CAG/0084.

For more information about the general use of patient data in research in the health service please visit <https://www.hra.nhs.uk/information-about-patients/>.

What we may do with your personal information

For research and innovation purposes, UHB (as the PIONEER Data Controller) may use aspects of your de-identified and anonymous information to answer specific health related questions or challenges, to improve healthcare processes and treatments for patients. This might mean sharing aspects of your information under license with external parties, such as academic researchers within universities or health companies who are developing new treatments for patients.

Some information about you may be linked to other information shared by primary care providers (e.g. GP) the ambulance service and secondary care providers (e.g. acute trusts) with the view to creating a more complete information set which will enable medical research for the benefit of public health.

Where your information is shared, it will be de-identified, so people cannot identify you from the data.

PIONEER shares data under licence in accordance with the principles of the “5 safes” – which means we only share where we can be sure we are working with:

- safe projects
- safe people
- safe data
- safe settings
- safe outputs

See the PIONEER website for more details about the 5 safes.

PIONEER also follows the principles of data minimisation. Data minimisation includes sharing only the information needed to answer a specific question, and no more.

We will not:

- Share your identifiable data.
- Sell your identifiable data.
- Share any de-identified data without a specific data licence agreement.
- Share any de-identified data unless it is deemed necessary to answer a specific health challenge or question, guided by the principles of data minimisation.

A Data License Agreement prohibits onward data sharing, linkage or attempts to reidentify patients and only permits data use for a specific research project, for a certain duration of time. A Data License Agreement sets out who may access the data, what data, where, for what purpose and for how long. A Data License Agreement also states what the agreed outputs of the data sharing will be, to ensure your identity and data are protected.

Data minimisation means that only aspects of anonymised data needed to answer a question will be shared, not the full healthcare record, and shared with the fewest people needed to answer a question, and for the shortest time possible.

All data access decisions are made against the principles of public good, and are made following agreement of the PIONEER Data Trust Committee, a group of patients and public members who provide public and patient oversight for all of our processes. See the PIONEER website for more information about the Data Trust Committee.

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](#).

Please also refer to our main patient privacy [notice](#) which explains when UHB or your healthcare provider might have to share information about you with the Care Quality Commission, the police or other regulatory/law enforcement authorities.

PIONEER will not include your health data if you have ‘opted-out’ of your data being used for research or service planning.

National Data Opt-Out

The National Data Opt-Out was introduced on 25 May 2018, enabling patients to opt out from the use of their data for research or planning purposes, in line with the recommendations of the National Data Guardian in her Review of Data Security, Consent and Opt-Outs. Further information about the national data opt-out can be found on the following website:

<https://digital.nhs.uk/national-data-opt-out>. You can choose to stop your confidential patient information being used for any research and planning purposes. This is called “opting out” and by “opting out” your health data can only be used for your health care and not to improve NHS services.

If you are happy for your health data to be used in this way, then you do not need to do anything.

Whatever choice you make, your individual care will not be affected.

Find out how to opt out on the NHS website. The option to opt out applies to anyone over the age of 13 who lives in England. If you live elsewhere in the UK, your data may be handled differently.

PIONEER specific Opt-Out

You can choose to opt out of PIONEER specifically. To do so, please contact the PIONEER team by following this link [pending] or by contacting the Patient Advice and Liaison Service (PALS) team at UHB, where you can register your request to opt out of PIONEER and will receive confirmation once this has occurred.

PALS can be contacted in writing, by telephone or by email.

Address:

PALS

Queen Elizabeth

Hospital Birmingham

Mindelsohn Way

Edgbaston, Birmingham

B15 2GW

Telephone: 0121 424 0808

Email: PALS@uhb.nhs.uk

Here, you can register your request to opt out of PIONEER and will receive confirmation once this has occurred.

COVID Specific notice

The Secretary of State for Health and Social Care has issued an instruction to NHS bodies to share confidential patient information for the purposes of research into COVID-19. For more information see: <https://www.gov.uk/government/publications/coronavirus-covid-19-notification-of-data-controllers-to-share-information> . Currently this provision is in place until 30th September 2021.

UHB's legal basis for processing personal information about you

The way in which UHB or your healthcare provider use your information is governed by law. The principal legislation that applies is the EU General Data Protection Regulation (EU GDPR) 2016/679, which is supplemented by the Data Protection Act 2018. The UK government has confirmed that the key provisions of the EU GDPR will continue to apply when the UK formally exits the EU on 31 December 2020 or sooner, by amending the current Data Protection Act 2018. Confidential information which you have shared with UHB or any healthcare staff to enable them to provide your care is governed by the common law duty of confidentiality, as described in:

<https://digital.nhs.uk/binaries/content/assets/legacy/pdf/l/o/confidentiality-nhs-cop.pdf>

When PIONEER uses your information for research, we rely on Article 6(1)e (*"processing is necessary for the performance of a task carried out in the public interest"*) and Article 9(2)j (*"processing is necessary for archiving purposes in the public interest, scientific or historical research purposes"*) of the General Data Protection Regulation (GDPR) in combination with Schedule 1, Part 1, Art 4 Data Protection Act (DPA) 2018.

Your rights

Under current data protection legislation (Art 13 to 18 GDPR), you have certain rights to manage your data as you see fit. However, for the purpose of research your rights to access, object, change, transfer and/or delete your information are limited. This is because PIONEER needs to manage the data in specific ways to ensure the research we conduct is reliable and accurate, and that we are accountable to those organisations which fund and monitor our research.

Information Commissioner's Office

The Information Commissioner's Office (ICO) is the body that regulates UHB under data protection and freedom of information legislation.

If you are not satisfied or believe we are not processing your personal data in accordance with the law you can complain to the ICO.

Information Commissioner's Office
Wycliffe House
Water Lane

Wilmslow
Cheshire, SK9 5AF
Telephone: 0303 123 1113 (local rate)
Telephone: 01625 545 745 (national rate)
Fax: 01625 524 510
Email: casework@ico.org.uk

[Changes to this privacy notice](#)

This webpage was last reviewed on 21/08/2020. It is reviewed when necessary and at least annually.