

Frequently Asked Questions

What is the Barts Life Science (BLS) programme?

Barts Life Science is a partnership between Barts Health (the hospital), and Queen Mary University of London (the University) focussed on transforming healthcare and reducing inequalities for London.

How will the BLS improve my health?

By working in partnership with a leading local university, the local hospital trust, and the community we expect to be able to improve our understanding of the health issues in our community through new research that will help improve treatments and outcomes for individuals.

How will you do this?

We routinely collect data about patients at every step of their passage through the hospital. This could include medical (e.g. blood tests, x-rays, scans) and non-medical (e.g. arrival and departure) information. If we can find patterns in the data that we routinely collect, we believe we can detect illnesses earlier and provide better treatment more quickly for the benefit of the community and the patients that we treat.

Who has access to my medical data?

Beyond your immediate medical team, some other authorised hospital staff will be able to access your patient data to generate internal management reports (e.g., performance improvement, financial reporting) and to provide legally required reports to the government. Anyone else will need to request and justify access to your data.

How can someone outside of the hospital get access to my medical records?

The main route is if you give your explicit permission as part of a research project. The medical teams in the hospital routinely take part in research projects and may approach you to join a study. If they do, they will discuss the data they will collect, how it will be used, how long the data will be kept for, and how if you change your mind the data will be withdrawn from the study. Barts Health describes the data that we may collect during your interactions with the hospital and how we handle it in the [privacy notice](#).

Can my medical records be released without my explicit consent?

Yes. A study may ask for medical data - for example - for all patients aged between 50 and 55 being treated for high-blood pressure. Each request must be approved by the Caldicott Guardian (see below) for the hospital, who is responsible for approving requests that meet legal and ethical safeguards for using medical data. If you do not want your medical data to be used for such research and planning purposes, you can opt out online.

Stricter controls apply to data requests that include personal data (for example, name, date of birth, home address or NHS number). These requests need to have a legal basis for the release of personal details. Further information can be found on the [NHS Digital website](#).

What is a Caldicott Guardian?

A Caldicott Guardian is a legally defined role within the hospital for overseeing the safe transfer of sensitive data to other organisations. This work is based upon public consultations in 1997 and 2013 which have established eight principles that need to be considered in any request:

1. Justify the purpose(s) of using any confidential information
2. Only use confidential information when it is necessary
3. Use the minimum necessary confidential information that is required
4. Access to confidential information should be on a strict need-to-know basis
5. Everyone with access to confidential information must understand their responsibilities
6. Understand and comply with the law
7. The duty to share information can be as important as the duty to protect patient confidentiality
8. Inform patient and service users about how their confidential information is being used

[More details are available here.](#)

What is Precision Medicine?

Precision medicine looks at all the healthcare data (e.g., patient record, genetics, environment, and lifestyle) of a person to identify risks of illness and to select treatment that could work best for them. The Precision Medicine Platform being built within the Barts Life Science programme will allow us to collect health care data, beyond the Barts patient record, from other health care partners in the community (e.g., GPs) where we have permission to do so. By analysing all the healthcare data,

we have about the patient, we expect to provide additional information to help the medical teams decide on the most appropriate treatment for that individual.

How will Barts Heath NHS Trust enable research into patient data?

We are placing the patient data that will be used for more general analysis including research purposes into a dedicated database – the research data core – that will remain managed and secured within the hospital like all other patient data. From this research data core, we will extract the data needed by approved research projects. Depending on the access requested and the consent that has been obtained we may release the full, partial, anonymised or pseudonymised patient record.

What is the research platform?

The research platform is where the data extracted from the hospital records that might be used for health research and more general analysis. It is still held within the hospital and managed by the hospital IT team. When a research project is approved, the required data will be extracted from the research platform and made available to the researchers.

How will I, the patient benefit from the research platform?

The research platform will allow approved researchers access to patient data to help better understand the health challenges we face within the community or to pioneer the development of new medical approaches. Once we can turn this patient data into actionable knowledge for the medical teams, individual patients will start seeing the benefits of this work.

What is anonymised or pseudonymised data?

Anonymised patient records have had all personal data (e.g., names, date of birth, address, etc) removed so there is nothing to identify the individual. Pseudonymised data has all personal data removed and replaced by a unique reference to a patient record. The link between this reference and the patient remains secure in the hospital meaning the patient can be identified later by the hospital if needed.

Will you sell my health data to commercial organisations?

Any commercial company requesting access to patient data as part of a study will have to meet the same requirements as any other data access request to receive hospital data. Any company that does meet these requirements will be under a contractual obligation to keep the data confidential and to only use it for the stated purposes. They will only get the data that they need to undertake the study – this is unlikely to include your individual contact details unless you have explicitly consented to be part of the study.

How can I find out more or stay connected?

In addition to the Barts Life Science website, we will send updates about the Precision Medicine program via email. You can subscribe to this email by contacting: bartshealth.researchdata@nhs.net.

How can I opt out of my data being used?

If you do not want your data to be used for anything other than your medical care and related administrative processing, then you can visit [NHS Digital website](#) and set your data opt-out choice.

What is data science, artificial intelligence, and machine learning and do you use them on my medical data?

Data science is the application of statistics to large data sets to improve understanding of the data. This is something we do routinely on our data to identify operational and medical performance, e.g., patient waiting times. With better understanding of the data, we can identify areas where we need to make improvements. Sometimes the patterns in the data can be harder to understand and more advanced techniques are needed.

Artificial intelligence is a technique that makes use of computer algorithms to find data patterns so that a model is developed that can predict future patterns. For example, this might be used to identify drugs and dosage that are mis-aligned to the patient's record.

Machine learning techniques can learn and adapt to patterns of data without explicit instructions and therefore able to predict future patterns. For example, a machine learning algorithm might be trained on images where a clinician had determined a particular diagnosis to see if a diagnosis could be made on new images.