

# Barts Life Sciences Precision Medicine Platform

## Patient and Public Involvement and Engagement (PPIE) strategy



## Glossary

| Term  | Definition  |
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| <b>Artificial intelligence (AI)</b>                                     | Artificial intelligence ('AI') is regularly used to describe when a machine or system (e.g., computers running algorithms) performs tasks that usually require human (or other biological) brainpower to be completed, such as learning behaviours or solving problems.<br><i>Credit: Alan Turing Institute</i> |
| <b>Data Science</b>   | Data science uses statistical methods and processes to extract knowledge and insights from data to find knowledge to help make decisions.   |
| <b>Anonymisation</b>  | The process of removing personal identifiers that may lead to an individual being identified.   |
| <b>Pseudonymisation</b>   | The processing of personal data in a way that the data can no longer be attributed to a specific individual without the use of additional information. The additional information is kept separately and subject to security measures to ensure non-attribution to an identified or identifiable individual.    |
| <b>Healthcare / patient data</b>  | Medical information held about an individual patient. Patient data may include information relating to their past and current health or illness, their treatment history, lifestyle choices and genetic data.   |
| <b>Patient and public involvement in research</b>                       | When patients and /or members of the public are actively involved in developing research projects in partnership in research organisations.   |
| <b>Patient and public engagement in research</b>                        | When information and knowledge about research projects is provided and shared with patients and / or members of the public.   |
| <b>Patient and public involvement and engagement (PPIE) in research</b> | The collective term used when organisations carry out both patient and public involvement and engagement in research.   |

## 1 Who we are

[Barts Health NHS Trust](#) is made up of five hospitals across east London – St Bartholomew's, The Royal London, Mile End, Whipps Cross and Newham. This group of hospitals provide a huge range of clinical services to the people of east London and beyond. Over 2.5 million people look to us and our services to provide them with the healthcare they need.

[Queen Mary University of London](#) (QMUL) is a public research university in London, England, and a member institution of the federal University of London. QMUL is an established university in London's vibrant east end committed to high-quality teaching and research.

[Barts Life Sciences](#) is a joint venture between Barts Health NHS Trust and QMUL, supported by Barts Charity, who have come together to help accelerate the latest healthcare innovations from bench to bedside.

## 2 The purpose of this document

The precision medicine programme<sup>1</sup>, established by Barts Life Sciences, is a joint programme between Barts Health NHS Trust and QMUL. Barts Health NHS Trust will design and build a database to hold certain patient data and provide secure environments for the analysis – together known as the Precision Medicine Platform. See section 3.2 for further details. QMUL are as part of the programme, seeing how to make the varied healthcare / patient data i.e., patient records, x-rays and scans easily accessible and useable for further research activities, by QMUL and other researchers.

The platform will be used to better improve health outcomes for our community, but it won't work unless it has patient data. We want to ensure that patients are involved from the outset of this programme, and that they have an opportunity to shape the data held in the platform and how the data is accessed.

This document describes the overall PPIE strategy for the precision medicine platform and includes content that can be used as part of the outreach activities.

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<sup>1</sup> <https://bartslifesciences.org/precision-medicine/>

## 2.1 Patient and Public Involvement and Engagement

The UK Standards for Public Involvement are designed to improve the quality and consistency of PPIE in research<sup>2</sup>. Primarily, they are geared towards research projects rather than the building and management of research databases and the processes of accessing them. Therefore, we will be using these research oriented standards as guidelines for our more infrastructure focused activities, aligning our work to them and there by:

- a) working in partnership with patients and the public to offer involvement opportunities that are accessible to a diverse group of individuals
- b) working together in a way that values all contributions, and builds and sustains respect and trust
- c) offering, promoting and supporting learning opportunities to our PPIE representatives
- d) always communicating in a plain and accessible way including different formats and different languages
- e) embedding public and patient involvement in the governance of the programme and data access management review
- f) assessing, measuring and sharing the difference that PPIE makes to our work.

### ***Working in partnership:***

We aim to ensure our PPIE work is inclusive and representative of the local communities that we serve. We will involve and work with patients, members of the public and healthcare professionals of all ages, abilities, gender, ethnicity, sex, religion, belief etc.

We will:

- openly and widely advertise opportunities for PPIE via existing channels such as patient groups, word of mouth, marketing via multiple social media channels such as Twitter, Instagram and LinkedIn, Barts Health NHS Trust and QMUL websites and others
- work with partners such as the Barts Health NHS Trust engagement team, the QMUL engagement team, community and faith leaders to ensure that we're involving people from as many backgrounds and communities as possible
- offer a range of ways that people can get involved in our work
- involving and working with patients and people with different views, beliefs, experience and expertise.

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<sup>2</sup> <https://sites.google.com/nihr.ac.uk/pi-standards/home>

### **Support and learning:**

PPIE representatives and researchers will be offered support and training on different topics (e.g., understanding research and data<sup>3</sup>, being a reviewer<sup>4</sup>) as well as bespoke face-to-face sessions to build confidence and skills around PPIE.

We will:

- offering PPIE training to all involved
- provide incentives, reimbursement for time and expenses incurred while supporting us
- acknowledge and thank our PPIE representatives in events, papers and any applicable communications
- providing a named person on the project to contact directly with any queries.

### **Communication:**

To ensure everyone involved understands the project, its aim and their role in it, we will communicate in plain and accessible ways. We want to ensure that everyone, but in particular PPIE representatives, understand the use, benefits and risk of health data for patients, NHS, researchers, commercial companies and others.

We will:

- develop public-facing communications such as leaflets, posts for social media, explanation videos and more in different languages
- co-design our communications and events with PPIE representatives.

### **Governance:**

PPIE representatives will be involved in the programme governance processes to ensure best practice and transparency around how healthcare / patient data in the precision medicine platform is stored, managed, accessed, used and shared.

We will:

- include a PPIE representative on the programme board to provide strategic advice, make recommendations for the processes, policies and procedures surrounding access, to be followed by the data access/management review board to follow for research project review

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<sup>3</sup> <https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-learn-about-research/>

<sup>4</sup> <https://www.learningforinvolvement.org.uk/an-interactive-course-for-new-and-experienced-patient-public-reviewers-of-health-and-social-care-research>

- recruit PPIE representatives to be part of the data access/management review board to ensure transparency, with particular focus on how data are used and kept secure.

### ***Impact***

To ensure we are achieving our PPIE aims and that our activities are effective, we will use a combination of tools to identify and collect information that will help us understand what has and hasn't gone well, and what improvements we can make to our PPIE work.

We will:

- record activities with consent from our participants for learning and training purposes as well as evidence of PPIE carried out
- ask participants to feedback on their experience of participating
- record the number of actives and events held as well as the number of participants attended to ensure we are monitoring the number of people we are reaching
- review and share learnings about the impact of PPIE in our work via multiple channels such as PPIE sessions, BLS website, Twitter etc.

## **3 Understanding data**

### **3.1 What is healthcare or patient data?**

Healthcare / patient data, also referred to as real world data (RWD), is information collected about a patient from their medical records, namely from visits to their GP and / or hospitals. It is interesting to scientists, healthcare professionals and other researchers for many reasons as it can be studied and examined for trends, patterns and much more. This information can then be used to improve the care and treatment patients receive, and to redesign clinical pathways and services. All data access requests are reviewed to ensure that only the minimum data needed for the request will be provided. Frequently, this means that only anonymised data will be released, which means that the people looking at it don't know who it belongs to. For example, they might know the person is a 67-year-old man who takes insulin to treat his type I diabetes and visits the hospital every month for a check-up. But they won't know his name or where he lives.

Thanks to the development of cutting-edge technology this healthcare / patient data can now be processed and analysed to eventually and ultimately provide individual

care and treatment to patients. It may also be able to help in the prevention of disease by looking at a person's genetic, environment and lifestyle. This is known as precision medicine.

This approach allows healthcare professionals and researchers to predict more accurately which treatment and prevention methods will work for a particular disease and the groups of patients / people they're most likely to work in<sup>5</sup>.

The Covid-19 pandemic is a good example of how healthcare / patient data has been used to monitor, manage and respond to a disease. It has played a crucial role in identifying patients who were more vulnerable to the virus, in the reporting of numbers of positive cases and deaths, and in monitoring the impact of new treatments. Applying data science techniques to patient data files was also invaluable in helping establish the link between ethnicity and socio-economic status and their impact on people's ability to overcome the disease<sup>6</sup>. The data was available in real-time, which enabled the government and the NHS to make decisions and implement changes quickly, and in turn that the impact of these changes was seen quickly.

### 3.2 What are we doing with healthcare or patient data?

Barts Health NHS Trust receives many requests from researchers for healthcare / patient data to be used for operational and research purposes. While the systems that are in place to support and manage these requests all work, they aren't currently designed to be analysed at scale using a range of data science techniques including AI.

Supported by funding from Barts Charity, Barts Life Sciences has established a precision medicine programme to better utilise one of the largest sources of hospital data within the NHS to predict health risks, prevent ill-health, and find new and personalised ways to treat patients. To meet the objectives of the programme, Barts Health NHS Trust would like to design and build a combined database and analysis environment (known as the 'Precision Medicine Platform'), which will store, manage and provide access to healthcare / patient data from Barts Health NHS Trust patients. Alongside this, we will develop new policies and procedures for sharing and using this data in a way that's easy for researchers and healthcare professionals to access, but more importantly, which ensures their use of the data meets the ethical and regulatory requirements and complete anonymity for patients and the public. We want to do this

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<sup>5</sup> <https://medlineplus.gov/genetics/understanding/precisionmedicine/definition/>

<sup>6</sup> [Ethnic disparities in hospitalisation and hospital-outcomes during the second wave of COVID-19 infection in east London - PubMed \(nih.gov\)](#)



so that patients and the public are confident their data are being used appropriately, and with their consent.

### 3.3 Why are we doing this?

We are creating the Barts Life Science Precision Medicine Platform so that once healthcare professionals and researchers become approved, they can easily access healthcare / patient data as part of their work in a consistent, safe and robust process that protects all involved, especially the patients / public.

We hope that by doing this and providing them access in this way, we can help drive innovation and research into new ways to diagnose, treat and prevent a variety of diseases, especially those that impact our local communities the most.

## 4 Importance of patient and public involvement and engagement

Patient and public involvement and engagement (PPIE) is an essential part of establishing the precision medicine programme. This is because the healthcare / patient data in it belongs to our patients, and so they have a right to have a say in how the data – their anonymised, healthcare data – is stored, processed, managed, used and shared.

In our PPIE work, we want to have meaningful discussions with our patients and the general public to ensure they fully understand what this platform is, how it will benefit patients and how it will help improve patient care. We also want to know what areas of improvement within healthcare are most important to them.

We want to:

- be transparent with all involved about what we are doing
- know the public and patients' views on data sharing with commercial companies
- understand the challenges we may face from the patient and public i.e., concerns about patients' data being used, opting out, selling data etc., and how to overcome them with the support and experiences, insights and ideas from our patients and public.



By involving and engaging patients and public in the development of this platform, we aim to ensure people understand how and why their data will be used, and to be a trusted voice in how AI technology is used with healthcare / patient data<sup>7</sup>.

## 4.1 Our aim

Our aim<sup>8</sup> is to create a Precision Medicine Platform that safely and securely stores healthcare / patient information accessible to researchers and healthcare professionals and which patients and the public have confidence in. This core will enable the development of new ways to diagnose, treat and prevent diseases, while still protecting the patient's right to confidentiality and choice about how their data are used.

We will achieve this aim by:

- PPIE focus group for open and honest discussions and guidance on PPIE activities
- engaging patients and the public in establishing the policies around accessing the platform
- involving and engaging patient and public representatives in the governance processes of the projects who request access to the data
- imbedding patient and public representatives in the data access review process
- putting equality, diversity and inclusion at the heart of our work.

Specifically, in relation to PPIE, our aim is to build and maintain patient / public trust, confidence and support in sharing healthcare / patient data by being transparent about:

- a) the importance, benefit and risks of healthcare / patient data being used in research
- b) our plans to ensure safe and secure access
- c) being transparent in all that we do.

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<sup>7</sup> <https://www.hdruk.ac.uk/news/why-ppie-is-so-important-to-health-data-research-hdr-uk-lay-members/#:~:text=Involving%20patients%20and%20members%20of,using%20health%20data%20for%20research.>

## 5 Activities

### 5.1 Engagement

PPIE activities will involve open and honest discussions and sharing of information in various ways, including face-to-face events and online sessions, via multiple channels to ensure it is accessible by everyone. Through engagement activities the following two objectives will be discussed:

**a. *The importance, benefit and risks of health data research***

We will:

- discuss why research is important
- listen, understand and respond to the concerns of our communities via our PPIE representatives
- explain what research studies are, what healthcare / patient data are and how they're linked
- explain the benefits and risks surrounding healthcare / patient data using examples
- discuss the need for and importance of commercial companies accessing our healthcare / patient data
- explain consent requirements according to the legal requirements
- explain the opt-out process.

**b. *Safe and secure access***

We will:

- communicate those records will be held safe and securely in the Precision Medicine Platform and if applicable will be anonymised/ pseudonymised appropriately before being accessed
- discuss what the five-safe framework is and how it would be implemented<sup>8</sup> for all data access requests.

### 5.2 Involvement

PPIE representatives will invited to be part of the programme board and the data access management review board. They will be involved in the decision-making process to ensure there is transparency in all that we do.

**a. *Transparency***

We will:

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<sup>8</sup> <https://ukdataservice.ac.uk/help/secure-lab/what-is-the-five-safes-framework/>

- have PPIE representatives be part of the governance process as well as making recommendations for the processes, review and endorsement of documents (e.g., the terms of references for the data access review board, policies and procedures) in language that is easily accessible to all<sup>9</sup> making the process transparent
- have PPIE representatives be part of the decision-making process<sup>9</sup> by being part of the of the data access/management review board, reviewing proposals for data access requests
- audit the work done to check data has been analysed as proposed in the data access report
- ensure all approvals for data use are published and there is a requirement for all those granted access to report the outcome to Barts Health NHS Trust and acknowledge Barts Health NHS Trust as data source
- ensure information about health data partnership should be made available on a central register<sup>9</sup>
- where possible streamline the data across different regions<sup>9</sup> by working in partnership with other NHS organisation and/or data hubs
- ensure that there is fairness and equality across the healthcare system for entering healthcare data partnership<sup>9</sup>.

## 6 Strategy into practice

The precision medicine programme management group with the support and guidance from the programme board will be responsible for putting the PPIE work stream into practice.

## 7 Contact

If you would like to get involved in the programme board and/or in the data access management review board, please contact [bartshealth.researchdata@nhs.net](mailto:bartshealth.researchdata@nhs.net).

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<sup>9</sup> <https://understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Summary%20and%20Analysis.pdf>

Your views, comments, feedback, queries and questions are important to us. Please get in touch with us at [bartshealth.researchdata@nhs.net](mailto:bartshealth.researchdata@nhs.net).

## 8 Review

Our public and patient involvement and engagement strategy – and in turn this document – will be reviewed annually by Precision Medicine Programme Manager.