NHS
Barts Health
NHS Trust

Barts Health Data Platform:

Patient and Public Involvement and Engagement (PPIE) Strategy

barts CHARITY

Queen Mary
University of London

Glossary

Term	
We	The collective term referring to the Precision Medicine Programme project team members, stakeholders, and any other individuals involved in the planning, execution, and delivery of the project as defined in the project management plan. “*We*” implies a collaborative effort among all parties to achieve project objectives.
Anonymisation	The process of removing personal identifiers that may lead to an individual being identified.
Artificial intelligence (AI)	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. Credit: Alan Turing Institute
Data Science	Data science uses statistical methods and processes to extract knowledge and insights from data to find knowledge to help make decisions.
Healthcare / patient data	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.
Pseudonymisation	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.
Patient and public engagement in research	When information and knowledge about research projects is provided and shared with patients and / or members of the public.
Patient and public involvement in research	When patients and /or members of the public are actively involved in developing research projects in partnership with research organisations.
Patient and public involvement and engagement (PPIE) in research	The collective term used when organisations carry out both patient and public involvement and engagement in research.

Who are we?

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 an established public research university in London's vibrant east end, and a member institution of the federal University of London. QMUL is committed to high-quality teaching and research.

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

The Barts Health Data Platform (BHDP) is a secure data hub that offers researchers a streamlined process to access research-ready patient data from the NHS. It also provides a safe place for them to analyse the data.

The purpose of this document

The Precision Medicine Programme[1] established by BLS is a joint programme between Barts Health NHS Trust and QMUL. Barts Health NHS Trust have designed and built a database to hold certain patient data and provide secure environments for the analysis – together known as the BHDP. 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 Patient and Public Involvement and Engagement (PPIE) strategy for the BHDP and includes content that can be used as part of the outreach activities.

Our mission...

Our goal is clear: to make it simple for researchers to access NHS patient data securely, speeding up medical breakthroughs for a healthier tomorrow.

Patient and Public Involvement and Engagement

The UK Standards for Public Involvement are designed to improve the quality and consistency of PPIE in research[2]. 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 organisation focused activities, aligning our work to them by:

- working in partnership with patients and the public to offer involvement opportunities that are accessible to a diverse group of individuals.
- working together in a way that values all contributions and builds and sustains respect and trust.
- offering, promoting, and supporting learning opportunities to our PPIE representatives.
- always communicating in a plain and accessible way including different formats and different languages to reach wider audiences.

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[1] https://bartslifesciences.org/precision-medicine/

[2] https://sites.google.com/nihr.ac.uk/pi-standards/home

- embedding public and patient involvement in the governance of the programme and data access committee (DAC) review.
- 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, social media marketing via channels such as the BHDP website, Instagram and LinkedIn, Barts Health NHS Trust and QMUL of London 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.

Support and learning:

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

We will:

- offer PPIE training to researchers and people in the community.
- provide incentives, reimbursement for time and expenses incurred while supporting us.
- develop PPIE digital training resources to facilitate self-learning.
- 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:

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[3] https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-learn-about-research/)

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

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, including PPIE representatives, understand the use, benefits and risk of health data for patients, NHS, researchers, commercial companies and others.

We will:

- increase the visibility of BHDP through promotional events such as community days and festivals.
- contribute to local blogs and publications with current and relevant case studies, events and opportunities to get involved in BHDP work.
- develop public-facing communications such as leaflets, posts for social media, explanation videos and more in different languages.
- hold focus groups to develop our visual identity and public facing materials.
- co-design our communications and events with PPIE representatives.

Share stories, case studies and events on the BHDP website

We will measure the outcome and benefits of this by:

- recording the frequency of our training and keeping a record of all attendees.
- collecting feedback from training to identify the participants understanding of PPIE and any knowledge gaps.

Governance

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

We will:

- include public representatives on the programme board to provide strategic advice, make recommendations for the processes, policies and procedures surrounding access, to be followed by the DAC to follow for research project review.
- recruit public representatives to be part of the DAC to ensure transparency, with particular focus on how data are used and kept secure.

Impact

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 better.

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 activities and events held as well as the number of participants attended to ensure we are monitoring the number of people we are reaching.
- highlight specific examples where PPIE has led to positive changes or improvements.
- compare outcomes and experiences between groups that have been actively engaged in PPIE activities and those that have not to help identify the added value of patient and public involvement.
- review and share learnings about the impact of PPIE in our work via multiple channels such as PPIE sessions, BHDP website, BLS website, , LinkedIn etc.

We will measure the outcome and benefits of this by:

- collecting baseline data including surveys, for each indicator to assess the effect of the PPIE work and comparing what happens after implementation.

Understanding data

What is healthcare / 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 1 diabetes and visits the hospital every month for a check-up. But they won't know his personal information such as 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[5].

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[6]. 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.

What are we doing with healthcare / 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 Artificial Intelligence (AI).

Supported by funding from Barts Charity, BLS 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 have designed and built a combined database and analysis environment (known as the 'Barts Health Data Platform'), which will store, manage and provide access to healthcare / patient data from Barts Health NHS Trust patients.

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[5] https://medlineplus.gov/genetics/understanding/precisionmedicine/definition/

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

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

PPIE in Action!

Scan the QR code to see how we're connecting with our local community, featuring insights from a public contributor!

Why are we doing this?

We have created the BHDP so that once healthcare professionals and researchers have approval, 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.

Importance of patient and public involvement and engagement

PPIE is an essential part of establishing the BHDP. 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 their anonymised, healthcare data – is stored, processed, managed, used and shared.

In our PPIE work, we want to co-design elements of the BHDP and have meaningful discussions with our patients and the public to ensure they fully understand what our 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.
- understand the public and patients' views on data sharing with commercial companies.
- recognise the challenges and concerns of the patients and public about their data being used, opting out, selling data etc., and collaborating to identify how to overcome them with the support and experiences, insights and ideas from our patients and public.
- actively recruit public representatives via the BHDP website

We will measure the outcome and benefits of this by:

- conducting regular surveys. One in the initial stages to gain insight into the views of the patients and public. Then after PPIE activities have taken place to analyse any changes.

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 [7].

Our aim

Our aim[8] is to provide a platform where healthcare/patient data is kept safe and accessible to researchers and healthcare providers. The public and patients will trust this platform and it 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:

- hosting PPIE focus groups to encourage open and honest discussions around the BHDP and to receive 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, benefits 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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[7] 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.

Activities

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.
- share case studies that exhibit positive outcomes in similar areas of research.
- 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 that the records will be held safe and securely in the BHDP and if applicable will be anonymised/ pseudonymised appropriately before being accessed.

- discuss what the fives-safe framework is and how it would be implemented[8] for all data access requests.

Reporting and Reflecting on PPIE Activities

To ensure transparency, consistency, and high-quality reporting of our Patient and Public Involvement and Engagement (PPIE) activities, we will adopt the **GRIPP2 Long Form (LF)** checklist across all projects. GRIPP2-LF provides a detailed framework to report the aims, methods, results, impact, and critical reflections of PPIE work.

By embedding the GRIPP2-LF into our PPIE practice, we aim to:

- Document the **purpose** and **scope** of involvement clearly
- Provide detailed reporting on the **processes** and **contributions** of patients and the public;
- Reflect on the **impact**, including benefits, challenges, and lessons learned;
- Enhance the **transparency and accountability** of PPIE in our research.

Completed GRIPP2-LF reports will be integrated into project outputs, such as reports, publications, and internal reviews, to support shared learning and continuous improvement.

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[8] https://ukdataservice.ac.uk/help/secure-lab/what-is-the-five-safes-framework/

Involvement and engagement

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

We will:

- 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 DAC, policies and procedures) in language that is easily accessible to all 9 making the process transparent.
- have PPIE representatives be part of the decision-making process[14] by being part of the of the DAC, 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[10].
- strive to simplify data management across various regions by collaborating with other NHS organisations and/or data hubs whenever possible.
- ensure that there is fairness and equality across the healthcare system for entering healthcare data partnership[10].

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

[10] https://understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Summary%20and%20Analysis.pdf

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.

Contact

If you would like to get involved in the programme board and/or in the DAC, please contact bartshealth.researchdata@nhs.net.

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

Visit our website at **data.bartshealth.nhs.uk**

Review

Our PPIE strategy – and in turn this document – will be reviewed annually by Precision Medicine Programme Manager.

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