NIHR | Barts Biomedical Research Centre

NIHR | Barts Clinical Research Facility

Patient and Public Involvement, Engagement & Participation Strategy

2022-2027

Executive Summary

The NIHR Barts BRC is a delivery partnership of Barts Health NHS Trust, Queen Mary University of London, St George's University Hospitals NHS Trust and St George's University of London; the NIHR Barts CRF is a delivery partnership of Barts Health NHS Trust and Queen Mary University of London. Both the BRC and CRF are part of the NIHR and hosted by Barts Health NHS Trust.

Our Patient and Public Involvement, Engagement & Participation (PPIE/P) strategy is designed to actively involve patients and the public in healthcare research. The strategy recognises the invaluable contributions of patients and the public in improving the quality and relevance of research projects and services.

The objective of the strategy is to make sure meaningful patient and public involvement and engagement at every stage of our undertakings; by involving patients and the public, we aim to enhance research relevance, improve patient-centred care, and foster a sense of ownership and accountability within the wider research community.

The strategy encompasses several key components. Firstly, awareness and education initiatives will be implemented to raise awareness among the public and healthcare professionals about the value and benefits of patient involvement. These initiatives will address misconceptions or barriers associated with public involvement and encourage participation in research.

Partnership development is another vital component of the strategy. We will actively collaborate with relevant advocacy groups, community organisations, and appropriate stakeholders to make sure that patient perspectives are integrated into the research agenda, policy development, and decision-making processes. This collaboration will foster inclusivity, transparency, and mutual trust, addressing the diverse needs and priorities of the communities we serve.

The strategy promotes a co-creation and collaboration approach, where patients and the public actively participate in the design, implementation, and evaluation of research projects and services. They will be involved in research prioritisation, study design, recruitment, data analysis, and dissemination of findings. By involving patients and the public as partners, we enhance the relevance, effectiveness, and impact of our initiatives, ultimately improving patient outcomes and satisfaction.

Evaluation and continuous improvement form an integral part of the strategy. Appropriate evaluation will be conducted to assess the impact of public involvement, measure outcomes, and identify areas for improvement. Based on evaluation results, we will continuously refine our processes and practices, keeping patient and public input at the core of our decision-making.

Contents

Purpose

This is the strategy of the NIHR Barts Biomedical Research Centre's (BRC) and Clinical Research Facility's (CRF) for Public and Patient Involvement and engagement (PPIE/P). The purpose is to make sure that patients and the public are heard. Their voices are central to the research conducted by the BRC and CRF.

We aim to increase the accessibility, reach, relevance and impact of our research. To make sure that we meet the needs and priorities of the people we aim to benefit, we will Involve patients and the public in our research activities. We aim to include:

- Patients and potential patients.
- Service users.
- People living with one or more health conditions. They may be current patients or not.
- Informal (unpaid) carers.
- Parents and guardians.
- People who use health and/or social care services.
- People who have used health and/or social care services.
- People with disabilities.

Vision

Our vision is that all health research across our centres is informed and enriched by involvement and engagement. This will be proactive and responsive. It will be designed and delivered in partnership with patients and the public. We will foster a culture in our research practice to base it in involvement and engagement that is meaningful and inclusive. Across NIHR Barts BRC and CRF we see active consultation and collaboration. This will be in individual research projects, on research groups, on committees and at board level. This will make sure that our work is accountable, transparent and relevant to our patients and public.

Context

Patient and public involvement and engagement in healthcare research is an essential element. It leads to higher quality research. It leads to meaningful and relevant research outcomes. To achieve this within the BRC and CRF we will require and make sure:

- Creation of an inclusive, equitable and collaborative research environment. Patients, families, communities and the public fully engaged and valued partners.
- A two-way dialogue between researchers and patients. Ground research questions in patients' needs and priorities.
- Active involvement of patients and public in research management, governance, design, study running and dissemination.
- Research conducted ethically. Sensitivity to patients' perspectives, values, and beliefs.

- Recognition to address power imbalances that can exist between researchers and patients. Empower patients and the public for a meaningful role in shaping our research agenda.
- Communicating the benefits of research clearly to patients and the public.
- Engaging patients and the public in research dissemination. Communicating research results — especially from studies they have helped or taken part in — in a way that is accessible, understandable, and relevant.

Aims and Objectives

The aim of the PPIE/P strategy is to improve the quality and impact of research conducted by the BRC and CRF. To achieve this, we have the following objectives across the BRC and CRF. We will:

1. Make sure that patients and public are involved in planning, designing, running, and broadcasting research projects.
2. Develop a rolling programme of projects and activities that align with the overall aims and objectives. Be responsive to the changing needs and priorities of patients and the public.
3. Build capacity including training and support for researchers and members of the public who are involved.
4. Evaluate impact and effectiveness Then use this information to improve and develop this strategy.

Rolling Programme of Projects and Activities

A rolling programme of projects and activities will be developed. The partnership includes patients and public, researchers, and other stakeholders. The programme will include a mix of activities designed to meet objectives and respond to all our changing needs and priorities. Examples of PPIE/P activities include:

1. Researchers, patients and public co-designing studies. Identifying topics, co-producing research proposals and grant applications.
2. Patients and public on research steering committees and advisory groups. Examples include Barts BRC Patient and Public Advisory Group (PPAG), Barts CRF Community Advisory Group (CAG), TrialsConnect & Patient Powerhouse UK.
3. Hosting public engagement events and activities that share research findings and showcase and celebrate PPIE/P. Examples include our ‘Let’s talk….’ series showcasing various clinical/academic specialties, International Clinical Trials Day, and global health awareness days.
4. Hosting public engagement events that are presented, co-presented or co-designed by patients/members of the public. Examples are the Annual Barts and Queen Mary Science Festival, Heart-to-Heart series, International Clinical Trials Day.
5. Opportunities for patients and the public to shape and influence research studies as co-researchers

6. Running focus groups and surveys to gather patient and public feedback on research projects and outcomes. Examples include patients of clinical trials feeding back directly to CROs, NIHR Patient Research Experience Survey.
7. Providing training and feedback opportunities to patients and the public. This will further their knowledge, skills and abilities as a key contributor to research. Examples are providing feedback to researchers inside or outside the BRC and CRF; undertaking an interactive course for reviewers of health & social care research[1]

Details of PPIE/P events will be published for both the BRC and CRF. They will use their websites and other appropriate communications channels to advertise them.

PPIE/P Embedded Across the BRC and CRF

PPIE/P will be embedded across the BRC and CRF. This includes management and governance structures, research themes, associated projects and clinical trials. We will support researchers to involve patients and public in their research from the outset. We will seek regular updates on PPIE/P activities and outcomes. PPIE/P activities will be included in milestones and measures of success for research themes, projects and clinical trials.

Delivery Resources

To support the implementation of this strategy, the BRC and CRF will provide resources, including:

- PPIE/P training and support for researchers, patients and public involved in research projects. Researchers will receive training on best practices. This includes how to involve patients and public in research projects and how to evaluate the impact. Patients and public involved in research projects will be able to access a range of training and development resources. This will enable them to carry out their different roles with confidence. Bespoke training will be provided in addition to training provided by local, regional and national organisations.
- The BRC and CRF are enormously grateful to our patients and members of the public for their time, effort and overarching contributions to our research. We will strive to make payments for these contributions in a timely fashion. We will provide our researchers with guidance and support to budget for PPIE in their studies. We will work with our patients and public to establish new ways to reward and recognise the many ways in which they enrich our work.
- A ring-fenced budget will be provided from the BRC and CRF NIHR infrastructure awards. This will provide resources for materials, venues and event delivery.
- Availability of post-participation training wherever practical will be encouraged. This can enhance the outputs and outcomes of studies. It will also help to widen participation in research and PPIE/P activities.

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

The BRC professional lead for PPIE/P is Dr David Collier and the CRF professional lead is Neeta Patel. Both David and Neeta have extensive, award-winning experience in the field. The BRC and CRF will also appoint PPIE/P Co-ordinator posts to make sure that there is sufficient staff resource to enable delivery.

Delivery Partners

Public and patients — work with us to steer, inform, and challenge our work. This follows from our strong commitment to creating an authentic inclusive research environment. We seek the involvement of people from diverse backgrounds and underserved communities. This includes working closely alongside locally developed groups. Examples are the CRF Community Advisory Group, NIHR Barts BRC Patient and Public Advisory Group, Patient Powerhouse UK and Barts Health Patient Research Champions.

Community organisations — work with us to increase our understanding and practice involving more diverse, marginalised or seldom heard communities. Within North, East and South-West London these include the East London Mosque, TrialsConnect, Social Action for Health, Newham Disability Rep Forum

Researchers, academics and practitioners outside the BRC and CRF — share our aims to reduce health inequality and increase diversity among those involved and engaged with research. Examples are The Turing Institute, HDRUK, Medical Charities, CROs and industry partners.

PPIE/P practitioners within North, East and South-West London — share best practice. Included are our host organisations and NIHR infrastructure. Some are Barts Health NHS Trust, Queen Mary University of London, St George's University of London, St George's University Hospital NHS Foundation Trust, NIHR Translational Research Collaboratives, Clinical Research Network, North-east London Integrated Care Board Research Engagement Network and UCL Partners (AHSN).

PPIE/P practitioners regionally and nationally — we continue to build relationships, share learning and collaborate on delivery with colleagues across London, and the UK. Included are the UKCRF Network PPIE/P group, NIHR Research Ready Community Champions, and national NIHR PPIE/P groups e.g., National PRES Advisory Group, UKCRC PPIE/P Group.

Leadership, Governance and Accountability

The BRC and CRF will make sure that public involvement and engagement is embedded in the management and governance. This is at the centres as well as in research delivery groups. Staff, patients and public are coming together to form a PPIE/P working group. This approach means coordination so that patients and public are involved in decision-making processes across the BRC and CRF.

We will appoint a PPIE/P lead and a PPIE/P group for each of the BRC and CRF. They will be responsible for overseeing the implementation of this strategy. They will make sure that it is aligned with the BRC and CRF's overall aims and objectives.

Ultimate accountability for effective BRC PPIE/P delivery sits at Board and Executive levels. Each are co-chaired by the Chair of the PPIE/P group (who is a patient and/or a member of the public). As a newly formed NIHR CRF, we will be working with our CAG to establish the roles and responsibilities of our members We will seek to embed CAG representation across the CRF management and governance structures.

We will also embed our delivery partnership policies and procedures for PPIE/P into the BRC and CRF. We will outline the roles and responsibilities of researchers, patients and public involved in research projects.

We will establish inclusive and transparent processes for:

- the selection, training, and support of patients and public;
- the management of conflicts of interest.

PPIE/P is integrated throughout BRC and CRF research governance processes. Included are ethical review and research monitoring. This will help the views and experiences of patients and public to be taken into account in all aspects of research governance.

In summary, this strategy aims to involve patients and public at all levels of the research process to improve the quality and impact of research conducted by the BRC and CRF. This strategy includes a rolling programme of PPIE/P projects and activities that align with the BRC and CRF's overall aims and objectives. They are responsive to the changing needs and priorities of patients and the public. PPIE/P will be embedded across the BRC and CRF. Resources will be provided to support researchers and members of the public involved in research projects. The strategy will be evaluated regularly to make sure ongoing effectiveness and impact.

Milestones and Measures of Success

To make sure that this strategy is delivering on its aims and objectives, we will develop a SMART delivery plan. It will contain milestones and measures of success (see Annex 3). These milestones will include:

- development and implementation of PPIE/P activities across the BRC and CRF.
- number of patients and the public involved in research projects, and
- quality of feedback received from patients and the public and research participants.

These measures will be tracked regularly and used to inform development and improvement of this strategy.

In addition, we will also monitor and evaluate the impact of PPIE/P activities on research projects. This will include looking at:

- how PPIE/P activities have influenced research design, recruitment, retention, and outcomes.
- how PPIE/P activities have contributed to the translation of research findings into practice.

We will also evaluate the impact of PPIE/P on the experiences and well-being of patients and the public involved in research.

Communications and Engagement

Effective communication and engagement are essential for the success of this strategy. We will plan to raise awareness of PPIE/P and its importance. This is both within the BRC and CRF and with external stakeholders.

Our communications plan will use a range of channels. These will include digital media, newsletters, and events, to reach different audiences. We will also work with patient and community groups to make sure that our communications are accessible and effective. We will engage patients, public, participants and community groups in the development and implementation of the PPIE/P strategy. We will ask for feedback and input from these groups throughout the process. And we will take their views and experience into account.

We will also engage with researchers and other BRC and CRF staff to raise awareness of PPIE/P and to provide support. This will include training on PPIE/P best practice, as well as guidance on involving patients and public in research projects.

Conclusion

The BRC and CRF's PPIE/P strategy aims to make sure that patients and public are involved in the research process to improve the quality and impact of our research. The strategy includes a rolling programme of projects and activities that align with the BRC and CRF's overall aims and objectives. They are responsive to the changing needs and priorities of patients and public. PPIE/P will be embedded across the BRC and CRF. Resources will be provided to support researchers and members of the public involved in research projects.

The strategy includes clear governance and accountability mechanisms, a rolling programme of projects and activities, and measures of success. We will allocate resources to support the implementation of the strategy. By embedding PPIE/P across all BRC and CRF research themes and projects, we will make sure that research is relevant to the needs and priorities of patients and the public. Research findings are more likely to be translated into practice leading to better health outcomes in the end.

The strategy will be evaluated annually for effectiveness and impact, as shown in Figure 1 below:

Development

- **Initial development of strategy and action plan**
- Annual opportunity to revise strategy and action plan

Delivery

- Activities, outcomes, impact
- Resources – knowledge & expertise, budget, training etc.
- Partnerships & collaborations

Self assessment

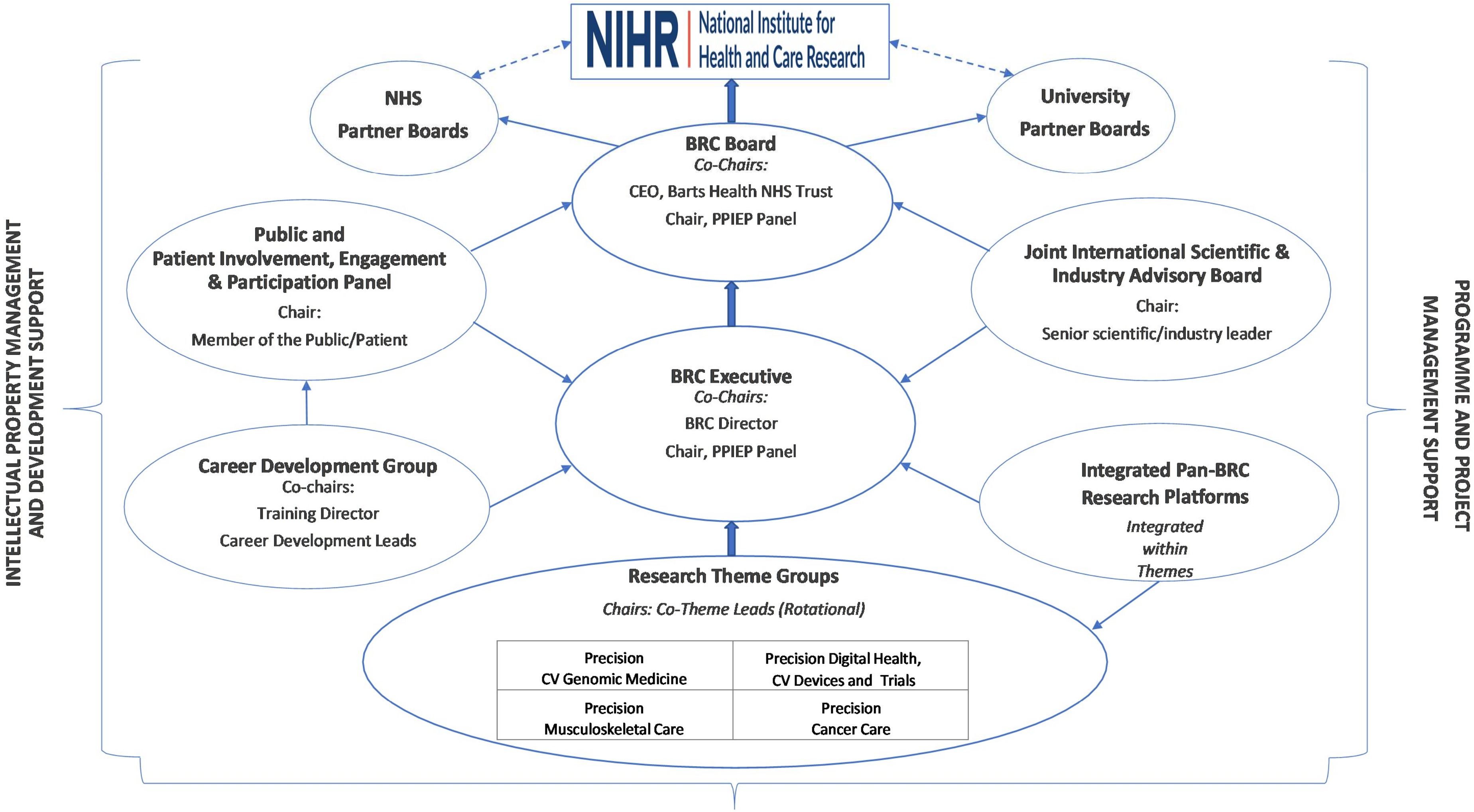
- Monitor and review progress in delivery – what is/isn't working?
- Identify improvements / modifications or new areas

Reporting

- Internal management and governance processes
- Annual reporting to CCF/DHSC
- Wider/public reporting

Figure 1: Monitoring and evaluating impact of NIHR BRC and NIHR CRF PPIE/P strategy

Annex 1: NIHR Barts BRC: Governance Structure



NIHR | National Institute for Health and Care Research

NHS
Partner Boards

University
Partner Boards

BRC Board
Co-Chairs:
CEO, Barts Health NHS Trust
Chair, PPIEP Panel

Public and
Patient Involvement, Engagement
& Participation Panel
Chair:
Member of the Public/Patient

Joint International Scientific &
Industry Advisory Board
Chair:
Senior scientific/industry leader

BRC Executive
Co-Chairs:
BRC Director
Chair, PPIEP Panel

Career Development Group
Co-chairs:
Training Director
Career Development Leads

Integrated Pan-BRC
Research Platforms
Integrated
within
Themes

Research Theme Groups
Chairs: Co-Theme Leads (Rotational)

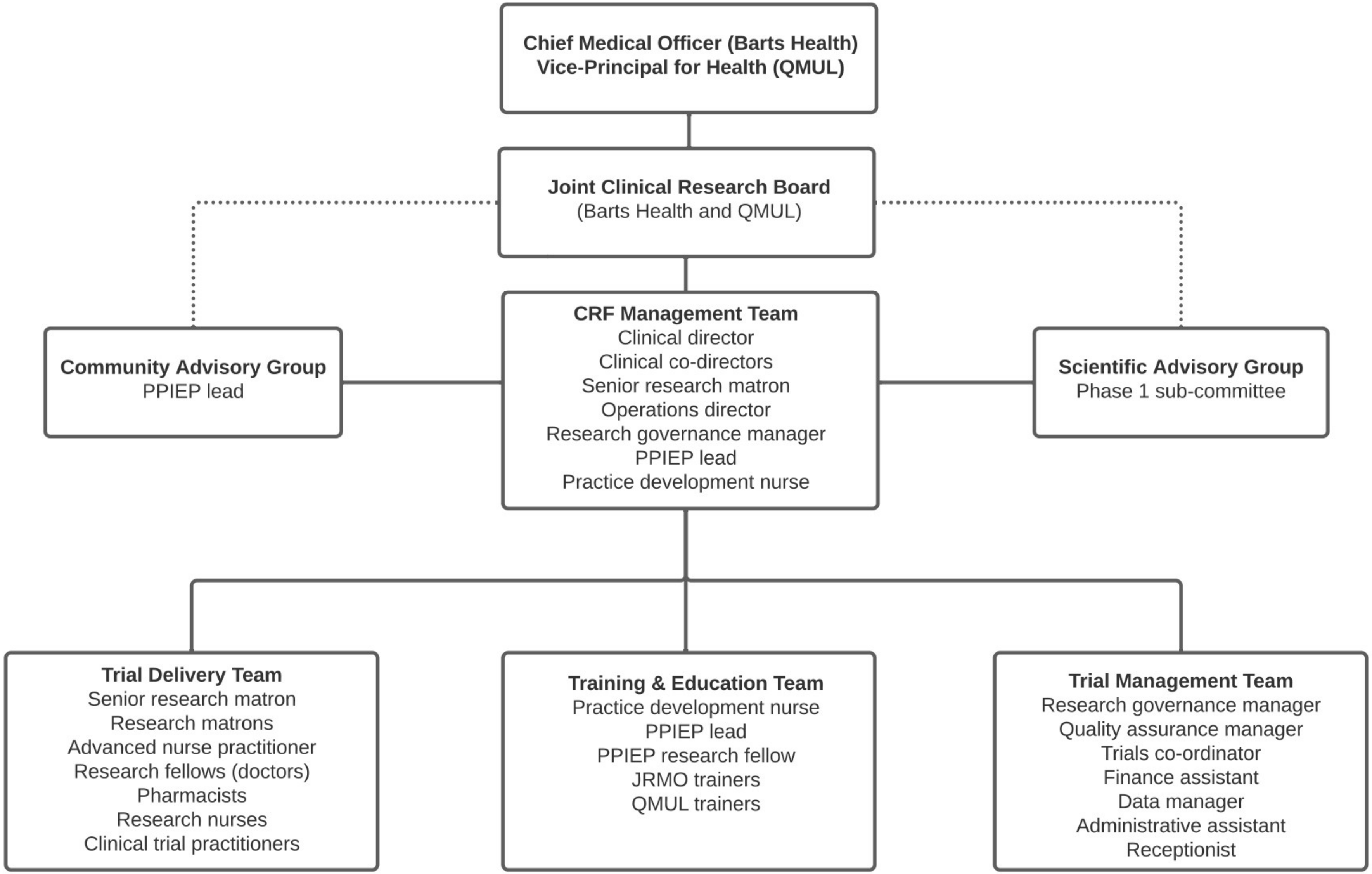
Precision CV Genomic Medicine	Precision Digital Health, CV Devices and Trials
Precision Musculoskeletal Care	Precision Cancer Care

INTELLECTUAL PROPERTY MANAGEMENT
AND DEVELOPMENT SUPPORT

PROGRAMME AND PROJECT
MANAGEMENT SUPPORT

EQUALITY, DIVERSITY & INCLUSION
Embedded throughout all aspects of the NIHR Barts BRC

Annex 2: NIHR Barts CRF: Governance Structure



Annex 3: NIHR Barts BRC and CRF PPIE/P Strategy - SMART Action Plan

The UK Standards for Public Involvement in Research provide guidance for researchers and organisations to involve patients, service users, carers and the public in the planning, management, and dissemination of health and social care research. SMART objectives help to clarify goals and make sure that they are specific, measurable, achievable, relevant, and time-bound.

SMART Objective	**Actions**	**Deliverables**	**Measurable Outputs/ Outcomes**	**Timeframe**
Increase awareness of the importance of public and patient involvement and Engagement (PPIE/P) in health research	• Develop and distribute educational materials on PPIE/P to researchers and patients • Host informational events for researchers and patients	Joint and ongoing – CRF and BRC as appropriate to respective infrastructure award objectives (to be developed during the award). CRF – Annual Open Day – showcasing CRF PPIE/P BRC – Series of PPIE/P events (organic development during award) including such as the Barts & Queen Mary Annual Science Festival, 'Let's talk….' Series of events etc.	• Increased number of requests for educational materials and training • Increased attendance and engagement in informational events	Short-term (1-2 Years) Nov 2024
Increase patient and public representation in BRC/ CRF and research teams	• Develop and use an inclusive recruitment strategy for patients and the public • Provide training and support for	Jointly produced by CRF and BRC as appropriate to respective infrastructure award objectives (to be developed during the award). CRF – 1 'PPIE/P and early phase research' training session p.a. BRC:	• Increased number of patients and the public on research teams • Improved satisfaction of patients and the public with their roles • Positive feedback from researchers on the contributions of patient and public representatives	Short-term (1-2 Years) Nov 2024

SMART Objective	Actions	Deliverables	Measurable Outputs/ Outcomes	Timeframe
	patients and the public	Post study PPI&E/P internally with study teams and external with sponsors et al (as appropriate to individual studies and sponsors) BRC PPI&E/P in training medical students in their engagement with research as a core component of their basic training.		
Increase the quality of PPIE/P in BRC/ CRF research	• Develop and implement a PPIE/P quality assurance framework • Provide training and support for researchers in PPIE/P best practices	Jointly produced by BRC/ CRF as appropriate to respective infrastructure award objectives (to be developed during the award). CRF – 1 'PPIE/P and early phase research' workshop p.a. BRC – e.g., patients supporting training of medical students; patients actively engaged with sponsors in study feedback events	• Improved quality of PPIE/P in research studies • Increased satisfaction of patients and the public with their involvement in research studies • Improved feedback from researchers on the contributions of patient and public representatives	Medium-term (3-4 Years) Mar 2026
Monitor and evaluate the impact of PPIE/P on BRC/ CRF research	• Develop and implement strategies to improve monitoring and evaluation of impact of PPIE/P on research studies	BRC and CRF to produce annual reports on their PPIE/P impact on their research. CRF to appoint Research Fellow to undertake independent evaluation of CRF PPIE strategy and action plan	• Increased numbers of participant's engaged in PPIE/P activities • Improved patient and public health outcomes and experiences resulting from PPIE/P in research studies • Positive feedback from researchers on the impact	Long-term (5+ Years) Nov 2027

SMART Objective	Actions	Deliverables	Measurable Outputs/ Outcomes	Timeframe
			of PPIE/P on their research studies • Positive feedback from participants in studies	
Increase sustainability of PPIE/P in biomedical and experimental research	• Develop and implement a sustainability plan for PPIE/P • Secure funding and resources for PPIE/P activities	• PPIE/P is embedded at all levels across the BRC and CRF • Lessons learned from impact and similar assessments are built into future PPIE/P strategies and operational protocols • Additional funding from internal/external funders has been sought to invest in the development and delivery of research related PPIE/P	• Envisaged increased funding and resources for PPIE/P activities • Improved sustainability of PPIE/P in research studies • Positive feedback from researchers and patients and the public on the sustainability of PPIE/P	Long-term (5+ Years) Nov 2027

Annex 4: Commonly used abbreviations

Abbr.	**Full title**
AHSN	Academic Health Science Network
BH	Barts Health NHS Trust
BRC	Biomedical Research Centre
CCF	(NIHR) Central Commissioning Facility
CRF	Clinical Research Facility
CRO	Clinical Research Organisation
DHSC	Department of Health and Social Care
EDI	Equality, Diversity and Inclusion
JRMO	Joint Research Management Office
NIHR	National Institute of Health and Social Care Research
PPIE/P	Patient and Public Involvement, Engagement and Participation
QMUL	Queen Mary University of London
SMART	Specific, Measurable, Achievable, Relevant and Time-bound (objectives)