



*National Institute for
Health Research*

5-year Strategy for Patient and Public Involvement


1 April 2017 to 31 March 2022

Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust
and UCL Institute of Ophthalmology

Clinical Research Facility for Experimental Medicines at
Moorfields Eye Hospital NHS Foundation Trust

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Overview



This document outlines our joint Biomedical Research Centre and Clinical Research Facility five-year strategy for the involvement and engagement of patients and the public in research (PPIE), which has been informed by patients, the public and researchers across our Moorfields, UCL and NIHR partnerships and beyond.

This strategy will develop and be refined further as we build deeper relationships with patients, the public, researchers and clinicians; and as we establish new external networks, partnerships and collaborations. This will help to ensure that our strategy is informed through shared experiences, informed discussions and best practices to enable us to respond to changes in need.

Background (i)



The NIHR, often referred to as the research arm of the NHS, was established in 2006 with the goal of ‘improving the health and wealth of the nation’ through research. Funded by the UK government’s Department of Health, the NIHR supports significant infrastructure that underpins academic, health and social care research as well as industry collaborations nationally, driving world-leading research innovations. Patients and the public are central to the NIHR’s mission. As the ultimate beneficiaries of research advancements, as participants in research projects, but also as decision makers whose significant experience and insight can help to focus research and ensure improvements in NHS services with greater relevancy and acceptability to society.

To this end the NIHR funds [INVOLVE](#), the national coordinating centre for the involvement of the public in research; and the [James Lind Alliance](#), which brings together the public and clinicians to prioritise areas requiring research. The NIHR has its own strategy for patient and public involvement called ‘[Going the Extra Mile](#)’ and funds a number of involvement programmes including the [Patient Research Ambassador Initiative](#), the ‘[I am Research](#)’ Campaign, and the [People in Research](#) portal that connects researchers with members of the public who want to get actively involved in their work. The NIHR welcomes [public suggestions on future research](#) topics and involves the public in deciding how to award [NIHR research funding](#).

Background (ii)

As part of the NIHR, the research conducted by Moorfields Eye Hospital and UCL Institute of Ophthalmology prioritises areas where there is an unmet patient need and where our track record of achievement and expertise at an international level is outstanding. As a result, new treatment techniques and practices that improve patient health are being brought through to clinical and surgical practice as quickly as possible, thereby benefiting patients, as well as the NHS and the UK as a whole.

[NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology \(BRC\)](#)

After two consecutive five-year terms starting in 2007, our BRC was awarded a third NIHR award in 2017 for a further five years. Over this five-year term, we will leverage £19 million of NIHR infrastructure funding to support the translation of novel experimental medicines research from the UCL Institute of Ophthalmology into early phase clinical safety studies via Moorfields. [We are one of 20 national BRCs and the only one dedicated to vision.](#)

[NIHR Clinical research Facility for Experimental Medicine at Moorfields Eye Hospital NHS Foundation Trust \(CRF\)](#)

After a successful first five-year term starting in 2012, our CRF was awarded a second NIHR award in 2017 for a further five years. Over this five-year term, we will leverage £5.3 million of NIHR infrastructure funding to support early and late phase clinical research studies funded by charitable organisations, collaborative partnerships with industry and research sponsored by external agencies. [We are one of 23 national CRFs and the only one dedicated to vision.](#)

Background (iii)

Patient and Public Involvement and Engagement (PPIE) at the BRC and CRF

Our PPIE team advise, train and support researchers at Moorfields Eye Hospital and the UCL Institute of Ophthalmology to engage and inform public audiences about research. Our team also supports the move towards a culture of active patient and public involvement, where research is carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them.

Meaningful partnerships with the public can take place at any and all stages of the research process, including:

- identification and prioritisation of research questions
- research design and material development
- support of funding and ethics processes
- implementation and management of research
- data collection and analysis
- results dissemination


By bringing together the wider knowledge, skills and experiences of researchers, patients and those closest to them, we can:

- address the right questions in the right way
- improve the design of studies to make it easier to take part
- deliver those outcomes most relevant for society
- demystify research so it is more meaningful and understandable for all

Getting involved in research provides researchers and the public alike with an opportunity to meet new people, to learn from one another and develop new skills, knowledge and understanding.

Further information: INVOLVE (<http://www.invo.org.uk>) and NIHR (<https://www.nihr.ac.uk/patients-and-public>)

Strategy development

A horizontal bar composed of seven colored segments: green, dark green, orange, purple, red, dark purple, and blue.

This strategy builds on the success and learnings we have gained over the last decade. It has been informed through discussions with patients, the public (Public Contributors), researchers and clinicians, and it aligns with national strategies and developments in PPIE.

The following sections provide an overview of the input that has fed into the development of this strategy, our strategic aims and objectives and our steps towards achieving these.

Public Contributors (i)



Thank you to members of Thomas Pocklington Trust who have kindly taken part in informing and reviewing this strategy with us.

[Thomas Pocklington Trust](#) are committed to increasing awareness and understanding of the needs of people with sight loss and to developing and implementing services which meet their needs and improve lives.

Working with Thomas Pocklington Trust enabled us to engage with a broader range of perspectives on sight and vision loss, from people who:

- have a sight loss condition themselves
- have experience of accessing sight loss clinical and support services
- have been involved or participated in research in the past
- are a friend or family member of someone with sight loss
- provide support to sight and vision loss service users

On the next slide is a summary of our discussions with these Public Contributors listing what they felt was needed from research to support a mutually beneficial interaction between researchers and the public.

Public Contributors (ii)

- ...to be able to influence research focus beyond causes and cures and research that benefits specific single conditions; to help identify the questions and outcomes of research most relevant to them and that offer the broadest benefits for the most people
- ...to make opportunities to participate in research more readily available / increase people's confidence in taking part in research by supporting them with the knowledge of what they should know to ask
- ...to know what happens to/is learned from their data/measures/samples when they participate in research
- ...to increase public awareness and understanding of research (benefits to individuals and to society) through the broadest channels
- ...to manage people's expectations of research and make available accurate and reliable sources of information about the results of research that are available to the public and allow them to follow trends and developments in research of interest longer-term
- ...assurances that research is joining up at an international level; that we are not needlessly duplicating research and that we are maximising new innovations
- ...researchers to take greater responsibility for engaging and communicating with public audiences about research
- ...researchers to be able to communicate in more visually accessible formats as well as through the use of plain English at all stages of the research pathway
- ...greater awareness of the 'user-centred pathway' and recognition that the public do not necessarily access, interact or understand research in the same way/order as researchers and clinicians do
- ...to make researchers/clinicians more aware of the emotional burden of being diagnosed with a condition and the ways in which people with a condition interact and use organisations and services to support themselves and access information
- ...to see people inspired and supported to be involved/participate through case studies and peer-to-peer interactions; providing public contributors with appropriate training to get involved where it is necessary, but without losing their perspective as a non-researcher

Researchers and Clinicians



Thank you to the researchers and clinicians who we have been working with us and who have informed this strategy.

What researchers/clinicians feel is needed...

- ...to have meaning interactions with the public that truly inform and raise the quality of their research
- ...to develop a better understanding of what PPIE is
- ...support to plan for and implement PPIE in their research
- ...training in how they can implement PPIE with limited time and resources
- ...support with opportunities to involve and engage patients and the public

NIHR strategic objectives

As part of 'One NIHR' we have a role to play in supporting the NIHR PPIE Senior Leadership Team in the delivery of their five strategic objectives that build on '[Going the Extra Mile](#)'.

These are being addressed at all levels of NIHR infrastructure nationally:

- Define [standards](#) of what good PPIE looks like
- Understand and show **impact** of PPIE
- Test new **invention** in PPIE and share learnings
- Ensure patients, carers and the public have a **voice** in the NIHR
- **Feedback** to patients, carers and the public on the difference they have made

Strategic aims



From 2017 - 2022 the mission of our PPIE programme will be to:

“Involve patients and/or representatives from relevant public charitable bodies in every aspect of the work of our Centre”

Our aims are to:

1. Optimise the alignment of our research to the needs of patients and those at risk of eye disease
2. Increase active involvement of patients and/or representatives from relevant charitable bodies in the design, management and reporting of all new clinical trials and other studies involving patients
3. Break down barriers to broaden participation in biomedical research
4. Open access to research at the earliest moment of interaction with our hospital

Strategic objectives



To achieve our PPIE aims the following objectives will underpin our programme of work:

1. Drive internal culture change among those with a role in research by raising awareness of and evidencing the value of patient and public involvement in research as a core component of research design and methodology
2. Educate and break down perceived barriers with external audiences around what research is and how patients and the public can be involved
3. More tightly embed PPI within BRC-CRF governance and make it easier for researchers to include active PPI in the majority of studies through the collation of best practices and experiences from patients/carers, public and peers
4. For those who are eligible, we will make information on how to participate in research more accessible

The following sections provide an overview of how we currently intend to deliver our objectives.

Objective #1 Internal Culture Change

Among those with a role in research, we will continue to raise awareness of the value of patient and public involvement in research as a core component of research design and methodology

Activity	Short term (within year one)	Long term (up to 2022 and beyond)
PPI training for research staff	Pilot new BRC PPIE training programme with key CRF demographics (e.g. recruitment coordinators - focusing on the value of PPI to support recruitment and retention of participants in clinical trials)	Embed PPI training for all new CRF staff inductions; target new BRC Training programme at researchers who are NIHR funded/CRF supported; make available PPI training to all Moorfields/UCL Institute of Ophthalmology staff; evaluate PPIE training to address identified needs such as communicating with non-scientists
Case study development	Collate a series of PPI case studies demonstrating impact throughout and at key stages of the research pathway	Present PPI case studies (from researchers and patient ambassadors) at internal research inductions/meetings; encourage research teams to publish and present on their PPI activity; emphasise the role PPI has played in research wherever possible within research communications

Objective #2 External Awareness

Educate and break down perceived barriers with external audiences around what research is and how patients and the public can be involved

Activity	Short term (within year one)	Long term (up to 2022 and beyond)
Public Engagement Events	BRC-CRF to collaborate on key milestone events including World Sight Day, Rare Disease Day and International Clinical Trials Day	Ensure BRC-CRF collaboration at all future PE activities (e.g. BRC patient research days); expand our reach to engage new audiences including, children and young people, isolated and disadvantaged groups and diverse cultural and ethnic communities
Moorfields Information Hub and CRF reception	Establish a joint BRC-CRF presence within the Hub including information on research, how to get involved and how to participate; extend materials to CRF reception; promote activities of the Patient Research Ambassador programme	Maintain the Hub and CRF reception materials; include updates on major research studies and summaries of annual PPIEP reports supported by the BRC; actively promote activities of the Patient Research Ambassador programme
Website	Update existing web presence to reflect current strategies and include relevant research and involvement links	Establish a combined BRC-CRF website to reflect our integrated research approach and streamline and reduce duplication of information
Comms and social media	Increase dissemination of major research findings and case studies through all appropriate available channels across the BRC-CRF, Moorfields, UCL, NIHR partnerships as well as via external collaborators and partners (e.g. charities)	
Patient Research Ambassadors	Work with our Patient Research Ambassador(s) to identify opportunities to highlight their experience with research to other patient and public groups	

Objective #3 Embed and Support PPI

More tightly embed PPI within BRC-CRF governance and make it easier for researchers to include PPI in the majority of studies through the collation of best practices and experiences from patients/carers, public and peers

Activity	Short term (within year one)	Long term (up to 2022 and beyond)
PPI Portal	Redevelop the PPI pages of the BRC website into a resource portal for patients and researchers	Continue to collaborate with other NIHR PPI Teams and broader, to ensure the portal reflects latest best practices
PPI Team Support	PPI Team will continue to support PPI planning and application development; for active research studies through the CRF, ensure 6-monthly check-ins from the PPI Team to monitor and support with troubleshooting PPI challenges	Catalogue problems and solutions, including new tools, making these available via the PPI Hub and sharing with collaborators
Research Community	Raise awareness of the 'Research Community', our patient involvement database, among those with a role in research and with patients/carers online, via the Hub and CRF reception etc.	Work with clinic teams to make the Research Community more accessible and to expand the number of conditions represented within it; move the community online to make in more accessible
Patient/ Carer Sounding Board	Long term: work with experienced PPI contributors (in the first instance) to set up a Public Contributor Sounding Board for the BRC-CRF and its terms of reference. Core responsibilities could include – review and oversight of research and PPIE strategies; PPI support for any studies without its own PPI contributors; assessing and improving the patient experience within the CRF; mentoring others, particular by former study participants, to take on future PPI roles	

Objective #4 Enable Participation

For those who are eligible, we will make information on how to participate in research more accessible

Activity	Short term (within year one)	Long term (up to 2022 and beyond)
Moorfields Hub and CRF reception/ webpage	Include information on how participant enrolment for CRF studies works; include details of 'UK Clinical Trials Gateway' etc.	Ensure information relating to study enrolment remains up to date and reflects latest best practices and policies
Advertising	Advertise opportunities to participate in research studies online including social media and with relevant patient organisations	
Registries	Ensure all registry entries for CRF studies are up to date	

Impact and evaluation



- As part of annual reporting we identify and report on impact case studies. As part of this process, we review activities against our overarching PPIE strategy to assess if we are delivering to meet it. This informs our actions for the next 12 months
- Following all our PPIE activities, discussion summaries are shared with Contributors to ensure that they feel we have accurately captured their input; and we collect anecdotal feedback from contributors after our activities about how they felt about the experience
- We encourage and support researchers in the write up of PPIE activity for inclusion in their research publications
- We conduct semi-quantitative/qualitative evaluation of public research days

Impact and evaluation of PPIE is of growing focus nationally. As new national standards for PPIE and new techniques to evaluate their impact are developed, we will adopt these locally to allow us to contribute to the broader evidence base while working with our Public Contributors and researchers to adapt these for local use to aid us in accessing and further improving upon the effectiveness of our PPI programme.

Funding



Excluding staff salaries we build cases for spending on PPIE-related activity from our NIHR budgets.

1. We will continue to do this to enable us in:

- Holding research days and public engagement events that facilitate public and researcher relationship-building and knowledge sharing
- Running involvement activities so the public can continue to directly influence the way we work across every stage of the research pathway
- Offering relevant reimbursements that enable Public Contributors to get involved
- Conducting research / development of new approaches towards engaging and involving the public
- Delivering training in PPI to embed skills and create a culture change towards involving the public in every aspect of our work

2. We will also continue to support researchers and the public in seeking other funding routes to expand PPIE opportunities, including:

- Planning and budgeting for PPIE activities within research grants
- Seeking financial support for PPI from commercial partners of research, where appropriate
- Taking part in competitions and award schemes

3. Over the next years of our BRC/CRF, as we establish our Public Contributor Sounding Board and embed new measures of evaluation and impact into our PPIE work, we will collaborate with Public Contributors to develop new review and decision-making processes that govern the best use of our PPIE budgets.

Management and Governance (i)



1. PPIE is incorporated into a new BRC cross-cutting theme for 2017 to 2022:

Patient and Public Involvement/Engagement and Clinical Studies Development.

Theme Lead: Professor James Bainbridge

As one of our BRC themes, PPIE will be a set agenda item for all of our research management and strategy meetings. In addition to our PPIE strategy and annual reporting of PPIE to the NIHR, our PPIE programme now benefits from the same level of strategic leadership, evaluation and impact assessment as our other research themes. This will improve its effectiveness and reach across both Moorfields Eye Hospital and the UCL Institute of Ophthalmology.

Management and Governance (ii)

2. Team support (see next slide)

Day-to-day implementation and support for PPIE is through our BRC PPIE team (reporting directly into the BRC Manager) and via the CRF research and operational management team. This work is supported further up, not only by our BRC PPIE Theme Lead, but our BRC and CRF Directors.

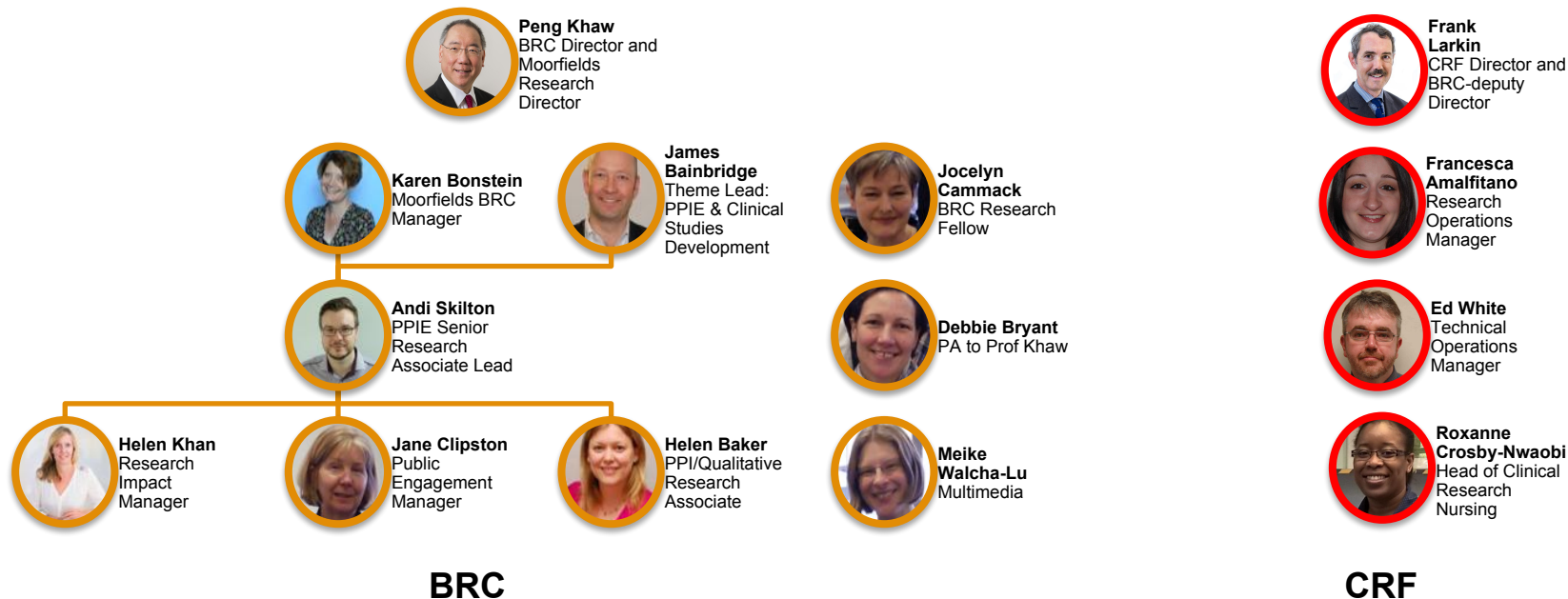
Our PPIE Team not only benefits from having professional PPIE, clinical and research experience within, but also includes patient and family members leading on implementation of various aspects of this strategy. The team is networked into a number of local and national PPIE networks including the NIHR BRC and CRF PPIE Leads Working Groups. This allows the team to retain a fresh approach to PPIE informed through shared learning, thinking and best practices.

Moorfields BRC & CRF



National Institute for
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PPIE Team and BRC/CRF oversight



Management and Governance (iii)

3. A new Public Contributor Sounding Board

Our new proposed sounding board will be a significant step in embedding patient and public voice into every aspect of our work. The sounding board will support with oversight and implementation of our PPIE strategy where they felt it appropriate to do so, including its annual review. There will also be a role for the group in providing PPIE input into active research where it hasn't be possible to previously establish Public Contributor involvement, support with implementing of PPIE training and co-production of relevant research, and initiatives that would improve the research participation experience.

We are proposing that the sounding board will:

- have an appointed patient/public Chair with a member of our PPIE team co-Chairing, in the first instance
- develop role descriptions and interview for members
- determine their own terms of reference and establish processes for a quorum (minimum number of members necessary to conduct the business) that will enable Public Contributors to take part when and as they can
- establish appropriate reimbursement procedures
- have members serve a minimum term but with an overlap to facilitate peer-to-peer training of new membership

Contact



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