



NIHR Moorfields Infrastructure (Biomedical Research Centre and Clinical Research Facility)

Patient and Public Involvement,
Engagement and Participation
Strategy 2022-2027

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Introduction

Joint statement from our leadership.



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(Co-Director NIHR Moorfields BRC and Director of Research at Moorfields Eye Hospital)



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(Co-Director NIHR Moorfields BRC and Director of UCL Institute of Ophthalmology)



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(Director NIHR Moorfields CRF)

The national and global impact on quality of life and cost of visual impairment and blindness is massive. As we age, every person is likely to be affected by an eye disorder at some stage of their life.

Our patients and staff are at the heart of everything we do. The ambitions we have can only be achieved with the integration of leading-edge science and research combined with outstanding healthcare specialists, all learning from the patients and public we meet across our sites.

This strategy consolidates our commitment to providing the opportunities, tools and environment for the involvement and engagement of patients and the public in our research across our National Institute of Health and Care Research (NIHR) Moorfields Biomedical Research Centre (BRC) and Clinical Research Facility (CRF).



Our mission is

“to change lives through leading-edge science and research by preserving sight and driving equity through innovation, particularly for those with the greatest need.”

Executive Summary

Patient and Public Involvement, Engagement and Participation (PPIEP) is central to our core ethos to maximise patient benefit. By working together, we make sure that patients, members of the public, carers and families are genuinely embedded in the development of our research, communications, governance, and strategy. We are committed to this approach because it ensures the benefits of vision research are returned to the NHS and the wider UK community.

Guided by the UK Standards for Public Involvement¹ and the Guidance for NIHR Award Holders², we have a detailed plan of work to enable us to deliver our four PPIEP strategic aims.

1 Setting research priorities for the future of vision research

2 Improving equality, diversity, and representation in PPIEP

3 Building capacity, training, and resources in PPIEP

4 Monitoring and measuring the impact of PPIEP

With this work we strive to innovate, learn, and share with an ever more diverse group of people, whilst developing bespoke approaches to PPIEP that research in sight loss demands. Our Involvement, Engagement and Communications teams have the experience, expertise and networks to ensure that PPIEP is at the centre of our research.

Overview

This document outlines our joint Biomedical Research Centre (BRC) and Clinical Research Facility (CRF) strategy for how we involve, engage and participate patients and the public in our research (PPIEP)

This strategy has been informed and developed with our patient partners, researchers and clinicians across Moorfields Eye Hospital and University College London (UCL) Institute of Ophthalmology (IoO).

Our overall strategic goals are as follows:

- 1 Make a major impact on common and rare blinding disorders including age-related-macular-degeneration, glaucoma and diabetic retinopathy, and those affecting young people that lead to life-long visual impairment to reduce large disparities in life opportunities.
- 2 Develop novel ways to detect and predict individuals who are at risk of losing vision and start preventative measures earlier. Develop innovative techniques for assessing eye health in home, community and hospital settings to streamline, speed delivery and availability of eyecare, particularly for chronic disease, through digital innovation.
- 3 Build on previous success using massive datasets including imaging, health records and genetics, and use artificial intelligence approaches to discover new information about what causes eye diseases and how to best prevent, minimise or treat them in individuals.
- 4 Continue to research and discover molecular, cellular and tissue functions in the eye including blood vessel, inflammatory and nerve processes. Disturbances in these systems underlie most causes of blindness and general diseases and further understanding will lead to better diagnosis and treatment of both.
- 5 Continue our previous successes in developing new and improved types of treatment by innovating with gene- and stem-cell therapy, antibodies, laser, and micro-devices, some of which regenerate ageing or diseased tissues. Some may take minutes to administer and are specifically designed to treat common eye conditions with a single treatment with benefit often lasting years.

Definitions

Involvement is where members of the public have an active role to play in the research, where contributors share decision making power with researchers and where they play the role of the critical friend, asking the difficult or 'obvious' questions that may not have been considered.

NIHR define public involvement in research as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them".

Engagement is when we share and communicate information about research and create opportunities for researchers and the public to hold two-way dialogues; to ask questions, discuss and debate research.

NIHR define public engagement as "where information and knowledge about research is provided and disseminated".

Participation is where a patient or member of the public has given informed consent to take part in the research study i.e., giving a blood sample or a tissue biopsy for research.

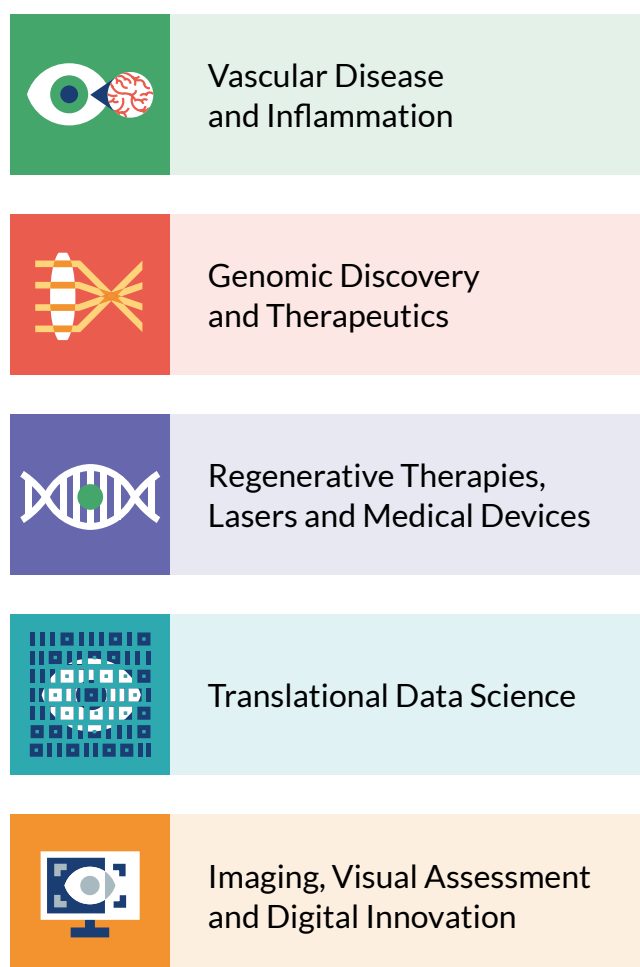
NIHR define participation as "where people take part in a research study such as being recruited to a clinical trial or other research study."



The NIHR provides infrastructure funding for the NIHR Moorfields Biomedical Research Centre (BRC) and the NIHR Moorfields Clinical Research Facility (CRF).

NIHR Moorfields BRC

The NIHR Moorfields Biomedical Research Centre (BRC) is a partnership between Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology. The BRC is dedicated to pioneering discovery and translating research into treatments and innovations that transform the lives of patients facing vision loss and blindness. Its research is divided into five themes:



NIHR Moorfields CRF

The NIHR Moorfields Clinical Research Facility (CRF) is the largest eye research facility in the world for early-phase clinical trials that aim to take laboratory discoveries into the eye clinic to benefit patients. The CRF contains 26 patient examination rooms with associated research and treatment units and is designed to test new methods of diagnosing common and rare eye diseases, as well as evaluate innovative treatments for them. The CRF is embedded within Moorfields Eye Hospital NHS Foundation Trust and is divided into five areas:

- Area 1 – Clinical assessment
- Area 2 – Functional assessment
- Area 3 – Structural assessment
- Area 4 – Treatment rooms
- Area 5 – Laboratories and tissue processing

Both the BRC and CRF have specific initiatives in place to create better outcomes in relation to improving patient and public involvement, engagement and participation, and these are reflected in this strategy.

Strategic Alignment

Our structure is complex. We work in both a hospital and an academic context, with our major funder being the NIHR. This complexity enriches us; it gives us opportunities for growth and learning.

There is a strong commitment to PPIEP from every institution we work with, and this page sets out how we align ourselves with their strategies. We first set out the key statements from Moorfields Eye Hospital, followed by University College London (UCL) and then show how our strategy mirrors NIHR's approach.

Moorfields Eye Hospital's Strategic Plan for 2022-2027³ sets out its approach as 'excellence, equity and kindness at the forefront of eye care'. Its ambition is to work together and 'collaborate with one another as individuals, in our teams, with our patients and our partners' to provide the best care for our patients now and in the future.

UCL, in its Strategic Plan 2022-2027⁴, recognises PPIEP as a critical enabler. To deliver its aims, it has recognised it needs an approach that builds 'meaningful partnerships between researchers, patients and the public in order to shape health research'.

We know from our work that including the perspectives of patients and members of the public in our research enables scientific discoveries and brings a culture of inclusion that allows different voices to be heard. This takes conscious effort to bring about and also reflects the foundation of our NIHR Moorfields Infrastructure (BRC and CRF) Equality, Diversity and Inclusion (EDI) strategy.

Purpose of the Strategy

Our Patient and Public Involvement and Engagement is central to our core ethos to maximise patient benefit.

Through shared learning, and working together, patients and the public play an essential role in the development and implementation of our research. Having an active role in our governance, strategy, research, and communications ensures our vision research provides maximum benefit to patients both locally and nationally.

We benefit from the wider insights and challenges that comes from the diversity of our patient and public advisors. Using the UK Standards for Public Involvement as our guide, we strive to innovate, learn from, and share with an ever more diverse group of people tailoring PPIEP to meet the demands of sight loss research.

PPIEP Strategic Aims

1 Setting research priorities for the future of vision research

2 Improving equality, diversity, and representation in PPIEP

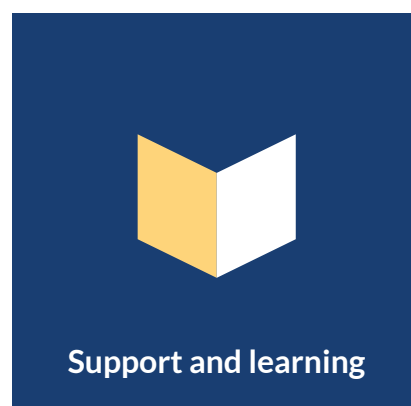
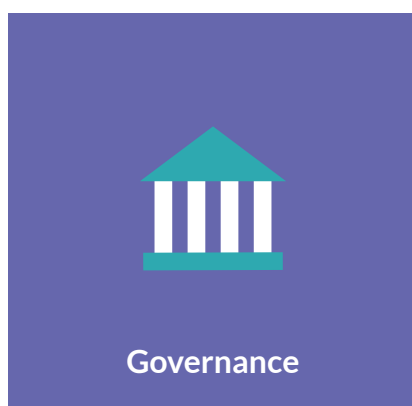
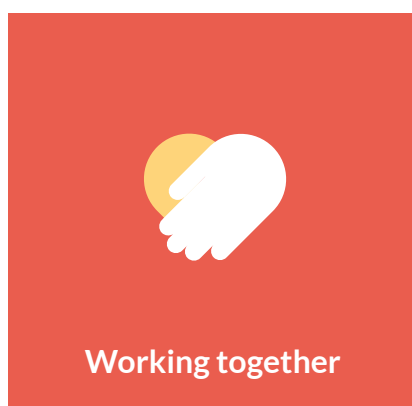
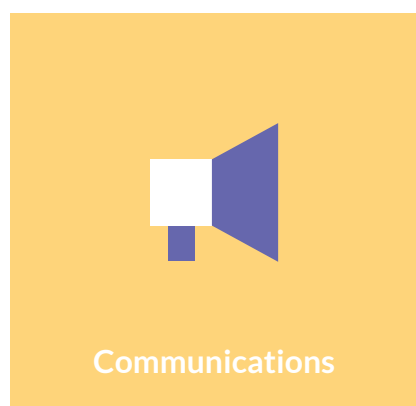
3 Building capacity, training, and resources in PPIEP

4 Monitoring and measuring the impact of PPIEP

Programmes of work

NIHR UK Standards for Public Involvement

The 15 PPIEP objectives and activities within our strategy reflect the six themes in the UK Standards for Public Involvement. The Standards are a comprehensive framework of what good public involvement looks like and are designed to support self-reflection and learning.³



Inclusive Opportunities

Aim: To be clear who our potential stakeholders are and where we can find and reach them.

We will involve and engage with our patients through our hospital sites, some of which are based in the most socially deprived areas in the UK. We will use local community outreach opportunities to identify, connect and bring research to a wider selection of members of the public and include currently under-represented groups in research.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
1. Collaborate in reviewing and updating the national James Lind Alliance-led Priority Setting Partnership for Sight Loss and Vision. Engaging a diverse community of stakeholders to input into the review.	Up to date patient priorities for sight loss and vision from a diverse group of patients.	Long term (5+ years)	BRC	BRC PPIE Lead
2. Use community hubs to recruit from diverse patient groups and underserved communities to input into studies that might impact them directly.	Increase in the diversity of PPIE contributors.	Long term (5+ years)	CRF	CRF Manager
3. Targeted recruitment in PPIEP to increase diversity using our ROAM (Research Opportunities at Moorfields) online portal.	Increase in the diversity of study participants and PPIEP contributors.	Medium term (3-4 years)	BRC & CRF	BRC PPIE Lead CRF Manager ROAM Team

Working Together

Aim: To effectively partner with public contributors in all areas of our research.

We will work collaboratively with our internal and external partners to ensure effective PPIE is embedded in CRF research and our BRC themes.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
4. Develop and publish a PPIEP strategy to embed, measure, evaluate and improve the impact of PPIEP across Moorfields Eye Hospital and UCL Institute of Ophthalmology.	- The PPIEP strategy will be published on our website and disseminated to stakeholders. - We will organise promotional workshops, co-delivered by members of the public, for researchers to be made aware of and embed PPIEP principles from our strategy.	Short term (6-12 months)	BRC & CRF	BRC PPIE Lead CRF Manager
5. To ensure PPIEP is embedded across all our themes. Offering advice on grant applications, research design, conduct and dissemination.	- Increase in the number of research studies with PPIEP embedded in them. - Increase in PPIEP activities within each research study.	Medium term (3-4 years)	BRC	BRC PPIE Lead

Support and Learning

Aim: Offer support and training that meets the needs of our patient and public contributors and staff.

We will support the development of skills and provide training to enable staff, researchers and public contributors to deliver effective PPIE in our research.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
6. Become a recognised centre for delivering high quality PPIEP for early translational ophthalmic research, by training researchers, engaging diverse groups, enabling sustainable PPIEP activities and improved dissemination practices.	• Training opportunities and resources developed and publicised. • Increased uptake and use of training opportunities and resources. • Increased outreach and engagement around training opportunities and resources.	Long term (5+ years)	BRC	BRC PPIE Lead
7. Develop our PPIEP training and resources to offer improved training.	• Increased uptake and use of training opportunities and resources by researchers staff and contributors.	Medium term (3-4 years)	BRC & CRF	BRC PPIE Lead CRF Manager

Governance

Aim: To have comprehensive processes in place to show accountability within our system.

We will continue to actively involve patients and members of the public in the governance and decision making of our BRC and CRF. We will ensure our patient and public contributors are empowered to participate in our strategic development.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
8. Consolidate PPIEP strategic approaches to increase public involvement in Moorfields governance structures and the visibility of the NIHR brand.	Improved recruitment for our lay membership enabling it to be more representative of our patient population. To be measured against MEH patient population.	Long term (5+ years)	BRC & CRF	BRC PPIE Lead CRF Manager
9. Increase opportunities and methods for lay members to input into governance committees, management groups and theme management.	- Increased number of lay members inputting into: - Governance committee - Management groups including themes - Study steering groups.	Long term (5+ years)	BRC	BRC PPIE Lead
10. Review progress and delivery over the 5-year period to identify and manage any risk to intended outcome.	Regular check point meetings to discuss outcomes and potential risks. Risks been identified and managed accordingly to limit impact on expected outcomes.	Long term (5+ years)	BRC & CRF	BRC PPIE Lead CRF Manager

Communications

Aim: To have the right communication mechanisms to reach the right people at the right time.

We will communicate our research in an inclusive, transparent and flexible format that is accessible for a visually impaired audience.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
11. Increase the visibility of NIHR Moorfields CRF research opportunities through promotional and dissemination events such as patient days and science festivals.	Number of events and Communication activities. Social Media metrics around these events. To do this it will require consolidation of public engagement activities through the Moorfields Trust Public Engagement Teams to ensure a coordinated approach.	Medium term (3-4 years)	CRF	CRF Manager
12. To deliver a highly active programme of patient and public engagement and involvement to identify priorities for research, design appropriate studies and share our findings effectively for greatest benefit.	Widen our links and collaborations with eye charities, community, and patient groups particularly in underrepresented groups. Increase internal and external engagement events to wider more diverse audiences	Long term (5+ years)	BRC & CRF	BRC PPIE Lead CRF Manager

Impact

Aim: To show how we will capture and measure the difference made.

We will review and assess the impact of PPIE in our research, share our findings and apply our learnings for continuous improvement.

Objective	Success Criteria (Key Performance Indicators)	Time scale	Benefits BRC/CRF	Delivered by
13. PPIEP: Implement and evaluate methods to monitor the effectiveness and measure the impact of our PPIEP activities.	- Measuring baseline PPIEP activities and reporting: - Percentage increase of workforce undertaking skills training on PPIEP - Staff feedback to assess competency in promoting, measuring and advocating for PPIEP in research - Metrics on projects and diversity within projects.	Medium term (3-4 years)	CRF	CRF Manager
14. Build an impact assessment tool to monitor the effectiveness of PPIEP activities and undertake research to improve methodologies (quantitative and qualitative) that measures PPIEP impact/outputs.	We will measure the percentage of our projects/ numbers of researchers who use the assessment tools/resources in their PPIEP activities.	Medium term (3-4 years)	BRC & CRF	BRC PPIE Lead CRF Manager
15. Gain annual feedback from PPIEP contributors and researchers on BRC PPIEP activities.	Review and implement change based on the annual feedback received.	Long term (5+ years)	BRC	BRC PPIE Lead

Monitoring, reviewing, and reporting

We map our PPIEP activities against the UK Standards for Public Involvement , gather feedback from participants and researchers (including annual PPIEP survey), and collect metrics to monitor our performance. To ensure our activities provide value for money and have a positive impact, we will develop, trial and evaluate an impact assessment tool to measure the effectiveness of PPIEP activities and undertake research to improve both quantitative and qualitative methodologies.



Resources

Our PPIEP activities are supported by an expert team with skills in mixed-methods research, public group facilitation and engagement. We continue to build knowledge, skills, and confidence in PPIEP in research amongst people and patients, staff and PPIEP practitioners, embedded within the BRC and CRF training programmes. Programmes include:

- **Supporting Public Contributors** – giving training and support for patient and public contributors either face-to-face or online.
- **Mandatory online training** in PPIEP for all BRC and CRF core staff.
- **PPIEP training** for anyone undertaking research at Moorfields or IoO.
- Delivering **bespoke interactive training sessions** for BRC themes and the CRF, as needed working with public contributors to co-design and deliver objectives.
- **Supporting staff** by providing bespoke support for PPIEP projects or problems. Support PPIEP professional development, including advice on grant ideas and preparing funding applications.
- **Providing teaching in PPIEP** to early career researchers through bespoke sessions for MSc courses such as “MSc Research in Ophthalmology.”



Partners and Collaborators

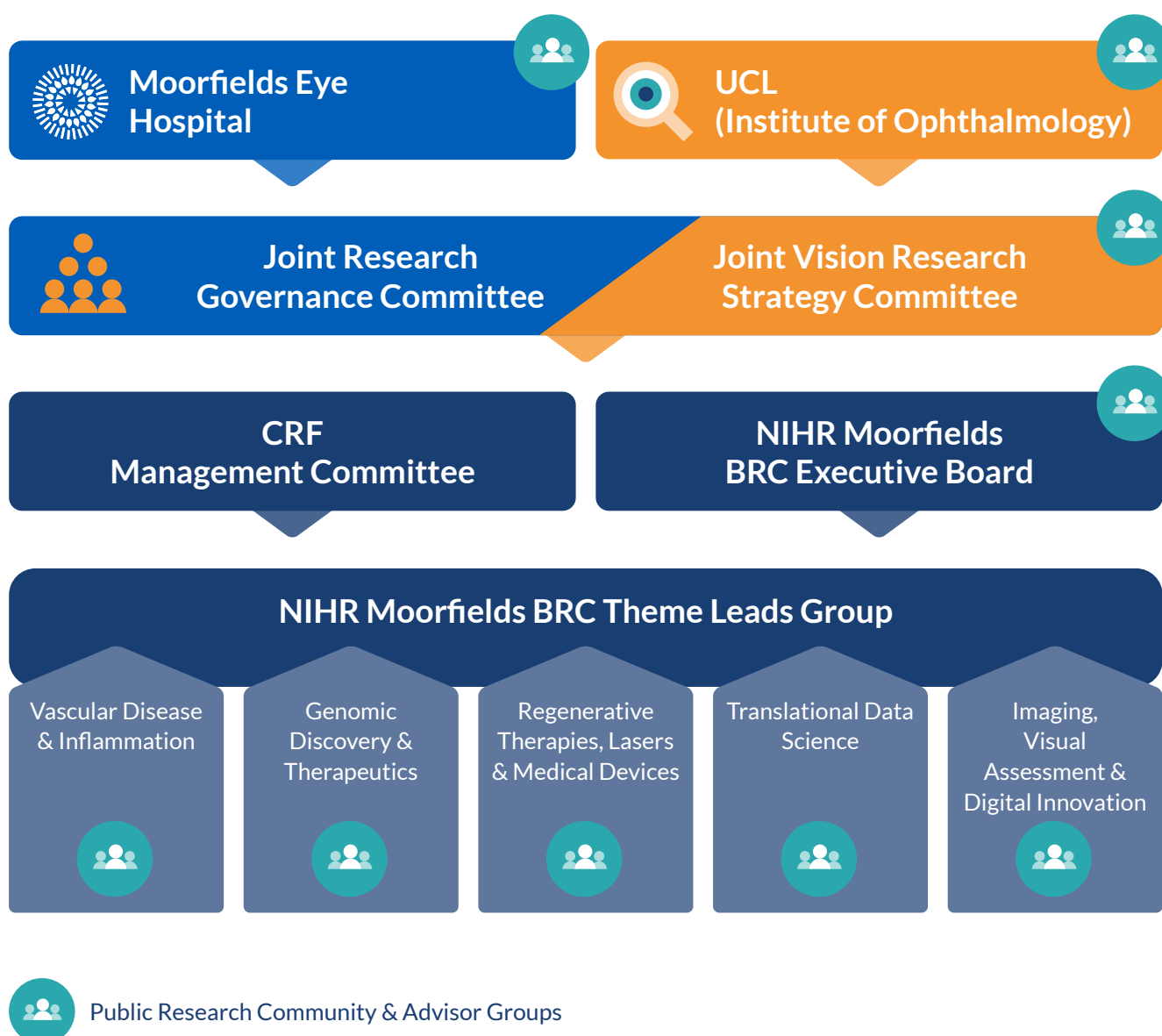
We actively collaborate with local, national, and international partners:

- **People and patients:** We ensure patients, and the public are actively involved in shaping research, working with us to steer, inform, and challenge our work. This includes working with Generation-R Young Persons Advisory Group: eyeYPAG.
- **Patient support charities:** We work closely with national vision charities such as Esme's Umbrella (Charles-Bonnet-Syndrome), Glaucoma UK and Stargardt's Connected.
- **Engagement partnerships:** Local community engagement activities including Bloomsbury Festival and Queen Mary's Science Festival. National engagement activities such as collaborations with Sense about Science.
- **Researchers, academics and practitioners:** External to our BRC and CRF with a shared interest in maximising patient benefit through the inclusion of PPIEP in research. Examples include:
 - **BRC Qualitative-Research-Network:** Share expertise and methodological developments.
 - **Our Future Health:** Support PPIEP for this national collaborative program in Polygenic Risk Scores.
 - **INSIGHT:** support the delivery of the PPIE strategy for the Health Data Research UK (HDR UK) Hub for Eye Health.
- **PPIEP Practitioners:** We continue to build relationships, share learning, and collaborate on delivery with colleagues nationwide. These collaborations include:
 - **UCL Partners PPIE Committee:** PPIE leads and patient representation across UCL BRCs to support joint-initiatives and collaborations.
 - **BRC PPIE Leads:** Communicate best-practice to support national NIHR efforts in improving PPIEP.



Management and Governance

The governance of our NIHR infrastructure and organisational links are outlined in the organogram below. Our long-standing investment and commitment to PPIEP is central to our core ethos to maximise patient benefit and is embedded in our governance.



Leadership for our NIHR PPIEP strategy is provided by the PPIE Lead. In addition, the PPIE Lead is responsible for the coordination of this strategy's implementation plan and delivery of objectives.

The BRC Executive Board is the ultimate decision-making authority on the performance management and strategic direction of the BRC. This group meets quarterly and the membership comprises of BRC Co-Directors, Moorfields Chief Executive Officer, Moorfields Chief Financial Officer, Director Research & Development, Clinical Director Research and Development, PPIEP Lead, Director UCL IoO, Joint Director of Education, Moorfields CRF Director, and BRC Manager.

The CRF Management Committee includes CRF Director, Deputy Director R&D, Head of Research Administration, and Head of Clinical Research Operations.

The BRC central office will provide secretariat support including reporting against objectives, key performance indicators and financial monitoring. Progress against the PPIEP objectives will be reported to the NIHR as part of the NIHR infrastructure annual report submission.



Our PPIEP Advisor Groups

Our patient and public advisors play an active role in our research management, the regulation and decision making around our structure and future plans, with specific emphasis in ensuring they promote public interest and provide maximum patient benefit.

Individuals from our PPIEP Advisor Groups will be invited to attend governance and management meetings for specific matters.

Each member is assigned to one of the groups listed below. They support us in the following with specific emphasis on their group area:

- Helping identify research priorities by working in partnership with researchers and collaborators.
- Reviewing documents to ensure that they are clear and meaningful.
- Ensuring the validity of research from public perspective.
- Discussing with us what our research means for patients, the public, and the organising of related healthcare services.
- Helping us with the design and implementation of our strategies.
- Ensuring communications for lay audiences are written in plain English.
- Work on specific research projects that have large implications for our BRC and CRF.

BRC Advisors – specific focus on the delivery of BRC objectives and theme related PPIEP.

CRF Advisors - specific focus on trial delivery including improving participation and early phase trial design.

EDI Advisors - specific focus on helping the BRC/CRF and researchers widen Equality Diversity and Inclusion (EDI) across all aspects of our research design and delivery.

Data Advisors - specific focus on patient data collection, data management and usage.

Young Persons Advisory Group (eyeYPAG) – specific focus on two-way learning where we offer education around vision and research and the group offers advice and involvement in research aimed at children and young people.

Acronym list

BRC	Biomedical Research Centre
CRF	Clinical Research Facility
EDI	Equality Diversity and Inclusion
eyeYPAG	Eye Young Persons Advisory Group
HDR-UK	Health Data Research UK
IoO	Institute of Ophthalmology
NHS	National Health Service
NIHR	National Institute for Health and Care Research
PPIEP	Patient and Public Involvement, Engagement and Participation
ROAM	Research Opportunities at Moorfields
UCL	University College London

References

1. UK Standards for Public Involvement:
<https://sites.google.com/nihr.ac.uk/pi-standards/home>
2. NIHR: Developing PPIE a strategy: Guidance for NIHR Award Holders. Internal NIHR document for BRC & CRF award holders.
3. Strategy 2022 web version-compressed. pdf (moorfields.nhs.uk)
4. UCL Strategic Plan 2022-27 | UCL Strategic Plan 2022-27 - UCL – University College London

Useful Links

Moorfields Biomedical Research Centre:
<https://www.moorfieldsbrc.nihr.ac.uk>

Moorfields Clinical Research Facility:
<https://www.moorfields.nhs.uk/nihr-moorfields-clinical-research-facility>

Moorfields Eye Hospital:
<https://www.moorfields.nhs.uk>

UCL, Institute of Ophthalmology:
<https://www.ucl.ac.uk/ioo>

NIHR:
<https://www.nihr.ac.uk>



For more information:

Visit our patient and public involvement
and engagement page or email
MoorfieldsBRC@nihr.ac.uk