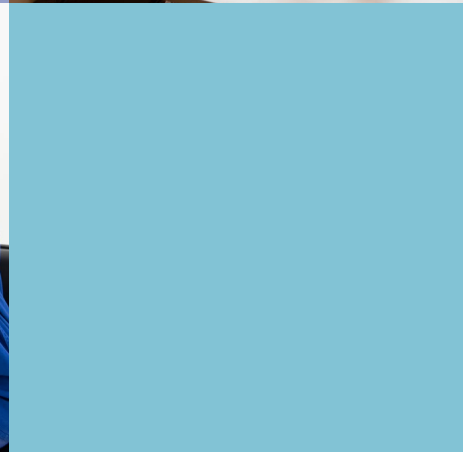
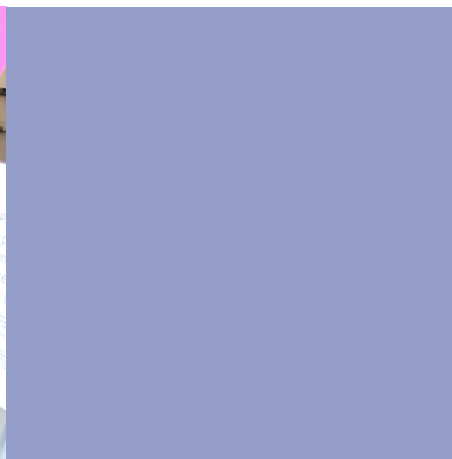


Strategy for involving people in health research 2022-2027



Researchers and public contributors attend a “Diversity in research - creative solutions” workshop.
June 2022, Old Fire Station, Oxford.



Section 1 Introduction

- What is the [NIHR Oxford Biomedical Research Centre](#)
- What this strategy is about and why it matters
- The ways people get involved in health research
- Explanation of some words used in the strategy

Section 2 The NIHR Oxford BRC patient and public involvement and engagement (PPIE) strategy

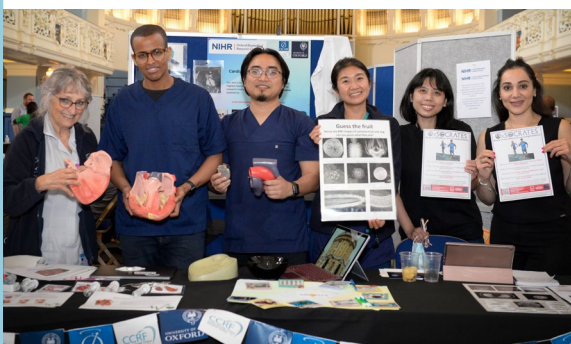
- Vision
- **Priority 1** People from all communities are supported to be involved, especially under-represented communities who are not usually involved
- **Priority 2** Researchers and staff undertaking research are given guidance and support to deliver PPIE
- **Priority 3** The value of health research and involvement is communicated effectively
- **Priority 4** PPIE knowledge and capacity is increased through work with local, regional and national organisations

Section 3 Co-production of the strategy

- How the strategy was developed
- Making it happen
- Responsibilities and resources

What is the Oxford Biomedical Research Centre?

- The NIHR Oxford BRC is a collaboration between the University of Oxford and Oxford University Hospitals NHS Foundation Trust to fund health and social care research.
- England's 20 **Biomedical Research Centres** are funded by the National Institute for Health and Care Research (NIHR), which has a **ten year plan** for public involvement. The NIHR mission is to have: "The public as partners in everything we do to deliver high quality research that improves the health, wellbeing and wealth of the nation."
- The Department of Health & Social Care publication, **Saving and improving lives: the future of UK clinical research delivery** echoes this commitment to "patient-centred research", research which is open to everyone.



Oxford BRC researchers at an Open Day for members of the public, 2022-2024.

What this strategy is about and why it matters

Health research improves people's health, well-being and lives.

To make sure that research is relevant and effective, we need the help of patients, carers and members of the public.

This strategy outlines how the Oxford BRC involves people from many different backgrounds and communities in research and how we plan to do this better in the future.

This strategy is informed by **the NIHR UK Standards for Public Involvement** and the NIHR's improvement plan which is informed by the voices of nearly 200 staff and members of the public and identifies the priorities for PPIE: **NIHR, Next steps for partnership working with patients and the public: Engagement report, 24 September 2021**



Patient and public involvement contributors participate in a “Diversity in research networking and learning” event March 2022, Blavatnik School of Government, Oxford.

Ways people get involved with research

There are three ways to get involved in research:

- Come to a talk or an event where researchers talk about their research e.g. an online talk about treatments for COVID-19 (in the research world, this type of activity is called **public engagement**)
- Help researchers design their studies e.g. research studies into blood disorders (this is called **patient and public involvement and engagement (PPI or PPIE)** in research)
- Take part in a research study, that is already designed, related to your condition e.g. if you have diabetes, you may be able to take part in a study looking at new treatments (this is called **participation** in research)

Some of the ways you can get involved are described in the films.

(please click on each one to watch)

Explanation of some words used in the strategy

Some of the words used in the strategy are explained below:

- Patient - a person who is or has been under NHS healthcare (or other provider) for a condition related to their involvement in health research
- Public – any member of the public, including those involved with public health research, e.g. vaccine development
- Carer – a family member or friend who has an unpaid caring role for a patient (as described above)
- Research themes – relate to the BRC areas of research, e.g. vaccines, musculoskeletal conditions, cancer. Here is information about the [**Oxford BRC Research Themes**](#)
- Under-represented (sometimes also called under-served) – people who are not usually involved and/or are more vulnerable to health conditions

Other words explained ([**NIHR Equality, Diversity and Inclusion strategy**](#)):

- Diversity - Being reflective of the wider community. Having a diverse community, with people from a broad range of backgrounds represented in all areas and at all levels
- Equality – Ensuring that everyone is given equal access to resources and opportunities to utilise their skills and talents
- Equity – Trying to understand and give people what they need to achieve their potential; promoting notions of fairness, justice, entitlements, and rights
- Inclusion – An approach where groups or individuals with different backgrounds are welcomed, culturally and socially accepted, and treated equally. Engaging with each person as an individual. A sense of belonging that is respectful of people for who they are

The Oxford Biomedical Research Centre PPIE Strategy

Oxford BRC is strongly committed to ensuring people's voices are heard and inform research.

This strategy has a vision and four priorities. A detailed yearly plan outlines how the priorities will be delivered. The Plan for Year 1 is [here](#) (link to be provided). Examples of the types of things that will be in the plan are outlined below each priority.

Vision

Oxford BRC's vision for patient and public involvement and engagement (PPIE) is that:

“Patients, their families and carers, and the public from all communities are involved as valued partners in research to improve the health and well-being of all society.”



Patient and public contributors support researchers with reaching people from under-represented communities, June 2022, Old Fire Station, Oxford.

Priority 1

People from all communities are supported to be involved, especially under-represented communities who are not usually involved

We will

- Increase the involvement of under-represented people and communities who are not usually involved
- Provide training, induction, support and development opportunities to new and existing PPIE contributors
- Ensure that treating people equally, valuing diversity and including everyone underpins PPIE

Examples of actions in the plan to deliver priority 1:

- Working with the **Diversity in Research Group** increase involvement from new community groups each year
- Deliver a training programme for PPIE contributors at different levels of experience, adapting the training for people who may face barriers to attend
- Ensure that each of Oxford's PPIE groups involve people from under-represented communities relevant to the area of research



Members of the public learn about health research at the Oxford and Oxford Health Biomedical Research Centres' Open Day 2022-2024.

Priority 2

Researchers and staff* undertaking research are given guidance and support to deliver PPIE

We will

- Working with PPIE leads in each research theme, we will ensure that each theme has a PPIE plan
- Provide direction and support so that research themes report PPIE activities and how it has a positive impact on their research
- Offer PPIE training sessions for researchers and staff
- Develop and maintain resources for researchers

Examples of actions in the plan to deliver priority 2:

- Each research theme will develop a plan to include details of: The research theme PPIE group; compensation and feedback to PPIE contributors; increased involvement of people who are not usually involved; improved reporting, impact and materials; and PPIE resources
- Work with our PPIE researchers to develop, pilot and evaluate frameworks for reporting and impact
- Provide Introduction to PPIE training to researchers and other staff (including BRC Research Interns)*



Ethnicity Inclusion in Health Research training, March 2024, Oxford.

*Researchers and staff include: University of Oxford researchers and PPIE coordinators, OUH clinical research staff, including Nursing, Midwifery, Allied Health Professionals (NMAHP)

Priority 3

The value of health research and involvement is communicated effectively

We will

- Communicate health research in a way that is understandable and encourages people to get involved in whichever way works for them
- Encourage PPIE through the clear communication of the positive impact of involvement in research
- Develop guidance for researchers on communicating their research

Examples of actions in the plan to deliver priority 3:

- Health research materials and activities are reviewed by PPIE contributors
- Co-produce guidance for researchers on communicating research to the public
- Review the website each year, using the findings from the [PPIE contributor website review](#)



Oxford researchers talk about developments in health research, March 2022.

Priority 4

PPIE knowledge and capacity is increased through work with local, regional and national organisations

We will

- Build PPIE effectiveness through working with local, regional and national partners, such as Oxford University Hospitals NHS Foundation Trust, University of Oxford, Oxford Brookes University and NIHR, charitable, community and patient organisations
- Further develop joint projects with Oxford Health and other BRCs
- Learn from and support academic research into PPIE

Examples of actions in the plan to deliver priority 4:

- Produce PPIE best practice guidance for researchers in collaboration with the Oxford PPIE Staff Group
- Work with other BRCs to develop INCLUDE framework training for researchers e.g. ethnicity inclusion, socio-economic inclusion
- Collaborate with Oxford Health BRC and a local voluntary organisation on the Oxford University Science Together programme

Key Partners



How the strategy was developed

The Oxford BRC PPIE Strategy was co-produced with PPIE contributors and researchers and is underpinned by the **UK Standards for Public Involvement**. A PPIE Advisory Group member, Sue Duncombe, chaired the strategy development team meetings. Alan Chant, the patient representative on the BRC Steering Committee, and Diversity in Research Group member, Magadalen Wind-Mozley were also involved, along with a clinical academic and PPIE staff.

The first draft was shaped by a comprehensive review and feedback from new PPIE contributors. New PPIE contributors from communities not usually involved (e.g. minority ethnic and LGBT+ communities, and young adults), contributed a total of 200 hours to develop the strategy. They reviewed materials and other activities and made recommendations on how research is communicated so people from all communities, especially those currently under-represented, see the value of getting involved and know how to do so. A short film about their work can be viewed [here](#).

We then asked the public, patients, carers, charities, academic and health organisations, and researchers for their views on the draft strategy. Nearly 90 people gave feedback on the strategy and improvements were made, resulting in the final strategy.

The review and consultation reports are on the [Oxford BRC website](#).



New public contributors helping to develop the strategy.

Making it happen

The Strategy was approved by the NIHR Oxford BRC Steering Committee in May 2023. The PPIEP team and Steering Committee Patient Representative reports annually on progress to the Steering Committee. An update on the Strategy progress is provided quarterly to the PPIE Advisory Group which provides critical insight from a public contributor perspective. PPIE leads in the Themes provide a PPIE profile every 2 year which tracks progress in embedding PPIE across the Themes and activity is captured in the annual report.

Responsibilities and resources

The NIHR Oxford BRC Patient and Public Involvement, Engagement and Participation (PPIEP) team is led by the Public and Community Involvement, Participation and Involvement Lead (PCIEP lead) with support from PPIE Training and Inclusion Lead and the Head of Operations. The responsibility for delivering the Strategy sits with the NIHR Oxford BRC PCIEP lead, the Head of Operations and the Director.

Authors and contributors

- Alan Chant, Sue Duncombe and Magdalen Wind-Mozley – members of the **Patient and Public Involvement and Engagement (PPIE) Advisory Group**
- Rachel Taylor, Roy Probert, Polly Kerr, Oxford BRC and University of Oxford patient and public involvement and engagement and communications staff
- John Spiliotis, Oxford BRC clinical academic

The strategy was reviewed in 2024 with support from existing members of the PPIE Advisory Group: Carra Anni, Nargis Begum, Corina Cheeks, Peter Deussen, Alan Dobson, Sue Duncombe, Jenny Gould, Richard Mandunya and Magdalen Wind-Mozley.

Other contributors

- With thanks to: Peter McQuitty, PPI Advisory Group member, who was instrumental in initiating this project
- Mahveen Alam, Henri Barrett, Arooj Butt, Corina Cheeks, Shamin Durrani, Will Fletcher Bird, Shamsideen Yusuf, Angeli Vaid (patient and public contributors) - for providing fresh eyes and perspectives on the Oxford BRC's work
- Nearly 90 members of the public and researchers who gave feedback on, and improved, the draft strategy
- Any comments on this strategy or for information on how to get involved with health research, please contact: **GetInvolvedOBRC@ouh.nhs.uk**

Strategy

This strategy has been informed by the:

- **NIHR UK Standards for Public Involvement**
- **NIHR Equality, Diversity and Inclusion strategy**
- **Going the Extra Mile**
- **Best research for Best Health** improving the nation's health and wellbeing through public involvement in research
- **NIHR Include project** supporting inclusion of under-served groups in clinical research
- **NIHR Race Equality Framework** a practitioner's guide for public involvement in research
- NIHR **Next steps for partnership working with patients and the public: Engagement report | NIHR**
- The Oxford BRC Patient and Public Involvement Review 2021:
oxfordbrc.nihr.ac.uk/wp-content/uploads/2021/11/Oxford-BRC-PPIE-Review.pdf
- Oxford BRC strategy, vision and aims
- Oxford BRC PPIE review and strategy consultation

For advice and support about getting involved, please contact:

Rachel Taylor - rachel.taylor@ouh.nhs.uk

Public and Community Involvement, Engagement and Participation Lead,
Oxford Biomedical Research Centre.

Angeli Vaid - angeli.vaid@ouh.nhs.uk

PPIE Training and Inclusion Manager, Oxford Biomedical Research Centre.

Website: **<https://oxfordbrc.nihr.ac.uk/ppi/>**

Email: **GetInvolvedOBRC@ouh.nhs.uk**

Strategy co-produced: 2021-22.

This strategy is reviewed every 2 years. It was last reviewed in November 2024.

Next review is November 2026.