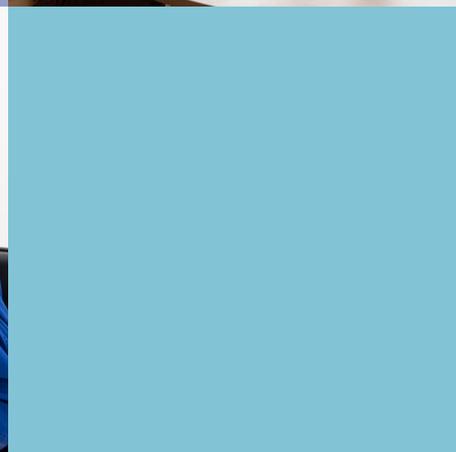
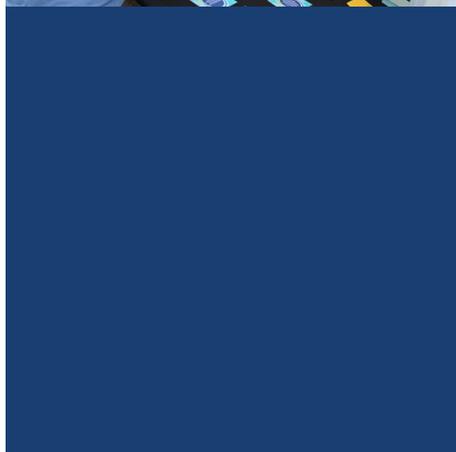
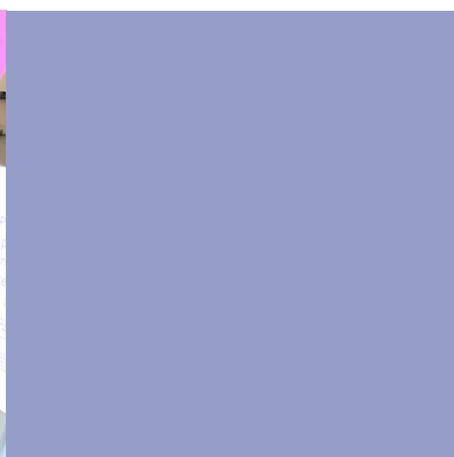


Strategy for involving people in health research 2022-2027



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



Section 1 Introduction

1. What is the Oxford Biomedical Research Centre (Oxford BRC)
2. What this strategy is about and why it matters
3. Ways people get involved in health research
4. Explanation of some words used in the strategy

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

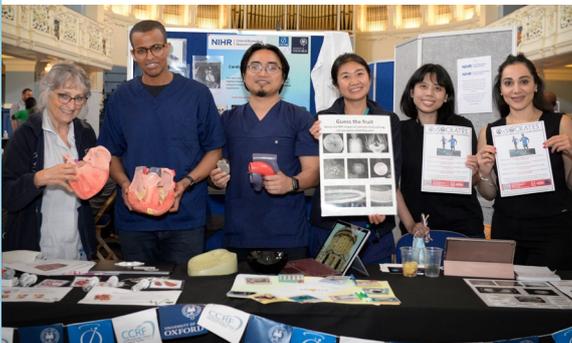
5. Vision
6. **Priority 1** People from all communities are supported to be involved, especially under-represented communities who are not usually involved
7. **Priority 2** Researchers and staff undertaking research are given guidance and support to deliver PPIE
8. **Priority 3** The value of health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

Section 3 Co-production of the strategy

10. How the strategy was developed
11. Authors and contributors

What is the Oxford Biomedical Research Centre?

- The 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 BRCs are funded by the 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.”
- A recent 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 open to everyone.”



Images bottom left and right: Oxford BRC researchers at an Open Day for members of the public, 5 July 2022, Oxford Town Hall.

What this strategy is about and why it matters

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.

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.



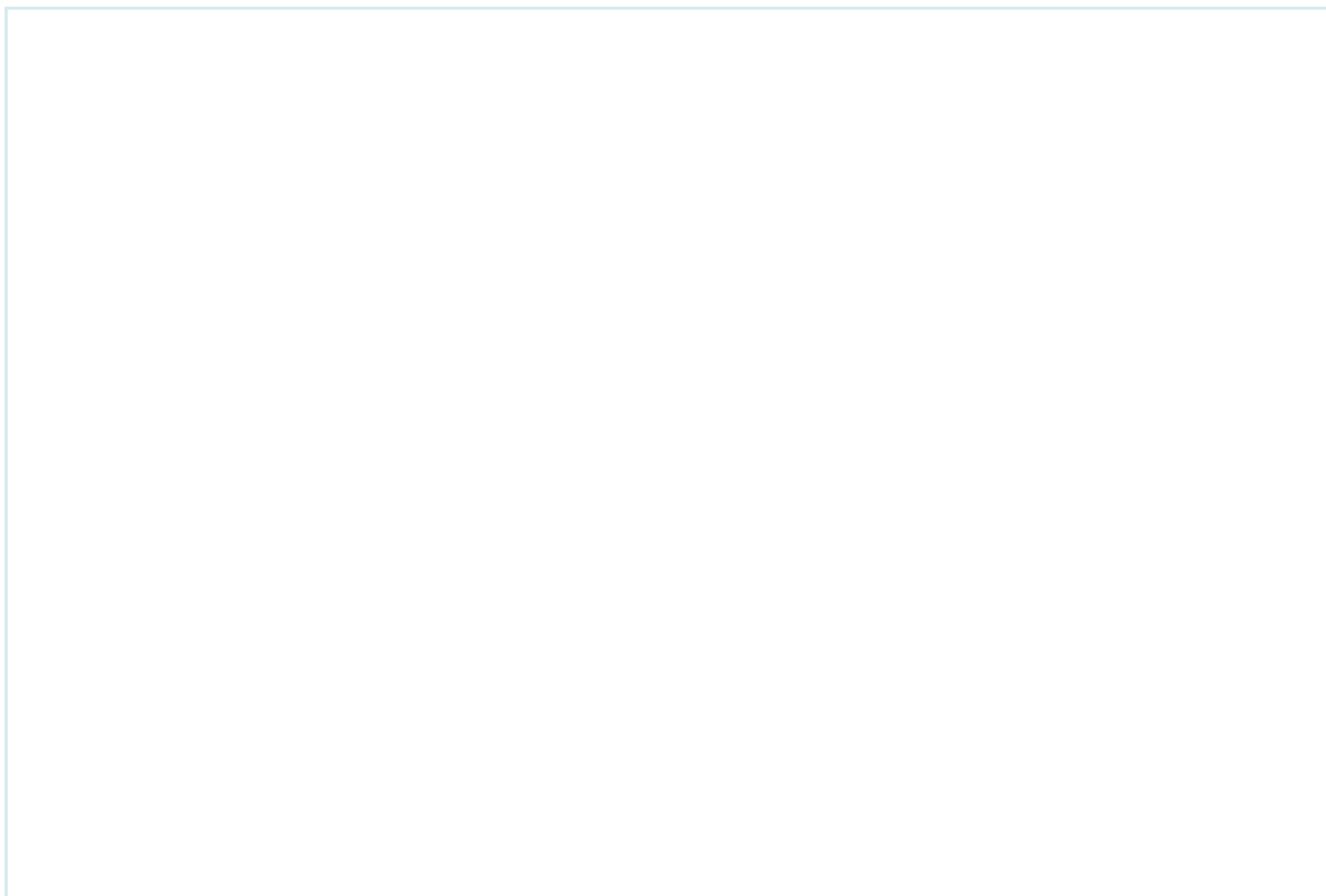
Patient and public involvement contributors participate in a “Diversity in research networking and learning” event March 2022, Blavatnik School of Government, Oxford.

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 (PPI)** 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).
- Themes relate to the BRC areas of research, e.g. stroke, 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.

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 plan is being developed to outline how the priorities will be delivered. 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 five new community groups each year
- Deliver a quarterly 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 at least four under-represented communities
- Develop a clear and meaningful definition of what "under-represented" means for Oxford BRC



Members of the public learn about health research at the Oxford and Oxford Health Biomedical Research Centres' Open Day 5 July 2022.

Priority 2

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

We will

- Provide direction and support so that each research theme has a PPIE plan (Oxford BRC research themes explore specific conditions or areas of research)
- Provide direction and support so that research themes report PPIE activities and how it has a positive impact on their research
- Embed PPIE training into the BRC researcher induction and offer a programme of PPIE researcher training
- 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 the financial and staff resource for PPIE
- Work with our PPIE researchers to develop, pilot and evaluate clear frameworks for reporting and impact
- Deliver a quarterly training programme for researchers at different levels of experience



Equality, diversity and inclusion training for Oxford BRC senior leaders, June 2022, Big Data Institute, Oxford.

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
- An Easy Read version of key public facing documents
- A clear guidance document for researchers is co-produced
- Implement the findings from the 2021 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 a PPIE handbook with Oxford University Hospitals NHS Foundation Trust to support involvement across organisations.
- Develop the existing PPIE groups so that they provide PPIE input on treatment and care, in addition to health research.
- Each year, undertake at least three collaborative projects with Oxford Health BRC, other BRCs and NIHR organisations.

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.

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 patient and public involvement and engagement and communications staff.
- John Spiliotis, Oxford BRC clinical academic.

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 Knowlton, 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**



Patient and Public Involvement and Engagement Advisory Group members.