

Patient and Public Involvement Welcome Guide



Contents

1. Welcome to the Oxford Biomedical Research Centre
2. What is patient and public involvement?
Why involve patients and public in medical research?
3. What is the Oxford Biomedical Research Centre?
How does PPI work in the BRC?
4. How do the public and patients contribute to research?
Do I need specific skills?
5. Meet some public contributors working at the Oxford BRC
6. Meet some public contributors working at the Oxford BRC
How do I get involved?
7. Are there any other options if I can't join a group?
What support will I get?
8. Will I get my expenses paid?
What's the time commitment?
9. What happens if I can't continue?
We look forward to hearing from you, so please do get in touch!

Welcome to the Oxford Biomedical Research Centre

Thank you for your interest in getting involved in research at the NIHR Oxford Biomedical Research Centre (BRC).

We are delighted to welcome you if you have just joined us. If you are thinking about getting involved as a patient and public contributor, we hope this information encourages you to take the next step and join us. We want people of all ages, abilities, sexual orientation, culture, religion and genders to be involved.

Working with patients and the public, people like you, helps to guide and shape our research. Your opinions and experience are extremely valuable to researchers and make a difference to how effective the research is.

We used the term Patient and Public Involvement (PPI) contributor to describe the people who work with researchers in this way.

We hope you will come and join us and that you find being a PPI contributor an interesting and rewarding experience.



Professor Helen McShane,
Director of the Oxford BRC



Rachel Taylor,
Lead for Public and Community Involvement,
Engagement and Participation at the Oxford BRC

What is patient and public involvement?

Our research is carried out in partnership **with** or **by** the public. Patient and public involvement (PPI) means that patients and the public work as part of the research team and share their experience and skills to improve research.

It's different from taking part in a medical research study or clinical trial.

However, many people who have taken part in a trial decide to go on and get involved with research afterwards.

Why involve patients and public in medical research?

The National Institute of Health and Care Research (NIHR) is the research part of the NHS and funded by the UK government. The NIHR says it is essential that patients and the public are involved in health research that is done for their benefit.

This is because patients and the public often have first-hand experiences of living with and treating the diseases or conditions being researched. They are best placed to explain to researchers what it's like for people in their situation.

When researchers apply for money to do research, the NIHR and other funders such as charities, want to know that patients and the public have been included in developing the research idea. They also want to know how patients and public will be actively involved in helping to make sure the research benefits patients. This means researchers need to find people from a wide range of backgrounds and experiences, who are willing to work with them on their projects.

So, this is where people like you come in as patient and public and contributors or partners in research. You can really make a difference by becoming a PPI contributor in our research.

What is the Oxford Biomedical Research Centre?

The NIHR Oxford (BRC) is based at Oxford University Hospitals (OUH) NHS Foundation Trust and works in partnership with the University of Oxford. The BRC is funded by the UK government and has been awarded £86.6 million to do health research from 2022 to 2027. There are about 600 research projects running at any one time.

Our researchers work on projects across the UK, to 'translate' or turn their scientific discoveries into new or better treatments for NHS patients. This might include better ways of diagnosing disease or developing new medical technologies. This work often involves running clinical trials and the Oxford BRC has one of the largest numbers of clinical trials running in the UK.

The OBRC also has some of the most respected, researchers in the world who recognise they need to work closely with patients and public from all backgrounds. Many researchers are medical doctors, nurses and allied medical professionals, such as dieticians, physiotherapist, occupational therapists, orthoptists, who also see patients in clinic.

How does PPI work in the BRC?

Our research is divided into 15 research themes shown in this wheel diagram. The best place to find out more about these themes is the BRC website, which has articles, videos and case studies showing the work they are currently doing and how it makes a difference to people's health. Each of the 15 research themes has a member of staff who supports people to take part in research - a PPI coordinator. Most research themes also have a group of public and patient contributors who work with researchers.



How do the public and patients contribute to research?

Some of the ways PPI contributors work with BRC researchers are:

- Giving a talk to researchers at a training session on personal experiences of living with a health condition so they understand how it affects people
- Joining a patient and public advisory group in one of the research themes to regularly meet researchers during the study and help them make decisions about sharing the research
- Writing and commenting on patient information and consent forms for people taking part in medical research or trials to make them easier to understand
- Helping researchers write about their research in a clear and understandable way to get people to participate in clinical trials
- Taking part in a discussion group about the research topic to help decide what research needs to be carried out
- Helping to ensure that the way the study is carried out is acceptable to participants by looking at how researchers will do the research
- Supporting other contributors who are new to PPI by sharing your experiences

Do I need specific skills?

People often ask, “Do I need special skills or a science qualification?”

The answer is, “No! You don’t need any special skills or qualifications.”

You don’t need to have knowledge about research or medicine either.

What is important is that you are willing to share your own life experience, for example, as someone with a health condition or illness who has received treatment, or perhaps as a carer for someone with a health condition.

It’s also important to be able to listen to other people’s views and to take part in the work on offer.

Meet some public contributors working at the Oxford BRC

Please meet some of the public contributors working with us from our Patient and Public Involvement and Advisory Group (PPIAG) and the Diversity in Research Group. They explain what motivated them to get involved in PPI work.

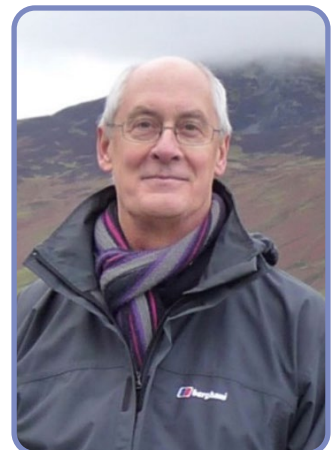


“My interest in research started when my husband was diagnosed with and later died of prostate cancer. I’ve been involved in a range of cancer research projects. It’s been rewarding to see researchers take patient views into account. Ultimately, researchers, patients and the public all want the same thing - research that can translate into benefits for patients and make a difference to their lives.”

Sue Duncombe, **PPIAG member**

“I am the patient representative on Oxford BRC Steering Committee and a member of the PPI Advisory Group. My interest in research started 10 years ago following my diagnosis of myeloma, a type of blood cancer. Then, I became a PPI representative in organisations including, Cancer Research UK, Wellcome Trust, Oxford Oncology Clinical Trials Office and the National Institute for Clinical Excellence. I have contributed to all aspects of PPI work. I have found that one small step into PPI leads to doing more, as it is very rewarding and important to add the patient voice to decision-making in health research.”

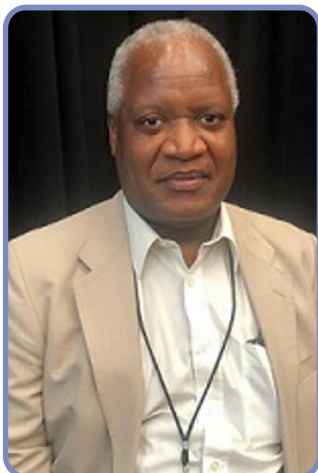
Alan Chant, **PPIAG member**



“I had a heart transplant when I was 11 years old, receiving outstanding pre and post-transplant NHS care. I am a commercial lawyer and have recently become aware of PPI projects. My parents and in-laws are of Pakistani origin, and I have often translated for them in medical settings. I see the barriers that people from ethnic minorities, especially the older generation, face as they are often not aware of health research taking place. I am passionate about using my experiences to help others, making participation in health research less taboo, better advertised, and more approachable and inclusive.”

Arooj Butt, **Diversity in Research Group member**

Meet some public contributors working at the Oxford BRC



“I joined the Diversity in Research Group because I have a passion for better health service delivery in the UK and internationally. It is therefore imperative for me to contribute to this goal for the common good as a service user. My many years of experience in public participation include being involved in health improvement campaigns within the social housing sector, Clinical Commissioning Groups, NHS England and NHS health trusts. I have participated in the International Learning Collaborative, as well as the GetReal Focus Group under the auspices of International Alliance of Patient Organizations.”

Richard Mandunya, **Diversity in Research Group member**

“Whilst taking part in an Ebola vaccine trial, I saw a poster regarding patient and public involvement with the Oxford Vaccine Group and I volunteered. Over the last few years, I have contributed to assorted trials; from grant applications to letters thanking volunteers for their participation; from feedback on photos, to texts for social media adverts. I find the work absolutely fascinating, and at times, inspirational. With the Covid-19 pandemic and scientific research at the forefront of many people’s minds, this is a critically important time to involve patients and the public at every stage.”

Magdalen Wind-Mozley, **Oxford Vaccine Group member**



How do I get involved?

We would be delighted if you chose to become involved as a patient and public contributor with us!

The Diversity in Research Group and Patient and Public Involvement Advisory Group are both looking for new members to join them as their work increases.

We want to make it as easy as possible for you to find out more.

If you are interested and would like to speak to one of us in the Patient and Public Involvement team, please contact us. We can answer your questions and tell you more about how you can get involved. Email us at:

GetinvolvedOBRC@ouh.nhs.uk

Are there any other options if I can't join a group?

There are lots of other opportunities to get involved in health research and you can find them online by signing up to two newsletters.

1. At Oxford BRC the Patient and Public Involvement Bulletin is a weekly email which shows health research opportunities in Oxford and the Thames Valley area. You can sign up to receive the email at:
2. The NIHR has a People in Research website which shows opportunities in health research in the UK. You can sign up to receive emails from them at:

What support will I get?

If you need support to take part, please tell us and we can ensure that we provide you with what you need. We will also provide:

- The chance to meet other PPI contributors with an interest in the same health condition or issues
- Invitations to events and talks on all areas of medical research
- Opportunities to take part in free training
- Help on where to get advice on payments whilst claiming benefits

Will I get my expenses paid?

Researchers should always reimburse you for any out-of-pocket expenses such as travel to meetings or care costs that you have from getting involved.

Wherever possible researchers will also pay you for your time. Members of the Diversity in Research Group and the Oxford PPI Advisory Group are paid £25 per hour plus expenses.

You are responsible for paying any tax or National Insurance on money you receive for your involvement. We know that payments can affect state benefits, but we can help you get advice on what to do in this situation.

You don't have to accept any payment you are offered, and you can still take part.

There is more information about payments on the NIHR website:

What's the time commitment?

When you join a group or a project, the staff member will explain the commitment needed in terms of your time. It often includes taking part in meetings in person or online, but the length of time you stay varies according to what is needed.

What happens if I can't continue?

All PPI work is voluntary, and you can leave the PPI work you are doing at any time.

You can ask to be taken off email and mailing lists at any time.

Researchers value your work, so they ask you to give as much notice as possible if you intend to leave.

If you want to come back, then you can contact the PPI coordinator or lead to let them know.

We look forward to hearing from you, so please do get in touch!

Acknowledgements

Thank you to patient contributors in the University of Oxford and Oxford Biomedical Research Centre for creating this Guide. Thank you to colleagues Polly Kerr, PPI Manager, Nuffield Department of Primary Care Health Sciences and the Life Saving Vaccine theme PPIE team for sharing their welcome packs.

Photo Credit: Professor Helen McShane, Oxford Mail