**PPI Template 6: Terms of Reference for PPI group**

**Diversity in Research Group**

**Terms of Reference to September 2023**

This template has been developed by PPI leads from the Oxford PPI Staff Group[[1]](#footnote-1). It is being piloted with researchers[[2]](#footnote-2).

Researchers and PPI leads are invited to adapt for their use. Any changes to the original document are those of the users and not necessarily those of the Oxford PPI leads group. Original versions of Researcher PPI guidance and templates are available on the Oxford BRC website or from one of the [PPI staff leads](https://www.medsci.ox.ac.uk/research/patient-and-public-involvement/section-5-ppi-resources-for-researchers/ppi-leads-and-coordinators).

The [National Institute for Health and Care Research Oxford Biomedical Research Centre](https://oxfordhealthbrc.nihr.ac.uk/)

(OBRC) is a partnership between the University of Oxford and Oxford University Hospitals NHS Foundation Trust to fund medical research.

The [National Institute for Health and Care Research Oxford Health Biomedical Research Centre](https://oxfordhealthbrc.nihr.ac.uk/) (OHBRC) is a partnership between Oxford Health NHS Foundation Trust and the University of Oxford. It aims to bring the best science to brain health.

The Diversity in Research Group is a joint Patient and Public Involvement and Engagement (PPIE) group for both BRC’s, established in May 2021.

**1. Purpose of Diversity in Research Group**

* To bring together diverse voices and experiences to influence PPIE in research at the Oxford and Oxford Health BRCs
* To advise researchers and clinicians undertaking research projects on issues related to diversity and inclusion with the aim of improving the quality and effectiveness of research.
* To increase the involvement of non-traditionally engaged communities in health research.

**3. Membership and co-chairs**

* Up to 15 patient, carer and public members (over the age of 16) from diverse backgrounds.
* Up to 5 staff members - to include researchers, BRC leaders, mental health staff and PPI staff.
* Other staff and stakeholders will be invited to attend meetings or projects as relevant.
* The group will have a Chair, who will be supported by the Patient and Public Involvement managers, Rachel Taylor and Cora Reilly-McGeown (starts 13 November 2023).

**4. Time Commitment**

* Membership will be reviewed in November 2023.
* The group has 6 meetings a year, online and in person (with ad-hoc additional meetings).
* Online meetings will last no longer than 1.5 hours, whereas in person meetings will last no longer than 4 hours.
* Events, such as workshops or networking events, organised by the group will last not more than 6 hours of a working day.
* Members are expected to attend, or send apologies, in advance of all meetings. We request members to attend annually at least 4 out of 6 meetings. Any difficulties in attending meetings please discuss with Rachel or Cora.

**2. Role of group members**

Members of the group include patients, carers, lay public and staff who have an interest in research and lived experience. We work closely to make the BRC’s research as good as it can be for the patients and be designed to benefit the patients’ bests interests.

Specifically, the role includes:

* Provide a unique perspective based on personal, cultural and professional experience.
* Consider the perspective of potential research study participants, PPI contributors and potential beneficiaries of research, particularly those of under-served communities.
* Actively participate in the group’s work.
* Actively participate in events that bring together group members and researchers.
* Attend meetings arriving no later than 5 minutes after the meeting start time.
* Contribute to meetings.
* Participate in the review process for the group every 2 years.
* Have a genuine interest in the initiatives and outcomes of the Oxford and Oxford Health BRC PPIE programme.
* Respond to requests for information (e.g. attendance at events) in the required timeframe.
* Raise any concerns with PPI leads promptly and constructively.

All members will agree to follow the Group’s Principles (see point 7) when engaging with, or on behalf of, the group.

**5. Oxford and OH BRCs responsibilities**

* The PPI leads will organise meetings and activities, giving at least 1 month’s notice.
* Make payments for time and expenses as soon as possible.
* Support the group to operate in line with the Group’s Principles.
* Following each Group meeting, action points will be circulated, and progress reported at future meetings.
* The group will use email to organise meeting dates, communicate between meetings, and to share items and papers related to the work of the group. If required and requested, printed copies of papers can be provided.
* Raise any concerns with members, and respond to any raised, promptly and constructively.
* Provide expenses and receipts within 2 months of the activity (see below).

**6. Payment and expenses (for patient, carer and public members)**

* We follow the OBRC/OHBRC Payment and Expenses Policy (Appendix 1).
* We reimburse non-staff members for any travel and/or carer-related expenses that you might incur in fulfilling your role (receipts are required).
* We discuss these with you in advance of the first meeting that you attend, together with the process for making a claim.
* In addition, we offer reimbursement for your time at the rate of £25 per hour per online meeting: it is your choice whether to accept this or not.
* Expenses with receipts must be provided within 2 months of the activity.
* Please note that if you are receiving state benefits, a pension, pension credits, tax credits or are liable for income tax and National Insurance, receiving any form of payment may affect you. See more information on the [NIHR website](https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372).

**7. Principles and Guidelines for Meetings**

The group adheres to the Seven Principles of Public Life (also known as the Nolan Principles) summarised below and available in full [here.](https://www.gov.uk/government/publications/the-7-principles-of-public-life/the-7-principles-of-public-life--2)  The group also adheres to the “Guidance for meetings with patient and public contributors” (Appendix 2) that were developed by the group and other PPI contributors.

**8. Raising issues**

Very occasionally, difficult situations arise for contributors and staff when working together. If this should happen, guidance (Appendix 3) is provided to ensure that everyone is supported.

**9. Privacy statement**

OBRC, O-BRC and the University of Oxford will collect member’s personal data with their permission (name, address, bank account details, emails, NI). This data is stored in a password protected file securely and looked after in accordance with GDPR. By signing these ToR you are indicating your agreement to this. Please see the OUH Privacy statement for the group (Appendix 4). Also please see: The [OHBRC privacy notice](https://www.oxfordhealth.nhs.uk/privacy/) and the [University of Oxford Privacy Policy](https://www.ox.ac.uk/privacy-policy).

**10. Confidentiality**

Content of discussions and any information shared in the meetings should be viewed as confidential unless specifically expressed otherwise.

**11. Conflict of interest**

A conflict of interest could be working for, or having involvement in activities, organisations or funders related to the research topic being discussed or being involved as a participant in a research trial directly related to the research being discussed. If unsure, Group Members are encouraged to speak to Rachel and/ or Cora.

**12. Sharing contact details**

We would like to have permission to share your email with other members of the group and staff involved with the group so that we can communicate easily amongst ourselves. By signing these ToR you are indicating your agreement to this. However, if you are not happy for your email address to be shared, please let Rachel Taylor or Cora Reilly-McGeown know and we will ensure your email is not shared.

**13. Definitions**

* Patient and Public Involvement is when people are actively involved in research projects and research organisations. It means research that is carried out with or by patients, carers and members of the public.
* Engagement is where information and knowledge about research is provided and disseminated to the public, i.e. science festivals, open days, media coverage.
* Under-served – ([NIHR Include](https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#:~:text=The%20work%20of%20the%20NIHR,would%20expect%20from%20population%20estimates)):
  + Lower inclusion in research than one would expect from population estimates
  + High healthcare burden that is not matched by the volume of research designed for the group.
  + Important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors.

**14. Glossary**

We avoid the use of ‘jargon’, and always spell out terms and names before using acronyms. Any acronyms that have been used within this document are also spelt out in full below:

NIHR National Institute for Health Research

OBRC NIHR Oxford Biomedical Research Centre

OHBRC NIHR Oxford Health Biomedical Research Centre

PPI Patient and Public Involvement

PPIE Patient and Public Involvement and Engagement

**15. Review of Terms of Reference (ToR)**

These ToR were developed at a meeting on 4 July 2022 and revised subsequently. They were drafted by Rachel Taylor and commented on by members of the group. These Terms of Reference will be reviewed every 12 months.

***Signature:*** *Each member of the Diversity in Research Group is required to sign up to the Terms of Reference and Principles*

***Date:***

## **Appendix 1 – OBRC/OHBRC Payment and Expenses Policy**

Currently being reviewed. While this is pending, please refer to the OHBRC Payment Policy as currently used: [OH-BRC-CRF-PPI-Payment-Policy-for-Researchers-Sept-2020.pdf (nihr.ac.uk)](http://oxfordhealthbrc.nihr.ac.uk/wp-content/uploads/2020/10/OH-BRC-CRF-PPI-Payment-Policy-for-Researchers-Sept-2020.pdf)

**Appendix 2: Guidance for meetings with PPI contributors**

*This guidance has been developed by Patient and Public Involvement (PPI) leads and PPI contributors.*

* It’s okay to ask questions

Every question is a good question – if one person is asking it, they need to know the answer and probably others in the meeting do too.

* Confidentiality/ privacy

We help people to share openly in the meeting by not talking about other people’s personal information outside of the meeting. We are aware of the space we are joining the meeting from. If there are other people in the space we are using, who are not part of the meeting, we try to use headphones to maintain confidentiality, and be aware of the information we are sharing when we speak.

* It’s okay to leave the meeting if you need

We can leave the meeting for personal reasons or answer urgent calls but stay focused on the meeting otherwise.

* Being respectful

We can challenge each other’s ideas in a friendly and supportive way. We don’t judge each other for our differences or ideas.

* We are all part of a team

Everyone needs to feel equally valued and has a valuable contribution.

* Contributing to meetings

Contributing during online meetings can be more difficult as we can’t gauge body language so easily. It is particularly important to ensure that everyone has a chance to speak. Use the ‘chat’ and ‘raise your hand’ tools or unmute to let the people chairing the meeting know you would like to speak. We all support the facilitator to include everyone.

* Plain speaking

We try to avoid acronyms or jargon. We ask for clarification if needed and explain further where necessary.

* Camera and sound

We try to keep cameras on during the meeting (if we feel comfortable and unless there are confidentiality or connectivity issues) to help us connect better with each other in the virtual world. We mute our sound when we are not talking or having a conversation.

## **Appendix 3: Raising a concern or difficult issue - guidance for PPI contributors and staff**

*This guidance has been developed by Patient and Public Involvement (PPI) leads and PPI contributors.*

Occasionally, difficult situations arise for contributors and staff when working together. If this should happen, this guidance is to ensure that you are supported.

Occasionally, difficult issues can arise in PPI work. If this should happen, it is important to support everyone involved, and resolve issues as soon as possible. We also want to ensure we learn from such occasions, to improve how we do things.

**Concerns or difficult situations when working with staff – guidance for contributors**

Occasionally, difficult situations arise for contributors when working with PPI leads and researchers. If this should happen, this guidance is to ensure that you are supported.

The types of things that might happen are:

* You do not have enough information about the project to make an informed choice about your involvement, or the involvement offer changes after you have agreed to something.
* You are given a task to complete but with a short deadline.
* You are given the opportunity to take part during a meeting but do not feel you have been supported to be involved.
* You are not encouraged by the meeting Chair to make a contribution.
* You have not been asked about, or provided with, adaptations or reasonable adjustments (for example large print documents) to support your involvement.
* It has not been explained what payment/expenses to expect, or you have not been paid as expected.
* A member of staff or another PPI contributor does not listen respectfully to your view.
* A meeting is cancelled at short notice.
* A staff member does not respond to emails or give you the information you need to take part in a project.

If you have any issues like the above, or something else which makes you uncomfortable, please raise it with any staff member you are working with that you feel comfortable with. This can be by email or phone, or if you would feel more comfortable, you could first contact Rachel Taylor (see details at end of this document).

If you have a concern that cannot be resolved by the PPI lead (rachel.taylor@ouh.nhs.uk), then you can contact [Jennifer.Anderson@ouh.nhs.uk](mailto:Jennifer.Anderson@ouh.nhs.uk) (Head of BRC Operations (OBRC).

**Concerns or difficult situations when working with PPI contributors – guidance for staff**

Occasionally there is a concern or difficult issue when working in partnership with PPI contributors e.g.

* Carer costs, travel or accommodation expenses are higher than the policy. (See Oxford BRC payment policy).
* An activity is not completed to a satisfactory standard and / or it seems that the PPI contributor has not spent the appropriate amount of time on the activity
* Regular late arrival or not contributing to meetings.
* Group dynamics that you feel uncomfortable about.
* There is something else you are concerned about and would like advice.

Please follow this guidance:

* Remember to maintain friendly and open communication throughout.
* Ask how the contributor is and how they are finding their PPI activities – do they have any concerns?
* Revisit with the contributor the initial request to ensure that there is clarity on what is being asked.
* If appropriate, provide a deadline for the completed work and if explain that if the next deadline is missed, there will be no extensions.
* Explain that for payment to be made, the work needs to be completed to a satisfactory standard **or** that appropriate time and/or effort has been spent.
* Ask the contributor if they are able to do it and if they need any support to complete it (e.g. give the information verbally rather than in written format).
* If unsatisfactory work is repeated another time or other changes are not made ask the contributor if they would rather not be asked to do this type of activity.

## **Appendix 4 – OUH Privacy Statement**

**Privacy Notice**

# Oxford Biomedical Research Centre (Oxford BRC) Patient and Public Involvement and Engagement (PPIE) Group and Diversity in Research Group

# Application for a role or membership to the group.

## **Data protection**

Oxford BRC is part of Oxford University Hospitals NHS Foundation Trust.

In the course of completing an application or membership form you have provided information about yourself (‘personal data’). We (Oxford University Hospitals NHS Foundation Trust) are the ‘data controller’ for this information, which means we decide how to use it and are responsible for looking after it in accordance with the General Data Protection Regulation and associated data protection legislation.

## **What is the purpose of this document?**

We use your data to assess your application and/ or to register you as a member of the Oxford BRC PPI Group.

This notice applies to anyone that registers and contributes to patient and public involvement activities with Oxford BRC.

## **How we use your data**

We need to process your data to register you as a member of the Oxford BRC PPIE group in order to meet our legitimate interests in recruiting public members to be involved in PPIE activities.

We will only use your data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another related reason and that reason is compatible with the original purpose. If we need to use your data for an unrelated purpose, we will seek your consent to use it for that new purpose.

## **Who will have access to your data**

Access to your data within Oxford University Hospitals NHS Foundation Trust will be provided to those who need to view it as part of their work in carrying out the purposes described above.

## **Where we store your data**

We store data manually or electronically and take reasonable steps to ensure that your personal data is treated securely.

Unfortunately, the transmission of information via the internet is not completely secure. Although we will do our best to protect your personal data, we cannot guarantee the security of data transmitted to the website and any transmission is at your own risk.

## **Security**

Your data will be held securely in accordance with Oxford University Hospitals NHS Foundation Trust policies and procedures. Further information is available on Oxford University Hospitals NHS Foundation Trust privacy notice. ([Privacy Notice - Oxford University Hospitals (ouh.nhs.uk)](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.ouh.nhs.uk%2Fprivacy%2F%23rights&data=05%7C01%7CRachel.Taylor%40ouh.nhs.uk%7Cf59719f8a1894aacfdc208dbad501701%7C25d273c3a8514cfba239e9048f989669%7C0%7C0%7C638294331706991365%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=wzE2oMCVso36ZIuRRZxAzcvVV4y939njaC4KcBnn0kw%3D&reserved=0)

## **Retaining your data**

We will only retain your data for as long as we need it to meet our purposes, including any relating to legal, accounting, or reporting requirements.

## **When we collect your data**

The majority of your data is collected when:

* You register as a potential PPIE member.
* You apply for a PPIE opportunity.
* Correspond with us by phone e-mail or otherwise.
* Submit a claim for costs associated with contributing to PPIE activities.

## **Types of data we collect about you**

We only collect data necessary for the purposes of our processing. We will collect, store and use the following data you give to us:

* Information provided by you such as your name, address and contact details, including email address and telephone number.
* details of our ongoing relationship and your involvement with us
* skills you would like to practice or offer and your motivations for wanting to join the PPIE group
* your photograph if you attend an event and consent to photos being taken.
* records of your involvement in PPIE activities arranged by Oxford BRC
* bank details to process expense claims
* records of interaction with us (for example by email)
* feedback obtained from you during your involvement activities.

## **Sensitive and personal information**

Certain types of information are sensitive, for example health information and genetic data. We will only collect and process this type of information about you if we have a valid reason for doing so.

## **How we use your data**

We collect your data so that we can process it for one or more of the following reasons:

* To process the data and enter into a relationship with you as a member of the Oxford BRC PPIE Group and to meet our obligations to you, for example to pay travel expenses.
* To send you information about training opportunities, involvement opportunities, or to contact you in relation to ongoing PPI activities.
* We may use information relating to your health to help us identify and assess your potential suitability for different PPI activities.
* Where we process special categories of personal data, such as information about ethnic origin, sexual orientation, health, employment status, and gender, this is done for the purpose of equal opportunities and monitoring the make-up and diversity of our PPI members.

## **The legal basis for processing your data**

We will only use your personal data where the law allows us to do so. Most commonly we rely on the following legal bases for processing your personal data:

* Performing a contract: information processed for this purpose includes, but is not limited to, the information you provide when you register to be a PPIE member, information you provide when you apply for a PPIE role.

## **Right to withdraw consent**

When you consent to us processing your personal information for a specific purpose, you can withdraw your consent at any time by contacting us at GetInvolvedOBRC@ouh.nhs.uk.

## **Your rights**

Information on your rights in relation to your personal data are explained [here](https://www.ouh.nhs.uk/privacy/#rights) ([Privacy Notice - Oxford University Hospitals (ouh.nhs.uk)](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.ouh.nhs.uk%2Fprivacy%2F%23rights&data=05%7C01%7CRachel.Taylor%40ouh.nhs.uk%7Cf59719f8a1894aacfdc208dbad501701%7C25d273c3a8514cfba239e9048f989669%7C0%7C0%7C638294331706991365%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=wzE2oMCVso36ZIuRRZxAzcvVV4y939njaC4KcBnn0kw%3D&reserved=0)

If you wish to raise any queries or concerns about our use of your data, please contact us at GetInvolvedOBRC@ouh.nhs.uk.

If you want to exercise any of the rights described in the link or are dissatisfied with the way we have used your information, you should contact the Oxford University Hospitals Information Governance Team on: Information.Governance@ouh.nhs.uk.  
  
**Changes to this privacy policy**

We reserve the right to update this privacy policy at any time and will seek to inform you of any substantial changes. We may also notify you in other ways from time to time about the processing of your personal data.

For the Diversity in Research Group please note that the [OHBRC Privacy Notice](https://www.oxfordhealth.nhs.uk/privacy/) also applies.

1. The group meets quarterly and includes leads from the [local NIHR organisations](https://www.healthinnovationoxford.org/our-work/our-programmes/community-involvement-and-workforce-innovation/community-involvement/working-together-thames-valley/) and departments of the Oxford University Medical Sciences Division. One or more PPI contributors from these [PPI groups](https://oxfordbrc.nihr.ac.uk/ppi/ppi-researcher-guidance/ppi-resources-for-researchers/) have also reviewed. [↑](#footnote-ref-1)
2. This document is being piloted (December 2023-April 2024) with researchers. Any suggestions for improvements should be sent to [Rachel.taylor@ouh.nhs.uk](mailto:Rachel.taylor@ouh.nhs.uk). [↑](#footnote-ref-2)