

NIHR Oxford Health Biomedical Research Centre

Patients and Research Group (PAR) Terms of Reference

The NIHR Oxford Health Biomedical Research Centre (OH BRC) is a partnership between Oxford Health NHS Foundation Trust and the University of Oxford. The PAR Group was established in December 2016.

Purpose of PAR

- To actively involve patients, carers and the public, to work with staff, in the development and delivery of the Patient and Public Involvement and Engagement [Strategy](#) (PPIE) for the OH BRC.
- To bring together a diverse range of voices and experiences to influence PPIE in research at the OH BRC, and help ensure PPIE contributes to improving the quality and effectiveness of research.

Role of individual group members

We want people to join this group of patients, carers, staff and public because they have had direct or indirect experience of mental ill health and/or have an interest in research; and want to work as partners to make Oxford's mental health research as good as it can be for the patients it is designed to benefit.

Specifically, the role includes:

- Prepare for and attend PAR Group meetings.
- Actively participate in the group's work and PPIE at the OH BRC.
- Represent the interests of PPIE at the OH BRC.
- Have a genuine interest in the initiatives and outcomes of the OH BRC PPIE programme.

Membership

- 15 - 17 patient, carer and public members (over the age of 18) - with a minimum of 10 patient members.
- 8 - 10 staff members - to include researchers, OH BRC leaders, mental health staff and PPI staff.
- Other staff and stakeholders will be invited to attend meetings as relevant.
- The group will have a patient/carers co-chair and a staff co-chair, who will be supported by the PPI Manager.

Attendance

- Members and chairs are asked to commit to their role in the group for 12 months, and membership and appointments will be reviewed every 12 months.
- The group will meet 4 times a year, mainly in Oxford. Meetings will last no longer than 3 hours.

Administration

- The PPI Manager will organise PAR Group meetings and associated activities.
- Following each PAR 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 on specific request, printed copies of papers can be sent by post or brought to meetings.
- The [PPIE Strategy](#) outlines accountability and reporting for PPI at the OH BRC. Progress in delivering the PPIE Strategy will be published at least annually.

Group principles

- This is a confidential group. Information discussed should not be shared with other individuals outside the group. Similarly, you should not reveal the identity of other group members to individuals outside of the group.
- The group will take an 'asset-based' approach to our work: bringing people together to achieve positive change using their own knowledge, skills and lived experience; and building on what works well whilst identifying potential to improve.
- To avoid any potential conflicts of interest, members will disclose relevant conflicts of interest or needs (personal or professional) at the point of joining the group (to the PPI Manager); and declare any ongoing interests at the time they arise, excluding themselves from discussions if necessary.
- Group members are asked to be respectful of the opinions of others and take care not to cause offence. Listen actively and if you challenge, challenge the statement, not the person.
- Care should be taken to use clear and concise communication.
- The group must not be used for the discussion of diagnoses or treatment at an individual level.
- The group recognises that it's OK to have a bad day. Members of the group will take time out if they need it, and take responsibility for looking after themselves or asking for help.

Payment and expenses (for patient, carer and public members)

- We will reimburse you for any travel and/or carer-related expenses that you might incur in fulfilling your role. We will 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 £75 per regular PAR meeting (to include preparation and follow-up): it is your choice whether to accept this or not.
- Reimbursement for other PAR related activity will be guided by the OH BRC [PPI Payment Policy](#).
- 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 [INVOLVE website](#).
- The NIHR provides access to a Benefits Advice Service (NB. they cannot advise regarding tax and National Insurance). We urge you to contact them to seek their guidance as we cannot provide this advice. You can see more information on the [INVOLVE website](#) or contact INVOLVE who will explain how to access the service (email involve@nihr.ac.uk, phone 02380 595628 - tell them you are involved with the NIHR Oxford Health BRC).

Definitions *Taken from NIHR Involve www.invo.org.uk*

- 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.

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:

OH BRC	NIHR Oxford Health Biomedical Research Centre
PAR	Patients and Research
PPI	Patient and Public Involvement
PPIE	Patient and Public Involvement and Engagement

This document was last reviewed in May 2018. It will next be reviewed in July 2019.