



National Institute for Health Research (NIHR)Oxford
Cognitive Health Clinical Research Facility

Patient and Public Involvement, Engagement and Participation Strategy 2022 – 2027

With thanks to the Engage Group for their support in developing this strategy.

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Introduction and background

This document sets out the strategy and framework for Patient and Public Involvement, Engagement and Participation (PPIEP) at Oxford Health Clinical Research Facility (CRF) for 2022-2027.

The Oxford Health NIHR Clinical Research Facility (CRF)

The NIHR Oxford Health Clinical Research Facility (CRF) opened in 2011. It received funding of over £4m to continue its work for another five years from September 2022. The CRF is a purposely equipped building which enables, encourages and facilitates high intensity research in neuroscience. It delivers new therapies, which are tailored to the needs of individual patients. It strives to break down boundaries between disciplines, and take advantage of scientific, technical and infrastructural capabilities that encompass a wide range of mental health disorders. The CRF is part of the UK-CRF Network and has existing PPIEP activities which will be developed further.

Patient and Public Involvement, Engagement and Participation (PPIEP)

The aim of PPIEP is to ensure that research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. Contributors include patients, potential patients, carers, service users, research participants and advocacy groups.

There are recognised differences between patient and public involvement, engagement and participation. Involvement refers to patient and public contributors being actively involved in the design and implementation of research processes. Engagement refers to the dissemination of research information and knowledge to the public. This includes engagement at events such as open days and in the media. Participation is when an individual takes part in a research study purely as a research participant. This might involve consenting to take part in a research study or completing a research questionnaire.

PPIEP at Oxford Health CRF

Oxford Health CRF recognises the importance of working with patient and public contributors. This practice helps develop research that better serves the needs and interests of service users. It is fundamental to achieving the aims of the CRF and will improve the quality of research we carry out by making sure that research is delivered and communicated in accessible, patient-centred ways.

Studies usually arrive at the CRF from external study teams with their protocols and procedures in place. These external teams include commercial, healthcare and educational institutions. There are therefore limited opportunities to influence the design of current trials. However, there are opportunities to influence research delivery, dissemination, and study set up. There may be opportunities to influence the design of future studies, e.g., through effective feedback to external study teams.

Purpose aims and objectives.

Our vision is for PPIEP activities to be embedded within the CRF, and to influence the way that research is delivered. Integrating PPIEP into CRF practice will ensure that processes are carried out in

person-centred ways. To achieve this, the strategy aims to establish processes that support researchers and the public to learn and work together.

Our overall vision for PPIEP, which is shared with the NIHR Oxford Health Biomedical Research Centre (BRC) is as follows:

“To embed PPIEP into our ways of working, ensuring active involvement of patients, carers and the members of the public in all aspects of our work, from research studies to funding applications and strategic decision-making.”

Three objectives have been identified to support the CRF to work towards this vision:

- To embed Patient and Public Involvement (PPI) into study set up, study delivery and dissemination activities.
- To facilitate and pro-actively respond to CRF participant feedback.
- To facilitate learning opportunities and training on PPIEP and Equality, Diversity and Inclusion for CRF staff and public contributors

Partners and collaborators

This strategy was developed and will be delivered in partnership with CRF staff, the Oxford Health BRC, and the Engage Group.

The Engage Group is the CRF's PPIEP group, which meets every 2 months to provide a participant perspective on CRF activity. It includes past CRF research participants, as well as people with lived experience of mental and cognitive health conditions (either as someone with a diagnosis or supporting someone with a diagnosis). This strategy's actions and objectives were discussed with this group, and three members reviewed the strategy as a whole prior to submission. This group will continue to be central to the delivery of this strategy, advising on the activity surrounding the identified actions. A representative from the group will also be invited to join the CRF Steering Committee to feed into CRF governance (see objective 1 action 3).

The CRF values collaborative partnerships in the delivery of PPIEP work. The CRF will continue to partner and collaborate with research teams such as BRCs, Applied Research Collaborations, and CRFs. The PPIEP Lead will continue to engage with local networks, and in collaborative activities. This includes the Trust's Experience and Involvement Team. This will ensure that practices are in line with, and feed into, the Trust's wider vision and values.

Leadership and lines of reporting

The PPIEP Lead reports to the CRF Manager. They are both responsible for delivering, monitoring, reviewing and reporting on this strategy. They are a member of the CRF's Senior Management Team and will feed back on short term strategy progress through this forum. Accountability for achieving the PPIEP strategy sits with the CRF Director. The strategy's overall progress will be reviewed at CRF Steering Group meetings, which a representative from the Engage group will be invited to, in order to directly inform CRF governance processes (see objective 1 action 3).

Monitoring, reviewing and reporting.

This strategy will be reviewed at least annually, and more regularly if needed. At this point, the actions will be marked as red (not started), amber (in progress) or green (completed). This will be discussed annually with the Engage group and fed back to the CRF Senior Management Team and Steering Committee. Actions marked as red and amber will be reviewed by the Engage group and CRF Senior Management Team to establish whether they are still feasible and a priority (if not, they will be replaced). Actions marked as green will be replaced with new actions, in partnership with the Engage group and CRF staff.

Progress on PPIEP, and examples of impact, are reported regularly to the CRF Senior Management Team meeting. The impact of Engage group feedback and advice is fed back to the group at subsequent meetings and recorded in meeting minutes. Progress and impact are also included in annual reporting to the National Institute of Health and Care Research.

Resources

The PPIEP Lead will oversee PPIEP activities at the CRF. This includes the delivery of this strategy, and reporting and monitoring its progress. The CRF is committed to adequately resourcing the activities described in this strategy. This includes reimbursing patient and public contributors, resourcing appropriate training, and funding associated activities.

Further information

For more information about this strategy and how you can get involved in PPIEP for the CRF, please contact: oxfordhealth.crf@nhs.net

Objectives and Programme of Activities

Three strategic objectives will enable us to work towards our vision and purpose:

Objective 1

To embed Patient and Public Involvement (PPI) into study set up, study delivery and dissemination.

Long term actions (5 years)	Short term actions (1-2 years)	How will we know if this action has been achieved?
To establish processes to allow PPI members to contribute more widely to activities at the CRF such as run throughs of study visits.	Within the first year, we will create guidance which outlines PPI processes. This will include a Confidentiality Agreement and Terms of Reference, as well as information areas such as payment, data sharing and complaints procedures. An accessible lay summary/toolkit for PPI contributors will be included. This will be created in collaboration with the BRC and be utilised within the Engage group.	Long-term: Engage group members will have opportunities to be involved in a range of activities relating to study set up, delivery and dissemination. This will be recorded in Engage meeting minutes and reviewed regularly. Short-term: Established PPI guidance used within the Engage group.
To involve PPI members in supporting the write up/review of lay summaries of previous research studies. These will be disseminated to past research participants.	To identify or organise training for researchers and PPI members in writing lay summaries. To work with Oxford Health NHS FT's library team to ensure that the lay summaries are visible to external audiences.	Long-term: Lay summaries of past research studies will be presented on the CRF/Research and Development website, as appropriate. Short term: completion of training, correspondence with library team.
For PPI members to have a meaningful influence on research governance.	For an Engage group member to be invited to each CRF Steering Group meeting. The Engage group will decide whether they would prefer the same person to represent them at all meetings, or whether they would prefer to rotate this role between group members.	Long-term: CRF Steering Group minutes will include PPI feedback and advice. Short-term: A representative from the Engage group will be invited to each CRF Steering Group committee meeting.

Objective 2

To facilitate and respond to CRF participant feedback.

Long term actions (5 years)	Short term actions (1-2 years)	How will we know if this action has been achieved?
<p>To respond to participant feedback consistently and effectively.</p>	<p>To review our co-designed patient feedback form to ensure questions remain relevant. This will be reviewed with the Engage group and CRF researchers.</p> <p>For the Engage group to contribute to the CRF garden and courtyard project by providing advice at Engage group meetings.</p>	<p>Long-term: Changes to practice will be displayed as “You said we did” posters in the CRF waiting room.</p> <p>Short-term: The reviewed feedback form will be in the waiting room in the CRF (in paper form), and on the website (in digital form via Microsoft Forms).</p> <p>Short-term: Documented advice in Engage meeting minutes, with associated changes to the project based on the feedback.</p>
<p>To establish processes that enable PPI contributors to be involved in recruitment for new staff members.</p>	<p>To outline a process for PPI involvement in interview panels within a new PPI policy.</p> <p>To identify appropriate training for PPI contributors to be involved in interview panels.</p>	<p>Long-term: Engage members will sit on panels for recruiting new staff members.</p> <p>Short-term: A documented and agreed process will be established. Engage members who wish to be involved in this way will have completed relevant training.</p>
<p>To develop a framework for the aftercare of research participants.</p>	<p>To complete a systematic review of the literature around aftercare of research participants.</p> <p>To create an information pack to give to participants at the end of study participation.</p>	<p>Long-term: A framework detailing considerations and actions to facilitate positive aftercare experiences for research participants.</p> <p>Short-term 1: Completion of a systematic review.</p> <p>Short-term 2: Creation of an information pack.</p>

Objective 3

To facilitate learning opportunities and training on PPIEP and Equality, Diversity and Inclusion for CRF staff and public contributors.

Long term action (5 years)	Short term actions (1-2 years)	How will we know if this action has been achieved?
To work with the BRC to create shared training resources. This will include training packages that can be delivered to/by researchers, PPI contributors and students.	To complete a scoping review of the existing PPI training available.	Long-term and short-term: Outputs (i.e., identified and developed training packages and resources) will be presented in appropriate forums, e.g., at the UKCRF conference.