National Institute for Health Research (NIHR)
Oxford Health Biomedical Research Centre
and cognitive health Clinical Research Facility

Patient and Public Involvement and Engagement Strategy, 2017-2022

Thank you to the public members of our Patients and Research Group, and especially the Strategy Advisory Group, for their support in developing this strategy.

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Logo updated February 2020

1 Executive Summary

The NIHR Oxford Health Biomedical Research Centre (BRC) and cognitive health Clinical Research Facility (CRF) is a partnership between Oxford Health NHS Foundation Trust (OHFT) and the University of Oxford. We aim to bring the best science to mental health and dementia, and to translate neuroscience into benefits for patients.

This document sets out the strategy and framework for Patient and Public Involvement and Engagement (PPIE) at the BRC and CRF for 2017–2022. Patient and Public Involvement (PPI) refers to research that is carried out 'with' or 'by' members of the public. Engagement is when information and knowledge about research is provided and disseminated to the public.

Our vision is for PPIE to be embedded within the research themes and influence the activity of the BRC and CRF. The PPIE strategy needs to be able to work with researchers at any stage of a research study, and needs to encourage researchers to design future studies with PPIE embedded at all stages, as a matter of course.

To achieve this, our PPIE strategy aims to develop processes that support researchers and the public to build learning and work together, with the ultimate aim of tailoring personalised treatment for people with mental disorders and dementia.

Our 6 strategic objectives are to:

1. Provide appropriate, central mechanisms to support BRC researchers to involve patients and the public
2. Provide opportunities for PPIE Learning and Development for researchers and the public across the BRC and CRF
3. Develop an outreach and engagement plan to promote and raise awareness of PPIE opportunities and research, at the BRC and CRF
4. Establish a CRF-specific PPI Advisory Group
5. Embed PPI within Research & Development procedures
6. Contribute to Evidence-Based PPI research in mental health

The PPIE strategy was developed and will be delivered in partnership with patients and staff. For each year of the strategy we will develop an annual work plan. We will conduct and publish a regular review of progress, identifying issues, challenges and improvements, and revise the strategy as appropriate.

For more information, please contact Claire Murray, Patient and Public Involvement Manager, claire.murray@oxfordhealth.nhs.uk.

2 Introduction and background

2.1 The NIHR Oxford Health Biomedical Research Centre

In 2016 a partnership between Oxford Health NHS Foundation Trust (OHFT) and the University of Oxford was awarded £12.8 million by the NIHR, over 5 years, to establish a Biomedical Research Centre (BRC) focusing on adult mental health, older adults and dementia, and precision psychological treatments.

The Oxford Health BRC aims to bring the best science to these complex problems, working with digital and other new technologies, to inform the development of new treatments and diagnostic tools to ultimately allow for tailored, personalised treatment.

The BRC has 6 research themes: Adult Mental Health; Older Adults and Dementia; Precision Psychological Treatments; Clinical Research Infrastructure and Experimental Medicine; Informatics and Experimental Medicine; Informatics and Digital Health; and Neuroimaging and Cognitive Neuroscience. Patient and Public Involvement is one of the cross-cutting themes, and underpins all 6 research themes.

2.2 The NIHR Oxford cognitive health Clinical Research Facility

The NIHR Oxford cognitive health Clinical Research Facility (CRF) opened in 2011, and received funding of around £3.7 million to continue its work for another 5 years from April 2017.

The CRF is a purposely-equipped building which enables, encourages and facilitates high intensity research in neuroscience. It delivers new therapies tailored to the needs of individual patients, by breaking down the boundaries between disciplines, and by taking advantage of scientific, technical and infrastructural capabilities that cut across mental health disorders.

The CRF is part of the UK-CRF Network, and has existing PPI activity which will be developed further.

2.3 Patient and Public Involvement and Engagement (PPIE)

The BRC is a new entity, and therefore research studies are being adopted at various stages of the research cycle, with PPI taking place to varying degrees.

Studies arrive at the CRF with all their protocols and procedures in place, so there is limited opportunity for participants to influence the design of current trials, but there may be opportunities for them to influence the design of future studies.

The BRC and CRF PPIE strategy therefore needs to be able to work with researchers at any stage of a current study to facilitate involvement and engagement. It also needs to encourage researchers to design future studies with PPI embedded at all stages, as a matter of course.

Definitions

http://www.invo.org.uk

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. This includes, for example:

- Working with research funders to prioritise research
- Offering advice as members of a project steering group
- Commenting on and developing research materials
- Undertaking interviews with research participants

When using the term **'public'** we include:

- Patients
- Potential patients
- Carers
- People who use health and social care services as well as people from organisations that represent people who use services.

Involvement in research refers to active involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research 'subjects').

Engagement is where information and knowledge about research is provided and disseminated to the public, for example science festivals, open days, media coverage.

Participation is when the public takes part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

The Oxford Health BRC and cognitive health CRF recognise the importance of working together with people with lived experience of health conditions (i.e. patients/service users, and family/friends who care for them), and – where appropriate – members of the public.

Patient and Public Involvement (PPI) helps develop research that better serves the needs and interests of patients, carers and researchers, than that developed by researchers alone. It is fundamental to achieving the aims of the BRC and CRF, and will improve the quality of research we carry out, by making sure that:

- Research and outcomes are relevant and important to the public
- Research materials are easy to understand
- The research process is sensitive and acceptable to potential participants

2.4 Developing the strategy

In December 2016, a Patient and Research (PAR) Group was established, to bring together a mix of patient, carer, public and staff members to guide the PPIE strategy for the BRC and CRF.

A small core group was set up in September 2017 to advise on the development of a draft strategy, consisting of: the PAR patient/carer co-Chair, and two further public members from PAR; the PAR staff co-Chair; a clinician with an interest in research; the BRC PPI Theme Lead; the CRF Clinical Lead; and the PPI Manager.

In December 2017, the draft strategy was then sent out for consultation to:

- PAR Group
- the BRC Director, Theme Leads, PPI staff links in the BRC themes and the CRF, and colleagues in the Communications Teams of the Oxford Health NHS Foundation Trust and Department of Psychiatry
- PPIE colleagues in the NIHR Oxford BRC, the Oxford Academic Health Science Network (AHSN) and Centre (AHSC), the NIHR Thames Valley & South Midlands Clinical Research Network (CRN), the NIHR Collaboration for Leadership in Applied Health Research and Care, Oxford (CLAHRC), and the NIHR Central Commissioning Facility PPI Team

Feedback was incorporated and the strategy was published in March 2018.

3 Vision and purpose

Our vision is for PPIE activities to be embedded within the BRC themes and CRF, and to influence future BRC/CRF funding applications - as well as research studies in the University of Oxford’s Department of Psychiatry and the Oxford Health NHS Foundation Trust more widely.

Embedding PPIE activities will enable the integration of PPIE across the full research cycle and into the design of new research studies, and ensure that PPIE influences the type research that is carried out in the future.

To achieve this, the strategy will develop and provide processes that support researchers and the public to build learning and work together, with the ultimate aim of tailoring personalised treatment for people with mental disorders and dementia.

4 Objectives

We have identified 6 strategic objectives to enable us to achieve our vision and purpose. See Appendix 1 for our Strategic Framework.

4.1 Objective 1: Provide appropriate, central mechanisms to support BRC researchers to involve patients and the public

As part of this objective, we will focus on building centralised resources that directly support researchers in the BRC themes to carry out PPI. This will include: developing a pool of relevant patient and public members for researchers to consult at any stage of research; building a central collection of PPI resources; and providing a payment policy for PPI.

We will work with the PAR Group to identify skills, develop roles and ensure there are involvement opportunities at a range of levels. We will promote the opportunities widely to the patient and public community, to enable the development and involvement of relevant public members.

We will establish and work with PPI staff links in each BRC theme and the CRF to understand researcher needs, and to promote the resources and mechanisms to ensure they are widely used.

4.2 Objective 2: Provide opportunities for PPIE Learning and Development for researchers and the public across the BRC and CRF

We will work with the PAR Group, the patient and public involvement group at the CRF, the BRC and CRF PPI staff links, and the BRC Training theme to identify the PPIE learning needs of researchers and the public. We will signpost to existing learning and development opportunities, and develop new resources where appropriate, to enable researchers and public to work together to develop research.

Working with wider staff at Oxford Health NHS Foundation Trust and Department of Psychiatry, we will aim to include PPIE in interview and/or induction procedures for new staff at the BRC, CRF, and relevant other Trust and Department of Psychiatry positions.

4.3 Objective 3: Develop an outreach and engagement plan

We will develop and deliver an outreach and engagement plan that: (a) promotes the work of the BRC and CRF generally; (b) raises awareness of opportunities for PPI and participation in research among the public more widely, ensuring as great a diversity and inclusion as possible (including people and groups often overlooked or ignored); and (c) raises awareness among Oxford Health NHS Foundation Trust staff of research so that they can promote opportunities.

In delivering this objective we will work with the Communications teams in the Department of Psychiatry and in the Oxford Health NHS Foundation Trust, the NIHR Oxford BRC, the Thames Valley and South Midlands Clinical Research Network, local mental health charities and organisations (for example the Oxford Mental Health Partnership), the Oxford Health NHS Foundation Trust PPI in service delivery and Community Involvement teams, and local carer and community groups.

4.4 Objective 4: Establish a CRF-specific PPI Advisory Group

We will set up and support a PPI Advisory Group from existing CRF participants, to enable them to work with staff to identify what they can influence and how they want to achieve this.

We will actively engage with the UK CRF Network to connect with wider CRF-focused PPIE activities.

4.5 Objective 5: Embed PPI within Research & Development (R&D) procedures

We will appoint public members to the BRC and CRF Steering Committees.

We will identify PPI activities (for example checking that new grant applications address relevant James Lind Alliance (JLA) Priorities and include PPI) that Oxford Health Foundation Trust and University of Oxford can adopt in their R&D procedures, and work with R&D colleagues to embed these into policies and practice.

4.6 Objective 6: Contribute to Evidence-Based PPI research in mental health

We will identify research into PPI that is important to patients and the public through working with the PAR Group, the Ethics and Society (NEUROSEC) group of the Department of Psychiatry, and the Partnerships for Health, Wealth and Innovation (PHWI) theme of the NIHR Oxford BRC.

We will work with these groups and other interested parties to develop ideas and carry out the research. We will work with external partners to develop and conduct research that addresses priorities that have already been identified by relevant James Lind Alliance (JLA) Priority Setting Partnerships (PSPs).

5 Delivering our objectives

We have identified a number of principles that will guide the way we work and deliver our objectives:

- We will work **collaboratively** - where it is sensible and practical for us to do so – with a range of internal and external partners, both within the NIHR and beyond.

- We will be **pragmatic**, recognising that we need to start where researchers are currently, whilst having an eye on moving to the point where new research studies address priorities that are important to patients and the public and have PPIE designed and costed in appropriately from the outset.

- We will **use existing tools and processes**, where it is sensible and practical for us to do so.

- We will **foster a culture of respect and equality**, that allows for the empowerment of all concerned.

- We will be **transparent**, striving for communications that are easily accessible to all.

- We will be **proactive** in raising awareness among researchers of the need for PPIE and the resources available.

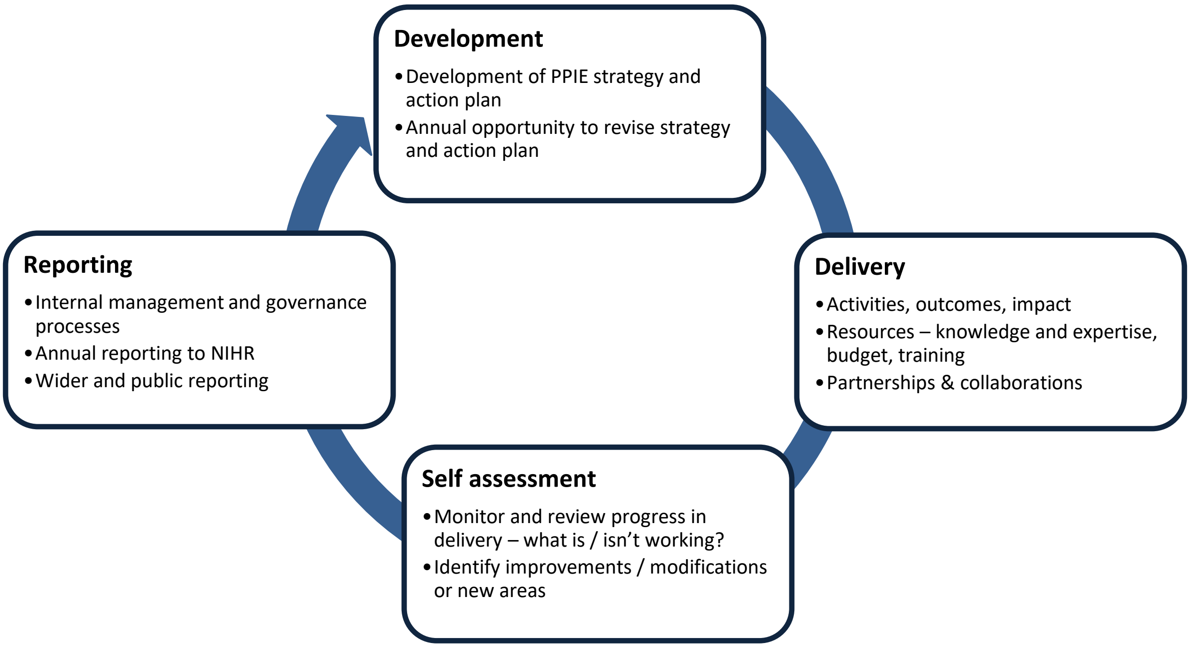
- We will **learn by doing**, recognising that this is an iterative process, and will review progress and consider learning outcomes on an annual basis.

- We will aim to **understand what impact our strategy is having**, and will adjust our approach to assessing impact in line with evolving NIHR guidance and in collaboration with local partners.

- We will aspire to **work in a co-productive fashion**, leading by example and encouraging staff in the BRC themes and CRF to do the same.

- We will aim to **deliver PPIE in keeping with the NIHR standards**, leading by example and encouraging staff in the BRC themes and CRF to do the same.

For each year of the strategy we will develop an annual work plan. We will conduct a regular review of progress, identifying issues, challenges and improvements, and revise the strategy as appropriate.



Development

- Development of PPIE strategy and action plan
- Annual opportunity to revise strategy and action plan

Delivery

- Activities, outcomes, impact
- Resources – knowledge and expertise, budget, training
- Partnerships & collaborations

Self assessment

- Monitor and review progress in delivery – what is / isn't working?
- Identify improvements / modifications or new areas

Reporting

- Internal management and governance processes
- Annual reporting to NIHR
- Wider and public reporting

In addition to specifying measures of success for each objective activity, we will develop documented processes to describe the support that is available, develop templates for recording BRC themes and CRF progress and feedback, and capture case studies of impact. For each activity we will develop and implement appropriate feedback and learning mechanisms and review regularly.

PPI is a cross cutting theme for the BRC, and has a designated Theme Lead, to embed PPI within each theme area and develop evidence-based PPI research in mental health.

A full time PPI Manager leads on the operational delivery of the PPI strategy across the BRC and CRF, and is supported by PPI staff links in each of the BRC Themes and the CRF. The PAR Group will support regular reviews of progress against the strategic objectives.

PPIE has a designated but limited budget that will be used to support public PAR members, the development of the PPI pool of interested public members, the CRF PPI Advisory Group, training and learning opportunities, and evidence-based PPI research.

The PPI Manager will link in with the wider Oxford and Thames Valley NIHR PPI activity, Oxford Health NHS Foundation Trust (OHFT) service PPI activity, and the communications teams for OHFT and Oxford University's Department of Psychiatry, plus wider engagement work undertaken across both organisations, to capitalise on existing opportunities to deliver our involvement and engagement work. We will seek to build relationships with external organisations and will develop initiatives to deliver the strategy, for example the McPin Foundation, Patient Research Ambassadors, and the Oxford Mental Health Partnership.

6 Accountability and reporting

The Patient and Public Involvement Manager is responsible for delivering the strategy and work plans, including reporting, and will work with the PAR Group and PPI staff links to monitor progress and review objectives.

The PPI Manager works closely with the BRC PPI Theme Lead and Clinical Lead for the CRF, the co-chairs of the PAR Group, and reports to the Oxford Health BRC Manager. Accountability for achieving the PPI strategy sits with the PPI Theme Lead and CRF Clinical Lead, and the BRC and CRF Director.

Progress on PPI is reported regularly at the BRC Theme Leaders meeting and Steering Committee, is included within the R&D report to the Oxford Health NHS Foundation Trust Board of Directors meeting, and the annual reporting to the NIHR for both the BRC and CRF. We will publish a summary of this annual reporting on the BRC PPI webpages.

7 Further information

For more information about this strategy and how you can get involved in PPIE for the NIHR Oxford Health Biomedical Research Centre and cognitive health Clinical Research Facility please contact:

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Appendix 1 - The Strategic Framework, 2017-2022

Objective 1: Support

Provide appropriate, central mechanisms to support BRC researchers to involve patients and the public

Activities:	Measures of success:	Timeframe
1.1 Develop PAR remit, ways of working and annual PAR Group plan, with PAR Group	Terms of reference and role descriptions agreed and published; annual calendar of meetings delivered	2017/18 established and ongoing
1.2 Develop a pool of relevant patients and public members for researchers to consult at any stage of their research	Number of researchers using pool, for which BRC theme, points in research cycle recorded; case studies of experience and impact captured	2018/19 and ongoing
1.3 With PAR, develop levels of involvement and roles for pool, and other interested public, allowing for involvement according to individual preferences	Roles defined and promoted, including on BRC PPI webpages; number, type and involvement experiences recorded	2018/19 and ongoing
1.4 Set up and maintain a database of interested, relevant public to keep them informed of opportunities	Issues in respect of 2018 General Data Protection Regulation (GDPR) recorded; mechanism established; usage recorded	2018/19 and ongoing
1.5 Provide a payment policy to researchers, and to the public, allowing for payment from either Trust or University systems	Policy reviewed annually; payment for PPI opportunities monitored	2017/18 established and ongoing
1.6 Identify and support nominated PPI staff links who will identify BRC Theme/CRF specific PPI needs	Role descriptions agreed; quarterly meetings to share learning; actions and progress recorded by theme	2017/18 established and ongoing
1.7 Explore small grant scheme to help with theme specific PPIE activity	Scheme researched and established; applications, themes, and point in research cycle recorded	2018/19 and ongoing
1.8 Create and share a central collection of internal PPI templates and guidance	Collection established and shared; updated quarterly, usage and feedback recorded	2018/19 and ongoing
1.9 Identify and signpost external PPI resources for researchers and public through dedicated web pages	Web pages updated quarterly; web visits recorded	2017/18 established and ongoing

Objective 2: Learning

Provide opportunities for PPIE Learning and Development (L&D) for researchers and the public across the BRC and CRF

Activities:	Measures of success:	Timeframe
2.1 Identify learning needs in PPIE, for staff and the public	Annual PPI L&D review for staff and public; learning needs identified	2018/19 and ongoing
2.2 Identify and signpost existing L&D opportunities and resources for both staff and public	Mechanisms for signposting developed; feedback collected on L&D opportunities provided	2018/19 and ongoing
2.3 Develop a plan to deliver L&D opportunities/resources	L&D gaps identified; new resources and opportunities provided and recorded	2018/19 and ongoing
2.4 Include PPIE in interview/induction procedures for new staff and public, whenever feasible	Induction resources developed and delivered; interview opportunities identified and addressed	2017/18 and ongoing

Objective 3: Outreach

Develop and deliver a patient and public outreach and engagement (PPE) plan that (a) promotes the work of the BRC/CRF generally, (b) raises awareness of opportunities to participate (i.e. be recruited to take part) in research and to be involved with research design and delivery among the public more widely (ensuring as great a diversity and inclusion as possible, and including people and groups often overlooked or ignored), and (c) also raises awareness among Oxford Health NHS Foundation Trust staff of research generally so that they can promote opportunities

Activities	Measures of success	Timeframe
3.1 Promote the work of the BRC/CRF at engagement events nationally/locally	Annual plan of events/activities developed, delivered and recorded	2018/19 and ongoing
3.2 Promote opportunities for the public to participate in research	New opportunities to promote identified and addressed	2018/19 and ongoing
3.3 Signpost and link with relevant NIHR engagement activity and resources	BRC PPI web pages regularly reviewed and updated	2017/18 established and ongoing
3.4 Increase diversity and inclusion of the patients and public we involve/engage	Key relationships with community groups identified and developed	2018/19 and ongoing
3.5 Promote public involvement roles and opportunities via the BRC website and other appropriate routes	BRC PPI web pages regularly reviewed and updated	2018/19 and ongoing

Objective 3: Outreach

Develop and deliver a patient and public outreach and engagement (PPE) plan that (a) promotes the work of the BRC/CRF generally, (b) raises awareness of opportunities to participate (i.e. be recruited to take part) in research and to be involved with research design and delivery among the public more widely (ensuring as great a diversity and inclusion as possible, and including people and groups often overlooked or ignored), and (c) also raises awareness among Oxford Health NHS Foundation Trust staff of research generally so that they can promote opportunities

Activities	**Measures of success**	**Timeframe**
3.6 Support nominated PPI staff links in BRC themes and CRF to identify and address theme/site specific PPE needs	Quarterly meetings to share learning; actions and progress recorded by theme	2018/19 and ongoing
3.7 Deliver annual activities/events to reach people in rural communities, local community hospitals, schools, voluntary and community organisations	Collaborators and opportunities identified; action plan developed and delivered	2019/20 and ongoing
3.8 Capture BRC theme and CRF level PPE activity annually	Quarterly meetings to share learning; actions and progress recorded by theme	2017/18 established and ongoing
3.9 Identify existing internal/external resources to help with PPE, for example University of Oxford Medical Science Division Engagement resources; CRN engagement and communications databases	Map existing resources and develop plan for how to use	2018/19

Objective 4: Clinical Research Facility

Establish a CRF-specific PPI Advisory Group

Activities	**Measures of success**	**Timeframe**
4.1 Recruit members of the group from participants in trials/studies at the CRF	Group remit agreed and published; annual activity plan developed; case studies of impact captured	2017/18 established and ongoing
4.2 Develop areas of activity and ways of working, engaging with UK CRF Network	Agree and publish TOR for group and areas of activity; review annually	2018/19 and ongoing
4.3 Establish regular link between CRF Group and PAR Group	Annual joint meeting delivered	2018/19

Objective 5: Governance

Embed PPI within Research & Development (R&D) procedures

Activities	**Measures of success**	**Timeframe**
5.1 Identify PPI activities that OHFT/University of Oxford can adopt in relation to R&D procedures	Identify and deliver activities and develop measures of success	2018/19
5.2 Identify how the PPI activities can be embedded within R&D procedures and implement	Identify and implement processes, develop measures of success	2019/20
5.3 Appoint public representatives to the BRC & CRF Steering Committees	Committees set up and representatives appointed	2017/18 (BRC); 2018/19 (CRF)

Objective 6: Research

Contribute to Evidence-Based PPI in Mental Health (a) to identify research into PPI that is important to patients/the public, and to work with them and other interested parties to develop the ideas and carry out the research; and (b) to encourage research that addresses the priorities that are of importance to clinicians and patients that have emerged from James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) in mental health.

Activities	**Measures of success**	**Timeframe**
6.1 Identify and take forward areas of mutual interest with PAR Group	Plan developed, with timeline and measures of success	2018/19 and ongoing
6.2 Identify and take forward areas of mutual interest with other entities; e.g. the Neuroscience, Ethics and Society (NEUROSEC) group of the Department of Psychiatry; the Partnerships for Health, Wealth and Innovation (PHWI) theme of the NIHR Oxford BRC	Plan developed, with timeline and measures of success	2018/19 and ongoing
6.3 Work with external partners, to develop and conduct research that address priorities identified by relevant James Lind Alliance (JLA) Priority Setting Partnership (PSPs)	Review the Priorities of relevant PSPs; develop a plan for taking forward, with measures of success included	2018/19 and ongoing