

Patient and Public Involvement and Engagement Strategy Progress Report, April 2019

Summary

This report outlines the progress made towards delivering the [Patient and Public Involvement and Engagement Strategy](#) (PPIE) (2017-2022) for the NIHR Oxford Health Biomedical Research Centre and cognitive health Clinical Research Facility.

Our [Patients and Research Strategy Group](#) (PAR) has continued to support the delivery of the PPIE Strategy. The group has ten patient, carer and public members and seven staff members. It is co-chaired by a patient/carers member and a staff member, with support from the PPI Manager and PPI Theme Lead.

Progress in the PPIE Strategy has been made across all objectives. Key activities include:

- PAR reviewed how it operates in relation to the NIHR Standards for Public Involvement. We undertook a review of the experience of group members to ensure members are supported and to identify future priorities. (Objective 1)
- We launched a register to connect BRC researchers with PPI contributors, and to support high-quality PPI activity. Over the last year, we provided PPI support to 18 projects and worked with 33 PPI contributors. (Objectives 1&3)
- A PPI small grants programme was launched to support PPI in the early stages of research and 9 awards made. (Objective 1)
- Public and research PAR members worked with the BRC Training theme to co-deliver a PPI session as part of the Oxford Short Course in Experimental Medicine in Mental Health. (Objective 2)
- We've worked with local NIHR partners and PPI contributors to co-develop a series of 8 [PPI Workshops](#) covering stages of the research cycle. (Objective 2)
- A PPI Group, ENGAGE, has been established at the Clinical Research Facility. (Objective 4)
- PAR has contributed to a [NEUROSEC](#) project exploring Ethics and Collaborations in mental health research. (Objective 6)

If you would like further information about anything contained in this report please contact the Patient and Public Involvement Manager, Claire Murray, claire.murray@oxfordhealth.nhs.uk.

Glossary

- BRC Biomedical Research Centre
- CRF Clinical Research Facility
- CRIS Clinical Record Interactive Search
- NEUROSEC Neuroscience, Ethics and Society Research Group at University of Oxford
- NIHR National Institute for Health Research
- OHFT Oxford Health NHS Foundation Trust
- OxDARE Oxford Dementia and Ageing Research
- OU University of Oxford
- PAR Patients and Research Group
- PPIE Patient and Public Involvement and Engagement

Progress against objectives

Objective 1: Support Provide appropriate, central mechanisms to support BRC researchers to involve patients and the public	
Activities:	Progress
1.1 Develop Patients and Research (PAR) remit, ways of working and annual work plan, with PAR Strategy Group	<ul style="list-style-type: none"> • Group Terms of reference agreed. (Jul 2018) • Quarterly meetings established. (Apr 2018 & ongoing) • NIHR Standards for Public Involvement reviewed. (Nov 2018) • Researcher Feedback added as a regular item meeting agenda. (Dec 2018) • Review carried out with members to understand experience and identify future priorities. (Mar 2019) • PAR Strategy Group has 17 active members: 10 patient, carer and public members; 7 staff members. (Mar 2019)
1.2 Develop a pool of relevant patients and public members for researchers to consult at any stage of their research	<ul style="list-style-type: none"> • PPI Contributor registration developed with PAR Strategy Group and launched. (Nov 2018) • 16 PPI contributors registered. (Mar 2019)
1.3 With PAR, develop levels of involvement and roles for pool, and other interested public, allowing for involvement according to individual preferences	<ul style="list-style-type: none"> • Developed PPI Monitoring and Evaluation Record for involvement in research projects. (Mar 2019) • Delivered PPI event 'Ketamine for depression' at in partnership with NIHR Maudsley BRC. (Aug 2019) • PPI theme provided PPI support to 18 research projects. (Apr 2018 – Mar 2019)
1.4 Set up and maintain a database of interested, relevant public to keep them informed of opportunities	<ul style="list-style-type: none"> • GDPR statement added to website. (May 2018) • Regular sharing of PPI roles and training opportunities to PPI Contributors. (Ongoing)

1.5 Provide a payment policy to researchers, and to the public, allowing for payment from either Trust or University systems	<ul style="list-style-type: none"> • Payment Policy published on BRC website. (Sep 2017) • Link to payment policy included within 'Introduction to PPI for researcher staff' guide. (Oct 2018) • Policy shared with all research staff who applied to PPI Small Grants Scheme. (Feb 2019)
1.6 Identify and support nominated PPI staff links who will identify BRC Theme/CRF specific PPI needs	<ul style="list-style-type: none"> • Role descriptions agreed. (Apr 2018) • Quarterly meetings established. (Apr 2018 & ongoing)
1.7 Explore small grant scheme to help with theme specific PPI activity	<ul style="list-style-type: none"> • First round of funding launched and 9 PPI projects supported. (Mar 2019)
1.8 Create and share a central collection of internal PPI templates and guidance	<ul style="list-style-type: none"> • 'Introduction to PPI for researcher staff' guide published. (Sep 2018) • PPI Project Form published. (Nov 2019)
1.9 Identify and signpost external PPI resources for researchers and public through dedicated web pages	<ul style="list-style-type: none"> • Web pages regularly updated including with new PPI opportunities and training. (Ongoing) • PPI Manager attends NIHR BRC Network PPI meetings. (Ongoing)

Objective 2: Learning Provide opportunities for PPI Learning and Development (L&D) for researchers and the public across the BRC and CRF

Activities:	Progress
2.1 Identify learning needs in PPI, for staff and the public	<ul style="list-style-type: none"> • PAR Survey with research staff. (Sep 2019) • PAR Member Review. (Mar 2019) • PPI contributors involved in development of Research Cycle Workshops. (Jul – Nov 2018)
2.2 Identify and signpost existing L&D opportunities and resources for both staff and public	<ul style="list-style-type: none"> • Training opportunities for PPI contributors shared directly, plus updated on website. (Ongoing) • Training resources for research staff signposted on BRC website and via OHFT and UO internal communications channels. (Ongoing)
2.3 Develop a plan to deliver L&D opportunities/resources	<ul style="list-style-type: none"> • Regular Q&A sessions provided for research staff. (Monthly in 2018) • Delivered PPI session at Oxford Short Course in Experimental Medicine for Mental Health. (Jan 2019) • PPI presentation at Department of Psychiatry Research Meeting. (Feb 2019) • Partner in Working Together PPI Training programme for research staff and PPI contributors. (Sep & Nov 2018)

	<ul style="list-style-type: none"> Designed and delivering 8 PPI workshops on the Research Cycle, in partnership with PPI contributors, and PPI Leads at the CLAHRC Oxford and Oxford BRC. (Jan – Aug 2019)
2.4 Include PPIE in interview/induction procedures for new staff and public, whenever feasible	<ul style="list-style-type: none"> PPI involvement in recruitment for PPI Manager. (Nov 2017) PPI involved in recruitment for CRIS PPI representative. (May 2018) 'Introduction to PPI for researchers' added to OU Department of Psychiatry Staff Handbook. (Sep 2018)

Objective 3: Outreach Develop and deliver a patient and public outreach and engagement (PPE) plan	
Activities	Progress
3.1 Promote the work of the BRC/CRF at engagement events nationally/locally	<ul style="list-style-type: none"> PPI session included in BRC/CRF Open Day agenda, plus a PPI stall in exhibition. (May 2018) Community events attended: Cowley Road Carnival (Jul 2018); OHFT Annual General Meeting (AGM) (Sep 2018); OHFT Healthfest (Sep 2018); Age UK Oxfordshire AGM (Nov 2018)
3.2 Promote opportunities for the public to participate in research	<ul style="list-style-type: none"> Research Assistants embedded within clinical teams at OHFT disseminate information within the Trust's mental health services. (Ongoing) Regular Bipolar Disorder and Treatment Resistant Depression Research Clinics located at the CRF. (Ongoing) The outreach activities of OxDARE, which also provide a liaison role in OHFT memory clinics. (Ongoing) A 'Consent for Research Contact' pilot within OHFT to capture research interest and consent to be contacted. (2018) We promote opportunities to participate through patientsactiveinresearch.org.uk, social media, community magazines, and the University of Oxford and OHFT websites.
3.3 Signpost and link with relevant NIHR engagement activity and resources	<ul style="list-style-type: none"> NIHR Standards shared, including on website and in Open Day presentation. (May 18) NIHR PPI resources and training shared with PPI contributors as available. (Ongoing)

	<ul style="list-style-type: none"> Member of BRC and CRF National PPI Networks. (Ongoing)
3.4 Increase diversity and inclusion of the patients and public we involve/engage	<ul style="list-style-type: none"> Hosted a stall at the Cowley Road Carnival – this event is a celebration of diversity in the local community. (Jul 2018) Took part in OHFT HealthFest event which invited the local community in to the Warneford Hospital. (Sep 2018)
3.5 Promote public involvement roles and opportunities via the BRC website and other appropriate routes	<ul style="list-style-type: none"> PPI opportunities added to BRC website, shared directly with PPI contributors, and shared with voluntary organisations. (Ongoing) PPI animation developed to introduce PPIE strategy. (May 2018)
3.6 Support nominated PPI staff links in BRC themes and CRF to identify and address theme/site specific PPI needs	<ul style="list-style-type: none"> OU Department of Psychiatry established a Public Engagement Group. (Dec 2017)
3.7 Deliver annual activities/events to reach people in rural communities, local community hospitals, schools, voluntary and community organisations	<ul style="list-style-type: none"> <i>Work to be progressed in 2019/20.</i>
3.8 Capture BRC theme and CRF level PPI activity annually	<ul style="list-style-type: none"> PPI Staff Links meetings take place quarterly. (Ongoing) Annual report submitted. (May 2018)
3.9 Identify existing internal/external resources to help with PPI, for example University of Oxford Medical Science Division; CRN engagement and communications databases	<ul style="list-style-type: none"> Member of University of Oxford Public Engagement in Research Network. (Ongoing) Member of Working Together Communications Group. (Ongoing)

Objective 4: Clinical Research Facility Establish a CRF-specific PPI Advisory Group	
Activities	Measures of success
4.1 Recruit members of the group from participants in trials/studies at the CRF	<ul style="list-style-type: none"> PPI Group 'ENGAGE' established, aims agreed, monthly meetings. (Mar 2018) Poster and flyer for group developed. (Nov 2018) PPI Training session with CRF staff to support their promotion of membership to the group. (Dec 2018)

	<ul style="list-style-type: none"> In 2018/19 7 research participants and study partners were involved with the group.
4.2 Develop areas of activity and ways of working, engaging with UK CRF Network	<ul style="list-style-type: none"> ENGAGE worked with staff to develop an Environmental Survey to improve facilities at the CRF. (Feb 2019) Reviewed CRF Application Pack to include link to PPI resources for researchers and to ask about PPI activities undertaken in the study design. (Oct 2018) Contributed to leaflet to raise awareness of research with service users accessing local voluntary sector organisations. (Mar 2019) Contributed to a session for the University of Oxford's NEUROSEC Young Person's Advisory Group, to identify questions young people have about research. (Feb 2019) PPI Manager attends UK CRF Network PPI meetings. (Ongoing)
4.3 Establish regular link between CRF Group and PAR Group	<ul style="list-style-type: none"> PPI Manager attends ENGAGE meetings and meets with CRF PPI Lead regularly. (Ongoing) CRF representative attends PPI Staff Liaison meetings. (Ongoing)

Objective 5: Governance Embed PPI within Research & Development (R&D) procedures	
Activities	Measures of success
5.1 Identify PPI activities that OHFT/University of Oxford can adopt in relation to R&D procedures	<ul style="list-style-type: none"> PPI section added to BRC Study Adoption form for Adult Mental Health and Experimental Health Theme. (Nov 2018) PPI section added to CRF Study Set-Up form. (Nov 2018)
5.2 Identify how the PPI activities can be embedded within R&D procedures and implement	<ul style="list-style-type: none"> <i>Work to be progressed in 2019/20.</i>
5.3 Appoint public representatives to the BRC & CRF Steering Committees	<ul style="list-style-type: none"> Public representative appointed to BRC Steering Committee. (Jul 2017) Experience reviewed of Public Representative to BRC Steering Committee. (Jul 2018) CRF Board agreed public representative role. (Jan 2019)

	<ul style="list-style-type: none"> • PPI Theme presented to BRC Steering Committee. (Oct 2019)
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Objective 6: Research Contribute to Evidence-Based PPI in Mental Health	
Activities	Measures of success
6.1 Identify and take forward areas of mutual interest with PAR Group	<ul style="list-style-type: none"> • NEUROSEC represented at PAR Strategy Group meeting to discuss Collaboration project. (Jan 2019) • PAR Strategy Group Co-chairs contribute to Ethics and Collaboration article. (Mar 2019 and ongoing)
6.2 Identify and take forward areas of mutual interest with other entities; e.g. the Neuroscience, Ethics and Society (NEUROSEC) group; Partnerships for Health, Wealth and Innovation theme of the NIHR Oxford BRC	<ul style="list-style-type: none"> • As above.
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)	<i>Work to be progressed in 2019/20.</i>