

Patient and Public Involvement and Engagement Strategy Progress Report, April 2020

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.

Progress in the PPIE Strategy has been made across all objectives. Key activities from the last 12 months include:

Objective 1: Support

- Between April 2019 and March 2020, the PPI Theme provided PPI support to 36 research projects and engaged around 40 patient and public involvement contributors.
- Projects funded by the 2019/20 PPI Small Grants Programme have reported on the difference PPI made to their study (full details in this [report](#)). PPI has influenced across the design of studies including:
 - How studies are advertised
 - Information include in Participant Information Sheets and provided to study participants
 - The design of study questionnaires and tasks
 - New outcome measures
- We launched a series of PPI Research Meetings (November 2019), co-developed with PPI contributors and research staff, to facilitate PPI involvement in research development. Positive feedback has been received from PPI contributors, and researchers have recorded how PPI has influenced their project. E.g. *'I was able to gain insight into public perception surrounding depression, dementia and pharmacological interventions. This has changed the idea of my future work.'*

- Feedback from our experience survey with PPI contributors (December 2019) will inform our PPI training and approach, e.g. offering more remote methods for people to get involved.

Objective 2: Training

- We delivered 8 workshops for PPI contributors to support understanding and confidence in the research process, partnering with the Oxford BRC and ARC Oxford and Thames Valley, and in co-production with a PPI contributor from each organisation. Further information is included in the [evaluation report](#).
- We delivered 2 workshops for PPI contributors and staff on 'Recording and impact' (September 2019) and 'Working with the seldom heard' (November 2019), in partnership with the Oxford AHSN, Oxford BRC, CRN Thames Valley & South Midlands, and ARC Oxford & Thames Valley.
- We held a PPI workshop for research staff, co-delivered with 6 PPI contributors, and in partnership with RDS South Central, Oxford BRC and ARC Oxford & Thames Valley. The focus was how to work with patients and the public, it was attended by 45 researchers (December 2019).

Objective 3: Outreach & Diversity

- The PPI theme worked with the Oxford Asian Cultural Centre to [co-develop a research engagement event](#) held on International Women's Day (March 2020). Community participants fed back that it was a positive and safe environment to talk about mental health and try new activities. BRC researchers valued the engagement opportunity. E.g. the Older Adults theme reported it allowed them to tackle dementia myths and introduce dementia research with a new community. We are building on this to develop a wider community engagement plan.
- The [NEUROSEC Young Person's Advisory Group](#) has recruited 23 new members from 12 schools in Oxfordshire (November 2019). Recruitment successfully focused on improving intersectional representation in the Group. We are exploring the development of a digital YPAG that deploys a strategic approach to increasing diversity and participation among under-represented and hard to reach groups.

- [OxDARE \(Oxford Dementia Ageing Research\)](#) was jointly awarded the Department of Psychiatry's Award for Public Engagement 2019. Activities included:
 - Developing new PE activities e.g. 'wheel of fortune' to motivate discussion topics including dementia statistics, myth-busting and critical appraisal of 'cure' articles.
 - Continuation of Friends of OxDARE registry and quarterly newsletter to 600 members.
- The PPI theme is developing an Equality Impact Assessment approach to integrate into future work.

Objective 4 relates to the NIHR Oxford cognitive health Clinical Research Facility, reported separately.

Objective 5: Governance

- The OH BRC Steering Committee includes a Patient/Carer Representative.
- The PPIE Strategy is delivered in partnership with our Patients and Research Strategy Group (PAR). PAR has nine patient, carer and public members and six staff members. It is co-chaired by a patient/carers member and a staff member.
- In November 2019 we held a facilitated PAR Away Day, where the group reviewed progress towards the PPIE Strategy and identified next priorities, including governance, leadership of PAR, increasing diversity and evaluating impact.

Objective 6: Research

- The patient/carers and staff co-chairs of the PAR Strategy Group were co-authors with PPI Theme researchers, in '[Co-Production: An Ethical Model for Mental Health Research](#)' (*American Journal of Bioethics*, July 2019, Volume 19, Issue 8).
- [NEUROSEC](#) is developing a normative paper on inclusion and diversity in PPI that will aim to provide guidance to OH BRC researchers who want to conduct PPI in a meaningful and ethical way.

- NEUROSEC is developing two papers on the ethics of partnerships among university researchers, industry, and patients, in mental health research initiatives.

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) • Regular meetings established. (Apr 2018 & ongoing) • Review carried out with members to understand experience (Mar 2019) and identify future priorities (Nov 2019). • Evaluation identified as priority area for 2020/21. • PAR Strategy Group has 15 active members: 9 patient, carer and public members; 6 staff members. (Mar 2020)
1.2 Develop a pool of relevant patients and public members for	<ul style="list-style-type: none"> • PPI Contributor registration developed with PAR Strategy Group and launched. (Nov 2018)

<p>researchers to consult at any stage of their research</p> <p>1.3 With PAR, develop levels of involvement and roles for pool, and other interested public, allowing for involvement according to individual preferences</p>	<ul style="list-style-type: none"> • Developed PPI Monitoring and Evaluation Record for involvement in research projects. (Mar 2019) • Survey to review PPI contributor experience (December 2019) • We currently have 38 patients, carers and public members registered with the PPI Theme.
<p>1.4 Set up and maintain a database of interested, relevant public to keep them informed of opportunities</p>	<ul style="list-style-type: none"> • GDPR statement added to website. (May 2018) • Annual GDPR database check. (Dec 2019) • Regular sharing of PPI roles and training opportunities to PPI Contributors. Between Apr 2019 and Mar 2020, the PPI Theme has provided PPI support to 36 research projects and engaged around 40 patient and public involvement contributors. (Ongoing)
<p>1.5 Provide a payment policy to researchers, and to the public, allowing for payment from either Trust or University systems</p>	<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) • Policy shared with all research projects that access PPI Contributor Pool.
<p>1.6 Identify and support nominated PPI staff links who will identify BRC Theme/CRF specific PPI needs</p>	<ul style="list-style-type: none"> • Role descriptions agreed. (Apr 2018) • Quarterly meetings established. (Apr 2018 & ongoing)
<p>1.7 Explore small grant scheme to help with theme specific PPI activity</p>	<ul style="list-style-type: none"> • First round of funding launched and 9 PPI projects supported. (Mar 2019) Report on small grant projects published. (Apr 2020)
<p>1.8 Create and share a central collection of internal PPI templates and guidance</p>	<ul style="list-style-type: none"> • 'Introduction to PPI for researcher staff' guide published. (Sep 2018) • PPI Project Form (planning resource) published. (Nov 2018) • PPI Contributor Experience questions developed for PPI Small Grants projects. (Nov 2019)
<p>1.9 Identify and signpost external PPI resources for researchers and</p>	<ul style="list-style-type: none"> • Web pages regularly updated including with new PPI opportunities and training. (Ongoing)

public through dedicated web pages	<ul style="list-style-type: none"> • PPI Manager attends NIHR BRC Network PPI meetings. (Ongoing)
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Objective 2: Learning Provide opportunities for PPIE Learning and Development (L&D) for researchers and the public across the BRC and CRF

Activities:	Progress
2.1 Identify learning needs in PPIE, for staff and the public	<ul style="list-style-type: none"> • PAR Survey with research staff. (Sep 2019) • PAR Member Review. (Mar 2019) • PPI Contributor survey. (Dec 2019) • PPI contributors involved in development and review of PPI Workshops. (Ongoing)
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"> • PPI session at Oxford Health BRC Short Course in Experimental Medicine for Mental Health. (Jan 2019, Jan 2020) • Introductory PPI Workshop for Researchers delivered with NIHR Oxford Biomedical Research Centre and Research Design Service South Central. (Dec 2019) • Partner in Working Together PPI Training Programme for research staff and PPI contributors. 2 workshops delivered between Apr 2019 – Mar 2020 • PPI Workshops on the Research Cycle, in partnership with PPI contributors, and PPI Leads at the CLAHRC Oxford and Oxford BRC. (8 workshops, Jan – Aug 2019; 4 workshops, Nov19 – Feb 2020)
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)

	<ul style="list-style-type: none"> • 'Introduction to PPI for researchers' added to OU Department of Psychiatry Staff Handbook. (Sep 2018)
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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"> • Community events attended: Cowley Road Carnival (Jul 2018); OHFT Annual General Meeting (AGM) (Sep 2018 & 2019); OHFT Healthfest (Sep 2018 & 2019); Age UK Oxfordshire AGM (Nov 2018); Oxford Health Carers Day (Jun 2019) • PPI session included in BRC/CRF Open Day agenda, plus a PPI stall in exhibition. (May 2018 & 2019)
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) • OxDARE (Oxford Dementia Ageing Research) was jointly awarded the Department of Psychiatry's Award for Public Engagement 2019. Activity includes Friends of OxDARE registry and quarterly newsletter to 600 members. • 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 workshops. (Ongoing) • NIHR PPI resources and training shared with PPI contributors as available. (Ongoing) • Member of BRC and CRF National PPI Networks. (Ongoing)

<p>3.4 Increase diversity and inclusion of the patients and public we involve/engage</p>	<ul style="list-style-type: none"> • Community awareness event on mental health and research delivered in partnership with local Asian community organisations – case study available on the website. (Mar 2020) • Brain Health Centre hosted a series of ‘afternoon teas’ for people affected by mild cognitive impairment (Oct 2019 – Mar 2020) • Equality Monitoring form developed for CRF participants to support equality, diversity and inclusion activities on research recruitment and participation. • The NEUROSEC Young Person’s Advisory Group has recruited 23 new members from 12 schools in Oxfordshire (November 2019). Recruitment successfully focused on improving intersectional representation in the Group. • Hosted a stall at the Cowley Road Carnival – this event is a celebration of diversity in the local community. (Jul 2018)
<p>3.5 Promote public involvement roles and opportunities via the BRC website and other appropriate routes</p>	<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)
<p>3.6 Support nominated PPI staff links in BRC themes and CRF to identify and address theme/site specific PPI needs</p>	<ul style="list-style-type: none"> • OU Department of Psychiatry established a Public Engagement Group. (Dec 2017)
<p>3.7 Deliver annual activities/events to reach people in rural communities, local community hospitals, schools, voluntary and community organisations</p>	<ul style="list-style-type: none"> • <i>Work to be progressed in 2020/21.</i>
<p>3.8 Capture BRC theme and CRF level PPI activity annually</p>	<ul style="list-style-type: none"> • PPI Staff Links meetings take place quarterly. (Ongoing) • Annual report submitted. (May 2018 & 2019)
<p>3.9 Identify existing internal/external resources to help with PPI, for example University of Oxford Medical</p>	<ul style="list-style-type: none"> • Member of University of Oxford Public Engagement in Research Network. (Ongoing)

Science Division; CRN engagement and communications databases	<ul style="list-style-type: none"> Member of Working Together Communications Group. (Ongoing)
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Objective 4: Clinical Research Facility Establish a CRF-specific PPI Advisory Group	
Activities	Progress
4.1 Recruit members of the group from participants in trials/studies at the CRF	<ul style="list-style-type: none"> The CRF PPI Group, ENGAGE, is made up of current and past research participants and service users that have accessed the CRF. It meets every two months and aims to promote participant involvement, improve the experience of research participants, and raise the profile of research in mental health. Poster and flyer for group developed and updated. (Nov 2018, Nov 2019) PPI Training session with CRF staff to support their promotion of membership to the group. (Dec 2018)
4.2 Develop areas of activity and ways of working, engaging with UK CRF Network	<ul style="list-style-type: none"> The Brain Health Centre (BHC) PPI Advisory Group supported the development of the centre. Activities in this reporting period have included producing 2 questionnaires to collect pre- and post-appointment feedback from patients, and participating in walk-through activities to provide feedback on length, structure and other practical aspects of the BHC clinic appointment. ENGAGE worked with staff in redesigning CRF participant experience feedback process (April 2020) 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)

	<ul style="list-style-type: none"> • 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	Progress
5.1 Identify PPI activities that OHFT/University of Oxford can adopt in relation to R&D procedures	<ul style="list-style-type: none"> • The PPIE Strategy is delivered in partnership with our Patients and Research Strategy Group (PAR). PAR has ten patient, carer and public members and six staff members. It is co-chaired by a patient/carers member and a staff member. • 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"> • PPI Manager attends R&D pipeline meetings. • PPI content included in development of OHFT R&D Training (March 2020 and ongoing)
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) Public Representative sat on mid-term review. (Oct 2019) • Experience reviewed of Public Representative to BRC Steering Committee. (Jul 2018)

	<ul style="list-style-type: none"> • CRF Board agreed public representative role. (Jan 2019) • PPI Theme presentation to BRC Steering Committee. (Oct 2018) • PAR Away Day reviewed progress towards the PPIE Strategy and identified next priorities, including increasing diversity and evaluating impact. (Nov 2019)
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Objective 6: Research Contribute to Evidence-Based PPI in Mental Health	
Activities	Progress
6.1 Identify and take forward areas of mutual interest with PAR Group	<ul style="list-style-type: none"> • The patient/carer and staff co-chairs of the PAR Strategy Group were co-authors, with researchers from the PPI Theme, in 'Co-Production: An Ethical Model for Mental Health Research' (<i>American Journal of Bioethics</i>, Volume 19, Issue 8).
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"> • NEUROSEC is developing a normative paper on inclusion and diversity in PPI that will aim to provide guidance to OH BRC researchers who want to conduct PPI in a meaningful and ethical way.
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>Not progressed</i>