

Oxford BRC patient and public involvement and engagement (PPIE) review 2021

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1. Purpose and context of report

In April 2021, the National Institute for Health Research (NIHR) launched its competition for five years' funding of NIHR Biomedical Research Centres (NIHR BRCs) in England. There are 20 BRCs of which Oxford BRC is one of the largest. NIHR BRCs undertake high-quality early translational and experimental research. This competition is the fourth round of funding for the NIHR BRC scheme since it was established in 2007/8 and, if successful, will be Oxford's BRC-4.

This report outlines the findings of a review of Patient and Public Involvement (PPI) and Public Engagement (PE) in Oxford BRC-3 (referred to as the PPIE Review). It has been undertaken in order to guide and inform the development of a new PPIE Strategy for the next round of funding for Oxford BRC.

While the NIHR gave Oxford BRC's PPIE work a green RAG¹ rating based on the 2019-2020 Annual Report, this PPIE Review is more comprehensive, provides a clearer picture to inform the BRC-4 PPIE Strategy. This report outlines the process and findings of the PPIE Review which included a range of work mainly undertaken over the last six months. This PPIE Review presents recommendations for the BRC-4 PPIE Strategy.

As required by NIHR, the Oxford BRC-4 bid submission will include a BRC-4 PPIE Strategy and a review of activities in BRC-3, the latter being a summary of this report. The PPIE Review has a greater focus on PPI than PE as initially the scope of the PPIE Review was solely PPI. This was later changed to include PE so that Oxford BRC-4 will have a combined BRC-4 PPIE Strategy (see Appendix 1.4).

2. NIHR's commitment to PPI

Background to the NIHR's policy and commitment to PPI are provided by the 2015 publication [Going the Extra Mile](#), the NIHR's ten-year plan for public involvement and engagement. Its vision is "A population actively involved in research to improve health and wellbeing for themselves, their family and their communities" and its mission is to have "The public as partners in everything we do to deliver high quality research that improves the health, wellbeing and wealth of the nation". Complementing this is the 2018 NIHR [UK Standards for Public Involvement](#) which provides a set of values unpinning PPI².

The NIHR has recently further demonstrated its commitment to PPI by requiring all funding applications to include PPI plans with an emphasis on PPI throughout the project lifecycle, and a named PPI Lead on the research team. In addition, the NIHR has identified five priorities³ for PPI going forward, as well as three overall priorities⁴. These documents and priorities are key pillars for the Oxford BRC-4 PPIE Strategy.

A further imperative for embedding PPI comes from a recent Department of Health publication, *Saving and improving lives: the future of UK clinical research delivery*. This has five key themes, one of which is "Patient-centred research, research open to everyone, participation as easy as possible".

¹ RAG is an acronym that stands for Red Amber Green and relates to project status reporting which is utilized to indicate how well a certain project is performing.

² Inclusion, Working Together, Support and Training, Communications, Impact and Governance.

³ Improved equality, diversity and inclusion in public involvement; appropriate standards, incentives and processes for involvement; adequate capacity for involvement; improved digital working and engagement; capturing the value and impact of public involvement.

⁴ Collaboration, levelling up, EDI.

3. Oxford BRC-3 PPI – structure and Strategy

PPI is delivered both centrally and in the BRC's Research Themes. Central PPI refers to organisation-wide PPI activities, such as training, processes and guidance. The PPI in Themes relates to PPI on particular projects. For most of Oxford BRC-3, central PPI has been delivered by one PPI Manager in the cross-cutting Theme of Partnerships, Health, Wealth and Innovation (PHWI) which has not been sufficient resource for a BRC of Oxford's size. Following a mid-term review in 2019, further resource has been provided by the appointment in October 2020 of a new Public and Community Involvement, Engagement and Participation (PCIEP) Lead.

The Oxford BRC-3 PPI Strategy is structured around five work streams – streamlining, benchmarking, mainstreaming, partnering and training⁵. While these work streams offer broad priorities for the central PPI function, they do not provide clear direction for Themes delivering PPI, an issue to be addressed in the new Strategy. In order to establish progress against the Oxford BRC-3 PPI Strategy, a mini progress review was undertaken in 2020 by the Steering Committee patient representative, PPI Manager and PCIEP Lead (Appendix ⁶). This current PPIE Review updates that work and, by looking at more material (including PPI delivered by Themes) and involving a wider group of perspectives, is more comprehensive.

Recently, Oxford BRC has decided to include PE with PPI in the new BRC-4 PPIE Strategy as have many other BRCs including Oxford Health (OH). The rationale for this is because PPI/PE work intersects and working more closely, with a joint strategy, will allow us to build capacity, provides opportunities for learning and widens the spectrum of the ways people can be involved/engaged (Appendix).

4. Project team

A PPIE Strategy Project Group is working on the PPIE Review and Strategy development. The group includes the Steering Committee patient representative, two PPI Advisory Group members, three PPIE staff and a Clinical Researcher who has recently joined. This PPIE Review has highlighted the value of working collaboratively with PPI contributors (new and existing) to provide a range of perspectives and skills and ensure the BRC-4 PPIE Strategy is widely accessible.

The Strategy Project Group takes a co-produced approach, applying principles such as, sharing power, accessibility and valuing each member's opinion equally. One of the ways this is demonstrated is by a joint PPI/Staff lead and the PPI lead chairing meetings. Prior to the work starting, the PCIEP Lead had a meeting with two co-production leads at Oxfordshire County Council to discuss principles and approach. This dialogue and mutual learning is continuing with the PCIEP Lead attending the Oxfordshire County Council Co-Production Champions meeting in May.

5. What is included in the PPIE Review

A number of work streams have informed this PPIE Review, as outlined below:

⁵ Examples of these are: Streamlining = simplifying processes and material. Benchmarking = internal process to compare PPI activity and provide frameworks. Mainstreaming = integrating PPI into research studies by providing researcher support. Partnering = working with other organisations (e.g. AHSN, ARC, OH BRC). Training = training PPI contributors and researchers.

⁶ Appendix 1 was written in 2020 and the timeline outlined in Section 5, page 10, has changed.

- **Central PPI function** mapped against the BRC-3 PPI Strategy. Prior to the Strategy Project Group being set up, the PCIEP Lead, PPI Manager and Steering Committee patient representative mapped PPI activity against the six UK Standards for Public Involvement (Appendix).
- **Annual reports by each Theme.** Five members of the Strategy Project Group reviewed the Theme Annual Report submissions over the last three years. They explored evidence of PPI impact, inclusion, support and learning and communications. (Appendix 2)
- **Work with new PPI contributors** to provide fresh eyes on existing work and identify priorities going forward. During the first quarter of 2021, we worked with a new group of eight PPI contributors from communities generally under-represented in our work, including: Black, Asian and other minority ethnic communities, LGBT+, carers and people who had used mental health services. Contributors undertook tasks over five weeks and we received written and verbal feedback on the Oxford BRC website, webinars and talks, PPI and PE materials, e.g. handbooks and brochures, and advice on outreach. (Appendix 3).
- **Meetings with Theme leads and liaisons;** PPI Manager and PCIEP Lead held 33 meetings with 31 Theme leads and liaisons covering 16 Themes. (Appendix 4).
- **Impact/reporting work** – this paper resulted from meetings with the patient representative on the Steering Group, the BRC’s Chief Operating Officer (COO) and Clinical Research Manager as well as discussions with Theme liaisons, the PCIEP Lead and PPI Manager. (Appendix).
- **Feedback from the [PPI Advisory Group](#)** – the BRC PPI Advisory Group were asked for examples of things that they thought were working well with regard to PPIE and things that needed improvement. This feedback is summarised in the document. (Appendix 5).
- **Benchmarking report.** Meetings to compare PPIE resources and priorities with UCLH and Manchester BRCs took place in 2019 (Appendix 6).
- **SWOT & PEST analyses** – all the Project Team (except the Clinical Researcher who was not yet working on the project) contributed to the SWOT and PEST analyses⁷ (Appendix 7).

6. Findings

Key findings are reported under the six UK Standards for Public Involvement.

Inclusion: Working with under-served communities has recently increased with the new PPI group. In addition, the Working Together Group (a PPIE partnership of research and NHS organisations hosted by Oxford AHSN) has delivered training workshops on working with Seldom Heard communities. There is evidence in the Annual Report of Themes involving people from under-served communities (e.g. young people, carers of people with dementia, mothers), however most of this reflects the condition being researched rather than efforts to include people from communities widely under-represented in PPI (e.g. people from minority ethnic groups or from the LGBT+ community). Current initiatives to improve inclusion include a new expanded group from under-served communities with Oxford Health; a literature review on outreach methods; the PCIEP Lead taking part in OUH Quality Improvement Hub in 2021 with a focus on EDI improvement; and changes to the website to reflect diversity.

Working Together: There is a strong culture of working together with the NIHR infrastructure, particularly in training PPI contributors. In addition there is collaboration with other BRCs on research projects, through the PPIE Leads network and with the Patient Experience Team at the

⁷ The PEST analysis is a framework to identify some of the external factors which may be relevant to our strategy. The SWOT is a way to analyse our organisation (Oxford BRC) - What we are good at (Strengths) and what we are not so good at (Weaknesses) along with the external world (i.e. outside Oxford BRC) where the Opportunities and Threats are identified.

Oxford University Hospitals NHS Foundation Trust (OUH). There is strong collaboration with PPI Advisory Group members, with recent greater input from members of this group on the work with new PPI contributors. However, there is a need for greater collaboration with BRCs and organisations from deprived areas in order to address the NIHR's levelling up agenda.

Training and support: A strong programme of PPI contributor training and development webinars is delivered in conjunction with the NIHR Applied Research Collaboration (ARC) Oxford and Thames Valley and Oxford Health BRC. However, there is a need for increased training for new PPI contributors and development support for existing contributors. Researcher training and support is delivered frequently on an ad-hoc basis and a pilot PPI researcher training session was held with the Diabetes Theme. As identified in the benchmarking report, some other BRCs have an established training programme for researchers and there is a need to embed training of researchers in both PPI and PE, to complement bespoke individual training and support. In order for this to be successful, Theme Lead support is required and for it to be embedded into induction or other training. Current initiatives include more Theme-specific PPI training, annual report training as well as a continued programme of webinars for PPI contributors.

Communications: The Involvement Matters e-newsletter is sent regularly to PPI contributors and combines activities and opportunities across the NIHR infrastructure. The PPI contributors looked at a range of materials, including the Oxford BRC website and a range of research materials. They highlighted that the way PPI and health research is communicated needs to be more accessible. They highlighted the importance of accessibility for a range of audiences and thought about how and where patients and public feature in content. They pointed out things that can be off-putting, such as the use of jargon, abbreviations and acronyms, lengthy videos and lack of engaging images, particularly of patients and their families. Current initiatives include: guidance for researchers and theme leads on improving their website pages.

Impact: The Theme Leader/Liaison meetings and annual report submissions indicate that there is an understanding of the need for and existence of PPI work, particularly for grant funding. However, there is a lack of consistent evidence on quantity, quality and impact of PPI. Improved reporting of PPI is required along with evidence of impact which requires both a systematic approach and full support from Theme Leads. Current initiatives include; 10 PPI best practice case studies, highlighting impact; four researchers are mapping PPI in their Themes as part of their leadership training; training on reporting impact in the annual report is being provided.

Governance: Over the course of BRC-3, there has been increased PPI representation in governance through a patient representative on the BRC Steering Committee (since March 2019), a revived PPI Advisory Group, 10 Theme-wide PPI groups (Appendix 8) and evidence of PPI representatives on research project steering groups. The PPI Advisory Group is engaged and highly skilled, three members of whom have worked in a co-produced way as part of the Strategy Project Group. Leadership support for PPI is demonstrated by regular support from the COO and an increased PPI slot in the regular Theme Liaison meetings. There has been increased resource through a new PCIEP Lead and funds to pay for PPI centrally, but a lack of resource to fund deliver and coordinate PPI in Themes.

7. Recommendations for priorities for the BRC-4 PPIE Strategy

Based upon the findings from this PPIE Review and the NIHR priorities, possible areas for the BRC-4 PPIE Strategy to focus on are listed below, mapped against how they link with the UK National Standards for Public Involvement, the five NIHR PPI priorities and NIHR's overall priorities. These draft priorities will be discussed, refined and agreed with the Strategy Project Group in May. Following this, the priorities will be included in the draft BRC-4 PPIE Strategy.

Potential BRC-4 PPIE Strategy priority	(Ref) UK National Standards for Public Involvement	(Ref) NIHR five PPI priorities	NIHR overall priorities
Making health research accessible	Inclusion, Communications	EDI/digital working	Levelling up, EDI
Equality, diversity and inclusion (EDI) (and Maximising the continuum between engagement and PPI)	Inclusion, Working together, Governance	EDI	Levelling up, EDI
Defining and collecting evidence of impact, including PPIE reporting	Impact, Governance	the value and impact of PI/appropriate standards, incentives, processes	?
Support and training	Governance, Working Together	capacity/resource	Collaboration, EDI
Collaboration (e.g. with OUH, BRCs, other PPIE groups, charities, NIHR, PPI contributors)	Communication, Inclusion	EDI	Collaboration, EDI

8. Conclusion

While it has not been possible in this PPIE Review to cover all aspects of PPI or PE activity in Oxford BRC-3, with PPI contributors and PPIE staff working collaboratively and with reference to a wide range of material, this PPIE Review provides clear direction for the BRC-4 PPIE Strategy.

The Strategy Project Group will lead the development of the BRC-4 PPIE Strategy from May until the bid submission in October. The development will include internal and external consultation.

Contributors:

All members of the Strategy Project Group have contributed to this Review:

Alan Chant - Patient Representative, Oxford BRC Steering Group and PPI Advisory Group member

Sue Duncombe - PPI Advisory Group member and Strategy Project Group co-lead

Polly Kerr – PPI Manager

Kelly Roddy – Events, Marketing and Engagement Manager

Rachel Taylor, PCIEP Lead and Strategy Project Group co-lead

Magdalen Wind-Mozley - PPI Advisory Group member

Report written by Rachel Taylor and reviewed by the Strategy Project Group (above members). Peter McQuitty, a PPI Advisory Group member, also contributed to the PPIE Review.

23 April 2021

Appendix 1: A proposal for developing the Oxford BRC-4 Patient and Public Involvement (PPI) Strategy

Please note: an Addendum has been added pages 11/12.

1. Purpose

The purpose of this document is to outline:

- A brief background to the NIHR BRC Patient and Public Involvement (PPI) landscape.
- Oxford BRC-3's PPI progress.
- A proposed approach to developing an Oxford BRC-4 PPI Strategy.

Discussions between Alan Chant (AC, Patient Representative), Polly Kerr (PK, PPI Manager and Rachel Taylor (RT, Public and Community Involvement, Engagement and Participation, PCIEP, Lead) initiated this document. This latest draft incorporates reviews by the Chief Operating Officer, Vasiliki Kiparoglou, and the BRC PPI Advisory Group.

It is noted that while there are references in some places to Public Engagement (PE), this document primarily explores PPI. This is partly due to the need for Oxford BRC to develop its PPI (see Section 2), and also because PE is more widely resourced and embedded across university research. However, there is the potential for a similar discussion and approach for Oxford BRC's PE activities.

2. Background

The increasing importance of PPI in NIHR funded research is evidenced by:

1. The launch in 2019 of the ["UK National Standards for Public Involvement"](#) (the Standards) which sets out the six Standards of: Inclusive Opportunities, Working Together, Support & Learning, Communications, Impact and Governance⁸.
2. Increased commitment to Equality Diversity and Inclusion (EDI) and co-production with PPI partners in the Standards.
3. NIHR's requirement that future research funding applications have a named PPI Lead on the research team and greater emphasis on PPI throughout the project lifecycle.

NIHR feedback on the Oxford BRC-2 and BRC-3 mid-term review highlighted the need for improvement in PPI, though detail on short-comings was not specified. Given this feedback and the points above, the assumption is that the NIHR will have increased expectations of PPI and PE in BRC-4 applications. Therefore, more robust and compelling PPI/PE activity is required, as well as evidence of this activity.

⁸ [UK National Standards for Public Engagement, NIHR Centre for Engagement and Dissemination, 2019](#)

In order to drive this, PPI/E capacity has been increased with the recent appointment of a new PCIEP Lead in the BRC Core Team who works closely with the PPI Manager and, where they exist, other theme specific PPI leads. In addition, PPI contributor profile has been increased through the appointment of AC onto the BRC Steering Group and the establishment of the BRC-wide PPI Advisory Group prior to the mid-term review.

4. Oxford BRC-3 PPI progress

4.1 Progress against the PPI Strategy for Oxford BRC-3

The *PPI Strategy for Oxford BRC-3*⁹ is structured around five work streams – streamlining, benchmarking, mainstreaming, partnering and training¹⁰. Significant progress has been made against each of these by the core PPI function: Appendix 1.1 (Column 1) shows key achievements mapped against the five work streams and the NIHR six Standards (Column 2).

However, the five work streams are quite broad and to ensure greater direction going forward in BRC-4, an Implementation Plan is recommended which would sit alongside the BRC-4 PPI Strategy. The Implementation Plan would detail SMART¹¹ objectives to deliver the Strategy and would allow for closer monitoring of progress.

4.2 Theme PPI

The annual report entry is the key reporting mechanism for PPI activity across the themes. Each theme outlines its PPI/PE activities in the annual report, providing a narrative and showcasing much excellent practice. However, it is difficult to get a full and consistent picture because theme entries vary in reporting quality, there is a lack of detail on outcomes, PE and PPI are not always distinguished separately, and measurable data is lacking. StudyLine has been explored as another option for recording activity, with questions about PPI and PE introduced onto the system in 2020. However, recent conversations with theme leads and liaisons indicate Studyline is not suitable for this.

Therefore, better PPI reporting/recording will be a priority for the remainder of BRC-3 and for BRC-4. Improved reporting will provide an important baseline from which to measure progress (an approach to improved reporting is outlined in Appendix 1.2).

5. Development of the Oxford BRC-4 PPI Strategy

To develop the BRC-4 PPI Strategy, it is proposed that a review of BRC-3 PPI activity is undertaken first. This review will benchmark progress against the Standards, identify achievements and gaps and recommend priorities for the BRC-4

⁹ [Oxford BRC PPI Strategy](#)

¹⁰ Examples of these are: Streamlining = simplifying processes and material. Benchmarking = internal process to compare PPI activity and provide frameworks. Mainstreaming = integrating PPI into research studies by providing researcher support. Partnering = working with other organisations (e.g AHSN, ARC, OH BRC). Training = training PPI contributors and researchers.

¹¹ SMART – Specific, Measurable, Achievable, Realistic, Time-Bound

PPI Strategy which will be structured around the Standards. A draft BRC-4 PPI Strategy will then be developed for wide consultation, with a final Strategy ready for BRC-4 submission to the NIHR in July 2021. Following this, the Implementation Plan will be developed, which we anticipate will have a particular focus on and EDI.

An approximate timetable is outlined below:

Approval of draft proposal (this document)	19 January
Evaluation of BRC-3 PPI activities and identification of BRC-4 priorities	February – 31 st March 2021
Draft Strategy	April 2021
Consultation with researchers, PPI contributors, partner organisations (and public?)	May 2021
Revise and finalise based on comments	June 2021
Implementation plan	July-September 2021

6. Co-production

To develop the BRC-4 PPI Strategy we propose to adopt a co-production model, working in partnership with PPI contributors. This approach reflects that of other BRCs and public bodies¹² and is supported by the BRC's PPI Advisory Group, Chief Operating Officer and Director We will follow the co-production principles outlined in the NIHR's Going the Extra Mile¹³ and Co-Production in Action (2019)¹⁴. These principles refer to research but also apply to strategic work.

Key Principles

- **Sharing of power** – *the research is jointly owned and people work together to achieve a joint understanding*
- **Including all perspectives and skills** – *make sure the research team includes all those who can make a contribution*
- **Respecting and valuing the knowledge of all those working together on the research** – *everyone is of equal importance*
- **Reciprocity** – *everybody benefits from working together*
- **Building and maintaining relationships** – *an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.*

The practicalities of co-production will be worked out collaboratively with PPI contributors once roles are filled. We will be looking to recruit PPI contributors from a range of backgrounds. We will particularly encourage applications from those

¹² [Leeds](#) and [Imperial](#) BRCs have co-produced PPI strategies. [Oxfordshire County Council](#) co-produces a range of strategies.

¹³ [Going the Extra Mile, NIHR, 2015](#)

¹⁴ [Co-Production in Action, NIHR, 2019](#)

currently underrepresented, including those who identify as Black, Asian, Minority Ethnic (BAME) or Lesbian, Gay Bisexual Transgender (LGBT+).

We will follow an open recruitment process inviting applications from both existing PPI contributors as well as those new to PPI, “buddying up” contributors with different levels of experience for mutual learning and providing training.

The PPI roles will be paid according to the Oxford BRC-3 *Multi-agency PPIEE POLICY for expenses and payments 2020*. We plan to recruit PPI partners to work in partnership with RT or PK. We estimate 60 days (@ £150 per day) = £9000 and estimate an allowance of £500 for expenses, total budget = £9500.

We estimate half of the work being undertaken in this financial year¹⁵, during which PPI contributors will work on the review of BRC-3. A role description for PPI contributors will be advertised in January (draft Appendix 1.3).

Paper prepared by: Rachel Taylor (BRC PCIEP Lead), with support from Alan Chant (BRC Patient Representative) and Polly Kerr (BRC PPI Manager)

January 2021

¹⁵ There is currently c. £15000 remaining in the PPI budget for use in 2020/21 financial year.

Appendix 1.1

Table 1: BRC-3 PPI activity

S= Streamlining, B= Benchmarking, M= Mainstreaming, P= Partnering T= Training*

Existing Activity (mapped against sections in BRC-3 PPI Strategy*)	National Standards for Public Involvement
<p>Working with seldom heard communities on training (P, T)</p> <p>PPI contributor contact details spreadsheet</p> <p>Involvement Matters - notifications about events, training and opportunities(S)</p> <p>Listings for involvement opportunities sent to researchers and PPI contributors (S)</p> <p>Training for PPI contributors (P,T)</p>	<p>Inclusive Opportunities</p>
<p>Working Together Group (ARC, AHSN, OH and Oxford BRCs, CRN) group meets bi-monthly (four areas – comms, impact, training and EDI) (P)</p> <p>BRC PPI Leads Network (P,B)</p> <p>Medical Sciences Division PPI/E and Comms meetings (P)</p> <p>Training delivered in partnership with OH BRC and ARC (P,S,T)</p> <p>UCL and Manchester visits - BRC benchmarking (B)</p>	<p>Working Together</p>
<p>Training delivered:</p> <p>Workshops and webinars for PPI contributors (roughly monthly) (T, P)</p> <p>PPI training session for researchers (Dec 2019) and other ad hoc talks (P, T, M)</p> <p>Regular ad-hoc support to researchers and PPI contributors (S,T,B)</p> <p>Guidance for contributors and researchers on website (S,T,B)</p> <p>Researcher survey (S,T,B)</p> <p>Social “help” session for PPI contributors (S,T,B)</p>	<p>Support and Learning</p>

<p>PPI opportunities listings (S)</p> <p>Involvement Matters (S,T, P)</p> <p>Website development/Google Analytics (S,B)</p> <p>Dissemination through partners – Working Together, University, individual researchers, theme liaisons etc (S,B)</p> <p>Case studies on website (M)</p>	<p>Communications</p>
<p>Working Together Group Impact work stream (B, P)</p>	<p>Impact</p>
<p>PPI Advisory Group (M, P)</p> <p>AC on Steering Group (M, P)</p> <p>Annual reporting on PPI (M, B)</p> <p>Studyline reporting (M, B)</p>	<p>Governance</p>

Appendix 1.2

Improving Patient and Public Involvement reporting in Oxford BRC

1 Introduction

This paper provides a brief description of the key drivers and challenges relating to reporting Patient and Public Involvement (PPI) in Oxford BRC and proposes a way forward.

2 Background

In recent Oxford BRC reviews, the NIHR has identified the need for improved PPI in research. Oxford BRC is committed to increasing both the quantity and quality of PPI, and to capture it more systematically. However, one of the challenges is the lack of a baseline of existing activity from which to demonstrate improvement. The BRC's Patient Representative, the PPI Manager and the PCIEP Lead, are working closely with the COO and Research Manager to develop a practical system that works across the 20 themes.

As well as evidence of activity, the NIHR requires evidence of PPI "impact" which is identified as a key responsibility for the PPI lead (a new requirement for all future NIHR studies). From the perspective of both PPI contributors and researchers, PPI impact (in addition to process) is important because it shows how PPI makes positive difference to research.

Given the requirement to capture impact as well as activity, and in order to avoid multiple reporting, it therefore makes sense to capture these together, at the end of a cycle of PPI input. This approach is reflected in tools, such as GRIPP2, which are designed to capture activity, outcomes and learning.

3. The challenges of PPI reporting

Capturing PPI activity and demonstrating impact is recognised as complex and challenging and is explored in a number of papers (see 4.3). Some of the difficulties are:

- PPI is delivered in a variety of ways (methods and points in the research cycle) and lends itself to narrative description that is difficult to quantify.
- There is often no allocated resource to a time-consuming task, with only a handful of themes having dedicated PPI staff and budget.
- The topic of "impact" in relation to PPI is contested, raising questions around the value of collecting data.
- There has been minimal firm requirement from funders until relatively recently for the PPI element of the research process to be included in published papers (unlike, for example, ethical approval, consent, and literature review).
- Like many other BRCs, the Oxford BRC has not made PPI reporting a requirement, except for the NIHR annual report.

Despite the challenges, there is widespread commitment amongst local and national NIHR colleagues to find an approach that works. This is demonstrated by "impact" being one of the four priorities for the regional Working Together partnership and it being a key topic of discussion at a recent annual BRC PPI Leads meeting.

4 Existing knowledge

4.1 Current channels for PPI reporting

Currently there are four ways PPI activity in Oxford BRC is captured:

- The PPI section of the Annual Report. This is useful because all Themes fill it out and it provides an interesting descriptive narrative, highlighting some great practice. However, it is only completed once a year, does not capture everything, does not provide a great deal of quantitative data and several sections, including “impact” are not completed by most themes (though it is recognised that the NIHR template for the PPI section changes every year, which doesn’t facilitate consistent reporting).
- Some Theme Liaisons collect PPI data. However this is done in different ways and not disseminated to the BRC PPI “core” team.
- Studyline. Themes have been asked to record PPI on StudyLine but only a small percentage has done so. It is limited in that it only captures quantitative information and has not been widely used to report PPI.
- Published papers. There does not seem currently to be an audit of PPI reporting in publications, but is something that could be explored.

4.2 Conversations with Theme Leads/Liaisons

Fifteen conversations (covering ten Themes) with Theme Leads/Liaisons and other staff with responsibility for PPI highlight the following:

- Four Themes have some sort of recording mechanism, but do it in a very different ways.
- Some Themes would welcome the requirement of a simple quarterly report, others not.
- Theme lead support for PPI reporting and it being a BRC requirement are seen as crucial to ensure it happens.
- There is lack of resource for reporting which is time consuming. Most Liaisons or other staff with “PPI responsibility” have minimal time allocated to PPI. Only one Theme employs a 0.5 FTE whose sole responsibility it is to support PPI. Another Theme is currently sourcing funding for the same for the duration of BRC-3 in recognition of the lack of resource and is recommending the same for BRC-4.
- For BRC-4, a PPI 0.5 FTE position for each Theme would provide the opportunity to embed PPI effectively across the BRC.
- Some have heard of Studyline, none recommended it as a reporting tool for PPI. One Liaison said that StudyLine is populated from SiteLine which is where researchers update their research projects – this needs more exploration.

4.3 Literature on reporting and impact

There are a number of key academic papers exploring PPI recording and impact which need to be read to inform our approach. Examples are listed below:

Impact:

- Mapping the impact of PPI on health and social care research: a systematic review - Brett et al (2012)
- Patient and public involvement in NIHR research 2006-2019 - Russell et al (2019)
- The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research – Brett et al (2010)
- Evaluating public involvement in research – People in Health, West of England (2018)
- The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? - Jill Russell et al (2020)

Reporting:

- 'Reaching consensus on reporting Patient and Public Involvement (PPI) in research: methods and lessons learned from the development of reporting guidelines' - Brett et al (2017)
- GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research - Staniszewska et al (2017)
- Frameworks for supporting PPI in research – Greenhalgh et al (2019)

5. Recommended Next Steps

Below are the proposed steps we take in order to increase our knowledge of challenges and solutions and work with the Themes on a solution.

Complete theme interviews ensuring a particular focus on views about reporting / impact	31 January	RT/PK
Read papers (4.3) and write summary	31 January	RT/AC
As a result of meetings*, invite 3-5 to help us with the reporting form and communications strategy	31 January	RT
Design reporting form	12 February	AC/RT/PK /Liaisons
Pilot reporting form (with 5 Themes)	01-15 March	AC/RT/PK /Liaisons
Evaluate and amend form	15-31 March	AC/RT/PK /Liaisons
Meeting to discuss pilot with key staff	15 March – 15 April	AC/RT/PK /Liaisons

*Lead, Liaisons or other staff with responsibility for PPI.

Rachel Taylor

10 December 2020 vs. 2

Appendix 1.3

DRAFT Advert for PPI Contributors



Can you help involve patients and the public in research?

The NIHR Oxford Biomedical Research Centre (Oxford BRC) brings together the University of Oxford and Oxford University Hospitals NHS Foundation Trust to fund medical research.

Patient and Public Involvement (called PPI) helps to decide what research to do, how to do it and what happens with the research.

We are looking for several people to help with this work.

We particularly encourage applications from those who identify as Black, Asian, Minority Ethnic (BAME) or Lesbian, Gay Bisexual Transgender (LGBT+). These communities are currently underrepresented in this work.

What's involved:

- Working with PPI staff to evaluate the BRC PPI work.

Are you:

- A patient, family member, carer or member of the public?

Do you:

- Have experience or interest in health research?

Can you:

- Undertake at least 5 days before the end of March 2021?

We would love to hear from you: Contact Rachel Taylor (rachel.taylor@ouh.nhs.uk) or 07515646822 for more information.

- **Start:** Apply by 31 January, interviews early February, starting as soon as possible after interviews.
- **Payment:** £150/day (7.5 hours) plus expenses. These roles can also be undertaken with reduced or no payment.

Appendix 1.4

Addendum to “A proposal for developing the Oxford BRC-4 Patient and Public Involvement (PPI) Strategy”

1. A joint PPI / PE (PPIE) Strategy

Following meetings with Kelly Roddy, Vasiliki Kiparoglou, Alan Chant, Rachel Taylor, Polly Kerr, PPI Advisory Group members we have agreed to merge the PPI /PE strategies for BRC4.

The rationale is outlined below:

- There is an overarching moral, democratic and ethical motivation to involve and engage the public in research, applying to both PPI and PE.
- PPI/PE work intersects. Working more closely together allow us to build capacity, provides opportunities for learning and widens the spectrum of the ways people can be involved/engaged. A joint strategy will help to achieve this.
- Working together on shared objectives provides the opportunity for a more coherent message to the public which provides both an “offer” (PE) and an “ask” (PPI).
- For the above reason, outreach to seldom heard communities will be better achieved if we work together. Rather than just asking for help (PPI), we can also offer educational and informative events (PE).
- The PPI Advisory Group (which Kelly is a member of) and other PPI groups would be a resource for PE to engage with more actively, providing public influence on the direction of PE.

Other notes:

Jo Crocker (PPI researcher) is possibly proposing a research project exploring the interface between PE and PPI – this might provide an opportunity to evaluate the approach.

We need to be clear about the potential benefits of this approach.

Up to 50% of other BRCs have taken this approach – here are some examples [Imperial](#), [Manchester Moorfields](#) and [Oxford Health](#).

2. Recruitment of new PPI contributors to support the review

The paper outlined an “open” recruitment, advertising through all our existing networks. This would have potentially resulted in a lot of applications and the need to have a competitive recruitment.

However, we changed tack after reflecting on the following 1. The need to recruit from seldom heard communities 2. The short timescale to complete the work 3. The desire to avoid a competitive recruitment for such a time limited piece of work (5days) and which could disadvantage minority communities or those who have not previously undertaken PPI.

We therefore decided to use a purposive sampling approach. We checked this approach with PPI managers in other BRCs and with Jo Crocker and Julie Darbyshire, all of whom agreed it was a valid approach. The approach is outlined below. It resulted in a quick response and nine new participants ranging in age from 18-50s, 8 of whom are from minority ethnic groups with a mixture of lived experience and public perspective.

- We send ad & role description to PPI Advisory Group and explain approach. Explain we are looking for about 3 PPI Advisory Group members to take on one of these roles (with priority given to those with experience working with minority communities).

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2017-2021

- We ask them to approach their contacts from minority communities (particularly specified on the ad) to see if they are interested in applying.
- At the same time, we make personal, direct contact with people from minority communities and those with links with these communities to explain the role etc.
- Contacts could include people known personally as well as professionally.
- We appoint on first come/first served basis, ie. We appoint as suitable people approach rather than having a deadline and competitive process.
- We will review the approach to establish lessons learned.

Rachel Taylor, PCIEP lead 8.2.21

Appendix 2: Analysis of PPI sections of BRC annual reports 2017-2020

Process

As outlined in the document *Developing the Oxford BRC-4 PPI Strategy*, we are reviewing BRC-3 PPI activity to identify achievements and gaps and recommend priorities for the BRC-4 PPI strategy. We are using the UK Standards for Public Involvement as a benchmark and are concentrating on three of these which we consider particularly relevant, namely:

- Inclusive Opportunities
- Support and Learning
- Communications

One element of the review of activity has been to analyse the PPI sections of the annual reports for each year of BRC-3 so far.

One member of staff and one member of the BRC PPI Advisory Group took a 'strand' (see Appendix 2.1 for more information) and independently looked through three annual reports (2017-18, 2018-19, 2019-20) for evidence of activity in this area. They also looked for evidence of impact of PPI (also one of the Standards) and for any other interesting or important PPI activity to highlight. See Appendix 2.2 for the table used to record this.

The group then met to discuss their findings which are summarised here, with some examples from each strand.

NB: For this task, we focused solely on evidence of PPI activity, not public engagement (PE).

General findings

It was agreed that the annual report is a very blunt instrument which doesn't enable themes to fully demonstrate the range or quality of PPI that may be going on. This section of the annual report asks for evidence of PPI, PE and participation, and this gives the impression that there is some confusion in understanding the difference between these terms. However, this may not reflect the reality and rather be a result of the reporting mechanism.

Reporting varies between themes – some give concrete examples, others make broad statements eg 'PPI is at the heart of all our research projects'.

The UK Standards for Public Involvement are open to interpretation, and are not well known or understood by many (the majority of?) researchers. Therefore, the content of the annual report is difficult to evaluate. The annual report is not a robust or systematic way of capturing PPI activity taking place, or not, in the BRC.

Support and Learning

'Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.' (UK Standards for Public Involvement)

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We found only a few examples that truly demonstrated this being achieved. Mostly the evidence is of researchers being encouraged to attend training, although specific examples of this weren't noted.

- PHWI (which has responsibility for PPI) had run training workshops for PPI contributors.
- The Cancer theme had contributed to a PPI handbook to clarify information about research, terminology etc.
- The AMR/MMM theme has PPIE as a mandatory part of researchers' annual performance review.

Communications

'Use plain language for well-timed and relevant communications, as part of involvement plans and activities.' (UK Standards for Public Involvement)

Evidence of this had been interpreted broadly and included newsletters, working with charities, keeping in touch with contributors and outreach work to engage with new ones. Because the reports encompass PE and participation as well as PPI, as described earlier, it was not always clear if these were specifically PPI activities.

- The Genomics theme has contributed to a website with a dedicated section for participants in the 100K Genomes programme, with opportunities for patient involvement. Participants have reviewed this website design, and provided patient stories for use in project communications.
- In the Haematology theme, Oxford Blood Group (OBG) allows cross-talk, sharing of good practice and sharing of skills between patients; they are also kept informed about PPI training opportunities and events. OBG commissioned a video explaining its purpose and publishes a monthly newsletter relevant to all haematology patients.

Inclusive Opportunities

'Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.' (UK Standards for Public Involvement)

Although there are many examples across the themes of researchers working with vulnerable groups, evidence of activity to specifically increase access to PPI opportunities to reach under-represented groups was hard to find. We know that Equality, Diversity and Inclusion is an area that isn't currently very strong and that the BRC wants to focus on improving in the future, but because, as described previously, the Standards can be interpreted in different ways, it is difficult to establish the current situation.

- The Obesity theme held roadshows for pregnant women to find out their views on diet, physical activity and weight management to inform online information about gestational diabetes.
- The Cardiovascular, Imaging and Stroke & Vascular Dementia themes have worked with the Alzheimer's Society to involve dementia patients and carers.
- The Musculoskeletal theme worked with the NIHR Young Persons Advisory Group and some, along with their parents, were mentored to become PPI Advisors.

Impact

‘Seek improvement by identifying and sharing the difference that public involvement makes to research.’ (UK Standards for Public Involvement)

The group described impact as ‘we did A, the PPI contributors said B, so we did C which led to D’; also the impact that doing PPI had on the contributors, and on the researchers. There were some good examples of the former but evidence of the latter was not found – this could be because it wasn’t thought to be ‘impact’ and therefore wasn’t collected rather than there not being any.

- In the Cardiovascular theme, input from a PPI steering group to one trial led to modifications in the study design, including the ECG monitoring method, and standard questionnaires being changed to Patient Reported Outcome Measures.
- In the Imaging theme, a study involving a scan while wearing a breathing mask had PPI input to test three masks, with the most acceptable to patients being chosen for the study. A breathing test using the mask before going into the scanner was added into the protocol as a result of this PPI activity.
- In the Musculoskeletal theme, feedback from young people on one trial about their acceptance of minor deformity if it meant they did not need surgery, in contrast to surgeons’ beliefs, changed the trial approach.

Appendix 2.1

Strand	BRC PPI Advisory Group member	PPIE staff
Communications	(Peter McQuitty)	Kelly Roddy
Inclusivity	Magdalen Wind-Mozley	Rachel Taylor
Support and Learning	Sue Duncombe	Polly Kerr

Appendix 2.2

Theme	Evidence of strand (ie. Inclusion, Comms or Support and Learning?)	Y/N	Evidence of impact?	Y/N	Interesting activity to highlight/showcase

Appendix 3: Working with new PPI contributors to support the development of the Oxford BRC-4 PPIE Strategy

Background

During February and March 2021, the NIHR Oxford Biomedical Research Centre (BRC) has been working with a new group of PPIE contributors. The project is part of the development of the new PPIE strategy and had a particular focus on making health research accessible.

We set up this group to help ensure that new PPIE strategy has the public and patients at the core and that it is outward looking. This group, whose members came primarily from under-represented communities, provided fresh perspective and helped point towards priorities for the new strategy.

A co-production approach was followed. To support this, Rachel, the BRC Public and Community Involvement, Engagement and Participation (PCIEP) Lead, had an advice session with Oxfordshire County Council Co-production leads who have co-produced a number of strategies with public contributors and have wide experience of working with under-represented groups. In addition, to support co-produced working, we held a “ways of working” meeting and offered training and support so people could be fully involved. We worked together as equal partners, each individual’s contribution was valued equally and decision making was shared.

Recruitment and group membership

We decided not to do an open recruitment due to the time constraints and because it would likely favour people who had been involved before. As existing Oxford BRC PPIE contributors tend to be of an older age group and from white British backgrounds, we thought that an open recruitment would result in members of a similar profile and be unlikely to result in a diverse group.

Instead we followed a process in line with purposive sampling. We contacted people we knew from under-represented groups and asked them to be involved or contact people they knew who would be interested. Nine new contributors came forward and eight were accepted for involvement following an interview with Rachel.

The group included teenagers, young adults, carers and people from Black, Asian and minority ethnic communities. Group members had a range of experience of health services; including learning disabilities, autism, cancer and mental health services.

They were supported by BRC staff (Rachel, Polly and Kelly) and three long-standing members of the PPI Advisory Group (Magdalen, Sue and Peter). The latter roles were filled after an email was sent to the PPI Advisory Group inviting expressions of interest from people who had experience of working with under-represented groups.

What the group did

The work totalled 5 days per person and payment was £150 per day, in line with usual PPI contributor payments.

After two induction sessions where the whole group met, the new contributors were assigned to one of three groups, which were supported by a staff member and one of the PPI Advisory Group members on the project.

Each week, the group spent around 5 hours on a task they were given. The tasks involved reviewing materials such as advertisements and handbooks, researcher talks and webinars. They explored the BRC's website, giving insight into what worked well and where improvements could be made. They provided insight into training for PPI contributors and how to improve our outreach with under-represented groups.

As the group was providing a primarily "public" rather than "patient" perspective, it was important that there was group discussion to arrive at a consensus¹⁶. After doing the written task, group members discussed their findings collaboratively at weekly group meetings. Once a week the group facilitators of all the groups met to share findings on each task.

What the group said

They highlighted the importance of:

- Accessibility for a range of audiences and how and where patients and public feature in content, including those from under-represented groups.
- Avoiding things that can be off-putting, such as the use of jargon, abbreviations and acronyms, too explicit images of treatment and an elitist-sounding narrative.
- Making documents, web pages and materials shorter and increase the use of images and short videos
- Using bullet points to break up text and plain English.
- Being imaginative in our outreach work and working through our community networks to outreach through mosques, butchers, barbers and taxi drivers.

What happens next

Following this work, Oxford BRC is committed to ensuring:

- Our strategy is outward-facing and patient-centred.
- Our website is accessible, engaging and more patient-centred.
- There is guidance for researchers to help ensure their talks are easy to understand and of an appropriate length and that web page content is accessible.
- Where possible, we will sense-check external materials with patients and members of the public.
- We will improve our outreach with under-represented groups.
- We will continue and develop our work with under-represented groups, starting with a pilot group in conjunction with Oxford Health over the next 6 months.
- In public facing activities, we will use "Get Involved" rather than PPI or PPIE.
- A new email address GetInvolvedOBRC@ouh.nhs.uk.

¹⁶ [Patient and Public Involvement: two sides of the same coin or different coins altogether? Matthew S McCoy et al, 2018.](#)

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The BRC's PPIE team will continue to work with the NIHR Oxford Health BRC to ensure that the voices of under-represented communities are heard and embedded in NIHR research in Oxford.

How did the members describe their involvement

An evaluation survey has been sent and findings will be incorporated when completed. The group members said they found the project rewarding: that they were listened to, and that their contribution made a difference. Speaking of the importance of patients and the public getting involved in research, one contributor, Shamsideen from London, said: "All of those tiny contributions coalesce into a massive breakthrough eventually".

The group's advice to someone thinking of getting involved with research was:

Angeli, from Oxford: "Your voice really matters."

Arooj, from Oxford: "I think if we want research and medicine and clinicians to benefit us, we should be involved."

Henri, from London: "Go ahead, go for it."

April 2021

Appendix 4: Key themes - Meetings with Theme Leads, Liaisons and staff responsible for PPI

Thirty-three meetings with 31 Theme Leads/Liaisons and other staff (covering 16 Themes) with responsibility for PPI highlight the following:

Overall understanding of PPI

We asked what understanding they thought there was of PPI amongst staff. Key findings:

- Researchers know that PPI is something they need to do e.g. for grant applications.
- However, there is variable understanding of what PPI actually means. Most researchers have an understanding (some in-depth). On the other hand, a few do not understand how it differs from conversations with patients about their individual care or they may think an informal conversation to inform their research is not PPI.
- Researchers who fully appreciate the value of PPI are not the norm.
- Some researchers do not have a good handle on how to do PPI and what “good” looks like.
- Some researchers do not understand key tools for PPI e.g. recruiting members to steering groups, undertaking focus groups.
- Most researchers do not find PPI easy, find it time-consuming and do not feel confident that they are doing it correctly.
- There is particular difficulty seeing the relevance of PPI in lab based work.
- There is lack of resource for PPI. Most Liaisons or other staff with “PPI responsibility” have minimal time allocated to PPI. Only one Theme employs a 0.5 FTE whose sole responsibility it is to support PPI. Another Theme is currently sourcing funding for the same for the duration of BRC-3 in recognition of the lack of resource and is recommending the same for BRC-4.

Training needs

We asked what training they thought would be most helpful. Key findings:

- Training sessions for researchers was widely welcomed.
- A pilot Introduction to PPI session in the new year could cover:
 - Why we do PPI
 - Tools for PPI (e.g. focus group, interviews, Steering Group, online meetings)
 - What “good” looks like
 - Recruitment including seldom heard groups
 - Payment and expenses
 - Supporting PPI contributors
 - Reporting
 - Feeding back to PPI contributors on how their input made a difference.
- Separate, in-depth sessions focussing on some of the above.

Recording activities and impact

We asked about recording activities and impact. Key findings:

- Three Themes have some sort of recording mechanism, but do it in a very different ways.
- Most Themes would be willing to engage with a BRC requirement for a quarterly report (as long as it was relatively easy).
- To ensure it is delivered, Theme lead support for PPI reporting is crucial.

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- Some have heard of Studyline, none recommended it as a reporting tool for PPI.

Appendix 5: Feedback from BRC PPI Advisory Group to review of current PPI activities

The BRC PPI Advisory Group comprises patient/public representatives from a number of the current themes, lay representatives, researchers and staff from across Oxford University Hospitals Trust and University of Oxford. Some group members have been involved for several years; others have joined the group more recently.

As outlined in the document *Developing the Oxford BRC-4 PPI Strategy*, we are reviewing BRC-3 PPI activity to identify achievements and gaps and recommend priorities for the BRC-4 PPI strategy. As part of this, all members of the group were asked for their input on what is currently working well with regard to PPI in the BRC, and what needs improvement.

Responses were received from five patient/public members and three researchers/staff from the group. The sections below summarise their comments. It's important to note that although there are fewer 'Working well' points, these were repeated numerous times. The full responses are in Appendix 5.1.

Working well key themes

- Commitment from PPIE staff.
- Commitment from PPI contributors.
- Increasing awareness of PPIE and its value among researchers.
- Awareness of and first steps taken towards the need to increase the diversity of PPI contributors we work with.
- Good relationships between PPIE staff in themes (where they exist) and lead researchers.
- Good networking between PPIE staff.

Needs improvement key themes

- Stronger, more visible endorsement of PPIE from BRC leaders and senior staff.
- Better understanding of what PPIE is among BRC leaders and senior staff.
- Go further to raise the profile of PPIE and its benefits.
- PPIE being embedded across the BRC rather than ad hoc.
- Feedback to contributors about their work.
- Better training/induction/mentoring for new PPI contributors.
- Streamline PPI activity within the BRC eg with standard documents and processes – currently too much duplication.
- Involve a wider cross-section of the population.
- Incentives for PPIE activity; consequences for PPIE inactivity.
- Direction and clarity of over-arching BRC PPIE strategy in order to know what to work towards.
- Lots of PPIE is still tokenistic, box-ticking rather than genuinely meaningful.
- PPI isn't always properly budgeted for – both in themes and individual projects.

Appendix 5.1

Working well

- Commitment from PPI contributors
- Commitment from PPIE staff
- Acceptance and action to create a more diverse PPI community (still a long way to go, but the will is definitely there)
- People (scientists and contributors) do truly seem to appreciate the benefits of involvement.
- It's seen as something you must do, and also something you must be seen to do.
- People who are involved in the process seem to get a lot out of it, and show great enthusiasm
- Genuine commitment to active PPI at the level of MMM/AMR theme and the BRC advisory group.
- High quality of the PP (other than myself) involved.
- There's definitely a growing commitment to the idea of PPI – both in theory and in practice. It's noticeable that the subject is moving quite rapidly up the agenda, which is really encouraging.
- The silver lining of the pandemic is the increased awareness of the importance of medical research. It's even a story line on East Enders - Patrick (Afro-Caribbean character) wants to take part in a stroke research project but his wife is against it, sparking a fierce family argument! We (national, local and individual levels) must build on this momentum.
- It works well to have the PPI rep for the theme included in theme meetings.
- Our theme included me in decision making about funding bids – looking at bids from the perspective of PPI and patient benefit
- It works well for the PPI rep to have established relationships with lead researchers and familiarity with patient experience in that theme
- It is good to meet up with other PPI reps as part of the forum – otherwise, the PPI reps can feel a bit lost and cut off from the rest of the BRC
- It is good to have you and Rachel as a point of contact for advice / networking / sharing ideas from wider experience

Needs improvement

- Needs streamlining – different areas are reinventing the wheel when it comes to setting up, recruiting, engaging PPI. Could share more and standardise processes/documents more.
- I know there are some workshops for PPIs, but some kind of induction training for new PPIs would be helpful. This would demonstrate active support.
- An (informal) buddy system within each theme might help new PPIs feel more welcome and provide answers to some of their many unanswered questions.
- Involvement of a wider cross section of the community. (*)
- I'd like more feedback on outcomes of projects where I've been consulted.
- Would I know that there was such a thing as PPI if I hadn't had my shoulder tapped to join a group? Relevant to (*) above! My quick fix, while something fairer is developed, would get a clued-up doctor or nurse involved in a research project to tap some shoulders!!
- Make sure everyone in the process, but especially the "sharp end" scientists and those with oversight (those "in charge", heads of department, theme leaders) UNDERSTAND what involvement means. That it isn't engagement. That it's not talking to people: it's listening to people.
- On this theme I would like to see "important people" at the NIHR and BRC making it clear involvement is a priority; especially in light of the pandemic.
- Make it relevant to the NOW.

- I would like to see the actual monetary value of involvement made clear. Not just “you need it to get funded.”
- Have some case studies where involvement saved money. Be that via time saved, resources saved...whatever.
- I would like to see case studies showing tangible benefits of involvement. The annual reports display a lot of...vagueness about benefits.
- I would like to see the profile of involvement raised. See the theme leads talking about involvement, showing understanding of the benefits. Explaining what it really means to them.
- On a very practical level I would like to see contributors getting feedback on their input, and to feel valued.
- PPIE becoming embedded in the work of BRC4 rather than ad hoc
- Active BRC leadership, promoting and facilitating a patient centric approach by actively endorsing PPI - this then cascades through the organisation
- Researchers automatically include PPI in all stages of their research as they recognise the added value it can bring, rather than it being a 'tick box' exercise
- It is difficult to know what the theme's "PPI strategy" should be without reference to what is expected across the BRC as a whole. Clearly each theme needs its own plan on matters of detail, depending on the challenges of that particular setting, but it can feel a bit like you are winging it, or missing out on something important, without a baseline framework to work to.
- I would like to see the muscle behind BRC more explicitly reinforcing the work of those of us who promote PPI. There is a lot of talk about its importance, but no clear incentives or consequences linked to PPI activity / inactivity.
- The only thing I would add is how to make yours and the group's PPI work more visible? How to use your group as an exemplar for other researchers to use. Researchers outside of the BRC in social sciences don't have this kind of 'role model' and we struggle to find help on PPI and hear from patients. Perhaps you could open up to more researchers in other disciplines whose research is health focused?

Appendix 5.2

My view **may** be biased ... 😊 I also recognise that I am as guilty of some of these practices as anyone else. PPI is hard and time consuming and there's no getting away from that. Most BRC research teams (esp the seniors) have half a day/week funded for BRC work. It's just not possible to be consistently 'on' PPI if there isn't the time allocated.

I think there has been a historical assumption that because PPI sat in the cross-cutting theme, any and all BRC related PPI work would be funded/organised through this route. This may be why there has been limited formal PPI co-ordination in the main research themes. The same is true of statistical and health economics support - themes didn't initially include costs for this in their five year plans so when it became clearer that the PPI support wasn't quite what the themes had assumed... there was a startling lack of funds to do anything meaningful.

Themes have been able to present engagement as involvement and include participation in James Lind Alliance priority setting partnerships as evidence of theme PPI activity. There's also no obvious benefit to doing PPI well and no downsides to not doing it at all.

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I remain unconvinced that every project needs a PPI plan but I do think that every theme should have a PPI group that is directly involved in decision making and planning projects and being a part of data collection (where feasible) and data analysis (again, where feasible). I've seen altogether too many examples of ad-hoc meetings with patients to satisfy a tick box (usually to say "patients think X is a good idea") with no further contact made until the end of the project when patients might be sent a summary of results and asked to comment on the readability of the lay summary.

Despite very clear messages being sent there is still a persisting sense that PPI means having evidence that "patients think X is a good idea", or that the PPI group is there to "help describe the study in a way that encourages other patients to agree to take part", or to "help share results to wider audiences" (this is especially true if patient support groups are approached...)

It is unbelievably difficult to truly involve patients/public in data collection/analysis due to their lack of experience with /understanding of academic methods. Also - it's quite common for patients to recognise this and be unwilling to be involved in this way precisely because that's what they think the researchers should be doing.

Presenting results for comment can be difficult because it is common for results to be presented in a way that tells the story the researcher wants to tell. It is hard for academics to pick this apart, let alone those without training in critical appraisal. Data sets are never as neutral as they appear to be...

In the re-start of studies after the first COVID19 'wave' I was in several meetings where the teams were discussing what precautions they needed to take/how patients would be able to interact. No-one spontaneously thought "oh, let's ask the patients". There's a deep-rooted thing in healthcare where clinical teams just tell patients what to do / where to go etc and that filters through to research practices.

I'll stop now 😊 I don't have any answers other than research teams are very (very) motivated by money... Having a central fund that paid for publication fees (they are ~£2K each) for projects where PPI can be demonstrated and evidenced as being high quality would be a good carrot to wave.

Appendix 6: Benchmarking with other BRCs

UNIVERSITY COLLEGE LONDON HOSPITALS BRC PPIE MEETING

CONTACT REPORT

Thursday 15 August 2019

Attendees:

Ros Yu (UCLH) – Head of PPI and Communications
Angela Wipperman (UCLH) (part time attendance) – PPI Manager
Polly Kerr
Alan Chant

BACKGROUND

- UHCL is one of the three largest BRCs in the country (Cambridge £114.3K; Oxford £113.7K; UCLH £111.3K).
- They have 13 Themes, including PPIE as a Theme itself.
- There are 4 staff in the PPIE team – including 2 communications staff.
- The team report to Nick McNally, who is COO for the BRC.
- They have a good PPIE Strategy paper (available online), which in addition to covering the good things being undertaken also includes the need to “...instigate a step change in PPIE” and “...only(!) reaching 10% of their research community”
- The BRC’s overall research strategy was developed with both a number of PPI contributors and with A-level and medical students.

DISCUSSION

Training

Researchers

UCLH train c.200 researchers pa in PPI, using 5 modules (Introduction to PPI; How to do PPI; Facilitation; How to find PPIs; How to fill in the PPI section of a grant form) running three times a year, and attracting 10-20 researchers per module. AW presents the courses personally – taken inside from 2014, previously Derek Stewart (of becaandderek) did them.

Researchers contact AW directly by email or phone to book places on the modules.

She relies on the training to enable researchers to find suitable PPIs; she does not put researchers and PPIs together herself – would require too much resource.

AW provides feedback from researchers’ appraisals forms, which have a section on PPI, to Theme Operational Managers, who then incorporate it into their operational manager reviews.

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The team obtained external funding for these courses, originally from HENCEL (Higher Education England – North Central & East London) in 2014 and now from Wellcome Trust.

PPIs

They undertake no training for PPI representatives. They rely on researchers doing their own training of PPI representatives.

Bursary Scheme

UCLH runs a Bursary Fund (originally funded by Wellcome Trust, but now from the PPIE Theme budget) to encourage PPI in projects. Each year they have 2 rounds in which they award 4 start-up grants of £500 (essentially for “pump priming”) and 1 £2,000 grants for innovative PPI projects, namely £8K pa.

Metrics

UCLH have little in the way of accurate information:

- Unaware of how many researchers are involved in BRC. They involve researchers outside the strict definition of the BRC-funded researchers. RY guessed at possibly a few thousand in total.
- Unaware of how many PPIs involved.
- Unaware of what percentage of projects involve PPI

Contact between PPI team and PPIs

This seems to be a relative weakness with UCLH:

- Their Strategy document refers to them having a lay panel of 6-8 people for each of the Themes to review applications to the BRC – but only about half of the themes actually have these panels.
- They have had experience of the “wrong type” of PPIs – who have been motivated to get involved in order to “tell the NHS how to manage things properly” – this has had led to RY and AW feeling demoralised at times, and raised the need for support for PPI staff in handling difficult/unpleasant PPI contributors.

Theme Managers

PPIE is a Theme itself, which provides it with reputational advantage, although it is a cross-cutting theme.

The PPIE team have good contact with the Theme managers as they both (University College personnel) occupy the same office space, and RY has held the position for some 8 years and built up personal relationships.

Internal Culture

There is recognition that as a large BRC there are institutional issues regarding hierarchy and structure, especially an issue with older members, which present barriers to change and developing

positive inter-relationships. RY had a concern that lack of successes for the PPI team could lead to dissatisfaction for the team members.

Some Theme managers can be obviously pro-PPI and others not so. One of the concerns of the latter category is that patients' views would result in changes being made to their projects (!)

Innovation

There is a recognition of the need for continuous improvement and innovation. Their (online) strategy paper states that *"The BRC has identified the goal of becoming innovative leaders in the field of PPI"*

They are engaged with a number of initiatives, including working with the UCL Centre for Co-production (Editor's note: the new buzzword in PPI) where patients are involved in a real partnership in proposing and developing research projects.

PP Involvement & Engagement

There is some internal confusion in the use of "labels". Academic UCL staff use the term "engagement" to include involvement and engagement. The engagement that AW and RY do is mainly related to the hospital – the University has its own PE team.

Whilst the team are responsible for both involvement and engagement, more of the latter is undertaken by the University – similar to Oxford BRC. They were aware of Oxford's Open Day (had an invitation) and recognised the benefit that this brings.

PPIE Team Stature

The driving force behind the team progressing within the BRC is to demonstrate an impact on NIHR funding, attracting external funding, and the benefit from good/impactful PR.

Other

UCLH has a real need to improve their PPI diversity and inclusion policy in order to reflect the diversity of the London local communities that they serve.

There is a recognition that involving PPIs in lab-based projects is more difficult, and are working with 4 charities (who by their nature are very patient-focused) to improve this area – trying things out to see what works and what doesn't.

The PPIE team would like to be more involved in the governance of the organisation

They have a good regard for Oxford BRC.

SUMMARY

UCLH Strengths	Oxford BRC Comparison
<ul style="list-style-type: none"> • Researcher training (200 pa) • Bursary Fund - £8K pa 	<ul style="list-style-type: none"> • No researcher training • No such funds – PPI included in Theme funds
<ul style="list-style-type: none"> • Attracting external funding for PPI • PPIE is a Theme 	<ul style="list-style-type: none"> • None • PPI is sub-theme
<ul style="list-style-type: none"> • A “continuous improvement” ethos • Head of PPI has 8 years’ experience in the BRC 	<ul style="list-style-type: none"> • Current reorganisation of PPI underway • No Head and PPI Manager relatively new (< 2 years)
<ul style="list-style-type: none"> • Information about researchers’ PPI work through appraisals 	<ul style="list-style-type: none"> • Only PPI information is from annual report
UCLH Weaknesses	Oxford BRC Comparison
<ul style="list-style-type: none"> • No training of PPIs • Metrics – much unknown • No PPI involvement in governance • Relatively small PPI team (2) 	<ul style="list-style-type: none"> • OxBRC/ OH BRC / ARC Train c.70 pa • We are getting there! • Patient representative on SC • Smaller PPI team (0.9 FTE)
Similarities	
<ul style="list-style-type: none"> • Operating in large institutionalised and hierarchical organisation • Small PPI team with limited staff resources • Need / room to improve PPI • Difficulty reaching researchers who aren’t already interested in PPI • Lack of diversity of PPI contributors • Similar split of PPI and PPE work in practice – more engagement handled by the University 	

Manchester BRC – meeting with Leah Holmes

Friday 22nd November 2019

Leah Holmes – Co-Director of Public Programmes

Claire Murray – PPI Manager, Oxford Health BRC

Polly Kerr – PPI Manager, Oxford BRC

BACKGROUND

- Manchester BRC received £28.5million in 2017.

Review of NIHR Oxford BRC-3 Patient and Public Involvement (PPI) and Public Engagement (PE) 2017-2021

- PPIE at Manchester BRC is led by the Public Programmes Team (hosted by Manchester University NHS Foundation Trust) – essentially this is a not-for-profit organisation; the BRC is a ‘client’.
- They are financially independent and are funded through various means (including the NIHR and a Wellcome Sustaining Excellence Award).
- They have a joint BRC and CRF PPIE strategy which sets out criteria by which aims will be met and how these will be measured.
- This PPIE strategy was developed over 18 months and involved patients and public, community groups, researchers, clinicians, cultural partners and funders.

DISCUSSION

Training

Researchers

There is nothing formal but they give out a lot of advice and have ‘drop-ins’ which all count towards ‘Capacity Building’.

PPIs

They have provided a great deal of one-to-one support for PPI contributors. There is an academic lead for PPI.

Metrics

All PPI contributors/engagement audiences complete a monitoring form which is given out ‘at the right time’ by the researcher they are working with. This is anonymous and collects demographic data – it’s based on the NHS equal opportunities form but with some extra questions. This enabled them to compare their PPI contributor data with CRN Patient Research Ambassadors data.

New PPI contributors are usually recruited from engagement events but also through social media (especially for their work with young people).

Communications

They rebranded with input from 300 (?) PPI contributors after being awarded the Wellcome Trust grant. Leah said the website is a ‘task in hand’.

Appendix 7: SWOT and PEST analyses

SWOT Summary

STRENGTHS

Resource/structure

- Future commitment to combine PPI and PE within Oxford BRC – recruitment of Public Community Involvement Engagement and participation Lead (PCIEP)
- Potential changes to structure of BRC4 – a larger core team
- New themes will be created in the next round of funding - could be a chance to start new PPI initiatives
- List of c250 PPI contributors who regularly receive email bulletins of PPI opportunities
- PPI Advisory Group has representatives from many themes
- Patient representative on Steering Committee
- BRC has resources to pay for involvement - more so than e.g. councils or NHS organisations.

Collaborations/relationships

- PCIEP links with OUH Patient Experience Team
- PPI managers in both university and OUH, providing links with both organisations
- Good relationships between PPI staff in central function and themes (where they exist)
- Good links and joint working with Oxford Health BRC, Academic Health Science Network (AHSN), Applied Research Collaboration (ARC), local NIHR infrastructure
- Good PE support within the University and Medical Sciences Division

Commitment and Implementation of PPI

- High level of commitment from some individuals
- Some examples of good PPI

Breadth and quality of research

- Potential for increased focus resulting from Themes reducing from 20 to 15
- Strong research – good for PE activity
- 4 early career researchers are undertaking a scoping project about PPI in 4 themes. This will inform our knowledge of PPI across themes
- Oxford BRC PHWI theme produced good quality academic papers on PPI

Support and learning

- Developed program of PPI training courses
- Some themes have training resources for PPI contributors eg. welcome pack, mentors
- University has lots of PE training resources

Technology

- Willingness to utilise new technologies

Diversity

- Awareness of need to increase diversity of PPI collaborators
- Recent developments to embrace under-represented groups as PPI contributors

WEAKNESSES

Clarity of overarching PPIE strategy

- What are we working towards?

Resource/structure

- Varied commitment and levels of support for PPIE across themes (good to non-existent)
- PPI isn't always properly budgeted for in themes and for individual projects
- Lack of resource within themes to support/deliver PPI
- C250 PPI contributors on list but little known about demographics, how they're involved in PPI
- Limited number of PPI staff
- PPI and PE has been managed separately
- Size and diversity of themes in BRC can make communications difficult

Collaborations/links

- PPI managers in OUH and University, but different systems, managers etc
- Weak links with OUH patients and patient groups and visa versa with OU PPI groups
- Could be stronger ties between Oxford BRC and Oxford Health BRC - until recently only joint ventures were PPI workshops/webinars
- Lack of 'joined upness' of PPI groups and activities
- PPI contributors confused by roles of different PPI groups in Oxford area

Commitment and Implementation of PPIE

- PPI contributors perceive PPIE being ad hoc rather than embedded in BRC
- PPI contributors perceive lack of visible proactive endorsement generally of PPI from BRC leaders
- PPIE can be tokenistic rather than meaningful
- Lack of PPI across whole research cycle
- Confusion by some researchers of difference between participation, involvement and engagement
- Researchers who fully appreciate PPI are not the norm
- Some researchers do not have a good handle on what 'good' PPI looks like
- No standard documents and processes for PPI across BRC
- Some themes have inaccessible materials that are not engaging on website

Reporting and impact

- Annual report is too blunt an instrument for meaningful reporting
- Significant variation between themes' reporting – some concrete examples, some broad statements
- Some researchers not convinced of the need for PPI or the benefits
- Limited case studies showing value of PPI
- No clarity on % of research which includes PPI or quality of PPI
- Measuring impact effectively not yet achieved
- Providing feedback to PPI contributors is patchy - people lose interest if they don't see results from their input
- No quantitative reporting of PPI within research studies ie no evidence about how many projects include PPI , at which stage of research cycle
- Incentives for PPI activity - most themes don't have objectives for PPI

Support and learning

- No standard induction/mentoring for new PPI contributors
- No program of PPI training courses for researchers (until recent pilot)
- Distinction between participation, involvement and engagement not understood within some themes or by some researchers

Diversity

- PPI contributors not a diverse group
- Lack of diversity in PE audiences

OPPORTUNITIES

PPI increasingly essential for publicly funded research

- Publicly funded models increasingly require PPI in design and delivery (NIHR, charities)
- NIHR increasing commitment to PPI
- Increasing attitude and behaviour of researchers from viewing PPI as tokenistic to integral / essential.
- Calls for more research on PPI impact– demonstrating benefits
- Where PPI works well , relationships, credibility and bonds created between researchers and PPI contributors

Patient centred research to be embedded in patient care across NHS

- Patient centred research - needs PPI to make it patient centred
- More involvement by more NHS staff?

Health research awareness at a high due to COVID

- COVID has increased the profile of health research and particularly Oxford
- Public interest in health research and motivation to get involved due to COVID
- Positive feeling for researchers to get air-time in national press/TV

Technology

- More people familiar with using on-line meeting platforms
- With more online meetings and people working at home - more opportunities for people to attend meetings – less travel and time commitments
- Online meetings are less expensive - allow us to undertake more PPIE
- Social media used increasingly by public and health researchers
- Web based opportunities to connect with public/patients, but need to ensure engaging and accessible
- Children taught to appraise information on-line

Diversity

- Research open to everyone - diverse communities
- COVID research relates to whole population
- Increased awareness of health inequalities because of COVID - importance of working with diverse communities
- Issues of mistrust of science and healthcare research by some communities is in the open and can be addressed
- Increased unemployment due to pandemic may increase opportunities for involvement as more people have spare capacity

COVID

- COVID has changed our lives in many ways – many opportunities

THREATS

Resource

- BREXIT may result in loss of historical pre-eminence in healthcare research and consequent diminished attraction of international funding and hence number of studies
- Reduced funding for BRC4 – reduction in research personnel, studies and may impact central PPIE budget
- Some themes will be lost in the next round of funding and with them their PPIE initiatives
- Long term effects of COVID – reduced capacity for research?
- Cost of increasing involvement from diverse groups
- PPI perceived as time consuming and resource is often not available
- Resources needed to ensure our materials are accessible to wide population

Reporting/impact

- Challenge of making reporting a meaningful exercise

Technology

- Online meetings can create digital exclusion issues

- People may not be thanked/appreciated in the same way as if face to face meetings - requires a more robust system
- Lack of social side of PPI/E may demotivate some people and they are less inclined to be involved
- Important not to forget the value of a personal phone call - can be motivating and supportive for PPI contributors to be phoned individually.
- Reduction in physical meetings reduces opportunity for PPI contributors to build trust with researchers
- The negative side to social media can put people off using it
- Time taken to address misinformation
- Ease of being able to put public materials on website can mean that little thought goes into how engaging and accessible it

Diversity

- Despite increased profile of COVID, research is still inaccessible to most and PPIE even more inaccessible
- Mistrust by some communities of science and healthcare research

Perception of researchers that PPIE not needed/no time for it/too difficult

- PPI perceived as time consuming and resource is often not available
- Researchers may feel that COVID has made research more difficult and that PPI would make things even more complicated for them
- Funding bodies do not always measure the quality of PPI, therefore it can seem tokenistic
- Increase in research considered too technical for PPI / lay involvement (e.g. AI, digital, lab-based studies)
- It takes time to develop engagement materials that are accessible and engaging
- Lack of PPI in Covid-19 research projects may spread to future COVID research and more widely to non-COVID studies

COVID -19

- Danger of concentrating resources to COVID-19
- Less “easy” PE opportunities for researchers available, e.g. school visits, festivals

Review of External Environment PEST Analysis

Political

1. Focus on research and importance for economy as well as health care
2. Clinical research to be embedded in patient care across the NHS
3. Focus on patient centred research - accessible and easy to participate
4. BREXIT has posed challenges for some research organisations

5. Long-term effects of COVID on NHS clinical care - e.g. backlogs as well as issues with clinical trials stopping/pausing
6. Publicly funded models should have PPI in design and delivery – increasingly increasing expectation that PPI included in research proposals
7. General feeling of instability due to COVID
8. Threat of COVID has led to ‘politicization’ of science, for example nationalism regarding vaccines

Economic

1. Next BRC will see a reduction in Oxford income as max funding for any BRC is £100m
2. Uncertainty about the impact of BREXIT on research (funding, researchers etc)
3. Research funding from medical charities has significantly reduced (COVID)
4. Some funding bodies require good PPI as part of approval process
5. Little (if any) external funding for PPI in research

Societal

1. COVID has increased awareness of the importance of health research
2. Profile of research in Oxford increased due to COVID vaccine work
3. Plethora of information available, not all of it reliable
4. There’s never been so much interest in science, unfortunately some negative effects e.g. anti-vax
5. How people access scientific info has changed, now likely via SM
6. COVID has increased public awareness of health inequalities
7. Public awareness of PPIE is very low.
8. Increased unemployment may mean people have less capacity to do more philanthropic work as they focus on survival issues

Technological

1. Pandemic has encouraged use of technology for communication eg more people familiar with Zoom type meetings
2. Increase in health research info on social media
3. Access to “facts” and “opinions” can get blurred by how things are accessed

Appendix 8: Theme-wide PPI groups

Themes with PPI theme-wide group

Theme	Name	On Theme website page?	Theme likely to be looking for ppl with condition only?	Other Key PPI groups in theme
AMR/MMM	No name	N	N	Covid?
Cardio	Cardiothoracic Public Partnership Group (PPG)	N	Y	CV Med patient panel (is that the same as the theme-wide one)
Diabetes	Diabetes Reference Panel (DRP) & Diabetes Online Review Group (DORG)	Y	Y	
Haematology and Stem cells	The Oxford Blood Group	Y	Y	
Multi-modal Cancer therapies	Oxford Cancer Research Patient and Public Advisory Group	N	Y	
MSK	NDORMS Patient Panel	N	Y	Oxford MSK Trauma PPI group RUDY
Obesity	Weight Management Public Panel	Y	Y	
PHWI	PPI Advisory Group & PHWI PPI Group	N	N	Remote by Default External Advisory Group Digital health PPI group
Stroke & Vascular Dementia	Stroke Prevention Research Advisory Group	N	Y	MM Frailty ORCHARD group Stroke PPI group
Vaccines	Vaccines Group	Y	N	
No Theme-wide PPI Group				
Theme	Would a PPI group be relevant to this theme (where doesn't exist already)	Theme likely to be looking for ppl with condition only?	Other Key PPI groups	

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Respiratory (planning to set up)	Y	Y	
Genomic	Y	Y	Cranial Facial Headlines
Clinical Informatics and Big Data	?	N	
Gastro	Y	Y	
Imaging	?	?	
Molecular Diagnostics	?	?	
Multi-morbidity & LTC	Y	Y	Rafael Perera-Salazar Anica setting up group for Rafael's project
Neurological conditions	Y	Y	
Surgical Innovation and evaluation	?	?	
Technology and Digital Health	?	?	