

Patient and Public Involvement (PPI) Strategy (2018 to September 2019)

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Introduction

Purpose

Building on the successes and experiences of CLAHRC Oxford since 2014, this document sets out the policies and procedures we will use during the extension period to September 2019, and beyond.

The strategy for improving our public involvement will be reviewed and adapted for subsequent funding in applied research across Oxford and the Thames Valley region, focussing on the anticipated NIHR Oxford Applied Research Collaboration (ARC), which it is hoped will succeed the CLAHRC.

Aims

- To match the excellence of our public involvement to the academic excellence of our research.
- To involve public contributors and to respect their perspectives equally to improve our projects.
- To support the public's right to be heard.

Objectives

- 1) Work towards an improvement in PPI activity across the CLAHRC in relation to the developed action plan against [NIHR PPI Standards¹](#).
- 2) Develop mechanisms within the CLAHRC which will enhance and embed PPI activity into the ARC.

Context

Involving patients and members of the public in research is embedded within UK health policy (Department of Health. [Best Research for Best Health](#): A new national health research strategy, 2006). It is recognised that patient involvement can lead to better research, clearer outcomes, and faster uptake of new evidence.

The National Institute for Health Research (NIHR) requires all research projects it funds to have active public involvement right from the start. The NIHR encourages patients and members of the public to be involved in all aspects of the research process and has put structures in place to support patient involvement in research ([INVOLVE](#)).

What is Public Involvement?

By '**Public**' we mean patients, potential patients, carers, service users, and members of voluntary, community and service user groups.

By '**Involvement**' we mean having an active role in decision making and having a significant influence in research design and outcomes. Amongst researchers this work is often known as PPI (Patient and Public Involvement) although the NIHR uses the term public involvement (PI).

To be clear, PPI is not about '*participation*' which is used to describe the role of patients or the public as the participants or subjects in research studies and clinical trials.

¹ NIHR propose to base evaluations on these standards from 2019

It is also different from '*Engagement*'. This term is used or combined (as in PPIE) to describe the related processes of sharing information and learning from research with the public and the promotion of participation in research.

Throughout this document we refer to our volunteers as 'PPI Contributors'. However, we acknowledge that individuals may prefer other terms and that each research project should adopt the terminology preferred by their own volunteers.

Types of Patient & Public Involvement

Some PPI Contributors are appointed because they bring a specific 'lived experience' of an illness, health condition or behaviour that could lead to ill health. These people can only reflect their own lived experience and are not expected to represent all people with that issue.

Others are appointed because of their non-health related life experiences – in management or project planning, for example – and provide a strategic input. Many will provide both.

There is no differentiation made in the terminology used to describe these PPI Contributors, nor in the way that they are involved.

Strategy and structure

Governance

Two PPI Contributors are included as members of the CLAHRC Management Board.

During the extension period (January-September 2019) their purpose is to advise the Board on all development plans of public involvement within the CLAHRC , including their own succession planning into the Oxford ARC. The ARC (Applied Research Collaborative) is the successor to the CLAHRC programme, funded by NIHR for five years [Oct 19 – Sept 24]. At the point of writing, the Oxford CLAHRC is awaiting notification of success in this bid.

They will also be involved in the detailed allocation of grants relating to the proposed ARC, by reviewing project applications for their level of PPI proposed and the potential for patient/public benefit.

General organisational management

PPI Contributors are to be part of the recruitment process for postdoctoral research and management staff in an advisory capacity, and directly in the decision making and appointment of staff specifically working on PPI at any level.

See Appendix 1 for a diagram of the preferred PPI Structure.

Research Themes

Where research themes have a management group PPI Contributors are currently included in these groups.

During the extension period we will work with all Theme Leads to run theme management groups and to develop recruitment processes for PPI Contributors to join these groups.

Further to this, we will work with the themes to develop mechanisms to recruit 'PPI Champions' (staff and public, see Appendix 3) who will begin their involvement as part of these management groups.

Aspirations and improvement: PPI Champions

The function of a PPI Champion is to act as a liaison point between PPI Contributors in their theme and the PPI members of the Board and the PPI Coordinator. PPI Champions will be involved in decisions about internal funding bids through their attendance at theme meetings.

We are developing the PPI Champion role to provide critical friends for themes and increase the quality and quantity of PPI across the programme.

We anticipate two *active* PPI Champions per theme, one staff and one public. Deputies will be added as required.

PPI Champions

Public Champions will have a direct frontline PPI role in at least one of the theme's projects and will work with the local community to gather information about the needs of patients and the public from the local community. Public Champions will also be encouraged to provide a mentor/buddy service to new PPI Contributors within their theme and provided with the support to develop these skills.

Staff Champions will be researchers in the theme who have undertaken some PPI and are passionate and committed to the principles of involving the public. They will provide the first line of support to public Champions, acting as an academic / clinical mentor supporting their full and active participation and be available to answer questions and address any issues or concerns.

Staff PPI Champions will promote the principles of PPI to their colleagues and raise PPI awareness and standards at staff meetings.

For more information see Appendix 3.

Project PPI

All programme funding bids are expected to specify the PPI they are intending to undertake.

The PPI Coordinator's role will, in part, be to support researchers with their plans but also to monitor activity against provided funding.

It is important that a PPI perspective be included at all eight stages of the research cycle (see box).

The CLAHRC will ensure that all new projects have a PPI plan and that programme managers will work with individual staff to ensure that they are fulfilling their proposals in relation to involving the public.

Theme Programme Managers will continue to have responsibility for reporting to the core team (for the NIHR) on PPI activity.

We will increase the level of public involvement activity that happens in the Thames Valley outside of Oxford. For example, holding training events in Buckinghamshire and Berkshire as well as in the county of Oxford. We will hold public engagement events aimed at recruiting PPI Contributors across the region and we will forge stronger links with Universities other than Oxford.

As part of this process the PPI Coordinator will work closely with the proposed ARC "Mental Health across the life course" Theme Lead, Professor Cathy Cresswell, sharing mutual work in the development of PPI structures and practices within the University of Reading's School of Psychology and Clinical Language Sciences.

The stages of the research cycle

- 1) Identify research question
(where possible we will use the NIHR James Lind Alliance (JLA) Priority Setting Process to understand what should be researched),
- 2) Write and submit funding application,
- 3) Design study and get approvals,
- 4) Carry out research study,
- 5) Analyse research outcomes,
- 6) Publicise research outcomes,
- 7) Influence clinical practice
- 8) Monitor and evaluate

Communications and engagement

The CLAHRC 'community newsletter' – an internal newsletter that goes to all CLAHRC affiliated researchers and partners – will be used to disseminate PPI ideas, events and training, such as how to act more innovatively, how to recruit more diversely and how to get

support. We will also continue to produce PPI Pulse – a magazine-like newsletter of features and stories related to PPI – to inform our volunteers of our research and developments in PPI. Feedback will be encouraged from the PPI contributors.

Our Communications Officer and research staff conduct a range of activities to increase awareness of our research work amongst the general public. This includes professional and public-facing media and the development of our websites. We will encourage research staff to undertake Public Engagement activity in a range of settings.

Each theme will be able to demonstrate how they have engaged with the public during the extension period and in each year of the ARC. Where appropriate, themes will be encouraged to collaborate in running joint public engagement events to share resources.

Expenses and fees

We will reimburse and recompense PPI Contributors in all levels of involvement work with us at the NIHR recommended rates as outlined in our payment policy².

Individual projects and themes will pay for their PPI from within their budgets. All central activity by the public will be covered by central budget.

Collaborative work

We will bring the CLAHRC strengths to a variety of collaborations within the NIHR and NHS Infrastructure organisations of the Thames Valley to further promote and develop PPI activity within the region. In particular, we will collaborate on those activities which bring added value to our work, cost benefits and development of new initiatives. With our partners we will test and develop innovative ways of involving the public.

We are active members of the Working Together Operational group. The [Working Together Operational Group](#) is a collaboration of organisations across the Thames Valley that work together to support improvements in patient, carer and public involvement in health care, research and education.



Workstreams of the Working Together Group include:

- 1) communication and engagement;
- 2) learning and development;
- 3) recording and impact; and
- 4) diversity and inclusion.

We will be active partners in all of these workstreams. We will continue to Chair the Learning and Development sub-group and act as editor of 'Involvement Matters', a PPI ebulletin that straddles research, education, service provision and commissioning.

We will increase the level of public involvement cross fertilisation between the CLAHRC and the Sustainability and Transformation Partnership for our area ("BOB STP"). This will include increased links with Healthwatch's in Bucks, West Berkshire and Oxfordshire, who currently receive Involvement Matters. This will also include increasing links with public leaders

² Available online at: www.clahrc-oxford.nihr.ac.uk/for-researchers/public-involvement-for-researchers

involved in the relevant STP groups, such as Helen Van Oss, Rosalind Pearce, and Wendy Bower in West Berkshire and any others as appropriate.

We will aim to increase the level of PPI activity happening with our industry partners by forging strong links with them and providing advice and information on good practice. We will learn from the experiences of the Oxford Community Healthcare MIC and use their contacts in developing our work with industry and ensure that public involvement is embedded in any partnership work.

We will also actively engage with other CLAHRCs and national NIHR national collaborations.

See also links with the Oxford BRC's PPI Research in Appendix 5.

Monitoring and reporting PPI activity

Each theme will produce a quarterly report on PPI activity and the PPI Coordinator will collate responses for the Executive group and the Management Board. During the extension period we will develop ways in which the Theme Champions (staff and public) will assist in providing the reports.

The purpose of the monitoring activity will be to assess progress against:

- 1) the PPI strategy;
- 2) what individual projects said they would do;
- 3) what themes said they would do; and
- 4) NIHR PPI Standards³.

Evaluation will consider if the public involvement work is as specified, but also whether it is having an impact on the research and if so, how.

Additionally, we will work to develop those areas of our work that are proposed in the ARC that respond to the NIHR PPI Standards (a separate action plan addressing how we will meet these standards is currently in draft at the time of writing).

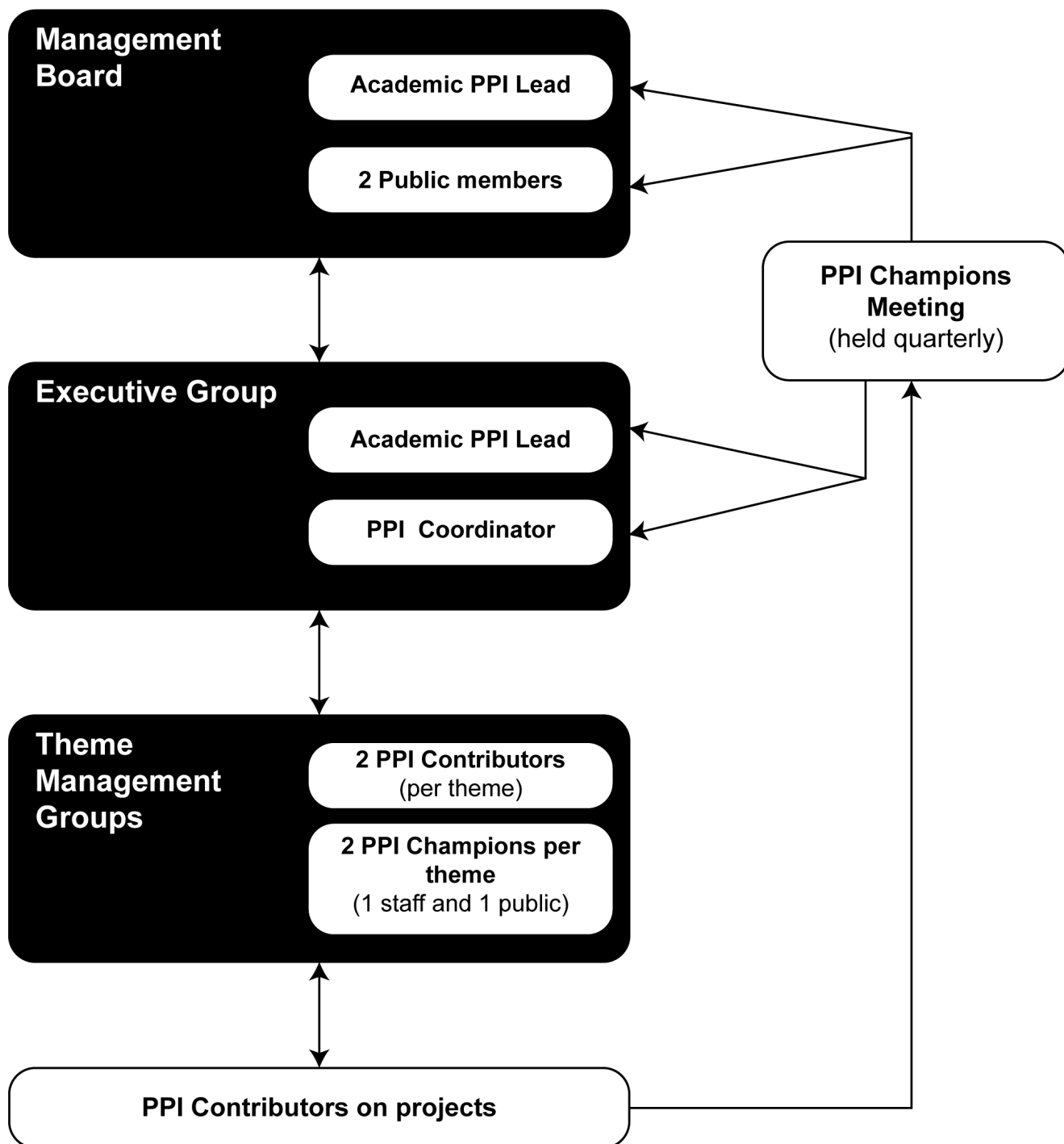
Reviewing the strategy

We will review the strategy in September 2019 and then again annually. Our annual review will include:

- 1) Checking progress against the action plan;
- 2) Inviting feedback from PPI Contributors including public members of the Board (not just annually but quarterly);
- 3) Inviting independent feedback from some of our partners;
- 4) Reflection on whether we feel that our approach and actions are proving successful and if not why not?;
- 5) Updating or amending the strategy as required based on findings; and
- 6) Approval of the revised strategy by the Executive Group.

³ Inclusive Opportunities, Working Together, Support and Learning, Communications, Impact and Governance.

Appendix 1: Preferred PPI Structure



Appendix 2: CLAHRC Senior Manager responsibilities

- Oversight of PPI policies and strategic plans
- Regular liaison with PPI co-ordinator, making contributions to role descriptions etc
- Attendance as required for workshops and PPI meetings
- Advising theme leads on compliance with CLAHRC guidance
- Arbiter of complaints or issues, escalating to the Director if necessary

Appendix 3: Provisional Role descriptions

Academic PPI Lead

Academic lead for PPI will:

- generate overall vision of the PPI programme, working with academic colleagues and PPI champions
- working closely and collaboratively with the PPI co-ordinator in:
 - oversight of the PPI strategy operationalisation, including achievement of milestones and deliverables
 - ensuring PPI is given sufficient and consistent consideration and resource throughout the period
 - communicating the PPI strategy and vision to broader audiences
 - contributing to reports for the programme board and funders in a timely manner

Public Management Board Members

CLAHRC Management Board public members will:

- provide a high level, strategic overview of the ongoing CLAHRC PPI work and the CLAHRC PPI strategy.
This oversight will ensure that the CLAHRC work is maximising the opportunities to provide patient benefit and stays focused on this agenda.
- develop mechanisms for liaising with PPI Contributors on theme steering groups as these are appointed so that they can represent their views.
- During the extension period they will advise the Management Board on monitoring this strategy, and on development plans of public involvement within the ARC, including their own succession planning.
- relating to the ARC they are expected to be fully involved in reviewing project applications for their level of PPI proposed and the potential for patient/ public benefit when the management Board decides on any grant allocations.

ARC PPI Champions – Staff and Public

Each ARC theme will have four PPI Champions (two 'champions and two deputies – two each of staff and public).

Appointment will be for one year in the first instance, from volunteers for the role, with a documented and transparent process.

The Champion role will be developed by the Champions in early meetings (including defining a new name if wished) but will include acting as a 'critical friend' of the ARC and championing increased quality and quantity of PPI in the ARC. The Champions will appoint a Chair from amongst their number.

At present it is envisioned that **Public Champions** will be expected to:

- have a direct frontline PPI role in at least one of their theme's projects;
- work with the local community to gather information about the needs of patients and the public from the local community (and for this reason will be expected to live in the ARC region);
- attend their theme management meetings;

- review progress on a quarterly basis and ensure that the strategy and standards are being worked towards; and
- act as a liaison point between PPI Contributors in their theme and the PPI members of the Board and the PPI Coordinator.

When recruiting Public Champions we will aim to include some who are well networked into a range of health-related organisations in their own community or beyond, e.g. Hospital and Patient Carer Councils, Healthwatch and Patient Participation groups.

A deliberate attempt will be made to ensure that the PPI public champions come from and represent all of the counties covered by the ARC.

At present it is envisioned that **Staff Champions** will be expected to:

- provide the first line of support to public Champions, acting as an academic / clinical mentor who will support their full and active participation;
- and be available to answer questions and address any issues or concerns;
- promote the principles of PPI to their colleagues and raise PPI awareness and standards at staff meetings;
- be researchers in the theme who have previously undertaken some PPI and are passionate about the principles of involving the public;
- attend their theme management meetings;
- review progress on a quarterly basis and ensure that the strategy and standards are being worked towards; and
- act as a liaison point between PPI Contributors in their theme and the PPI members of the Board and the PPI Coordinator.

Additionally, PPI Champions will be encouraged to provide co-presented training and presentations at ARC events, and will be provided with the support to develop these skills.

Appendix 4: Membership of the ARC PPI Champions meeting

PPI champion meetings will be held quarterly, with a Chair nominated by the members each year, and will rotate across venues in all three Thames Valley counties.

Attendees will be:

PPI Champions, or their deputies (public and staff)	10
PPI Academic Lead	1
PPI Coordinator	1
Public members of the management Board	2
Senior Manager	1
TOTAL	15

Observers may attend as invited.

Meetings will be minuted and the minutes shared.

Appendix 5: Collaboration with Oxford BRC

Joanna Crocker is a postdoctoral Research Fellow funded by the NIHR Oxford Biomedical Research Centre. She is working on defining 'What difference does patient and public involvement (PPI) make?'.

In the CLAHRC we believe that PPI is appropriate in terms of transparency in the use of public funding, and support the concept that PPI should be carried out to improve the reach, relevancy and impact of research.

However, there are still questions to be answered in terms of how should the limited time and budget for PPI be best spent to ensure the most benefit for patients and the least possible harm? Who should be involved, when and how? Findings will initially come from the PIRRIST study which is seeking to find if PPI improves recruitment into surgical trials and we will work with the BRC Fellow to explore the relevance of the findings to our non-surgical settings.

Revision History

Author Name	Version # amended	New version #	Description of Revision (brief description and reason)	Date
Lynne Maddocks, <i>PPI Coordinator</i>	0.9	1	<ul style="list-style-type: none"> New document for approval by Executive group 	07 Nov '18
			<ul style="list-style-type: none"> 	