# Patient and Public Involvement (PPI) Operational Strategy

## (March 2021)

## Contents

# Introduction

## 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 public 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 a framework in place to support patient involvement in research (INVOLVE).

The NIHR's new Centre for Engagement and Dissemination (CED) recognises the importance of public involvement, but acknowledges the progression of patient and public involvement to encompass engagement and working with whole communities or groups not just individuals. This is a fundamental part of the NIHR ARC funding programmes. Community involvement should be at the heart of all the research we do.

## Methodology and Review

The strategy has been developed over the last eighteen months alongside patients and the public, who currently shape and influence our research, researchers and staff working in Patient and Public Involvement (PPI). It was also informed by the 2018-2022 Manchester BRC and CCF PPIE Strategy, which has been highlighted as an exemplar of "best practice". The strategy builds on existing strengths and good practice developed in the CLAHRC Oxford but aspires to go further by creating an integrated plan for PPI across the Thames Valley and Oxfordshire ARC, with a greater emphasis on outreach work and engaging with the community, charity and third sector groups as well as individuals.

As PPI is a rapidly developing practice, it is essential that this strategy is regularly reviewed. This strategy will be formally reviewed annually with a first formal review in September 2021. This will include:

1) Checking progress against the action plan;
2) Inviting feedback from PPI Collaborators including public members of the Board and PPI Champions from research themes;
3) Inviting independent feedback from our partners;
4) Monitoring the outcomes from our reporting of PPI activity and outcomes, reflecting on whether our approach and actions are proving successful, and identifying why if not.
5) Updating or amending the strategy as required, based on the findings, with approval of the revised strategy by the ARC Strategy Board.

## Our Definition of Public Involvement?

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

As PPI has become more established in healthcare research this definition has recently been updated by INVOLVE to clarify that this also includes members of the public with lived experience of a condition or a service being researched and a current or previous career in academia or health and social care.[1] Although these members of the public may be classified as "professional" they do not lose their lived experience and there are benefits for research quality, relevance and practicalities from including a range of perspectives.

By '**Involvement'** we mean having an active role in decision making and a meaningful influence in research design and outcomes.

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

It is also different from '*Engagement'*. This term is used separately, or combined, (as in PPIE). Engagement is defined by the NIHR as information and knowledge about research being provided and disseminated. However engagement is increasingly seen as an opportunity to be more interactive with the public and Wellcome's definition of public engagement is providing the opportunity to explore, debate and shape science and health research.

There are common approaches and challenges in engagement and involvement and both are essential to our research. This strategy focusses more on PPI and has used this acronym, rather than PPIE, which not all public collaborators or researchers are familiar with. However we recognise the role of public engagement in the context of involvement and engagement will be part of our monitoring and reporting process.

*Throughout this document we refer to our volunteers as 'PPI Collaborators'. 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 Collaborators 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 involvement and experience of interacting with vulnerable people, such as carers, charity workers, or people with links to community organisations, such as Healthwatch, or patient participation groups or charities.

We define some of our key collaborators below. There is no differentiation made in the terminology used to describe these PPI Collaborators, nor in the way that they are involved.

**People and patients** – individual patients and members of the public who have not been involved in research, and individual patients and the public who have been actively involved in shaping research, working with us to steer, inform, and challenge our work. We aim to recruit individuals from across the region.

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[1] Available at https://www.arc-oxtv.nihr.ac.uk/files/ppi/a-framework-for-considering-who-might-be-involved-in-research.pdf

**Community organisations** - working with us to further our understanding and practice of involving more diverse, marginalised or seldom heard public voices within Oxfordshire and the Thames Valley, for example mental health charities such as ASPIRE or children with one or both parents in prison, such as Children Heard and Seen.

**PPIE practitioners within Oxfordshire** - including our host organisation, Oxford Health Trust, and the NIHR infrastructure e.g. NIHR Oxford Biomedical Research Collaboration and NIHR Oxford Clinical Research Network amongst others.

**PPIE practitioners across the Thames Valley and nationally** - We will continue to build relationships, share learning and collaborate with other Universities and ARC programmes across the UK to ensure that our PPI is as diverse as possible.

## Our Vision

Our vision is a world where everyone has the opportunity to live a healthy life. PPI is an essential part of achieving this.

Our mission in the Thames Valley and Oxfordshire ARC is to advance the elimination of health disparities through innovative research, support and networks. We will engage whole communities or groups and embrace charities or industry partners, not just individuals.

We will increase our co-production and co-creation with public collaborators to make the focus less of a central committee room and more of a citizen's initiative or grassroots approach. Equality, Diversity and Inclusion will be central operating principles, not just through designing bespoke research studies for specific groups but to include a diversity of relevant views and perspectives for all our work.

We will place an emphasis on better monitoring and measuring the direct and indirect outcomes from our PPI work to highlight the impact and value the PPI has added and to inform our work in the future.

This strategy will strengthen our vision by creating an integrated, embedded structure of PPI throughout the ARC, with greater outreach ambition than ever before to connect with the seldom heard and marginalised groups.

## Overarching Aims

- Identify all relevant and potentially interested populations for our work and increase the accessibility of opportunities to be involved throughout the research process with particular focus on implementing evidence into practice.
- Ensure that individuals and groups from seldom heard groups have space for their voices to be heard and use their involvement to identify new engagement strategies, focusing particularly on reaching ethnic minorities, disengaged and vulnerable groups to build relationships and create opportunities for a two-way dialogue for research ideas, priorities and dissemination.
- Work in partnership with our key community contacts, patients, stakeholders and researchers to ensure the excellence of our public involvement matches the academic excellence of our research.

- Increase the capacity and confidence for PPIE across the ARC amongst researchers, staff, patients and communities by offering training and supporting learning from each other.
- Create a culture of inclusive, accessible and engaged research by using governance to enhance and embed PPI activity across all levels of the ARC programme.
- Communicate our research outputs and opportunities to increase awareness for involvement, engagement and participation, particularly in those populations who are most likely to benefit.
- Add to the evidence base for PPI, particularly capturing the direct and indirect impact of PPI activity across the ARC programme, enabling us to learn what effective and innovative PPI is and use these findings to refine our strategies in the future.
- Ensure that planning, priority setting, fund allocation and reconfiguration of the ARC’s projects and activities is driven by the needs, views and preferences of the region’s population.

# Visual Overview of the Oxford and Thames Valley NIHR ARC Patient and Public Involvement Strategy

## An Integrated Inclusive Public Involvement Partnership To Increase Research Relevance and Quality

**A multifaceted public involvement infrastructure that is based on proven, successful strategies along with trialling and evaluating innovative approaches for collaboration with the involvement and expertise of our public collaborators.**

### Inclusive Opportunities

- Research is informed by a diversity of public experience and insight.
- Relationships are built or developed with the region's communities
- Public oversight of all communications to ensure information is transparent and accessible

### Working Together

- ARC Public Involvement Strategy developed in partnership with public collaborators to establish the shared purpose
- Clear roles and responsibilities are defined.

### Support and Learning

- Capacity development for staff partners and public collaborators run by the ARC and partners
- Mentoring opportunities for new public collaborators from experienced collaborators
- Partnerships across the Thames Valley to widen our outreach

### Communications

- PPI feedback on the content and format of ARC public communications
- Communications on governance and strategy decisions will be publically available
- Aim to encourage a two-way dialogue with the public through greater transparency

### Impact

- Regular monitoring and reporting of direct and indirect involvement activity and outcomes
- Formal annual reviews to reflect how our involvement approaches are meeting our aims
- Assess changes, benefits and learning from public involvement.

### Governance

- PPI representation at every level of decision making –overall ARC Strategy Board, research theme governance and project level
- Policies and processes in place to support inclusive involvement
- Adequate resources and accountability in the organisation.

## Structure

There are two key mechanisms for PPI:

- PPI that arises from the needs of research, researchers and involvement.
- PPI that arises from the needs of the public, patients and the community.

We will use proven, successful strategies to achieve this, as well as trialling and evaluating innovative approaches

### ARC Strategic Governance

- ***Two PPI Collaborators are included as members of the ARC Strategy Board.***

Their purpose will be to advise the Board on all development plans of public involvement and engagement within the Thames Valley and Oxfordshire ARC.

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

See Appendix 1 for a diagram of the ARC Governance and Organisational Structure.

### Research Themes

- ***Named PPI Collaborators or ‘PPI Champions’ included in the management of smaller theme groups will cover governance of the five Oxford and TV research themes. Theme meetings will take place at least once a term.***

PPI Champions (staff and public, see Appendix 3) will act as a liaison point between PPI Collaborators in their theme, the PPI members of the Board and the PPI Co-ordinator.

### PPI Champions

- ***The PPI Champion role provides critical PPI support for themes.***

Champions will be involved in governance decisions about internal funding bids through their attendance at theme meetings but also provide advice for researchers about engagement with the community through their own networks. The expected outcome is to increase the quality and quantity of PPI across the ARC programme.

There will be two *active* PPI Champions per theme, one staff and one public.

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

The PPI Programme Manager’s role will be, in part, 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 where it is feasible (see box).

**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

In order to help researchers support involvement in all stages of the research cycle, PPI training will be provided by the ARC (see “Capacity and Talent Building” section).

The ARC will ensure that all new projects have a PPI plan and the PPI Programme Manager will work with individual staff to ensure that they are fulfilling their proposals in relation to involving the public. PPI Champions also have a role in this.

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

## Response-Led PPIE

We will support opportunities to develop and support research, project and involvement ideas that are created, driven and co-delivered by people and patients.

### Relationship building with communities who are seldom heard in research

We will continue to work with established community groups and influencers through the networks and contacts our PPI champions bring, as well as taking opportunities to connect with existing PPI groups in the Thames Valley and Oxfordshire, such as those within Oxford Health Trust. The ARC will build a relationship with the Young Persons Advisory Group (YPAG) in Oxford, and similar partners, to support the involvement of young people in research. Through this connection we will support campaigns specific to young people and provide mutually beneficial opportunities for young people to support and co-create our work.

There is a growing patient voice in digital health innovations and the ethical use of NHS patient data in research. We will increase the opportunities for these patients and the public to access opportunities to influence and shape this research by building a relationship with patient-led organisations such as UseMyData, who aim to build confidence in the use of patient data in research, and Health Data Research UK, the national institute for health data science.

Identifying partners who work with vulnerable, minority and seldom heard populations will be key to building mutually beneficial relationships and ensuring that a diverse, broad range of the population is represented by our research. We will learn from other models of community engagement, such as Connecting 2 Communities (C2C), and utilise the expertise of relationship brokering organisations like Egality Health. To understand how this type of involvement will fit amongst the work we already do, we have partnered with PPI colleagues in the BRC and two researchers from the Department of Primary Care Health Sciences to carry out a scoping exercise on current research practices for increasing equality and diversity. Results will be discussed with PPI collaborators to develop guidance for researchers on overcoming the barriers in recruiting these populations.

Having made connections with the communities, we will work to develop the relationship, creating a two-way dialogue between communities and researchers that encourage co-production, co-creation and legacy partnerships that will flourish beyond the lifespan of the ARC.

## Capacity and Talent Building

Continuing to build knowledge, skills and confidence for PPI in research amongst people and patients, staff and PPI practitioners embedded within the ARC.

*Supporting public collaborators*

- Continue training and support for public collaborators with our joint research training sessions with the Oxford BRC and Oxford Health BRC organised between PPI coordinators and public collaborators. At least six training sessions for the public are delivered over 12 months.
- Identify opportunities for public collaborators to co-deliver training with researchers, *e.g. more experienced collaborators delivering training to those new to involvement roles*.
- Support mentoring approaches amongst public collaborators, *e.g. more experienced public collaborators to provide support or shadowing opportunities to public collaborators new to the role*.
- Increase the wider level of public involvement activity across the Thames Valley partly through our membership of the Working Together group, e*.g. holding joint events and online activities for training, dissemination and public engagement in Buckinghamshire, Berkshire, Milton Keynes and Oxfordshire itself*.
- 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, *e.g. the use of technology and social media for virtual interaction and activities.*

*Supporting staff*

- Deliver staff interactive training sessions in PPI informed by needs assessment and evaluation, working with public collaborators to co-design and deliver these sessions in collaboration with the Oxford and Oxford Health NIHR BRC and the NIHR Research Design Service (RDS) in Oxford.
- Mentorship and advice for ARC researchers from the PPI Programme Manager with a response-mode offer providing bespoke support for PPI projects or problems.
- Support PPI professional development through practice including advice on grant ideas and preparing funding applications.

*Collaborations*

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 carer, patient 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.

WORKING TOGETHER
Patient and Public Involvement
in the Thames Valley

We are active partners in all of these workstreams.

We will bring the ARC strengths to a variety of collaborations within the NIHR and NHS organisations of the Thames Valley to further promote and increase PPI activity within the region and increase the access to opportunities for communities to engage with us about their research ideas.

We will increase the level of public involvement cross fertilisation between the ARC and the Sustainability and Transformation Partnership for our area (Buckinghamshire, Oxfordshire and Berkshire West (BOB) Integrated Care System (ICS) "BOB ICS"). This will include increased links with Healthwatch in Bucks, West Berkshire, Milton Keynes and Oxfordshire. This will also include increasing links with public leaders involved in the relevant ICS groups.

We will 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.

## Communications and Engagement

ARC communications will be critical to engage with the public and community already collaborating with us in the ARC, but also those communities and groups we haven't connected with.

They will be used to disseminate PPI ideas, events and training, including ideas and best practice on diverse recruitment and where to get support. Themes will also be expected to contribute to communications.

Feedback on this communication will be expected from the PPI champions and stakeholders working in the ARC. It is important that governance, strategy decisions and the processes behind these are completely transparent and available for the public to view. For example, Strategy Board meeting minutes will be published on the website. By increasing transparency we hope to generate a two-way dialogue with the public.

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 in collaboration with our PPI champions where appropriate.

Themes will be expected to demonstrate how they have engaged with the public in each year of the ARC and report any outcomes from the engagement so that strategies can be assessed. Where appropriate, themes will be encouraged to collaborate in running joint public engagement events to share resources and best practice.

## Expenses and Fees

We will reimburse and recompense PPI collaborators in all levels of involvement work with us at the NIHR recommended rates as outlined in the Working Together Organisations joint payment policy[2].

Individual projects and themes will pay for their PPI from within their budgets. All core ARC activity with the public will be covered by the central budget. When involving community contacts, who work with vulnerable or seldom-heard groups, we will reach a mutual agreement over who will be best placed to receive and distribute payments.

We will draw up service contracts, if this is appropriate, to ensure a fair and transparent process for payments made in this way.

## Monitoring and Reporting PPIE Activity

Each theme will produce a quarterly report on PPI activity and the PPI Programme Manager will collate responses for the Executive Group and the Strategy Board. 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 PPIE strategy;
2) what individual projects said they would do;
3) what themes said they would do; and
4) NIHR PPI Standards[3].

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 frame our work in the ARC with reference to the NIHR PPI Standards[3].

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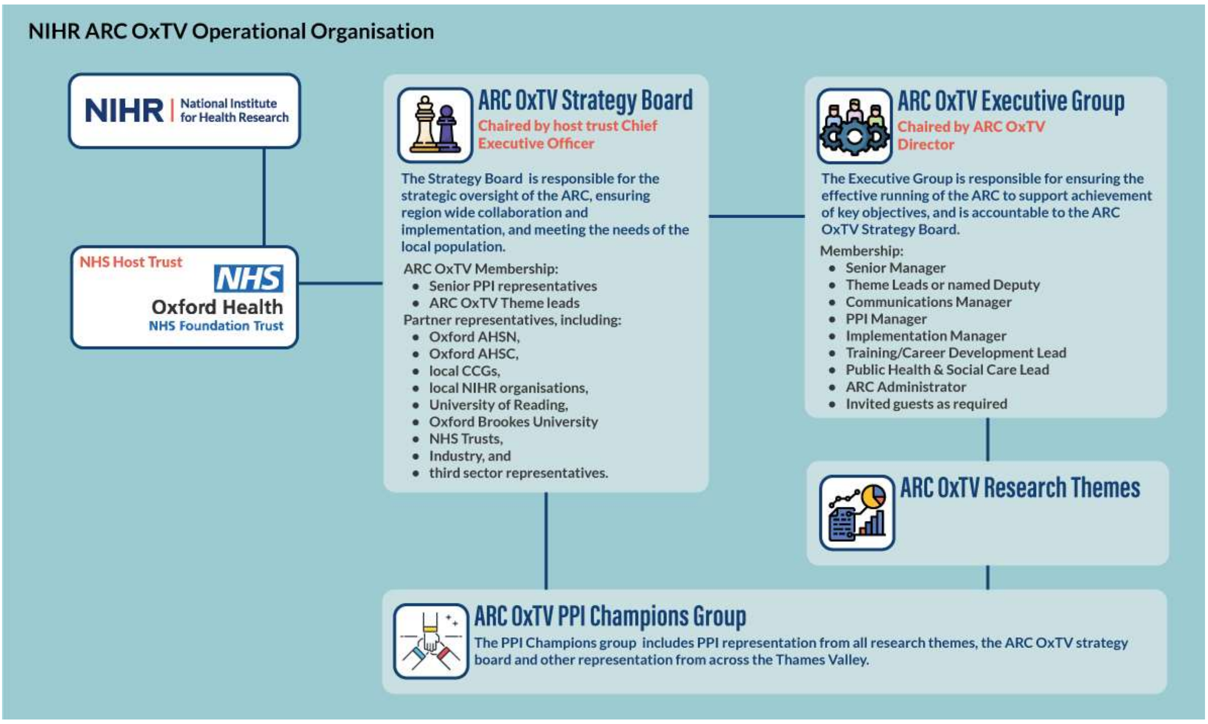
[2] Available at https://www.arc-oxtv.nihr.ac.uk/files/ppi/multi-agency-ppiee-policy-for-expenses-and-payments-2020-final-including-only-members-who-have-agreed-the-policy.pdf

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

# Appendices

## Appendix 1: ARC Governance and Organisational Structure



NIHR ARC OxTV Operational Organisation

**ARC OxTV Strategy Board**

Chaired by host trust Chief Executive Officer

The Strategy Board is responsible for the strategic oversight of the ARC, ensuring region wide collaboration and implementation, and meeting the needs of the local population.

ARC OxTV Membership:
- Senior PPI representatives
- ARC OxTV Theme leads

Partner representatives, including:
- Oxford AHSN,
- Oxford AHSC,
- local CCGs,
- local NIHR organisations,
- University of Reading,
- Oxford Brookes University
- NHS Trusts,
- Industry, and
- third sector representatives.

**ARC OxTV Executive Group**

Chaired by ARC OxTV Director

The Executive Group is responsible for ensuring the effective running of the ARC to support achievement of key objectives, and is accountable to the ARC OxTV Strategy Board.

Membership:
- Senior Manager
- Theme Leads or named Deputy
- Communications Manager
- PPI Manager
- Implementation Manager
- Training/Career Development Lead
- Public Health & Social Care Lead
- ARC Administrator
- Invited guests as required

**ARC OxTV Research Themes**

**ARC OxTV PPI Champions Group**

The PPI Champions group includes PPI representation from all research themes, the ARC OxTV strategy board and other representation from across the Thames Valley.

## Appendix 2: ARC Senior Manager Responsibilities

- Oversight of PPIE policies and strategic plans through line management of the Programme Manager responsible for PPIE co-ordination
- Attendance as required for workshops and PPI meetings
- Advising theme leads on compliance with ARC guidance
- Arbiter of complaints or issues, escalating to the Director if necessary

## Appendix 3: Provisional Role Descriptions

### Public Strategy Board Members

ARC Strategy Board public members will:

- Provide a high level, strategic overview of the ongoing ARC PPI work and the ARC PPI strategy.
  *This oversight will ensure that the ARC work is maximising the opportunities to provide patient benefit and stays focused on this agenda.*
- Develop mechanisms for liaising with PPI Collaborators on theme steering groups as these are appointed so that they can represent their views.
- Advise the Management Board on monitoring this strategy, and on development plans of public involvement within the ARC.
- Review ARC project applications for the appropriateness of the PPI proposed.
- Review and advise on the potential for patient/ public benefit when the Strategy Board decides on any grant allocations.

### ARC PPI Champions – Staff and Public

Each ARC theme will have two PPI Champions (one each for staff and public).

Appointment will be for one year in the first instance, from volunteers for the role and following discussion with the theme lead and ARC PPI lead. It is expected that champions will have prior experience of PPI but any inexperienced volunteer could be offered a deputy role with mentoring from a more senior champion or PPI representative. When recruiting public champions we will aim to include those 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, Patient Participation groups or third sector charity groups.

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 programme. The ARC PPI Manager and a public member from the strategy board will act as co-chairs for the Champions meetings. Going forward the chair could be nominated by the members themselves or the meetings could continue to be co-chaired between PPI and staff.

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

- have a direct PPI involvement in at least one of their theme’s projects or equivalent experience in the research theme as a whole;
- work with the local community to gather information about the needs of patients and the public from the local community (and for this reason, living in the ARC region would be preferred);
- attend their theme management and Champions meetings;
- review progress on a quarterly basis as part of the Champions meetings and ensure that the strategy and standards are being worked towards; and
- act as a liaison point between PPI Collaborators in their theme and the PPI members of the Board and the PPI Coordinator.

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;
- 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 and report progress on a quarterly basis for the Champions meetings and ensure that the strategy and standards are being worked towards.

Additionally, PPI Champions will be encouraged to provide co-presented training and presentations at ARC events and, where necessary, 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 every 8 weeks, with the PPI Programme Manager and a public member of the Strategy Board as Co-Chairs in the interim period. Location may rotate across venues in all three Thames Valley counties, if appropriate.

Proposed Attendees will be:

| | |
|---|---|
| PPI Champions - public | 5 |
| Programme Manager - PPI | 1 |
| Public members of the ARC Strategy Board | 2 |
| ARC Senior Manager | 1 |
| **TOTAL** | **9** |

Guests may attend as invited.

Meeting minutes will be circulated to the group and approved by them. They will then be shared more widely in the collaboration.