NIHR | Applied Research Collaboration Oxford and Thames Valley

Review of Patient and Public Involvement

in the

Applied Research Collaboration Oxford and Thames Valley 2019 -2026



Review of Patient and Public Involvement (PPI) in the Applied Research Collaboration Oxford and Thames Valley (ARC OxTV) 2019 -2026

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Abbreviations used throughout the document:

- NIHR – National Institute of Health and Care Research
- PPI – Patient and Public Involvement
- ARC – Applied Research Collaboration
- OxTV – Oxford and Thames Valley
- ARC OxTV– Applied Research Collaboration Oxford and Thames Valley
- TV – Thames Valley
- ARC TV – Applied Research Collaboration Thames Valley

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Thank you to ARC core team members, Theme Leads and Deputies and Strategy Board members for your time and honesty.

Executive Summary

The aim of this review is to report on the Patient and Public Involvement (PPI) in the governance of the NIHR Applied Research Collaboration for Oxford and Thames Valley (ARC Ox-TV) over the course of the ARC (2019-2026). The project has been led by the ARC PPI Champions (governance public contributors).

This project set out to capture the experience and reflections of key groups in the ARC about PPI during the ARC. It also made use of other PPI information and data including a review of PPI documentation, the PPI Monitoring to Learn development project and pilot, and PPI activity and task data.

There are many detailed findings but a summary of the key things we have learnt from the review are:

- **Partnership working** is key to successfully work together.
- P**ower sharing** is vital to create meaningful involvement.
- **Safe spaces** are essential for openness and transparency.
- **PPI approaches and activities** need to be fit for purpose.
- **Reward and recognition** is necessary to show value.
- **(Local) PPI Infrastructure** supports PPI consistency and continuous improvement.

The overarching recommendations are:

Continue doing what has worked well: Make use of co-created documents, and adapt them, with partners, as needed. Explore PPI practice to build knowledge, capability and capacity across the whole PPI community. Devolve decision making and meaningful activity to public contributors and strive to value and understand all lived experiences, knowledge and expertise.

Do more of what we already know works well: Make a habit of providing information (or ways to access information) in different formats. Avoid 'silo' working and centre PPI within the leadership team. Don't reinvent but extend the good PPI practice we have into more areas such knowledge mobilisation and implementation, building capacity, research prioritisation and designing from the very beginning and throughout the whole research cycle for every project.

Embed quality: Build the UK Standards for Public Involvement and the NIHR PPI Strategic Commitments into PPI processes and practice. Support PPI capability, capacity and confidence across the research system. Encourage continual PPI improvement through ongoing PPI review and reflection.

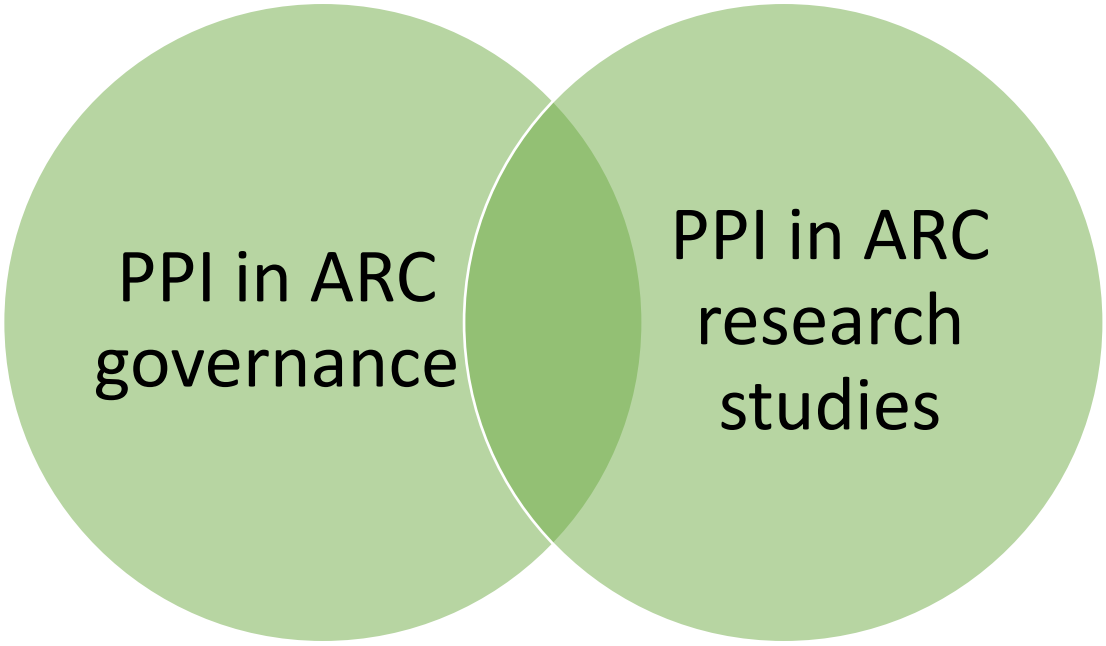
1. Introduction

The ARC OxTV is a collaboration between health and social care, public health organisations, public contributors, and universities in the Thames Valley region. The research undertaken by the collaboration is allocated to six different Themes. For more information about ARC OxTV please see Welcome — NIHR Applied Research Collaboration Oxford and Thames Valley.

ARC OxTVs aim was to ensure PPI was embedded in the governance and decision making activities of the collaboration. This is an activity that is distinct from PPI in research studies, although there are overlaps and linkages (see diagram 1).

Governance and decision making activities include influencing priorities, reporting, funding decisions, PPI policy and process development, staff recruitment, and implementation of PPI across the ARC. To do that it needed to be properly resourced and take a co-production approach. For example PPI policy developed by the governance group will impact the implementation of PPI in projects and the development of PPI monitoring resources affects the knowledge and quality of PPI across the collaboration.

Diagram 1: Governance PPI and Project PPI

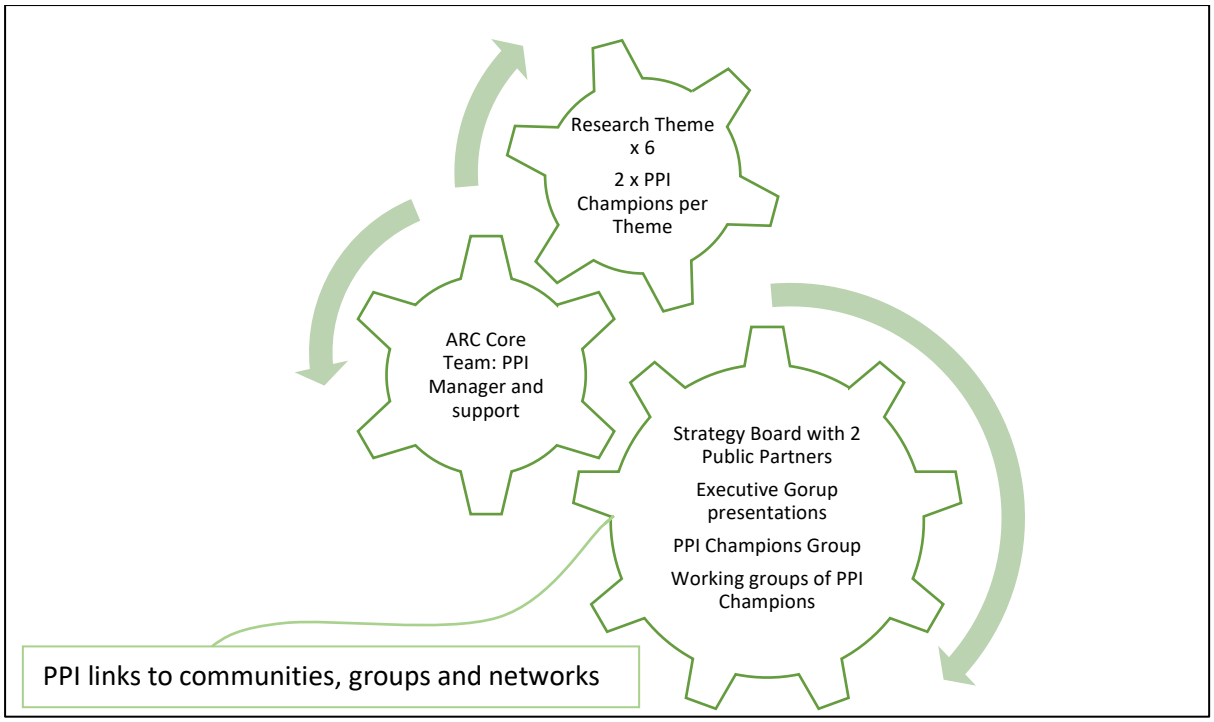


Each of the ARC Themes has two public members, they are called PPI Champions. These PPI Champions meet as a group to share learnings from different Themes and to develop PPI across the ARC. They also work to support PPI governance activities and ensure consistent PPI messages across the ARC's governance and strategic committees (see diagram 2).

Over the course of the ARC there have been external and internal changes and influences that have resulted in adjustments to the PPI in ARC governance. The ARC has aimed to be

reflective about its PPI practice and have established a 'reflect, review and adapt' approach. This approach is reflected in the ARC timeline (Diagram 3) on page 6.

Diagram 2: Where does PPI fit into the ARC?



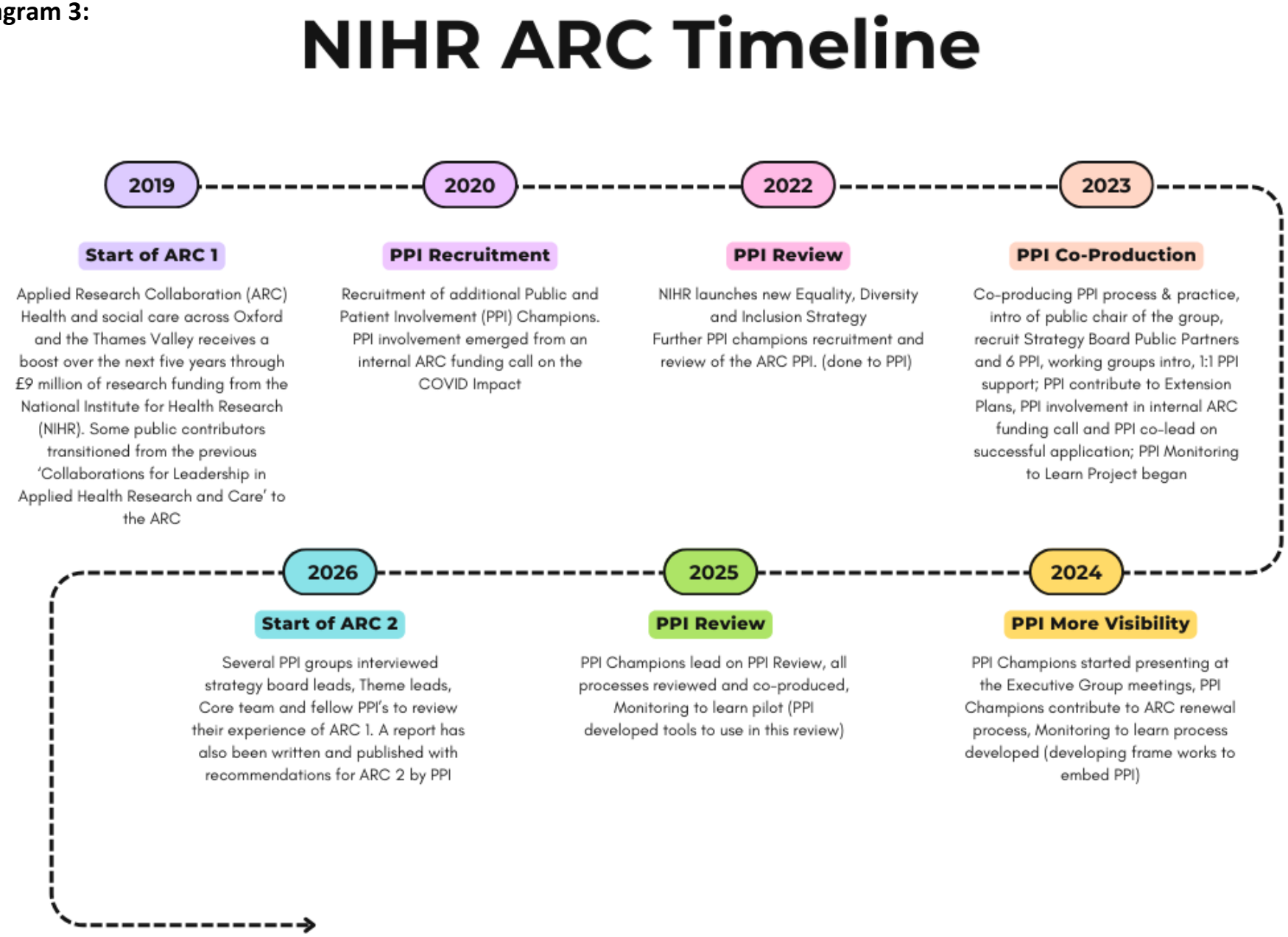
The PPI Champions undertook a review to evaluate PPI in ARC OxTV governance. To help manage the process nicknames were used for some of the projects: ELEPHANT (the things we don't want to forget) was used for the whole review and EAGLE (the process review project) for the document review.

The review makes use of additional end of contract activities such as completion of the PPI Monitoring to Learn resource we have been developing and the final review of our processes and documentation. It also looks at the activities and impact of the PPI Champions group and members. The additional activities for the review were to have conversations with key partners in the ARC. We wanted to explore their experiences and understanding of PPI in the ARC.

Overall, the purpose of looking at these different findings has been to identify lessons learnt about PPI during the life of the ARC. We have been particularly interested in understanding what has worked well and what has worked less well.

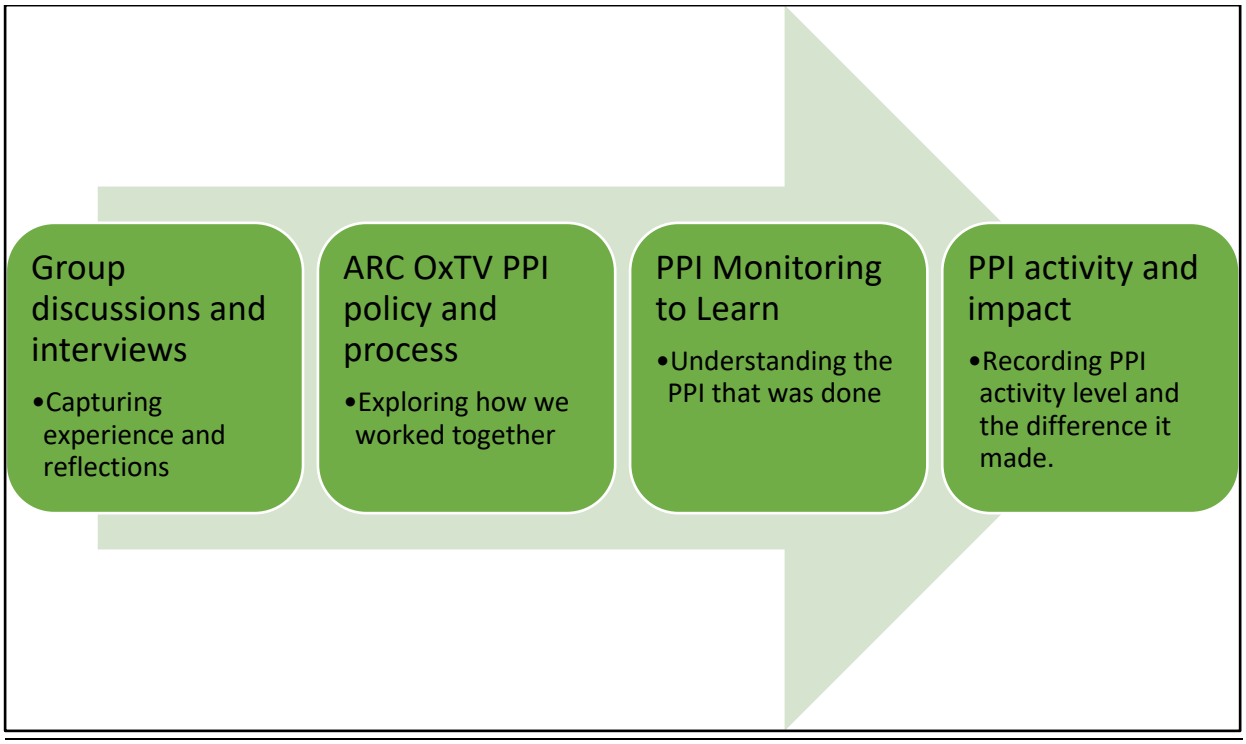
Ultimately our aim is to make recommendations to further improve PPI within a research infrastructure organisation. We are particularly keen to carry lessons learnt into ARC Thames Valley so that we strengthen PPI practice from the outset. The ARC PPI document review and the PPI Monitoring to Learn project will also contribute to ARC Thames Valley PPI processes.

Diagram 3:


NIHR ARC Timeline
2019
Start of ARC 1
Applied Research Collaboration (ARC) Health and social care across Oxford and the Thames Valley receives a boost over the next five years through £9 million of research funding from the National Institute for Health Research (NIHR). Some public contributors transitioned from the previous 'Collaborations for Leadership in Applied Health Research and Care' to the ARC
2020
PPI Recruitment
Recruitment of additional Public and Patient Involvement (PPI) Champions. PPI involvement emerged from an internal ARC funding call on the COVID Impact
2022
PPI Review
NIHR launches new Equality, Diversity and Inclusion Strategy
Further PPI champions recruitment and review of the ARC PPI. (done to PPI)
2023
PPI Co-Production
Co-producing PPI process & practice, intro of public chair of the group, recruit Strategy Board Public Partners and 6 PPI, working groups intro, 1:1 PPI support; PPI contribute to Extension Plans, PPI involvement in internal ARC funding call and PPI co-lead on successful application; PPI Monitoring to Learn Project began
2024
PPI More Visibility
PPI Champions started presenting at the Executive Group meetings, PPI Champions contribute to ARC renewal process, Monitoring to learn process developed (developing frame works to embed PPI)
2025
PPI Review
PPI Champions lead on PPI Review, all processes reviewed and co-produced, Monitoring to learn pilot (PPI developed tools to use in this review)
2026
Start of ARC 2
Several PPI groups interviewed strategy board leads, Theme leads, Core team and fellow PPI's to review their experience of ARC 1. A report has also been written and published with recommendations for ARC 2 by PPI

2. How did we do the review?

Diagram 4: How we gathered our information



a. Group discussions and interviews

This work stream aimed to capture the experience and reflections of key groups in the ARC about PPI during the ARC:

- Governance Public contributors – Strategy Board Public Partners and PPI Champions
- ARC Core Team about their experiences and reflections of PPI
- Strategy Board members
- Theme leads and deputies

The work was led by members of the PPI Champions group with support from the PPI Lead and other support staff. The whole group agreed the general approach and a framework for questions to be asked.

Each key group had an agreed team who were leading on the discussion groups and interviews for that group. Each team used the agreed framework to develop specific questions and the process for working with their group.

A mix of in person and online discussion groups and individual interviews were arranged. Where appropriate and possible discussion groups were prioritised with individual interviews used to capture the views of those unable to attend the discussion groups.

Where possible discussion groups and interviews were recorded and a transcript aided report writing. Key messages and themes were identified by one member of each team and were checked with other team members.

Each of the individual reports were then combined to create the key messages addressed in the discussions section.

b. Review of ARC PPI processes and documents

This work stream aimed to review the ARC's PPI processes and documents that had been co-created with members of the PPI Champions group. The development work had been undertaken in response to an earlier PPI review in 2022 which highlighted a greater need for understanding and clarity about the role of the PPI Champions.

We split the documents in this review into two distinct areas. Operational documents and processes and Support and learning documents and processes. This was a slightly artificial division but allowed us to split the task between two separate working groups (with some membership crossover for consistency).

<u>The review of operational processes focused on asking the following questions:</u>

I. Are the existing documents and processes fit for purpose?
II. Do the documents capture our existing practices and processes?
III. What additional processes would we suggest for the future?

The review process involved a working group of PPI Champions which addressed the questions above and then presented the outputs to the whole PPI Champions group for final agreement.

<u>The review of support and learning processes was undertaken in three phases:</u>

I. The PPI Champions working group undertook a review of existing documents. They developed new documents to capture existing practice not already recorded. They made recommendations about additional support.
II. A survey of the outcomes from the initial review was undertaken with all members of the PPI Champions group. This was analysed and summarised in partnership with members of the working group.
III. Using the survey data the working group revised the documents. They also produced a report of the survey findings and made some recommendations for future consideration. These final outputs were presented to the PPI Champions group for final agreement.

A more detailed report of the support and learning review process and outcomes is available.

c. PPI Monitoring to Learn review and development.

The PPI Monitoring to Learn project aimed to create a resource and process that helped the ARC to better understand what PPI was happening across the ARC and how we could use it within the ARC to improve PPI quality and capacity.

As with most things there was no existing product which did exactly what we needed so we used existing resources and knowledge to inform what we did. We designed an initial set of resources that we continuously reviewed and adapted as we piloted it across the ARC Themes.

As we neared the end of the ARC we took on board all that we had learnt during the pilot and undertook a final review of the resources we had been using. We also analysed the project PPI reviews that had been undertaken. The outputs from these two processes have been used to create a detailed report.

This detailed report is available separately to this document.

d. PPI activity and the impact of ARC OxTV PPI in governance.

Over the course of the ARC, we have put in place processes to record who we are involving, how we are working with our public partners and PPI Champion and Strategy Board Public Partner activity and impact. This has helped us to understand how we have developed over time, what has been done and what has been achieved.

3. Findings

This section of the report details the key insights from each element of the review.

A. Key insights from interviews and discussion groups in the ARC

There were remarkably similar insights across the different groups we spoke to. There were particular similarities between the thoughts of the governance public contributors, the ARC Core Team and the Strategy Board Partners. The conversations with the ARC Themes reflected many of the same thoughts but also explored PPI at a project level, thus identifying additional insights.

Commonalities across all of the groups included:

- It was acknowledged that the ARC PPI infrastructure developing and evolving PPI processes over time was important to success and effectiveness;
- Diversity is valued but needs investment to be meaningful;
- Supporting shared learning and good practice is important for PPI consistency and capacity building;
- Opportunities need to build on peoples interests and lived experience;
- It's important to identify and reflect on challenges.

The following provides more detail about the key insights and themes identified during the group discussions and interviews with key players in the ARC. The coloured boxes identify a specific theme and each is followed by a list of insights. These are all drawn from the group summaries in appendix 1.

Getting the process right is important - it can ensure a positive experience and successful involvement. It includes connecting people and building relationships across the ARC, understanding of roles and being clear about where PPI sits in the Leadership Team.

- Understanding of process, activity, roles and function are important to success and how people perceive their experience.
- The work of PPI support staff needs to be recognised and valued across the system.
- As PPI develops and grows communication is key, but it becomes more complex.
- Good chairing and support are essential to meaningful and successful involvement.
- When PPI is fully embedded it cannot be separated from other aspects of the research.
- You need the right approach in the right place.

PPI infrastructure is essential in supporting sustainability – building a robust, accessible, well-resourced and valued PPI infrastructure can help facilitate and support meaningful and sustainable PPI within the wider research environment.

- When PPI infrastructure and support is in place it becomes easier, more consistent and less burdensome for researchers.
- Individual relationships are important but robust systems help mitigate the potential fragility when those people move on.

Length of involvement can make a difference – given time and the chance to reflect the PPI system can adopt a continual improvement approach which will improve, develop and impact the wider research environment.

- Increased PPI activity overtime has led to increasing support for PPI.
- Those involved for longer have seen more growth in the PPI Champion role and appears to have led to more positive experiences.
- The response to the 2022 review has resulted in PPI improvements including increased diversity, increased PPI structure and a shift in PPI thinking – less tokenistic.

Aligning what public contributors do in PPI with their personal interests and lived experience matters – the experiences and commitment of public contributors involved in governance roles are improved when they are also provided with activities and tasks that link to their own interests and lived experiences.

- Whilst making sure that ARC PPI processes are robust is seen as valuable, the link to relatable research is also important for people and there appears to be greater satisfaction when involvement aligns with one's own lived experience and interests.
- Personal and community links are valued and beneficial.
- There is a sense that there has been a lack of strategic 'decision making' and influence in terms of ARC direction with some notable exceptions: discussing issues of importance in the Thames Valley, the 'so what' of reporting and the ARC extension

Sharing what we learn about PPI is important for capacity building – these learnings can support knowledge and confidence building for researchers and public contributors if we can find innovative ways to capture and share them across the ARC.

- Understanding that involvement can support personal growth for public contributors is important and should be valued.
- We need to be better at sharing good practice in order to support capacity building.

Diversity is valued - efforts to focus on and invest in inclusion and diversity are essential but we should also assess and reflect on the success and challenges of these activities.

- Increased diversity is valued but questions are raised about the value versus the increased cost of wide geographic involvement.
- Reaching out to and involving seldom heard voices takes time, trust building and creativity.

Challenges and missed opportunities – there will inevitably be missed opportunities but the reflective process allows us to identify and learn from them. Creating safe and non-judgemental spaces will encourage reflective PPI practice and learnings about missed opportunities.

- PPI is often present at the beginning and end of projects but opportunities can be missed to involve people early in research prioritisation and during the middle stages of projects.
- Balancing different perspectives can mean lived experience gets lost.
- Researchers struggle to know how to involve members of the public in more complex or academic projects.
- Lack of time in the 'system' is the problem not a lack of belief in the value of PPI.
- Funding expectations can push towards compliance and the risk of PPI becoming 'a tick box exercise'.
- Governance public contributors want opportunities to engage their lived experiences and interests.
- There needs to be a greater focus on knowledge mobilisation, implementation and building capacity.
- Think more about how to maintain and stimulate involvement in wider ARC activity and planning.

B. Key insights from the review of ARC PPI documents and processes

The PPI Champions co-created processes and documents to record how we work. This has provided a much clearer picture of the role of public contributors in the governance of the ARC.

Ours ways of working together have also modelled good practice in terms of co-producing with public contributors. We did this by creating the essential components for successful co-production: a warm welcome, space to talk, inclusivity, ongoing individual support for public contributors and most important of all genuine sharing of power.

As a result of the review:

We updated existing processes to better reflect what we were actually doing. In the main the changes made were minor changes or additions to wording to add clarity and/or current practice that was not reflected in older documents.

One of the most significant changes was to finalise and record the information about and process surrounding the groups chair role plus the formal addition of a co-chair role and a small planning group to support the work of the chair.

Another outcome of the review was to record the processes that were already in place but were not already documented or formally agreed. In most cases these had been informally agreed so we took this opportunity to formally record and agree them or they were co-produced and agreed with the PPI Champions group.

Some processes addressed issues that had arisen over time (either within the ARC or more broadly in the PPI networks we connect with) such as role boundaries and dealing with

difficult issues. Others were created to record our existing practice (e.g. records, individual support and team building etc).

We also agreed to create separate documents for some issues that were embedded in other processes but we felt should also have a standalone document for clarity (e.g. confidentiality and conflicts of interest).

In addition, for our support and learning activities we compiled a report of all the survey responses. It contains the feedback provided with a summary of what action was taken or recommended for the future. A further document was created that highlights all the suggestions we could not include in the ARCs final processes but that are recommended for consideration in the future, please see appendix III for further details.

Finally, we identified recommendations for the future:

- The main recommendation is to make use of the documents and processes we have co-created, adapting them to individual context as needed.
- We also recommend creating a frequently asked questions document (and/or space on the PPI webpages) which provides a questions based route to searching for information about processes.

C. PPI Monitoring to Learn Development Project and Pilot

The PPI Monitoring to Learn project set out to develop a resource that could be used to plan, monitor, and evaluate PPI in ARC projects in a consistent and robust way. We also aimed to establish how we could use the data collected to improve quality and build capacity for PPI across the ARC. We are therefore reporting on two separate but connected activities: the development process and the results from the pilot. Both were overseen and co-designed with the ARC's governance public contributors, known as PPI Champions.

Developing and reviewing the PPI Monitoring to Learn Process

The co-design group took an iterative development approach. They continually reviewed and adapted the resources as they were piloted. As the ARC drew to a close, they undertook a final review and created a combined planning and monitoring form. They also developed PPI impact and evaluation guidance.

What we learnt about PPI in ARC OxTV from the Monitoring to Learn Pilot

The oversight group collated and analysed the information gathered about PPI in the ARC through the PPI Monitoring to Learn process. The key learnings were:

The Monitoring to Learn Process supported **knowledge building and relationship development** between public contributors and researchers. This in turn led to the creation of '**safe and non-judgemental spaces**' to discuss concerns about enablers of and barriers to PPI.

The monitoring forms identified multiple cases where **PPI changed the way a study was conducted and/or impacted the outputs of the study**. They also showed that over the course of the ARC that a **consistent and supportive PPI infrastructure can help maximise the impact of PPI.**

Researchers acknowledged that PPI could be broad, deep, and impactful. It could also keep them grounded, provide a sounding board and provide context. On reflection they also understood the importance of the PPI approach being appropriate for the community you want to involve and that the process you plan needs to be flexible, so you can adapt to individual need.

ARC projects reflected all six of the **UK Standards for Public Involvement** and supported the implementation of all 5 **NIHR PPI Strategic Commitments**.

Recommendations for the future:

- **Embed in ARC Practice.** ARC Thames Valley should embed the PPI Monitoring to Learn process in their work. There should be a requirement for all Applied Research Collaboration Thames Valley (ARC TV) research projects to develop a PPI plan and to monitor it. They should monitor and adapt the resource as needed.
- **PPI Knowledge Mobilisation.** Use the outputs from the PPI Monitoring to Learn process to identify opportunities to share good practice and build knowledge. This applies to both public contributors and academics. They can also be used to identify where central support could further enhance PPI capacity building (for example where central infrastructure could support PPI activity more effectively and where central learning opportunities can support capacity building).
- **National PPI Agenda.** Explore how to better embed the UK Standards for Public Involvement and the NIHR PPI Strategic Commitments into the process.

D. PPI to Activity and impact of ARC OxTV PPI in governance.

The tables in appendix II identify and summarise some of the important information about PPI governance in ARC activity over time. It is important to note the impact of the 2022 PPI review in the increase in activity in this area. For reference Diagram 3: NIHR ARC Timeline on page 6 (also in appendix V) explores some of the key milestones of the ARC.

The ***first table*** provides details about the 11 working groups established to support the work of the PPI Champions and development of the ARCs PPI systems. The working groups weren't just a construct but each group had a meaningful purpose and objectives. They were held to account through the full meetings of the PPI Champions group and the wider ARC governance system. Each working group produced valuable outputs that are identified in the table.

The ***second table*** provides information about activity levels. We can see a clear change of pace in activity after the 2022 PPI review. The numbers of PPI Champions doubled in the year following the review. The number of active working groups increased from zero to

seven in this period and the number of meetings increased alongside the increase in groups. We also saw a rise in regular personal support and other activities.

The ***third table*** is a summary of the PPI impact log for the ARC. It identifies some of the key impact highlights from 2023 when the log began. This sample of impacts reflects the breadth and depth of the PPI Champions on PPI development and activity in the ARC. It covers:

- strategic influence
- data collection
- operational guidance
- PPI monitoring
- funding decisions
- feedback process development
- engagement with the wider governance structure in the ARC
- support for researchers undertaking PPI
- evaluation of ARC PPI

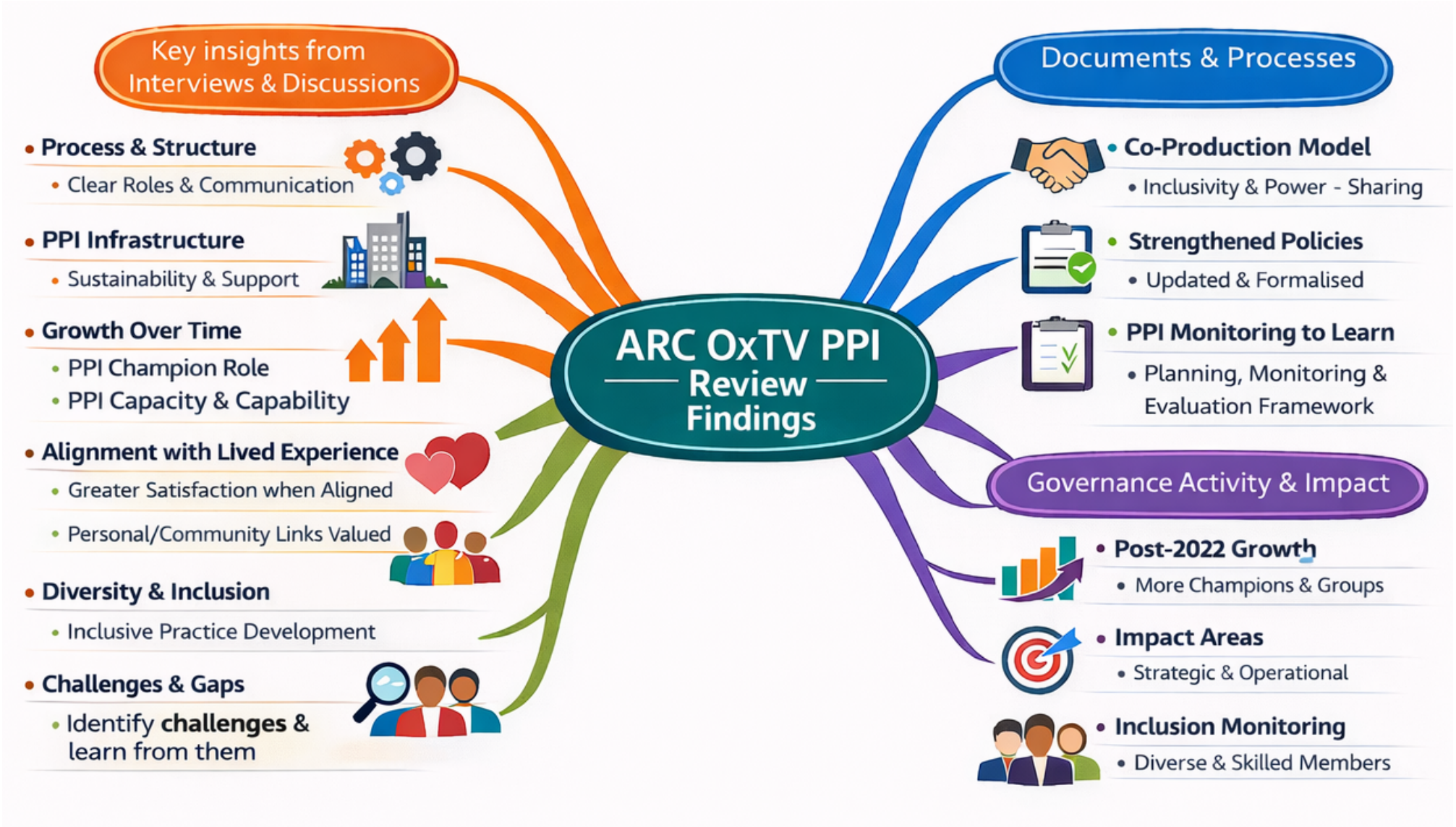
The ***fourth table*** is a summary of the key findings from the ARC's inclusion monitoring in 2025. Whilst we can't share our PPI Champion specific data we can confirm that the group data indicated a diverse group. The group members learnt about PPI from a variety of places. Their length of involvement ranged from newly involved to more than 10 years of experience. They had considerable lived experience between them and they came from diverse communities.

The ***PPI Champions experience map*** in Appendix VI helps explain the depth and breadth of lived experience, knowledge and interests that our PPI governance public contributors brought to the ARC. This information is drawn from multiple sources including our skills audit (instigated and facilitated by our PPI Champions), building broad and meaningful relationships with individuals and our inclusion monitoring. It has helped us see each other as individuals and more than the 'role' we fulfil. It has enabled us to value all experience and knowledge and to offer opportunities that allow people to excel, develop and add meaning.

Recommendations for the future:

- Embed ongoing review and reflection to ensure continual improvement.
- Devolve decision making and meaningful activity to public contributors to widen the skills pool and to make best use of available resources.
- Take a more pro-active approach to engaging and integrating the PPI governance team with the core ARC team, the wider ARC community and PPI networks.
- Strive to value equally and understand the different lived experiences, knowledge and expertise that individuals bring to the process, regardless of the role they fill.

Diagram 5: Summary of review findings



Conclusions

The following is a summary of the key findings that have come out of all elements of this PPI review: the group discussions and interviews; the review of PPI documents and processes; the PPI Monitoring to Learn project and the PPI activity and the impact of ARC OxTV PPI in governance. Many of the messages were consistent, albeit expressed differently, across the four key components of the review.

Partnership working is key. The cornerstones of co-production and co-creation are invaluable: a warm welcome, space to talk, inclusive practice, ongoing individual support for public contributors and most important of all genuine sharing of power.

P**ower sharing** is vital and can only be done meaningfully if you genuinely value all knowledge and lived experience equally and devolve power to your public partners.

Safe spaces are essential to be able to both surface and explore challenges and barriers to PPI. Those spaces need to be safe for both public partners and academics and need to apply non-judgemental approaches to achieve this. A key part of this process is to build in space to talk and enable relationship building opportunities.

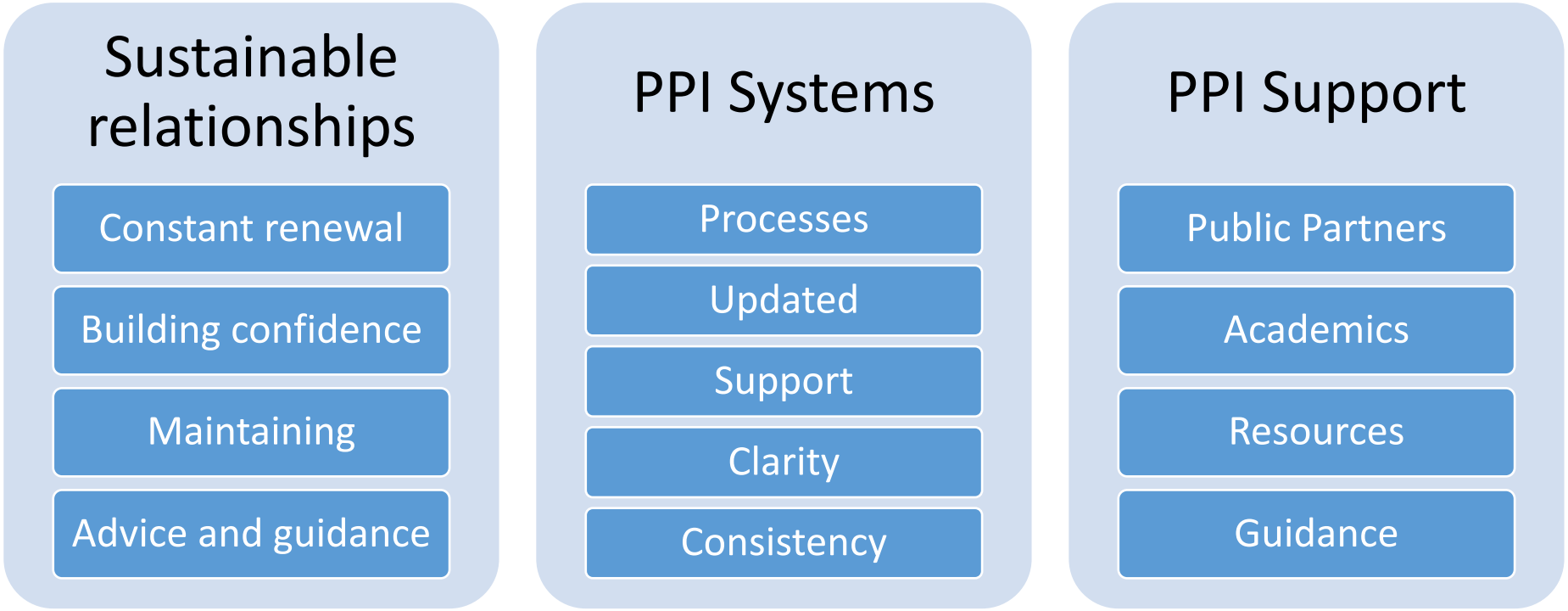
PPI approaches and activities need to be fit for purpose. They need to meet the needs of the community to be involved so their contribution can be as meaningful as possible. We can look at what others did before but we always need to think about and adapt to the current context.

Reward and recognition payments for time are important but so are personal interests, lived experience, personal development and respect. PPI opportunities need to be valued financially but also offer opportunities for personal growth.

(Local) PPI Infrastructure supports PPI consistency and continuous improvement as it allows processes to be developed and maintained over time. It offers support to the wider research system ensuring that academics have local access to guidance and up to date information and resources. This in turn supports PPI success and effectiveness. There was a clear message that PPI is valued but there is often a lack of time/resource to do it well. Good local PPI infrastructure was seen as a way to help with this as it can build:

- **PPI processes** that are clear, understood and consistently implemented. People need to be confident about what they are doing and who to ask if they are in doubt.
- **PPI sustainability** in the longer term. PPI infrastructure can think about how to maintain relationships, how to plan for when people ‘move on’, how to ensure consistent and up to date PPI processes.
- **Diversity**, which is widely valued and seen as important, through collective investment that can be used to build and improve meaningful engagement and involvement with diverse communities.
- **Opportunities to share learning and good practice** to facilitate PPI capacity building.

Diagram 6: PPI Infrastructure can offer



Leading to:

Capacity to support individual research projects and teams
PPI capability and capacity building
Confidence to do PPI

Summary of Recommendations

The following summarises all of our learning and recommendations that have come out of this review of Patient and Public Involvement (PPI) in the Applied Research Collaboration Oxford and Thames Valley (ARC OxTV) 2019 -2026. This is not a substitute for the detail in the report and appendices but does attempt to summarise and capture the ethos and direction of our recommendations.

Continue doing what has worked well:

- Make use of the documents, processes and resources we have co-created.
- However, everything is a work in progress so pilot and adapt them to individual contexts as needed.
- Use the resources we have created to identify opportunities to share PPI good practice and build knowledge, capability and capacity across the whole PPI community.
- Continue to devolve decision making and meaningful activity to public contributors.
- Strive to equally value and understand the different lived experiences, knowledge and expertise that individuals bring to the process regardless of the role they fill.

Do more of what we already know works:

- Make a habit of providing information (or ways to access information) in different formats such as documents, aural/video outputs, visuals, animations, tips, FAQs.
- Take a more pro-active approach to engage and integrate the PPI governance team with wider ARC planning, activities, processes and support functions through robust relationships with the core ARC team, the wider ARC community and PPI networks.
- Think carefully about where PPI sits within the leadership team.
- Build on what we have learnt and explore our detailed recommendations.
- Extend the good PPI practice we have into more areas such knowledge mobilisation and implementation, building capacity, research prioritisation and designing from the very beginning and throughout the whole research cycle for every project.

Embed quality:

- The UK Standards for Public Involvement and the NIHR PPI Strategic Commitments into our processes and practice.
- Build capability, capacity and confidence across the system for public partners, PPI leads and researchers.
- Recording impact and activity.
- Ongoing review and reflection to ensure continual improvement.

To be successful requires a partnership approach with commitment from across the ARC – board members, senior staff, academics and governance public contributors. Each has their role to play in embedding and learning form PPI throughout the ARC.

Diagram 7: Summary of review recommendations



Appendices

I	**Group discussion and interview summaries:** ARC Themes, PPI Champions, Core Team and Strategy Board	**Page 22-29**
II	**PPI Champion data:** Working Groups, Activity Record, Impact Log, Diversity Data	**Page 30-38**
III	**EAGLE documents:** ARC PPI processes and documents review	**Page 39-42**
IV	**Abridged PPI Monitoring to Learn report**	**Page 43-53**
V	**NIHR ARC Timeline**	**Page 54**
VI	**Public contributor experience map**	**Page 55**
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APPENDIX I: Group discussion and interview summaries

ARC Themes Summary

This summary provides feedback from the ARC OxTV Themes about experiences and reflections of PPI over the course of the ARC.

Method

Interviews were undertaken with all six themes. The questions and process were developed by the planning group. Follow up communications were conducted as necessary. Meetings and interviews for each theme were recorded and a transcript produced. These aided the cross theme summary report writing. AI was used as needed.

The themes in this summary were developed by one member of the planning group and checked with the others. They identified:

1. Themes that were duplicated across multiple themes
2. Themes that appeared in only one/fewer themes

Key themes repeated across multiple themes

PPI Has Become More Embedded Over Time

- Across themes, PPI has clearly evolved from being more ad hoc or limited to becoming more integrated.
- There is a shared sense that PPI is now thought about earlier in projects than it was at the start of the ARC.
- Several themes describe a shift away from tokenistic involvement towards more meaningful engagement.

PPI Works Best When Embedded, Not Bolted On

- PPI is most effective when it is built into projects from the start and runs alongside the research.
- Where PPI is fully integrated, it becomes hard (and unnecessary) to separate "PPI input" from the rest of the work.
- This applies across clinical, policy, digital, and methodological research.

The Role of Infrastructure and Coordination Is Critical

- Central infrastructure and resourcing (PPI managers, coordination, payment systems, BRC/ARC support) repeatedly comes up as essential.
- Where infrastructure exists, PPI is easier, more consistent, and less burdensome for researchers.

- Concerns are shared across themes about sustainability once ARC-level infrastructure reduces or ends.

Time and Capacity Are the Main Barriers (Not Attitudes)

- Across themes, lack of time and capacity — not lack of belief — is the biggest barrier.
- Recruiting, briefing, coordinating, and sustaining PPI all take time that is often squeezed by funding deadlines.
- Short grant timelines and last-minute proposal writing make early PPI harder, even when researchers value it.

PPI Is Strongest at the Start and End of Projects

- Many themes describe a similar "U-shaped" pattern:
    - High PPI input at idea generation and design
    - Drop-off during delivery and analysis
    - Increased involvement again at dissemination and reflection
- Several themes note missed opportunities for lighter-touch involvement during the middle stages.

PPI Champions Add Significant Value — but the Role Needs Clarity

- Where PPI champions were in place, they were consistently described as valuable.
- Champions worked best when their role was clearly defined (e.g. strategic, critical friend, connector).
- Reliance on individuals creates vulnerability when they leave unless PPI is embedded structurally.

Creative and Flexible Approaches Improve Engagement

- Multiple themes highlight that traditional methods (interviews, focus groups) are not always effective.
- Creative, informal, or digital approaches (art, storytelling, TikTok, workshops) enabled engagement that wouldn't otherwise happen.
- Flexibility in how PPI is done is repeatedly seen as a strength of the ARC.

Cross-Theme Learning and Sharing Is Weak

- Nearly all themes mention limited cross-theme working, especially around PPI.
- Good practice exists, but it is siloed.
- Opportunities to share *how* PPI is done (not just outputs) are missed.

- Capacity and lack of shared spaces are recurring barriers.

Key themes mentioned more selectively or unevenly across themes

Tension Between Policy Engagement and Lived Experience

- Some themes (particularly those with strong policy links) note that policy engagement can dominate over lived-experience PPI.
- This is not universal across all themes but is a clear pattern where it appears.

Challenges of PPI in Highly Technical or Methodological Work

- Most explicit in Theme 6 and parts of Theme 5.
- Researchers struggle with how to apply PPI meaningfully to:
    - Economic modelling
    - Statistical methods
    - Code or process-focused work
- There is confusion about expectations, particularly for small or technical grants.

Risk of PPI Becoming a "Tick-Box" Requirement

- Raised explicitly in some themes, implied in others.
- Concern that external funding expectations can push PPI towards compliance rather than meaningful involvement.
- Linked to lack of shared understanding of what "good PPI" looks like in different research contexts.

Importance of Diversity and Reaching Seldom-Heard Groups

- Some themes describe strong efforts to involve seldom-heard voices.
- Others acknowledge this as important but more difficult to achieve.
- Where it worked well, it required additional time, creativity, and trust-building.

Dependence on Individual Relationships

- Several themes note that strong PPI often depends on specific relationships.
- While powerful, this creates fragility when people move on.
- Highlights the need for systems, not just good individuals.

Sustainability Beyond the ARC

- Raised particularly in later reflections.

- There is shared concern about what happens to PPI once ARC-level support ends.
- Budgeting PPI into individual grants helps, but may reduce flexibility and continuity.

PPI Champions Summary

This summary provides feedback from the ARC OxTV PPI Champions about experiences and reflections of the ARC. Members have joined the ARC at different points in the timeline and this is reflected in the feedback.

Method

A one-hour discussion was undertaken with six PPI Champions as part of a regular online meeting. The questions and process were developed by the planning group. Follow up online interviews were conducted by the planning team with a further six PPI Champions, some of whom are still active in the ARC and some that have stepped away. Two PPI Champions opted out. Meetings and interviews were recorded and a transcript aided the report writing, along with AI for one interview. Themes were developed by one member of the planning group and checked with the others.

Key themes

The PPI Champion experience

- Both positive and challenging experiences of being a PPI Champion. This is related to how long PPI Champions have been in place (the longer, the more likely positive experiences and observed growth of PPI Champion activity in research).
- Higher levels of satisfaction were noted where interaction with Themes and other aspects of ARC research aligned with peoples lived experience of healthcare, or interests.
- Being involved in the ARC Showcase Event in 2024 was very positive.
- For some Champions the role has been an enabler for personal growth, aided by the diversification of membership over time

Working with Research Themes

- The way that the research Themes work seems to have an important influence on how Champions perceive their experience. Frequency of meetings and mainly online interactions are common, as were patchy preparation and notice of agenda papers.
- More success has been noted with regular meetings, PPI on the agenda and occasional in person contact, helping to build relationships. Most Theme leads have been welcoming and respectful of the PPI role.
- Some Champions have cited how important and useful their links with and reach to local communities with Theme researchers

- Factors to note for future improvements include; building relationships with Theme Leads their PA or admin support; regular meetings and PPI being 'present,' listening to PPI insights, normalising PPI as part of research dialogue and reminding themes of PPI Champions external links and networks.

PPI Champions group, meetings, and support

- People remarked upon the quality of communication within the group, less so with the wider ARC, especially the Theme Leads.
- For most of the Champions there was *"too much focus on processes in PPI, rather than the actual research."* It was noted however that there was a lot of catch up on Governance and processes post the ARC PPI Review in 2022
- Very positive experiences of the support from the Public Involvement Officer (Una) and the core team. This includes organising practical arrangements for meetings, responding to needs of PPI Champions, and payments processing.

Strategy Board

- A mixed experience as both public board partners felt they had not had much impact in the proceedings, except where they had challenged the impact and reporting agenda for the research programmes, and the ARC extension. The Board was well chaired and the PPI input was respected. The problem was felt to be the agenda with mainly 'reporting in' to members, and little scope for decision making or strategy development.

Development of PPI in the ARC overall

- For the PPI Champions that have been involved since its inception, or early history there is a sense that PPI has evolved over time and grown in its' reach and influence.
- For the newer members, they tend to compare their experience with external PPI activities, sometimes expressing frustration with their PPI experiences.

Core Team Summary

This summary provides feedback from the ARC OxTV Core Team about their experiences and reflections of PPI over the course of the ARC.

Method

An online meeting of four members of the core team (two sent apologies and the PPI Lead did not attend, so that people could speak freely about PPI). The process and questions were developed by the planning group and the meeting was recorded. One follow up 1:1 interview was conducted. Meetings and interviews were recorded and a transcript aided the report writing, along with AI for one interview. Themes were developed by one member of the planning group and checked with the others.

Key Themes

Supporting PPI Champions

- The team provides a wide range of support for PPI Champions – ranging from 1:1 conversations, practical adjustments so that people can participate fully, arrangements for travel, parking and accommodation as needed.
- PPI Co-ordination and oversight is also situated in the core team, this consists of scheduling and supporting PPI champion meetings, providing individual support and co-ordinating PPI initiatives and activities across the ARC.
- Whilst many champions value this support there has perhaps been an undervaluing of the work invested in these arrangements, especially the practical support.
- Improved communications and understanding of roles between the core team, PPI Champions and Themes might reduce instances of last-minute cancellations and loss of funds for the ARC, as well as a broader understanding of how PPI is happening in the ARC and the impact of this on ARC research.

Where and how PPI happens

- The team feel that there is obvious PPI occurring at project level in the ARC and in governance arrangements. There is less clarity about PPI being effective in the Knowledge Mobilisation and Implementation and building research capacity. The irony of this is that putting research into practice and making change is of huge interest to PPI Champions and is often why they get involved in research.
- In terms of the Strategy Board the two public partners were to seen to be 'working as well as you can within a board that does not really do what a board should do.'
- The 2024 Showcase was agreed as an excellent example of PPI in planning and delivery of a large research event.
- There was discussion about the role of PPI in ARC communications, perhaps with a nominate PPI Champion lead for this. There was some push back on this idea, as it was felt that more understanding systemically of PPI in the ARC and possible communication outputs would be more appropriate.

PPI changes over the time of the ARC

- Following the PPI Review in 2022 there have been significant improvements in PPI including; increased diversity of PPI champions following a recruitment drive; increased perspectives of underserved communities; increased structure for PPI Champions as a group and within the Themes they work with.

- The increased complexity of PPI Champions (numbers and roles) has meant that there has been an increase in PPI activity but this makes it more challenging to communicate this within the ARC.
- The network of PPI Champions has extended to beyond the Thames Valley region and there were questions about what added value this brings – especially given the extra costs incurred in supporting those to travel and stay for ARC activity.

Strategy Board Summary

This summary provides feedback from some members of the ARC OxTV Strategy Board about their experiences and reflections of PPI over the course of the ARC.

Method

Two half hour Zoom sessions were held with members of the Strategy Board (one internal to the Nuffield Department of Primary Care Health Sciences and three external partners). The process and questions were developed by the planning group. The sessions were recorded and a transcript aided the report writing, along with AI for one interview. Themes were developed by one member of the planning group and checked with the others.

Key themes

Added value of having public members of the OXTV Strategy Board

- A 'reality check' on the overall direction of travel (themes associated with the ARC) and related debate, providing different perspectives, non-academic viewpoint and from lived experience.
- Public Board members have given a 'little bit of shaping' in one of the meetings, and some of the conversation has been steered by them.
- Initiating a debate about the 'so what' element of research reporting (as the ARC completes its cycle) in addition to meeting targets and contractual obligations what does the research mean for the public?
- The discussion led to a process of Themes discussing how they could provide impactful case studies to illustrate the 'so what' factors of their research.
- 'it's very easy to lose sight that we're here to support research that translates into patient benefit''

The Strategy Board Structure and contractual obligations

- The nature of the Board agenda was not very conducive to public participation (or more general participation), this was in stark contrast to examples such as a presentation from the ICB about ageing populations in the region which generated much discussion. This was because it was not a 'this is what we're doing' input but 'here's a Thames Valley population problem' and both public partners participated

fully in this conversation. Similarly, the work on the ARC contract extension allowed for public partners to contribute ideas.

- Stronger messaging about what the Board is for was suggested, 'so perhaps we need to get the language right, we need to communicate to the outside communities of what really strategy board is doing.'
- The Chair was effective in bringing in the public partners to the discussion.

Wider influences of having PPI as part of the ARC

- Noted increases in PPI funding, support, and activities across the ARC 'most of the teams that receive ARC support have become increasingly supportive of the PPI.'

What changes are needed going forward – for example with ARC 2?

- Learn from the PPI Review of ARC 1
- Think carefully about Boards and Executive groups – both generally and with a PPI lens
- Recruit effective chairs of strategic groups where there will be PPI to maximise the effectiveness of the public voice
- Consider how public involvement will work as part of the leadership team, who is in that room to be part of the conversation and feel part of that conversation?
- Working with the Community Research Network

APPENDIX II: PPI Champion Data

PPI Champions Working Groups: These groups undertook specific tasks and reported to the PPI Champions Group who had oversight of projects.

PPI Champions Working Groups – Purpose and Membership		
Working Group Title	**Main purpose and outputs**	**Membership (PPI Lead Una Rennard is a member of all working groups)**
Chairs Planning Group	The purpose of the group is to plan PPI Champions group meetings and annual work plan for the group. Planning days are held at least annually. There are also a minimum of at least one pre and one post PPI Champions group meetings. Main outputs of the group are annual action plans, review and monitoring of the plan and adjustments as required, agenda and minutes for meetings, ensuring process is adhered to and ensuring support is offered as needed.	Mary Zacaroli (Chair) Millie Khisa (Co-Chair) Sally Crowe (Strategy Board Public Partner
Website Working Group	The purpose of the group is to support the development of the ARC PPI webpage and its content. Regular meetings were held to re-develop the page and the content. Oversight of implementation and ongoing monitoring and updates.	Sally Crowe Firoza Davies Emily Slade

	Main output is the revised webpage.	
PPI Monitoring to Learn Working Group	The purpose of the group is to support the development and pilot of the Monitoring to Learn Project. The group has grown over time as the pilot has been rolled out. Regular meetings have been held as part of the development and revision process. As the pilot neared its conclusion the group met to do a final revision of the documentation, produce guidance and record the development process. The group have also use the data collected to report of ARC PPI. The group members also worked independently to gather information about PPI in projects via their Themes. Main outputs are Monitoring to Learn documentation, ARC PPI stories and a report of ARC PPI and the Monitoring to Learn development process.	At least one person representing each theme: Sally Crowe (T6) Millie Khisa (T4) Judith Williamson (T1) Georgina McMasters (T1) Mary Zacaroli (T3,4&5) Jo Flowers (T2&5)
PPI Funding and Researchers Capacity Development Working Group	The purpose of this group was to initially review the process for accessing ARC (and department) PPI funding for researchers. Later work has involved piloting PPI Surgeries for Theme 6 and more recently the department.	Sally Crowe Firoza Davies Georgina McMasters Judith Williamsons Rashmi Kumar (added for PPI Surgeries)

	The main output has been a revised funding process and the PI Surgeries pilot	Mary Zacaroli(added for PPI Surgeries) (Polly Kerr)
ARC Renewal (sits outside PPI Champions) Working Group	The purpose of this group was to ensure PPI input into the ARC2 tender process. They met on a number of occasions and voiced the views of the wider group drawn from meetings in autumn 2025. The main output was contributions to PPI plans for ARC2 and development of the plain English summary.	Jo Flowers Mary Zacaroli Sally Crowe Graeme Johnston plus capacity to co-opt as required (all group members had the opportunity to contribute through meetings and email correspondence)
Who does what and EAGLE Working Group	The original purpose was to develop a fair process for selecting who got involved with what pieces of work. This was then extended (and the group expanded) to review all of the ARCs PPI operational processes as we neared the end of the ARC. The group met in person and worked via email to undertake this project. The main output is all of the revised documentation that is now available via the website PPI page.	Sobia Afridi Jo Flowers Mary Zacaroli Graeme Johnston
PPI Mapping and Support and Learning Working Group	The original purpose of the group was to develop the Skills mapping exercise that the group undertook.	Mary Zacaroli Jo Flowers Millie Khisa Sally Crowe

	The group then extended (and expanded) to review and make recommendations about the support and learning practices for ARC PPI. Although undertaken separately the support and learning review is aligned with the EAGLE work above. The membership crossover between the two groups made this possible. The group met as needed to undertake this work and also worked offline and via email to complete the tasks. The main outputs were the skills audit, the support and learning survey and analysis, the revised documentation for support and learning (available via the website PPI page) and the recommendations for the future.	
ELEPHANT Working Group	The main purpose of the group was to undertake an ARC PPI review. The group met regularly as a whole group but also worked separately in sub groups to complete elements of the review. They also worked independently or in small groups to undertake interviews, focus groups, analysis and writing up sections of the review. The main output of the review is the ELEPHANT evaluation report plus all of the separate components	Sally Crowe Millie Khisa Rashmi Kumar Mary Zacaroli (Paula Wray as needed)

	that the report is built on, many of which are contained in the report as appendices.	
Showcase Planning Group (sits outside PPI Champions)	The purpose of this group was to plan and implement the ARC Showcase (2022 and 2024). The group met as needed. Public members of the group took an active part in the process and in the Showcase including facilitating a session. The main output were the Showcase events and brochures.	2024 Planning group: *PPI Champions:* Katharine Keats-Rohan Rashmi Kumar *Staff:* Sarah Brown Dawn Shaw Paula Wray)
Recruitment Working Group (informal)	The purpose of this group was to develop the PPI Recruitment materials for the ARC. Initially the group met informally (and was out first working group) but became more formal and active through the process. The outputs included the Strategy Board Public Partners recruitment materials, PPI Champions recruitment materials and a combined recruitment resource. This led to the successful recruitment of a diverse group of six new PPI Champions and two Strategy Board Public Partners.	Sobia Afridi Mary Zacaroli

PPI Champions Activity Record: The following summarises the activity of the PPI Champions 2019-2026

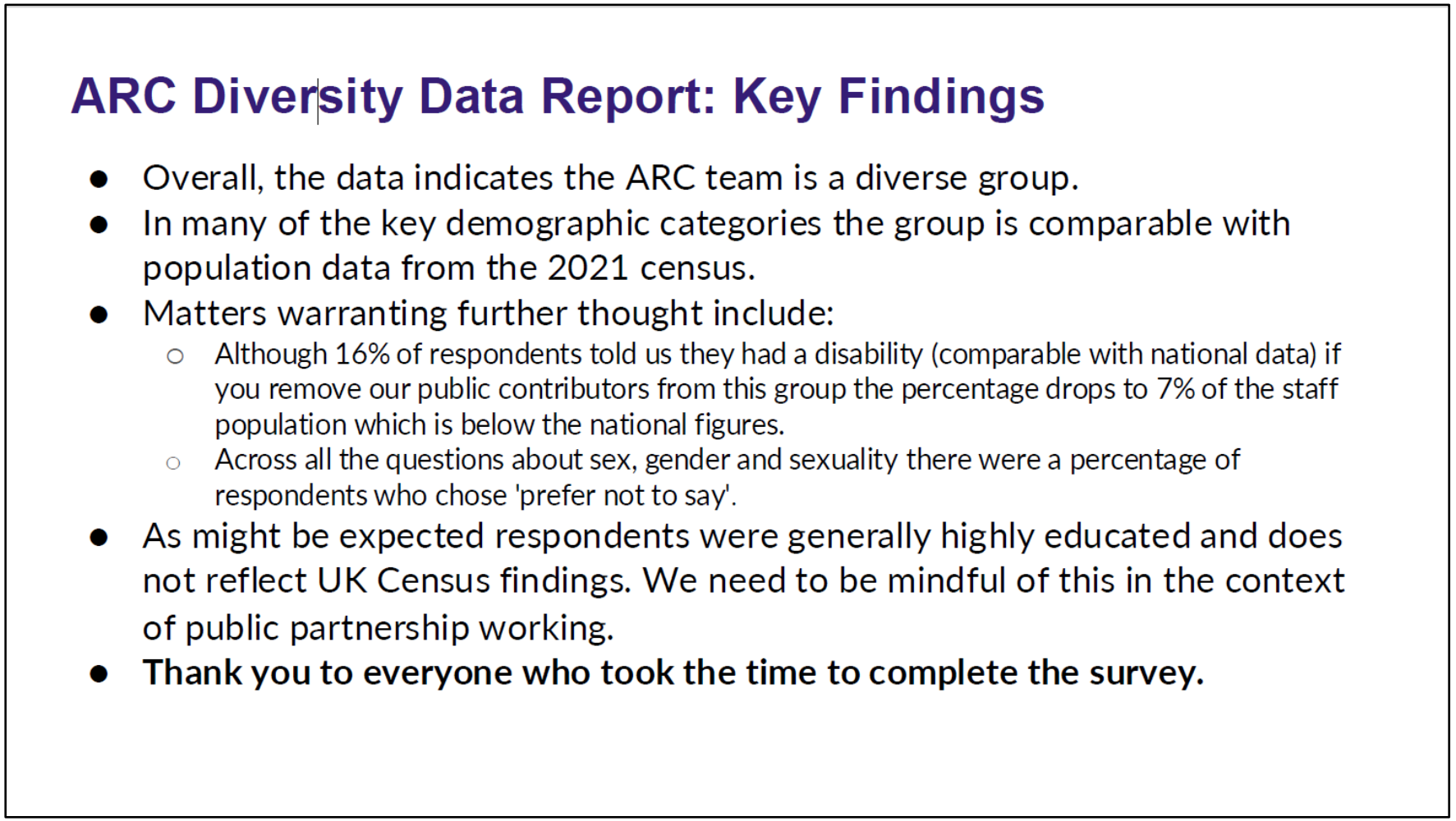
NIHR ARC OxTV PPI Champions Activity Record 2019-2026								
Year	**No. of PPI Champions**	**No. of PPI Champions Meetings**			**Working Groups**		**No. of 1:1 Support**	**Other activities** (such as blogs, facilitating, training etc)
		In person	Online	Total	No. of groups	No. of meetings		
2019				0	0	0	0	0
2020	6			0	0	0	6	2
2021	7	2	4	6	0	0	1	0
2022	6	5	1	6	1	5	0	0
2023	13	3	3	6	2	17	11	1
2024	13	3	3	6	4	16	17	2
2025	13	0	5	4	7	31	10	3
2026	13	1	1	2	5	10	10	3

PPI Champions Summary Impact Log: The following summarises some of the key PPI Champion impact highlights from 2023-2026

NIHR ARC OxTV PPI Champions Key impact highlights 2023-2025	
Year	**Key Impact Highlights**
2023	The PPI Champions had a significant influence over how the 2022 PPI Review was presented to the Strategy Board. The group collectively had a significant impact on the wording, layout and content of the survey being designed to collect EDI data. Members of the group helped to shape the successful extension plans for the ARC. How the group worked changed significantly due to the work of the members: ☑ they suggested introducing a public chair and implemented this. ☑ they co-produced Terms of reference and ground rules for how they worked. ☑ they began work on producing clear guidance on the role of PPI Champions. ☑ they co-produced recruitment materials for Strategy Board Public Partners and PPI Champions. Members of the group influenced the design and implementation of the PPI Monitoring to Learn Project. Group members were central to the successful recruitment of a diverse new group of PPI Champions. Group members supported the internal ARC Funding call process which included allocation of funding to community led groups and a public member co-led project.
2024	The group continued to improve how the group worked and shared through the leadership of the public chair of the group. They helped improve how we communicate information through the development of the PPI Update and feedback process.

	Members of the group led a skills and experience mapping exercise which helped members to build confidence and get to know each other. The group successfully presented their work at Executive Group meetings. They co-produced a new PPI Funding model for the ARC and department researchers to access. Building on the skills mapping exercise they co-produced a process to ensure fair decisions about choosing 'who does what' in the group. Members of the group led the re-design of the website PPI pages. The group agreed a process to ensure co-ordinated PPI input into the ARC renewal process and sought and contributed agreed ideas and feedback.
2025	The group continued to provide input into the ARC renewal process and significantly influenced the PPI plans and Plain English Summary. Members of the EAGLE group reviewed all existing processes and co-produced new documents as required. They also produced additional recommendations for the future. The PPI Monitoring to Learn working group led on the final review of the pilot and the documentation for the project. Theme PPI Champions ran PPI workshops and piloted PPI surgeries. Members of the group formed the ELEPHANT working group and led on the review of PPI.
2026	The PPI Monitoring to Learn working group completed the final report for the project. The ELEPHANT group completed the report of the review The Theme PPI surgeries pilot was expanded to a pilot across the department.

ARC OxTV Diversity Data: The following summarises the key findings from ARC OxTV's inclusion monitoring in 2025. Whilst we can't share our PPI Champion specific data we can confirm that the group data reflected a diverse group. They learnt about PPI from a variety of places. Their length of involvement ranged from newly involved to more than 10 years of experience. They had considerable lived experience between them (see appendix VI for more details) and they came from diverse communities.



APPENDIX III: EAGLE documents: ARC PPI processes and documents review

Summary and key themes from the ARCPPI processes and documents review

All of the ARC's PPI processes and documents have been co-produced with members of the PPI Champions group. This work has been undertaken in response to the earlier PPI review in 2022 which highlighted a greater need for understanding and clarity about the role of the PPI Champions.

The work that has been undertaken has provided a much clearer picture of the role of public contributors in the governance of the ARC and the processes that sit around that. Our ways of working together also model good practice in terms of co-producing with public contributors. We did this by creating the essential components for successful co-production: a warm welcome, space to talk, inclusivity, ongoing individual support for public contributors and most important of all genuine sharing of power.

We split the documents in this review (which we internally nicknamed EAGLE to help us keep track of which project we were working on) into two distinct areas. Operational documents and processes and Support and learning documents and processes. This is a slightly artificial division but allowed us to split the task between two separate working groups (with some membership crossover for consistency).

Operational documents and processes

The 2025 review of operational processes focused on asking the following questions:

1. Are the existing documents fit for purpose?
2. Do the documents capture all of our existing processes?
3. What additional processes would we suggest for the future?

The review process involved a working group of PPI Champions who presented the outputs to the whole PPI Champions group for final agreement.

As a result of the review:

We updated existing processes to better reflect what we were actually doing. In the main the changes made were minor changes or additions to wording to add clarity and/or current practice that was not reflected in older documents. The most significant change was to finalise and record the information about and process surrounding the groups chair role plus the formal addition of a co-chair role and small planning group to support the work of the chair.

Another outcome of the review was to record the processes that were already in place but were not already documented or formally agreed. These were mainly issues that had arisen over time (either within the ARC or more broadly in the PPI networks we connect with) such as role boundaries and dealing with difficult issues. In most cases these had been informally agreed so we took this opportunity to formally record and agree them.

We also agreed to create separate documents for some issues that were embedded in other processes but we felt should also have a standalone document for clarity (e.g. confidentiality and conflicts of interest).

Finally we identified recommendations for the future:

- The main recommendation is to make use of the documents we have co-designed, adapting them to individual context as needed.
- The only additional recommendation was to create a frequently asked questions document (and/or space on the PPI webpages) which provides a questions based route to searching for information about processes.

Support and Learning documents and processes

The 2025 review of support and learning processes was undertaken in three phases:

1. An initial review, by the working group, of existing documents, development of documents to capture existing practice and recommendations about additional support.
2. A survey of the outcomes from the initial review was undertaken with all members of the PPI Champions group. This was analysed and summarised in partnership with members of the working group.
3. Using the survey data the working group revised the documents, produced a report of the survey findings and made some recommendations for future consideration. These final outputs were presented to the PPI Champions group for final agreement.

As a result of the review:

Existing documents and processes (i.e. Induction and Payments) were updated to better reflect current practice. New documents were created to record our existing practice (e.g. records, individual support and team building etc). These were all co-produced and agreed with the PPI Champions group.

A summary report of all the survey responses was written. It contains all of the feedback provided with a summary of what action was taken or recommended for the future.

A further document was created that highlights all the suggestions we could not include in the ARCs final processes but that are recommended for consideration in the future.

A summary of these suggestions are:

- Induction Process: Add a group re-cap session and offer to all governance public contributors who would like to attend; also build a 'buddy' system into the induction.
- Payment Process: Consider alternatives to offering payment e.g. a personal training budget; revisit the suggestions around alternative payment rates for attending some events.

- Practical processes: Going forward some thought should be given to how we encourage others to adhere to our agreed timeframes for providing papers for meetings etc.

NIHR ARC OxTV PPI resources including PPI processes, documents and reports:

Inclusive Opportunities: We aim to offer opportunities that are accessible to all.

- Recruitment materials: our latest recruitment pack for governance public contributors including details of the role and experience needed.
- Ways of Working: descriptions of the different ways we work together and how we decide which method we use
- Practical matters: explains practical matters such as accessibility, timeliness and how we manage things like conflicts of interest.
- Payments Process: explains the process for payment of fees and expenses including rates paid.
- Inclusion monitoring documents: what we did, the questions we used and the key findings.

Working Together: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

- Terms of Reference: outlines the PPI Champions group purpose, membership and how the group operates.
- Ground Rules: describes the PPI Champions group ethos and how group members are expected to work together in a respectful way.
- Role boundaries: describes what falls within the remit of ARC governance public contributor roles and what doesn't.
- Who does what: describes how we allocate tasks and activities to our governance public contributors.

Support & Learning: We aim to offer support and learning opportunities that build confidence and skills.

- Induction Process: outlines the induction process for ARC governance public contributors.
- Training and Learning opportunities: describes how we support learning for our governance public contributors.
- Individual Support and Team Building: describes what we have in place to support individuals and work towards building a team.

Communications: We aim to use plain language which is jargon free, but also aim to explain more complex language and ideas.

- Glossary: includes definitions for terms that our public contributors may come across.

Impact: We drive improvement through aiming to recognise and understand the difference that public involvement makes in our research.

- Feedback and Updates: describes the things we have developed to keep our governance public contributors updated on PPI news and how we provide feedback about the projects they are involved in.
- PPI Monitoring to Learn documents
- PPI Monitoring to Learn report
- The ELEPHANT Review: Review of Patient and Public Involvement in the Applied Research Collaboration Oxford and Thames Valley 2019 -2026

Governance: We involve the public in our governance and leadership.

- Governance Public Contributors roles and opportunities: a table detailing the kinds of tasks and activities our governance public contributors might be asked to undertake.
- Public Contributors in ARC Governance diagram: shows how governance public contributors feed into different parts of the ARC governance structure.
- Conflicts of interest: provides a more detailed look at potential conflicts of interest and how we manage them.
- Confidentiality: outlines the confidential nature of being an ARC governance public contributor.
- Personal Records: details the personal data we hold for our governance public contributors and the reason we hold it.
- Chairing role: explains how the role of the chair (and co-chair) is appointed.
- Dealing with difficult issues: explains the process for how to deal with difficult issues should they arise.

APPENDIX IV: Abridged PPI Monitoring to Learn report

Please note this is not the full version of the PPI Monitoring to Learn report.

The full version, including review summaries and PPI Monitoring to Learn documents, is available here: https://www.phc.ox.ac.uk/files/arc-impacts/2026-nihr-arc-oxtv-ppi-monitoring-to-learn-report.docx

The PPI Monitoring to Learn documents are separately available here: https://www.phc.ox.ac.uk/files/arc-impacts/2026-arc-oxtv-ppi-monitoring-to-learn-documents.docx

Section 1: Developing and reviewing the PPI Monitoring to Learn Process

The PPI Monitoring to Learn Process

Why – we wanted to better understand what PPI was happening across the ARC and how we could use it within the ARC to improve PPI quality and capacity.

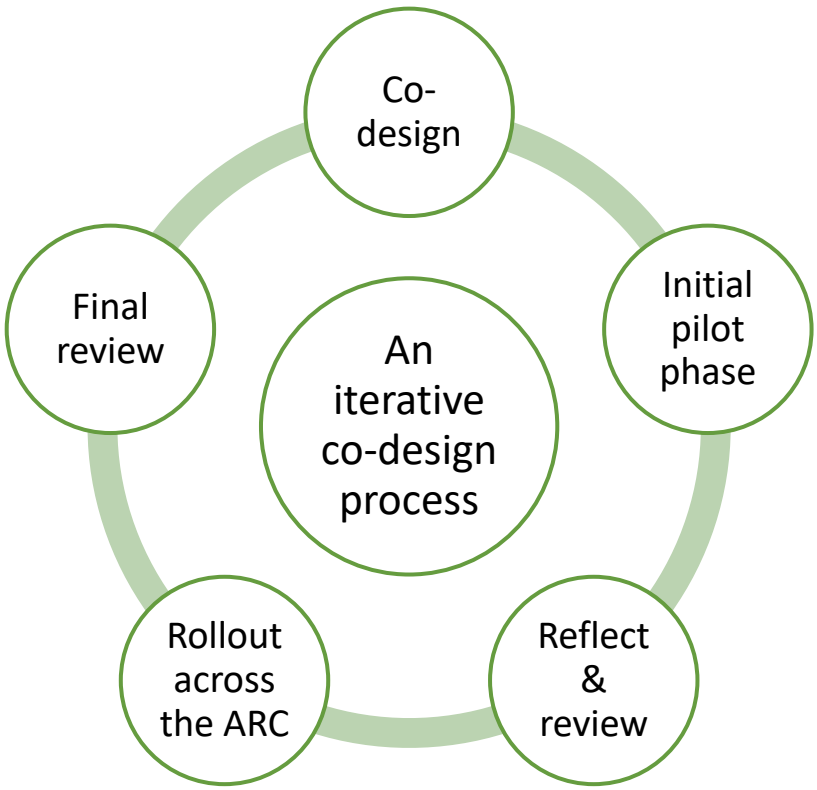
What – Nothing already available quite worked for our situation so we designed a bespoke tool to do it effectively.

How - We used existing resources and knowledge from within the ARC team and the PPI community to inform what we did. These included PPI planning and evaluation resources such as the UK Standards for Public Involvement, PIRIT, impact logs, The Cube, and the Monitoring to Learn concept from PFMD (see tables in Appendix III for more details).

When – This project began midway through the ARC. We, therefore, focused entirely on monitoring projects and their PPI that were already set up and running.

What we did

Diagram 1: How we worked



Step 1 – Design

We designed an initial monitoring form and guidance document to help gather data about PPI from ARC research projects. We also created a form to gather data about Research Theme level PPI. ARC research projects were organised into Themes, with a topic for each, there was also inter Theme working. See Table 1 for more information.

We also thought about how the process/data gathered could be used to improve the quality of PPI and PPI capacity within the ARC. A member of our PPI Champions group with considerable experience of PPI reviewed the resources and we revised them based on their advice.

Table 1 ARC OxTV Research Themes

Theme 1	Changing Behaviours for Better Health and Preventing Disease
Developing and trialling new ways the NHS can support people to improve their health through weight loss and informing their decisions about the food they buy.	
Theme 2	Helping Patients to Manage Their Own Conditions
Developing and trialling new ways for patients to manage their own long-term conditions and treatments, with a focus on cardiovascular health, such as heart disease and high blood pressure.	
Theme 3	Mental Health across the Life Course
Developing and assessing new psychological treatments and services for people of all ages; creating tools to aid mental health service providers to deliver rapid, effective support for mental health problems.	
Theme 4	Improving Health and Social Care
Research to develop, assess and improve community health and care services. This will focus on local people with the greatest need, such as older people living with multiple health conditions ("multimorbidity").	
Theme 5	Applied Digital Health
Examining large health and social care data sets to deliver new insights, treatments, and services; developing new digital tools to aid researchers and health and social care professionals.	
Theme 6	Novel Methods to Aid and Evaluate Implementation
Developing and trialling strategies and methods to evaluate new tools, services and techniques in health and social care by bringing together statisticians, data scientists, software engineers and health economists with clinicians, other health practitioners, and patients.	

Step 2 – Pilot

We piloted the process in one of our Themes. By doing this, we quickly learnt that each Theme/project/PPI Champion is likely to need/use a different approach. We also needed to make sure PPI Champions had access to detailed lists about the research projects in the Themes they worked with.

Step 3 - Development

We continued to pilot the tools and added two more Themes. At this point we began to put together a PPI Monitoring to Learn development team (the people who were working with it from our PPI Champions group). The group helped us to further revise our approach.

Step 4 – Reporting

We reported to the ARC Executive Group about what we were doing and agreed to formally extend the pilot project to all Themes. We agreed our primary focus would be on projects rather than PPI in the Themes more generally. The aim was to do at least one PPI Monitoring to Learn review of a research project in each Theme. We were also aiming to do reviews with a range of projects with different experiences of PPI. We wanted the tool to be functional for all levels of PPI and to not put off those with little or no experience of PPI.

Step 5 – Rollout

The pilot grew as we introduced the concept to all the ARC OxTV research Themes. We promoted it and prompted researchers to take part in the project. We made it very clear that we wanted projects with no PPI through to extensive PPI. We wanted the questions to be sensitive enough to be able to probe barriers to PPI, explore what might be done differently and encourage discussion of the suitability/possibility of PPI in the most complex research without causing anxiety or stress. We also decided to explore how the process would work beyond traditional research activity. We chose to explore using it in the context of an MSc that had been developed as part of one of the Themes.

Step 6 – Review

As we neared the end of the ARC, we felt it important to review the process and documentation so we made use of all that we had learnt. The PPI Monitoring to Learn working group undertook a review of the PPI Monitoring to learn resources. They decided that one document could be developed and then used in multiple ways – the key is using it with flexibility in mind rather than rigidly sticking to formulaic questions.

The ethos underpinning the process was also important. The aim is to encourage creating safe spaces to explore PPI in a non-judgemental and supportive way. The resource aims to encourage reflection either independently or with a supportive PPI ‘expert’. The resource also aims to approach PPI in a way that aligns with the national direction of PPI travel.

The working group revised existing materials to create a new planning resource with embedded monitoring. The document can be used to create a PPI plan, review progress against that plan, adapt it as needed and track PPI across the life of the project.

The group also reviewed a wide range of PPI impact and evaluation resources and literature. They created a guide to PPI impact and evaluation to sit alongside the planning and monitoring resource to try and encourage the inclusion of PPI impact and evaluation activities in future PPI plans.

The group also analysed the PPI Monitoring to Learn reviews to better understand PPI in the ARC. The review also looks at how PPI activities have aligned with the UK Standards for Public Involvement and the NIHR PPI Strategic Commitments. During the review process they have identified lessons learnt by those undertaking the PPI, and how these might relate to the wider PPI community. *(See Section 2 of this document for the full review)*

The future

The PPI Monitoring to Learn project is recommended for ARC Thames Valley (ARC TV) and other similar programmes wanting to embed PPI in their work.

It is useful to remember that the intention is that the ethos and approach surrounding PPI Monitoring to Learn is perhaps more important than the specific questions. We have shown that the questions can be adapted to the context.

The recommendation is to embed the process in ARC TV. The planning and monitoring tool should be used to develop PPI across the research of ARC TV.

We also recommend using the ongoing PPI plans and monitoring data produced by the PPI Monitoring to Learn process to report on PPI across the programme and identify ARC wide learning opportunities and the sharing of PPI experiences across the team.

Section 2: What we learnt about PPI in ARC OxTV from the PPI Monitoring to Learn Pilot

Method

During the pilot of PPI Monitoring to Learn 11 research projects and five themes were reviewed. It's important to note that whilst the pilot ensured all themes provided reviews, participants were, in the main, either chosen by PPI Champions or self-selecting.

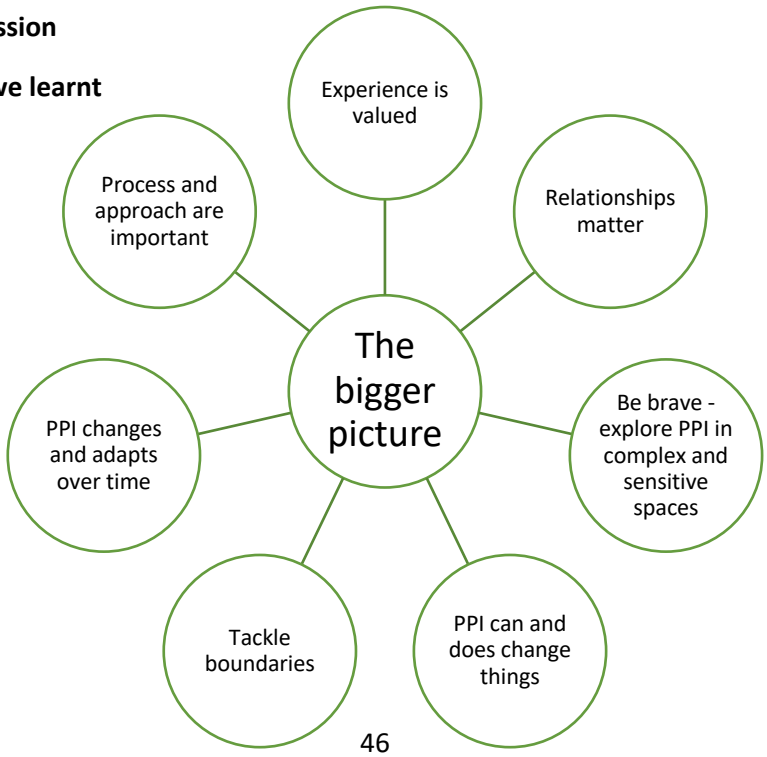
The PPI Champions involved in piloting the PPI Monitoring to Learn process planned an approach to draw learning from the information gathered during the project:

- Summaries of each monitoring to learn review were written and analysed.
- The summaries were reviewed in relation to the UK Standards for Public Involvement (see Table 2), and the NIHR PPI Strategic Commitments (see Table 3).
- Key messages were discussed and agreed.
- The key messages were thematically analysed.

The outcomes are intended for a broad audience, for example the current ARC OxTV, ARC Thames Valley, NIHR (funder) and the wider audience of research stakeholders.

Analysis and discussion

Diagram 2: What we learnt



Key learnings from all reviews were synthesised into the following themes:

1. Researcher Development and engaging with PPI:

There was significant evidence that researchers 'developed' as a result of their PPI activities. Participants indicated in different ways how PPI had affected them, including skills development and an increase in knowledge.

There was a sense of relief that PPI was a more natural and iterative process than expected. Initially it seemed complex and daunting. They found that PPI could impact study design, that it gave them a useful 'sounding board and gave context which helped to keep them 'grounded'. They also implied that PPI offered more than they expected and that PPI would continue impacting their work and its dissemination.

Even where PPI was limited the Monitoring to Learn (particularly in more complex research) conversations led to a wider discussion about PPI. By creating a safe space and harnessing the natural curiosity of the researchers, it was possible to build on and explore existing knowledge and experience by using workshops and PPI surgeries.

It was evident that there were those already aware of the value of public involvement in some of the more complex and ethical conversations about big data usage. Others began to explore the possibility and value of involving those with lived experience in conversations about the findings and results of their work.

2. PPI as a vehicle for change:

PPI was frequently evidenced as being a vehicle for change and having a significant impact on the research. This presented in different ways.

There was an indication that PPI improved accessibility of the study, health information, and study outputs. There was also evidence that PPI helped to improve the quality of research and that involvement from the early stages enabled impact at all stages of the research.

PPI involvement also led to changes in study parameters. PPI was also integral to refining and testing interventions for wider role out and helped a study progress to developing a full trial.

It became clear that the PPI Monitoring to Learn process can facilitate conversations about PPI in research where it is not always clear how to involve the public. This was achieved through ARC OxTVs PPI approach and involvement of experienced public contributors who were supported over time to create safe and supportive spaces to allow open and transparent communication.

3. Role of 'Experienced' Public Contributors:

We identified a number of occasions when the level of experience of the public contributor had a significant impact on the research or the researcher(s). It became evident that the confidence, experience, and knowledge of the public contributor can be an essential component to success or progression in some circumstances.

A well supported and experienced public contributor can support and mentor an early career researcher to build their own PPI knowledge, confidence, and experience. To do this, however, the public contributor needs to be given autonomy to act. They also need financial and personal opportunities and support, for example a budget for fees and expenses, one to one support and training opportunities.

Given the opportunity, public contributors can also bring skills and knowledge that facilitate PPI learning and development in a more generic fashion. The reviews include examples of the development of PPI workshops and PPI surgeries built from the ground up by PPI Champions who were given the autonomy to explore and implement approaches to best support their Themes. This is not done in isolation but facilitated through support, reflection, and discussion with the PPI team.

More generally researchers valued the range of expert knowledge, experience and skills public contributors brought with them. They valued community knowledge and links, the PPI knowledge and experience that individuals had and shared, the sensitivity around challenging issues and the proactive nature that was facilitated within the ARCs PPI approach.

Supporting the personal development and aspirations of public contributors is also valuable. Through the supportive nature of the ARCs PPI approach PPI Champions could be consistently involved in the same Theme throughout the course of the ARC. They were also encouraged to explore and develop their own interests. This led to funding of a PPI Champion initiated research idea that was actively supported by Theme researchers. Another PPI Champion was also given the opportunity to build confidence and experience and ultimately utilised those opportunities to secure employment as a PPI Lead.

It is, however, important to remember that regardless of experience levels, when public contributors 'join' later in the process there needs to be special attention paid to integration. Thought needs to be given to how we support public contributors to become an effective 'team' member in the same way we would for new researchers joining a research Theme.

4. Complex and sensitive research:

There were a number of comments that reflected experiences around opportunities to explore PPI in more complex research scenarios. The main focus was on how building relationships and trust enabled honest conversations about PPI in research.

The PPI Monitoring to Learn process helped create 'safe spaces' that facilitated conversations about PPI in more complex research. It was possible to explore how public voices could add to data driven and methodological research by adding reflections on what is found. There was also acknowledgement that PPI can be the 'middleman' helping ensure that interventions are refined for patients and health professionals alike.

There were learnings around ensuring that studies which might affect the wider population, rather than just specific patient groups, should have PPI groups that better reflect the general population.

5. Boundaries of PPI:

There was a range of evidence that reflected the difficulties or challenges presented by the 'boundaries' or potential limitations of, or imposed on, PPI. There were learnings from the reviews about resourcing PPI in research to ensure there is capacity to do what is planned and address the unexpected.

There is a need to build in support for people who are new to research so they can understand the process. This is not just about the budget to pay for involvement but also about building in time to facilitate people getting familiar with the project and research more generally.

Whilst it is good to plan PPI it is also important to remain flexible, so you can adapt the way you do the PPI to meet different public contributor needs as they arise. This flexibility can affect budget or other resources such as staff time.

Projects (co) led by public contributors can struggle with access to tools and training to help facilitate the project. There is a need to think through what access might be needed and how to resource and facilitate this before the project starts otherwise delays and frustration can occur.

Researchers need to think carefully about who/what a study might impact and therefore who the 'right' public contributors are to involve. Is it population specific (e.g. a specific condition, geography, or characteristic) or is it more 'general population' in nature?

6. PPI changes through the life of the ARC:

Some evidence indicated significant changes to PPI during the ARC contract.

The most notable change was because of the ARC PPI review in 2022. There was a distinct shift in PPI direction (e.g. strive for a clearer direction, more inclusivity, 'power' sharing etc). This enabled PPI activity to be more tailored and confident in approach (e.g. confidence and knowledge building, autonomy, structured approaches etc).

During the ARC, the support given for PPI from the ARC PPI team was valued and maximised the impact of PPI and resources. Building mechanisms to offer individual support to researchers (e.g. PPI funding pot, advice and guidance for individuals, PPI surgeries etc) and Theme based activity (e.g. more knowledgeable and diverse PPI Champions, structured approaches, PPI workshops etc) all helped to underscore the value of the core PPI offer.

The opening up of ARC funding to community and public led research firmly put public voices at the centre of prioritising research investment. Public voices helped decide allocation of funds and both community and public led projects were funded.

7. PPI processes and approaches:

A considerable number of comments centred on topics which addressed the importance of PPI processes and approaches being appropriate. They also reflected the importance of getting 'things right' from as early as possible to have the most impact.

Some general comments included the need to identify useful ways to continue involvement and connection during the 'middle' stages of projects when there might be 'less' for the PPI group to do. There was also an acknowledgement, across the reviews, that payment for involvement is a key factor for success and satisfaction.

The need for clarity about roles and transparency about what is possible for those involved to change is important. They help ensure satisfaction and can allow communities or individuals to make informed choices about whether to get involved.

Flexibility about how PPI is carried out (e.g. activities, contact, resourcing etc) is essential. When PPI is fluid and flexible, it can adapt to meet individual or group needs and can make involvement possible and impact more likely and meaningful.

Exploring and trying new and alternative ways to PPI is important. It can help expand how people can get involved. At a Theme (or organisational) level being actively involved in decision making ensures the role is meaningful rather than a 'tick box' exercise. Alternative vehicles (such as art) can

provide more accessible ways for diverse (often unheard) communities to be meaningfully involved. When planning to expand or offering new ways to involve people it is important to plan carefully and consider the potential for unintended consequences.

The reviews indicated that providing public contributors with autonomy (within agreed limits) can enable and facilitate meaningful involvement. When this autonomy is channelled through a structured and supported approach (such as PPI Monitoring to Learn) it can facilitate safe spaces to explore PPI in a non-judgemental way. These approaches can facilitate learning opportunities for researchers and public contributors.

One of the key findings of the reviews was the value of relationships and the consistency they can offer. The opportunity to build sustainable relationships can lead to positive outcomes. These can include deep and meaningful conversations, a sense of 'security', increased capacity to contribute or the confidence to explore new opportunities. It is important to remember, however, that the need to focus on relationship building still exists regardless of experience levels or familiarity with the process/system. This helps people feel embedded in the 'role' and 'space' where they are being involved.

Finally, 'the when and what' of PPI was also identified as important in the reviews. Researchers need to be encouraged to think about and include PPI at all stages of their research and in all the activities involved with their research. That includes presentations about their work (before, during and after). As a matter of course they need to be explaining how the public has been involved in their work. As a result of the 2022 ARC PPI review and during the PPI Monitoring to Learn process it was clear that public contributors, even when involved at a strategic or governance level, want to be able to engage with research that is of interest to them.

Mapping ARC PPI to National frameworks and strategy

The ARC OxTV exists in the context of a university department, geographical area and population, and a network of allied research and healthcare organisations. The network activity is guided by national priorities in research and healthcare, and PPI. Mapping the results of the Monitoring to Learn review against the NIHRs PPI strategic Commitments and the UK Standards for Public Involvement (see Appendix V for more information) is helpful in being able to see how ARC OXTV is contributing to a wider PPI strategy, priorities, and standards.

1. UK Standards for Public Involvement *(see Table 2)*

An integral part of the analysis process was mapping the individual Monitoring to Learn reviews against the UK Standards for Public Involvement. We concluded that all six of the standards were reflected across the range of projects reviewed.

The highest scores were for the Working Together and Impact standards. There was considerable evidence that projects had effectively worked together with their public contributors. The Impact standard reflections involved impact on the researcher doing the PPI and the impact PPI had on the research they were involved with. There was little direct discussion of the impact on public contributors, however, there were reflections about adapting the approach used to meet the needs of different contributors, which in turn led to a high score in respect of Inclusive Opportunities.

The remaining standards (Support and Learning, Communications and Governance) were evidenced in half (nearly half for governance) of the reviews.

Almost all of the reviews reflected activity that evidenced *three or more* of the standards in their work.

2. NIHR PPI Strategic Commitments *(see Table 3)*

We also mapped the reviews against the NIHR PPI Strategic Commitments.

The range of reviews evidenced that PPI in the ARC supported all the NIHR PPI Strategic Commitments.

There was particularly convincing evidence for Strengthening Capacity and Capability (often reflecting the development of researchers undertaking PPI). Embedding Research Inclusion (e.g. reflecting, adapting PPI plans to meet need, or working with specific communities) and Strengthening Partnerships (e.g. working with relevant patient facing/community groups) also scored highly.

There were reviews that identified activities supporting all the commitments and many of them evidenced three or more of the commitments.

Table 2 Mapping Monitoring to Learn reviews with the UK Standards for Involvement

Where evidence was seen in a review summary for a standard this was recorded. When the scores were combined some standards were supported by many projects (green) and some supported by around half of projects (yellow).

UK STANDARDS FOR INVOLVEMENT					
INCLUSIVE OPPORTUNITIES	**WORKING TOGETHER**	**SUPPORT AND LEARNING**	**COMMUNICATIONS**	**IMPACT**	**GOVERNANCE**
10 ★	**15** ★	**9** ★	**8** ★	**13** ★	**7** ★

Table 3 Mapping Monitoring to Learn reviews with the NIHR PPI Strategic Commitments

Where evidence was seen in a review summary for a strategy area this was recorded. When the scores were combined some standards were supported by many projects (green) and some supported by around half of projects (yellow).

NIHR PPI Strategic Commitments				
1.EMBED RESEARCH INCLUSION	**2.STRENGTHEN PARTNERSHIPS**	**3.IMPROVE REWARD AND RECOGNITION**	**4.REQUIRE FEEDBACK**	**5.STRENGTHEN CAPACITY & CAPABILITY**
9 ★	**9** ★	**2** ★	**6** ★	**12** ★

Section 3: Conclusion and Recommendations

The PPI Monitoring to Learn project set out to develop a resource that could be used to plan, monitor, and evaluate PPI in ARC projects in a consistent and robust way. We also aimed to establish how we could use the data collected to improve quality and build capacity for PPI across the ARC.

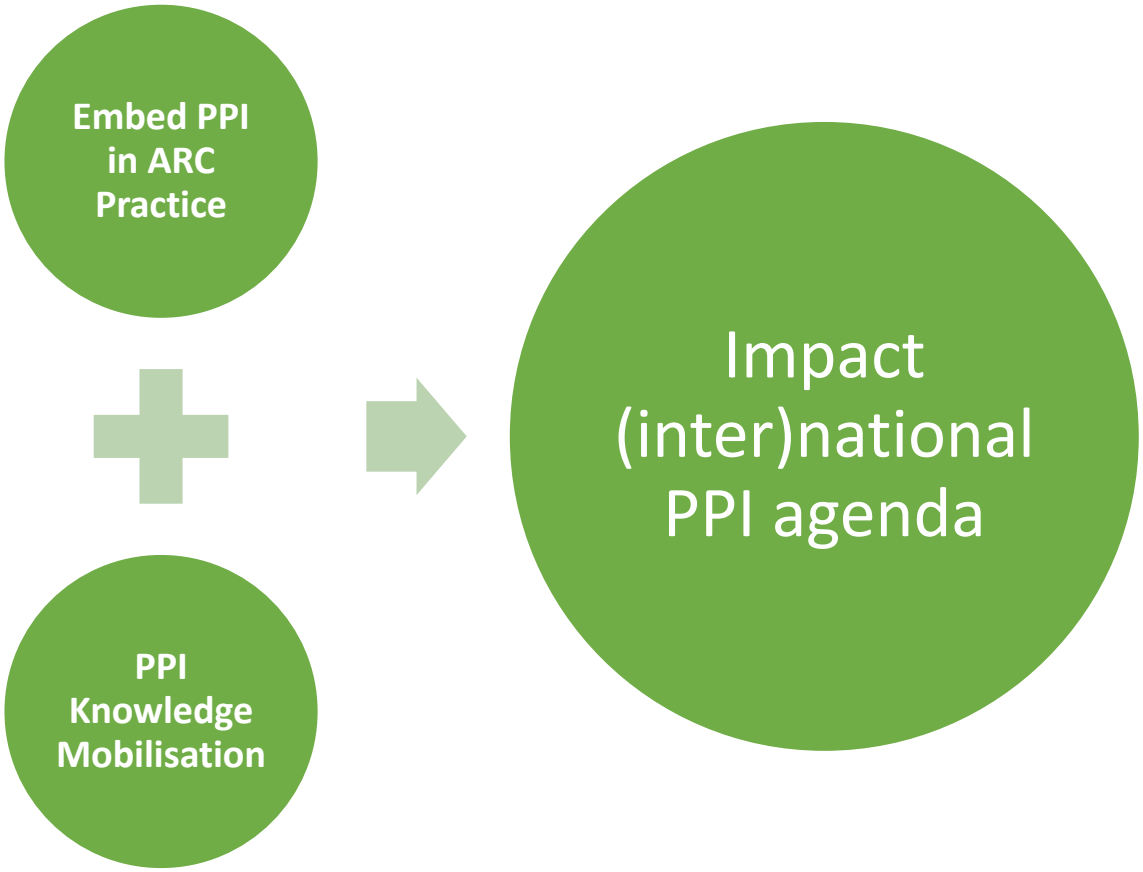
PPI Monitoring to Learn Resources:

- **A combined planning and monitoring form.** The purpose of this is to provide a consistent approach to planning and designing PPI in individual ARC research projects. This can then be used to monitor, update, and evaluate PPI throughout the course of the research project.
- **PPI impact and evaluation guidance.** The purpose of this is to encourage research projects using the planning and monitoring tool to think about and embed PPI impact and evaluation processes into their project.

What we learnt from the pilot project:

- The Monitoring to Learn Process supported knowledge building and relationship development between Theme PPI Champions and researchers in their Theme. This in turn led to the creation of 'safe and non-judgemental spaces' to discuss concerns about and barriers to PPI.
- The monitoring forms identified multiple cases where PPI had changed the way a study was conducted and/or impacted the outputs of the study. They also showed that over the course of the ARC that a consistent and supportive PPI infrastructure could help maximise the impact of PPI.
- Researchers acknowledged that PPI can be broad, deep, and impactful. It can also keep them grounded, provide a sounding board and provide context. On reflection they also understood the importance of the PPI approach being appropriate for the community to be involved. The process planned also needs to be flexible so it is possible to adapt to individual need.
- The analysis also helped us to identify that across the ARC, projects in the pilot project between them reflected all six of the UK Standards for Public Involvement. Working Together, Inclusive Opportunities, and Impact were the most frequently identified standards. The remaining, Communications, Support & Learning, and Governance, were all frequently seen. For more than half of the projects we were able to identify more than half of the standards.
- We also looked at how our projects were supporting the NIHR PPI Strategic Commitments. We were able to identify activities that supported the implementation of all five commitments. There was particularly convincing evidence around Strengthening Partnerships and Strengthening Capacity and Capability.
- At times PPI activity appeared transactional in nature. The Support and Learning gap was often clear. Both researchers and public contributors often seem to think that the 'other' comes 'fully formed' in PPI terms and they don't have development needs. There is immense potential for researchers and public contributors to undertake PPI development together.

Diagram 3: Going forward

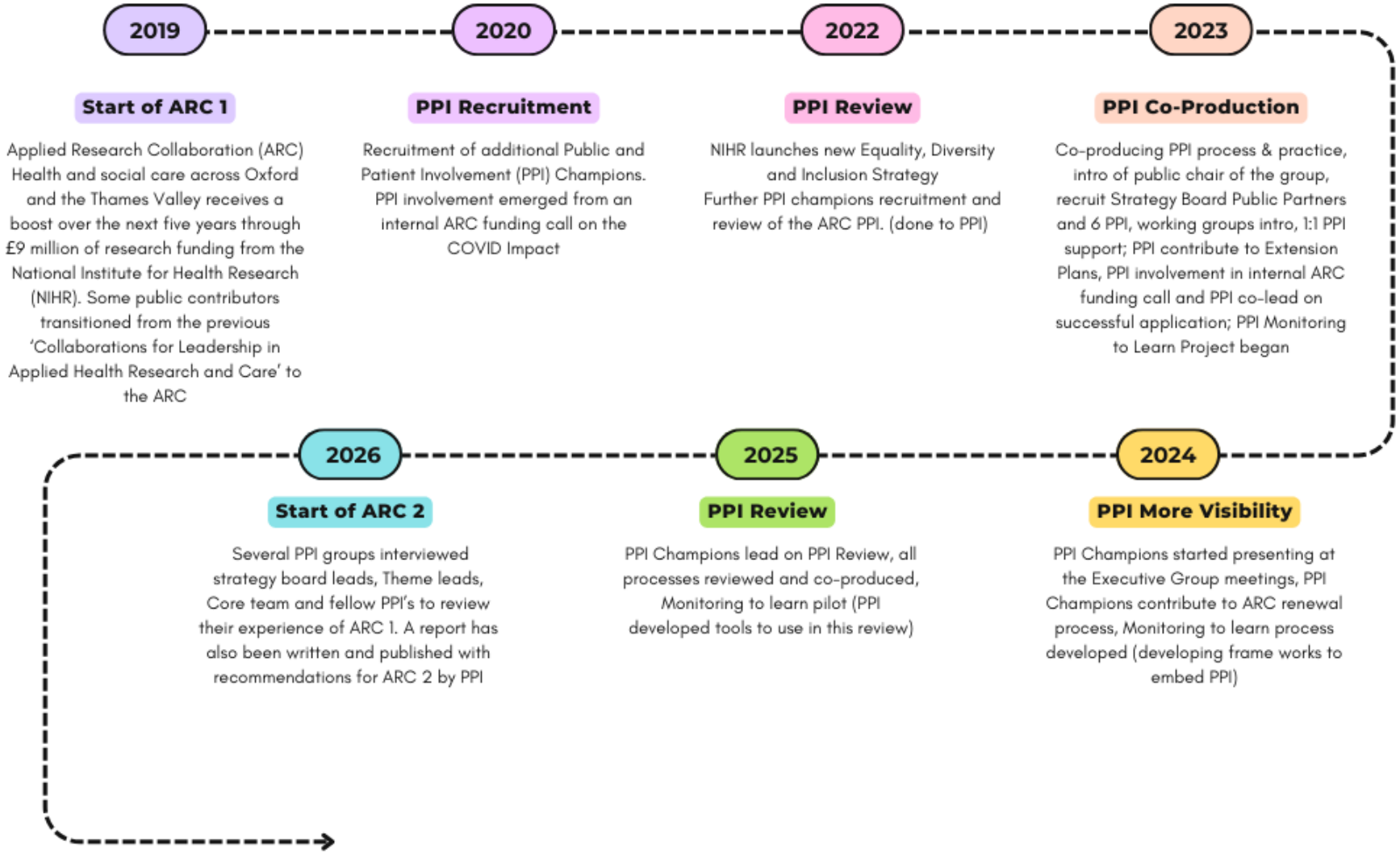


Recommendations for the future:

- **Embed in ARC Practice.** ARC Thames Valley should embed the PPI Monitoring to Learn process in their work. There should be a requirement for all ARC TV research projects to develop a PPI plan and to monitor it. They should monitor and adapt the resource as needed.
- **PPI Knowledge Mobilisation.** Use the outputs from the PPI Monitoring to Learn process to identify opportunities to share good practice and build knowledge. This applies to both public contributors and academics. They can also be used to identify where central support could further enhance PPI capacity building (e.g. where central infrastructure could support PPI activity more effectively and where central learning opportunities can support capacity building).
- **(Inter)National PPI Agenda.** Explore how to better embed the UK Standards for Public Involvement and the NIHR PPI Strategic Commitments into the process. There is also the potential to have impact internationally through feedback to and connections with Patient Focused Medicines Development (PFMD) whose Monitoring to Learn Tools model we have used to create PPI Monitoring to Learn.

APPENDIX V: NIHR ARC Timeline

NIHR ARC Timeline



APPENDIX VI: PPI Champions experience map



APPENDIX VII: How the role of PPI Champions and their experience has changed over the life of ARC OxTV

The ARC OXTV started in late 2019 with a funding extension to take it through to March 2026.

Over time changes to the structure, personnel, and a review of PPI meant that things changed a great deal after 2022. This included increasing and diversifying the group of PPI Champions and putting in place more governance and embedding of PPI Champions in the six ARC research themes.

This case study draws from information given for the final review of PPI as the current ARC reaches its conclusion. It explores what the differences and similarities are between the experiences of original and newer PPI Champions.

Original PPI Champions

These champions were less in number and there was less systematic support for their work, however they (some) were in at the beginning of Theme research development and as the ARC formed.

They were a key part of the 2022 review of PPI and expressed their frustration at the lack of clarity in terms of their role within the ARC. They were instrumental in forging ahead with the changes to ARC PPI understanding, role clarity and PPI systems development.

The most obvious change is that one of the PPI Champions moved into a paid role as the PPI lead for the ARC in 2022. This has meant that they have been able to take an 'insider' view of both the role of a PPI Champion and of PPI in the ARC OxTV. They have then been able to use this for strategic and operational purposes.

Another long-standing PPI Champion has taken on leadership roles in chairing and co-ordinating PPI meetings, since 2023. Additionally, they have had time to develop close relationships with researchers in their allocated theme of research and see opportunities for collaborative research. This developed into pilot research in upcycling in a community setting as a form of therapy for vulnerable people. The idea was to assess participants' mood, using a Moodscope tool to understand the potential impact, https://www.arc-oxtv.nihr.ac.uk/blog/mary-zacaroli-expert-by-experience-arc-oxtv-part-2

Finally, a third original PPI Champion has had the time and connections with the Dementia Fellows Programme to help researchers think about their research ideas in Dementia and assist with funding applications. As a PPI Champion with dementia carer experience this has been satisfying and they have felt they can challenge existing research ideas; *'It was really nice to work with somebody who was being asked to think about things completely differently.'*

Post 2022 PPI Champions

The experiences of PPI Champions that have joined post 2022 feels a little different to those embedded at the beginning. They have benefitted from increased systematic support and from working with a wider group of PPI Champions with differing lived experience and skill sets. PPI Champions generally work in pairs within research themes enabling peer support.

Some have come a long way, as they were new to both this role and to PPI more generally, but had great experiences in community working and charitable expertise. Others that had PPI experience were able to help others develop into the role.

Confidence levels have increased. This has come from greater participation with researchers. This is especially so where relationships have been built and there is an appreciation of PPI Champions who bring community links and networks which many researchers do not have.

The suite of processes and guidance has been entirely updated with the help of the new PPI Champions who perhaps have come to this with fresh eyes and opinions. Initiating the Monitoring to Learn feedback process for PPI within themes has involved many of the newer PPI Champions. Again they come to this new, with constructive feedback on how to go about this and capture learning about PPI in ARC research.

The feedback about the new PPI members of the ARC Strategy Board has been broadly positive with examples of their steering of conversations. This was especially welcome when they challenged the concept of impact of ARC research and knowledge translation. They also contributed to the ARC funding extension with fresh eyes.

All the research themes have been populated with two PPI Champions with mixed experiences, the key success factors being relationship building, regular interactions via meetings, and framing PPI as a 'critical friend' role rather than 'doing PPI for their research.'

Shared experiences

Current PPI Champions really value the core PPI support team and feel very positive about the operational changes that have been made and the level of support provided. They recognise the value that lived experience as a public contributor can bring to leading PPI in an organisation.

All PPI Champions have benefited from the 'democratisation' of PPI in the ARC. The introduction of a public contributor as chair of the group (and more recently a co-chair) and the working groups to progress projects has devolved decision making. The process has facilitated the inclusion of more voices in the development and decision making process.

The whole group values and learns from the lived experience of different members. They also value the peer support and mentoring that those with different life experience can provide. Everyone benefits from the transition to being a learning group that encourages identification and support of personal development goals.

In addition valuing the different types and level of experience that people bring has facilitated the development of our PPI operational processes. It has also influenced the development of PPI Monitoring to Learn Process.

The change in the direction of ARC PPI and increasing value placed on this PPI has ensured that all members have had growing opportunities to expand their roles and experience during the course of their time with the ARC.

Finally, as a group the PPI Champions have been very positive about how much they have learnt from each other both in meetings but also in PPI activities where opportunities to observe and support have been taken up with enthusiasm.

APPENDIX VIII: Blogs and other musings

Date	Article name and author	Page number
March 2026	To workshop or not to workshop? That is the PPI question. Sally Crowe	Page 59-60
March 2026	Entering the PPI unknown – working with methodologists and statisticians Sally Crowe	Page 61
22 July2025	ARC Digital Health - A round trip Katharine Keats-Rohan	Page 62-63
7 May 2025	Evolving Patient and Public Involvement in ARC-OxTV – Part 1 Mary Zacaroli	Page 64-65
7 May 2025	Evolving Patient and Public Involvement in ARC-OxTV – Part 2 Mary Zacaroli	Page 66-67
23 July 2020	COVID-19 lockdown Mary Zacaroli	Page 68-69
7 July 2020	PPI in the time of COVID-19 Bernard Gudgin, Julia Hamer-Hunt and Una Rennard	Page 70-71

To workshop or not to workshop? That is the PPI question.

After joining the Oxford and Thames Valley Applied Research Network (ARC OxTV) I was allocated as a PPI Champion to a theme that provides methodological and statistical support to other researchers across the network, and has their own funded research. There is also an attached group of 'Dementia Fellow' researchers that specialise in prevention and treatment of dementia.

As I learned more about the work of the researchers it became apparent that their research was often methodological (modelling and statistical development), working with large data sets and undertaking statistical analysis of healthcare data (economic evaluations).

I was also beginning to appreciate that for these researchers it was not always clear what the role of PPI was in their research but they knew that there was an established rule of principle from many funders that PPI was to be included in their work.

As I read more about their work and also how others had integrated, or not, PPI into these areas of research I offered to share the conclusions from my reading and initiate a conversation about PPI. We scheduled a one-hour online meeting in March 2025, this was well attended and we started with small discussion groups focussing on the 'good, the bad and the ugly' of PPI. In retrospect this was a much too risky exercise so soon in our relationship! Participants were polite and positive, but there wasn't much bad or ugly to discuss. I ploughed on with my presentation of the literature – and made a schoolgirl error – it was pointed out to me that research into large datasets was very different from statistical methodology – I had conflated them in my presentation and this hadn't helped how it landed. The participant who pointed this was very polite and I took the comment in the constructive way it was offered and it opened up the debate about why I had got confused.

This was the opening of the conversation proper – by maybe showing that I was willing to learn about their expertise they were willing to learn about mine? We started to explore PPI in a frank and realistic way in the last 10 minutes of the meeting. A rushed list of items 'to do next' was compiled and this gave me hope that there was more ground to explore. We agreed that workshop two would be built around the 'to do' list', and would be in person, as well as online.

The format of the second workshop took the form of a debate about PPI in Statistical Methodology Research (with speakers for and against) and a presentation from a team member about decoding the language used in statistical methodology research, and how this can be made more accessible to the public.

Summary of discussion themes:

- Most research in the methodology in Prediction Modelling is on a continuum – rather than a binary, yes or no to PPI. It is not a question of *whether* PPI is desirable, but more 'how far up the chain'?
- A useful starting point that we could all agree on is 'there should always be *consideration* of PPI'
- Consider the outcomes that are being proposed for the model – as this (be they binary or continuous) may determine the choices of statistical approaches. PPI or stakeholder engagement may offer insights in terms of choices of outcomes and how the model might be used in real life.
- Consider the 'opportunity cost' of PPI in methodology studies – PPI is desirable but not cost-free since it uses time and resources. When is the benefit of PPI worthwhile vs. outweighed

by the resources used? Where should funders and researchers prioritise PPI efforts? Being clear about why you want to do PPI and when or where is the clearest priority is helpful

- Be prepared to articulate your arguments about where PPI is not suitable for (stages of) your research to show how you have critically reflected on it.
- Think in terms of stakeholders (that includes PPI if appropriate) for methodology research as there are many potential users of Clinical Prediction Model methodology papers.
- Using metaphors for concepts and language in Statistical Methodology can be very helpful and entertaining.
- Researchers could be filmed presenting their ideas to broad audiences and learn about their personal communication styles.

Both workshops offered opportunities to discuss PPI in a frank and realistic way and enable researchers to share both their PPI 'wins' and challenges in a safe environment.

Sally Crowe
March 2026

Entering the PPI unknown – working with methodologists and statisticians

Whilst I have been working in Patient and Public Involvement (PPI) for many years in a professional and patient/public capacity I have always been curious but shy of entering the worlds of research methodology and statistics. It took me several goes to get my Maths 'O Level,' so as a number phobic I cautiously accepted an invitation to be a PPI Champion to a research theme where the main currency was statistical methodology research, economic and predictive modelling, and using big data sets.

As part of the Oxford and Thames Valley Applied Research Network (ARC OxTV) the theme provides methodological support to other researchers across the network, but also has their own research, and a group of Dementia Fellows (post-doctoral researchers focussing on dementia research).

I was warmly welcomed by the Theme Lead, Prof Rafael Perera and joined an online team meeting in early 2024. As is often the way with external people joining internal university meetings, the technology was challenging and we got there in the end, but it is a reminder that you *are* an outsider.

My main impression of those early meetings was how the researchers interacted and talked a different language from what I was used to in PPI. Phrases like 'stepped wedge,' 'calibration slopes,' 'predictive AI models,' 'system dynamics,' and 'logistic regression' littered the conversation. I made lots of notes and looked for relevant articles and papers to acclimatise myself, spoiler alert there wasn't much material to work with. I wondered how I could provide any help or insights.

However, early 1:1 conversations, with 'Dementia Fellows' as part of the Monitoring to Learn process provided some answers. I chatted informally with the researchers listening to their research ideas and hopes. Whilst all of them were interested and keen on PPI – few had relevant experience. As I became a more visible PPI research partner, there were requests for me to join projects. This presented me with a dilemma. My role as a PPI Champion was to support PPI in the team not 'be' the PPI for their research. The ARC core team helped me set boundaries and expectations.

I gradually provided commentary and advice on research protocols and applications, and linked up researchers with my networks, for example LGBTQ+ representation (for a statistical project).

By the end of 2024 I was beginning to appreciate how PPI for these researchers was not always an obvious or beneficial choice, at times they felt trapped in a PPI 'orthodoxy'. To explore these issues further we had two workshops both of which were well attended. PPI was discussed in a frank and realistic way, enabling researchers to share both their PPI wins and challenges in a safe environment. It felt timely to welcome a second PPI Champion, Rashmi Kumar, who is experienced and interested in a challenge.

We decided to pilot a series of monthly PPI surgeries (October 2025 – March 2026) whereby two researchers had time with the champions to work through a PPI idea, challenge, or problem. This way the researchers set the PPI agenda and the PPI Champions work with where they are, and where they want to be.

The surgeries are currently being evaluated but we can say that they were popular, judging by the attendance, provided PPI insights for the researchers and statistical methodology insights for the PPI Champions. Most of the surgeries addressed researchers PPI plans for grants applications, fellowship applications and project work.

Sally Crowe, March 2026

ARC Digital Health - A round trip

I eventually joined the ARC Digital Health theme in early 2021, having answered the third call for a theme champion. I had been tempted on all three occasions, but hung back because of the demands of being a town councillor. I had been involved in workshops on using technology to monitor health at home before the pandemic, and had trialled and reported at length and negatively on the experience of using an Alexa for a daily reporting My Arthritis Friend exercise which had nearly driven me mad, but had a more positive experience wearing an exercise tracker for UK Biobank. As a patient with a long-term condition, I had been part of the PPI for the NIHR CLARCH's MedTech and In viro Diagnostics Co-Operative. Responsible use of patient data had always been part of my PPI experience, including as a participant in a randomised double-blind clinical trial. Like many others, I gave input to covid research right from the start and took part in numerous longitudinal studies that came out of it. A long-term member of the UK Biobank, as well as HDUK and UseMyData, a family carer for my mother, it seemed possible that I would have something to offer.

It did not really work like that for quite a while. The problem with being inserted into something already established and very successful, is that there is no neat round hole for the new peg to drop into. Nor, because of the complexities and sensitivities around digital healthcare, is it an area into which you can insert yourself unbidden. There have been opportunities to discuss patient-public involvement with doctoral students, including commenting on the first draft of Sami Adnan's Human Centred Medical AI Design Bootcamp, and talking to Brenna Loufek about her qualitative study to assess perceptions of patient harm among providers, policymakers, and patients. She is collaborating with a patient advocacy group to develop guidelines for the notification process when artificial intelligence is used within clinical care at the Mayo Clinic.

However, I have had sessions with other students (including Sami, above), and with Dr Caroline Potter, whose Healthy Ageing workshop at the Oxford Martin School I attended in March 2024, and have become part of the DEM COMM fellows team, which has proved very worthwhile.

Things changed early in 2023 when a number of initiatives looking at dementia coincided with other work I was doing. I had worked for sometime alongside the remarkable Wallingford octogenarian founder of the Caring for Carers in Wallingford group, which meets monthly in St Mary's church. I have long been a 'healthy volunteer' in dementia studies, and as a former carer and councillor am very concerned about the effect of caring on care-givers. Val and I trialled a 'dementia friendly Wallingford' programme that was embraced by all town centre traders, and I represent us on the newly formed Oxon Dementia Action Alliance, ably led by care worker Suzi Morgan. Both Caroline Green and Caroline Potter have visited the Wallingford group to talk about the experience of carers. Things changed again in May 2023, when I was also elected a District Councillor and became SODC's member on the Health Oversight Scrutiny Committee, which gives me a different insight into healthcare delivery.

Social care now unites the ARC themes and one result is the adoption of the Dementia Community Fellowships. Attending some of their meetings has been very fruitful. Along with other patient partners, including Sally Crowe and Suzi Morgan, I have worked with health economist Joseph Kwon, who was completely new to PPI and has found our perspective useful. We contributed to his application to Alzheimers Society in March 2024, and though unsuccessful, we have continued to support him, most recently in relation to a Postdoctoral Fellowship with the Alzheimers Society, for

which I was PPI co-applicant and which was awarded in December 2025 for his BINDING project. In addition, I have supported as co-applicant Dr Lei Clifton's proposals for a project on the use of wearables in care homes, so far without success, and am also currently supporting Prof Bee Wee's Virtual Hospice project, which started on 1 June 2025.

Back in 2018 I was part of a workshop led by ethicist Mark Sheehan and together we laid the groundwork for a co-produced paper on Trust, trustworthiness and sharing patient data in NHS research, which was published in the Journal of Medical Ethics in 2020. This argues that trust is a state of vulnerability and that the word is far too casually used in relation to the NHS and patient data. The formerly named Trusted Research Environments are now Secure Data Environments, partly due to this paper, according to some amongst us when we reconvened in July 2025 for another three day workshop, on what makes an NHS research institution trustworthy, aimed at a follow-up paper. I subsequently attended a discussion on the use of patient data convened by Claire Bankhead in an ORCHID Epidemiology PPIE Focus Group on 14 July, after which I agreed to be part of an ongoing PPIE group for this project.

There have also been regular meetings of the PPI members across the ARC looking at PPI methodology, though council obligations have conspired to prevent me attending a number of these. With Rashmi I helped the ARC team led by Sarah Brown to prepare the very successful ARC Showcase November 2024.

Katharine Keats-Rohan
22 July 2025

Evolving Patient and Public Involvement in ARC-OxTV – Part 1

Public contributor Mary Zacaroli shares her journey in patient and public involvement at ARC OxTV in part one of a two-part series. Follow her evolution from questioning her role to co-leading innovative health research projects, showcasing the growing impact of lived experience in academic studies.

When I became a PPI (Patient and Public Involvement) Champion for the ARC's Improving Health and Social Care theme in March 2020, I never thought that one day I would be devising and co-leading a research project.

In fact, it took a while to understand why I was there. Of course I was made very welcome by the theme lead, (the much-missed Professor Ray Fitzpatrick), but my role seemed undefined beyond being a "critical friend." It didn't help that Covid lockdown had just started, so I would sit looking at a computer screen of academics in their blurred homes, struggling to understand acronyms and their roles as they whisked through updates of their work.

I did ask questions and make the odd suggestion and received feedback that they were helpful, but beyond that there didn't seem to be much I could do. Although once lockdown had eased, I met up with a couple of academics from my theme just to get to know them better.

Part of the role was to have occasional meetings with other theme champions where I discovered I wasn't the only one to question why I was there, and we realised that the academics were also trying to figure it out.

We started thinking about the bigger potential of patient and public involvement, and how we could diversify so that we were more representative of outside society, as we were all white, mainly middle-aged, mainly Brits, and nearly all women.

Then fellow PPI Una Rennard was employed as the ARC's Public Involvement Officer, responsible for coordinating everything related to patient and public involvement and brought her wealth of knowledge and fantastic skills for process and detail. Building on the work of present and former PPIs and complementing the great work of the ARC admin team, she set about facilitating the development of a framework and systems to improve how PPI was done in the ARC, which, like all such things, took time to bear fruit.

Fast forward a couple of years and we are now a much more diversified group that better represents the local community, while the scope and range of what our involvement can be is being developed in several ways. This includes developing a road map called PPI Monitoring to Learn to better understand existing patient and public involvement.

Now that we have a bigger team, we are drawing up a database of our professional and personal skills. What we have found in the meetings to map our own expertise is how well our skills complement each other, what we can learn from each other and how much we have to offer the academic community as colleagues, to enable and enrich applied research from conception onwards

We are also making contact with other PPI groups nationally to find out what is going on in their spaces. At a national meeting in November 2023, for example, we were told about the IDEAL project at Exeter University, which is about improving the experience of dementia and enhancing active life. A group of PPIs, half of whom were living with dementia and half of whom were carers, had a huge impact on the development of that decade-long project.

It is still early days, we are probably going to hit road blocks, not least because the collaborative way in which we work may bump up against the hierarchical, siloed way in which academia can operate, as well as funding issues, but what I have seen is a committed, enthusiastic and helpful ARC Ox-TV team doing what they can to help us succeed, backed by welcoming theme leads who are also committed to change.

Meanwhile, within the community health and social care theme, PPI is now an agenda item where I update on what the PPI group is doing and a second PPI has joined the team, bringing with her a wealth of community-based expertise and experience from the immigrant diaspora with whom she works. We will be using PPI Monitoring to Learn to benchmark what PPI involvement there is and what form it takes in our theme. I think one of things that we as PPIs offer though is just to reflect back to academics that they have and can access their own lived experience, their personal selves.

Relationship building within the theme also started to bear fruit in ways I hadn't imagined when Dr Caroline Potter, the staff PPI theme champion, helped me do a small piece of research for the upcycling social enterprise I used to run, to find out whether it helped improve quality of life for the vulnerable people I was working with. This led eventually to our pilot project, which is the subject of Part 2 of this blog.

Mary Zacaroli
7 May 2025

Evolving Patient and Public Involvement in ARC-OxTV – Part 2

In part two of her series, Mary Zacaroli explores being an 'Expert by Experience' at ARC OxTV. Discover how she co-led an innovative pilot study using Moodscope cards to measure wellbeing in community projects, demonstrating the value of public contributors in health research.

In the last blog I wrote about how things have changed in the Arc Ox-TV since I became a Patient and Public Involvement (PPI) Champion.

You may be wondering what a PPI even is? Why we would get involved in research and what we bring to the table?

We are sometimes called Public Partners, but I recently heard a term that I think explains much better who we are and what we do; that we are Experts by Experience.

That's certainly true for me: I had gained a lot of experience and skills that I had already used elsewhere, for example, when policy was being made nationally and in Oxfordshire around suicide prevention; and I see it in my fellow PPI champions.

But conceiving and co-leading on a pilot project, whereby you see if the idea is feasible, and then getting funding for it was not something I envisaged - although it has happened elsewhere, for example, the Dementia Enquirers programme has supported over 20 groups of people living with dementia to conduct their own small-scale research projects.

Two of my skills are the ability to build relationships and a strategic brain that can see how to make connections. Both of those were helpful when Dr Caroline Potter, staff PPI theme champion for Improving Health and Social Care, and I started to have conversations on how one could gain useful data on the impact of community-based work with people of different ages, vulnerabilities and ethnicities in a way that was low-cost, simple and appealing to the participants.

I had told Caroline about Moodscope cards that I had trialled before and after an upcycling class, to see if they showed an improvement in mood, which they did.

So, Caroline suggested we seek funding to run a formal pilot study, looking at the impact of a community-based project on health and wellbeing, using mood as a benchmark. We thought that using the cards would chime with one of the aims of the ARC, to find innovative methods of data collection.

Moodscope cards are based on the American Psychological Association's Positive and Negative Affect Schedule (PANAS scale). The cards measure 10 positive emotions and 10 negative emotions from 0 to 3, added up and then scored to form a percentage between 0 and 100%.

Moodscope was developed by a lay person, Jon Cousins, who was looking for a way to measure and track his mood each day and the positive results led him to get the cards validated and set up as an online tool.

I had used it online when going through a particularly difficult time many years before and had always liked the balanced focus of positive and negative (because of my life experiences I feel very deeply that if you just focus on what's wrong with a person, it skews your perceptions of them and their perceptions of themselves).

Having got to know the current Moodscope owners a little from writing anonymised blogs for them, they had sent me some of their demonstration cards. When I trialled them in the upcycling classes, what I also found was that they were a conduit to conversation, but that this could trigger deep-seated emotions and memories, so it was very important to have safeguarding measures in place should difficult topics come up.

All of this prior experience informed how we set up the project, while Caroline brought her many academic skills honed as an academic researcher in anthropology and primary care. She knows how funding bids work, what you need to do for applications, including how to get ethics approval, what questions to ask, how to analyse the data and the language of academic report writing as well as the knowledge of where to go to cite sources.

I brought my own research skills too, but technology has advanced hugely since 1998 when I completed my Masters, so having Caroline's help to get up to speed on the programme we used was invaluable, and all in all we made a good team.

Together, we worked with a charity I had got to know in my upcycling days, Children Heard and Seen, that looks after children with a parent in prison and their families. That prior relationship was a major reason why they took part – usually they say no to research requests as they are understandably protective of the vulnerable people with whom they work, but they knew they could trust me and, by extension, Caroline.

Our project used the Moodscope cards to measure an arts therapy course run with two mothers and two grandmothers.

The Moodscope cards showed that three out of the four participants saw a positive change in mood, and it was clear from interviewing the participants and the support workers afterwards how and why they found the arts therapy course of benefit, the impact of outside life on their scores and how doing the cards with their balanced approach to mood gave them a better understanding of the nuance of their mood; that they could be feeling really negative, but still feel positive in some ways.

More information about the course is in the video above.

What we would like to do now is a much bigger project with different groups to see how and where using these cards might be of benefit; not just about how to use Moodscope as a benchmarking project, but also how it could be used online as a research tool.

We are seeking potential collaborators from third-sector organisations and more researchers to develop this next phase, as well as funding, so if you are interested in getting to know more, please contact us via moodscopeproject@gmail.com.

Mary Zacaroli
7 May 2025

COVID-19 lockdown

We asked PPI contributor Mary Zacaroli to let us know how the COVID-19 lockdown had affected her and the third sector and PPI work she does in her own words.

I run a social enterprise, Paint Buzz, using eco-friendly paints and finishes made by a UK-owned firm Frenchic; my aim being to help people find an upcycling project that has lasting positive effects for them and helps the planet. Upcycling can be wonderfully therapeutic and these particular paints, which are extremely safe and versatile, allows anyone of any age or ability (including those living with dementia) to take part.

Thanks to a two-year grant from Oxfordshire County Council I've been offering funded craft and upcycling activities to care homes and community organisations within Oxfordshire.

I was planning 2020's programme when COVID-19 closed everything down. Once it became obvious that lockdown was long-term, I contacted Children Heard and Seen (CHAS), a charity that supports the family where children have a parent in prison and suggested we run a pilot project together.

CHAS runs a Zoom group on Wednesday evening for the adults to have fun and reduce isolation, so I joined in one evening and they came up with lots of projects to paint. Via Zoom meetings and their closed Facebook group, plans were refined, and colours chosen. I then dropped off materials and ran two Zoom tutorials demonstrating how to use the different paints. Those taking part loved sharing pictures of their newly painted doors, kitchen cupboards and furniture on their Facebook page.

I asked for feedback on whether this had improved their quality of life and if so, how? Responses included: "It helped with my anxiety and PTSD massively. It helped relax my mind" and "I feel that upcycling improves my mental health as when I'm extremely stressed, I paint to give my brain something different to focus on." Some have continued painting, finding it a great way to deal with stress in lockdown.

Working with CHAS was an eyeopener, seeing how nimble they were at reacting to the new reality even though they are a small charity with limited funding. When lockdown started, they realised that families who already felt isolated and stigmatised would need their services even more, but many families were lacking the technology and internet access for staying in touch, so they ran an appeal, had 20 second-hand laptops donated and taught themselves how to use dongles and passed the knowledge and dongles on.

Initially they started with their regular Wednesday group, asking what people wanted and it grew from there. They have been running up to twenty groups a week. Activities include an author reading a story book, art group, fitness sessions, bingo, a youth advocate group, cooking sessions and a Teddy Bears picnic. Beforehand, staff send out ingredients or materials. Tuesday evenings two parents run a group for children who are concerned about their parent in prison. CHAS has been able to reach far more families in this way and maintain the strong rapport with the families they work with. I love their can-do attitude and fierce support for the families they work with and how they are guided by them in so much of what they do. They show what a community can do in lockdown when it pulls together.

I've started two more projects. One is with adults with learning disabilities who co-farm with the charity Farmability and their carers. The co-farmers painted a pot to fill with seeds while their carers are painting a small item of their choice to give them a bit of me time. The other project is with Aspire, an Oxfordshire charity that supports vulnerable people with housing and employment.

Longer term I'm looking to do a research project that underpins the evidence I see every day that this kind of activity can improve quality of life, both immediately and the longer term, and leave the participant with something beautiful and useful, such as a dirty white uPVC front door transformed by colour.

Mary Zacaroli
23 July 2020

PPI in the time of COVID-19

Public involvement is central to high-quality, ethical research. So, what happens when a pandemic hits and life is turned upside down? We reached out to three experienced PPI contributors – Una Rennard, Julia Hamer-Hunt and Bernard Gudgin – to ask how COVID-19 had affected their personal lives and their PPI work.

Perhaps unsurprisingly, the effects of the lockdown have been as diverse as the people it affected.

"Personally, life generally remains much the same as normal," said Una. "We are restricted by our son's autism/anxiety/OCD, so the main differences have been his response to the situation – increased anxiety prior to the lockdown and again with discussion of loosening the lockdown (he feels safer with our movements restricted!)."

Whereas Julia Hamer-hunt, who lives alone, hadn't been able to have face-to-face contact with anyone. "2D screen images do not replace people – I miss hugs!"

Bernard felt fortunate compared to many because he could see his family and his daughter could do his shopping for him. And with 'many wonderful country walks on his doorstep', he found he'd been able to do much more walking and exercise than before lockdown.

Thinking about the types of PPI work people have been asked to do, Bernard said there had been the expected skew towards COVID-19 related projects with many pre-COVID-19 projects put on hold, delayed, or with only preparatory work being done. For Julia, a lot of the COVID-19 work was initially 'quick turn-around stuff', reflecting the urgency with which researchers and healthcare workers were switching priorities. Una noted that non-COVID-19 related work is now beginning to restart to some extent as new working practices are put in place and lockdown restrictions ease.

As for how they are carrying out PPI activities during the lockdown, well, there are few surprises now. However, when this all started in March, organisations and PPI contributors suddenly found themselves thrust into a world of video conferencing, ready or not.

"Some early events were affected as organisations struggled to adapt – meetings became less inclusive due to limited access (telecon only) and the ability to manage multi-people discussions." Says Una.

Of course, it wasn't just organisations that faced problems caused by the sudden adaptation.

"Not particularly enjoying IT, it added a degree of anxiety in case something breaks down." Said Julia. "My laptop charger broke and for 48 hours I was stressed about whether I had ordered the correct replacement and if it would turn up on time. Or, if it wasn't the correct replacement, what would be the cost of sourcing and finding one? The final concern was that I'd end up having to try to work from an iPhone instead of a laptop – a small screen for my poor eyes!"

"I find the hardest thing is not being able to meet other 'PPIers' and researchers in person," said Bernard, "video conferencing isn't the same! The most telling / important remarks are often made over coffee in the margins of formal meetings."

In terms of the support organisations were able to offer our three contributors, there was mixed response. Una noted that it very much varied from organisation to organisation but that all offered help and guidance on using the meeting technology or software to some extent. Bernard noted that

his computer was on much more than before, while Julia felt there wasn't that much more a PPI manager could do to help.

Thinking about whether COVID-19 has wrought any positive or negative changes to research applications and proposals, all three contributors have noticed that they are taking a lot less time than before.

On the positive side, Bernard said that "There is much more emphasis on speed and results, and less on bureaucracy – both of which are good news!" While Julia suspected that this change of pace, reducing the time between revisions and steps in the process, might help to keep up momentum for the 'lay communities' involvement in projects.

There is much more emphasis on speed and results, and less on bureaucracy – both of which are good news!
- Bernard Gudgin

Una, who had reviewed multiple NIHR COVID-19 applications, noted that the majority included PPI to a reasonable extent. However, she also noted that while the change of pace in applications had good aspects, there remained concern that "…COVID-19 studies might be being 'rushed' into as this is a 'crisis' and there is a perceived need to be 'seen' to be acting."

Most concerningly, Una said that "some studies are not fully involving patients and the public and therefore might not be the best, or acceptable, research as a result."

While this article is from a 'quick catch up' with just three PPI contributors it's clear that opportunities as well as problems have emerged from the lockdown and, overall, we should be mindful that there is much learning to be taken from it.

PPI in research has, perhaps, never been so important, particularly in terms of the public health response to the pandemic. PPI is more-or-less the only tool in the box that can highlight important unmet needs amongst diverse communities. The importance of which has been especially underscored as it became increasingly apparent that black and ethnic minority groups appear to be disproportionately affected by COVID-19.

"Ultimately," said Una, "what we need are robust studies that will have useful results to help us move forward, not rushed science that does not improve outcomes for people."

So, while we may have all grown tired of hearing about the 'new normal', we should be careful about thoughtlessly returning to the 'old normal' when the time comes.

7 July 2020
Bernard Gudgin, Julia Hamer-Hunt and Una Rennard

APPENDIX IX: ARC OxTV PPI Governance Poster

Embedding Public Involvement in the Applied Research Collaboration Oxford and Thames Valley's decision making processes

Using a partnership model built trust. We created open and accountable systems. We developed ways of working that shared power. We encouraged relationship development.

We offered a warm welcome

Inclusive recruitment
Time, space and support to settle in
Payment for time and expenses
Accessible and flexible
Regular and personalised support
Learning and development

"You specifically have helped me so much, not just in settling so quickly at the ARC but also support me personally so much in many other ways." Public Contributor



We created inclusive ways of working

Public led
Space to talk
Working Groups
Governance and strategy
Feedback
Working together
Influence
Clear expectations

We encouraged relationships and openness

Strategy Board
Executive Group
Themes
Researchers
Staff
Networks
Communities
Individuals

"Having the time to get to know my fellow PPIs and researchers has been key to helping build good communications and great ideas on how to move forward." Public Contributor

We had many activities to get involved with

PPI Monitoring to Learn
PPI Surgeries
PPI policy and process development
Impact and evaluation and strategy
Funding decisions
Recruitment
Workshops