NIHR | Applied Research Collaboration Oxford and Thames Valley

Patient and Public Involvement Monitoring to Learn

Report
March 2026



PPI (patient and public involvement) Monitoring to Learn report

Content	Page numbers
Executive Summary	Page 3
Section 1: Developing and reviewing the PPI Monitoring to Learn Process The PPI Monitoring to Learn process What we did – Steps 1-6 The future	Page 4-6
Section 2: What we learnt about PPI in ARC OxTV from the Monitoring to Learn Pilot Method Analysis and Discussion Mapping ARC PPI to National frameworks and strategy	Page 7-13
Section 3: Conclusions and recommendations PPI Monitoring to Learn Resources What we learnt from the pilot project Recommendations for the future	Page 14-15
Section 4: Appendices Appendix I: PPI Monitoring to Learn process and guidance Appendix II: PPI Monitoring to Learn planning and monitoring form Appendix III: PPI Monitoring to Learn PPI impact and evaluation guidance Appendix IV: PPI monitoring to Learn review summaries Appendix V: UK Standards for Public Involvement and the NIHR PPI Strategic Commitments	Page 16 - 58

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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

Executive Summary

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).
- **(Inter)National PPI Agenda.** Explore how to better embed the UK Standards for Public Involvement and the NIHR PPI Strategic Commitments into the process.

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.

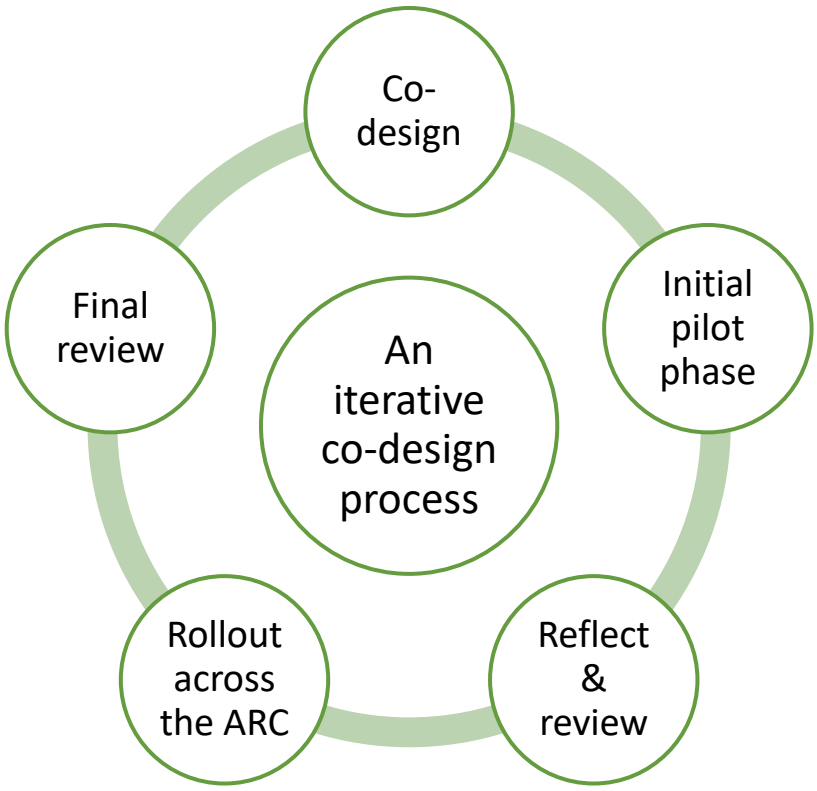
What – Nothing already available quite worked for our situation so we designed a bespoke tool to do it effectively.

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:

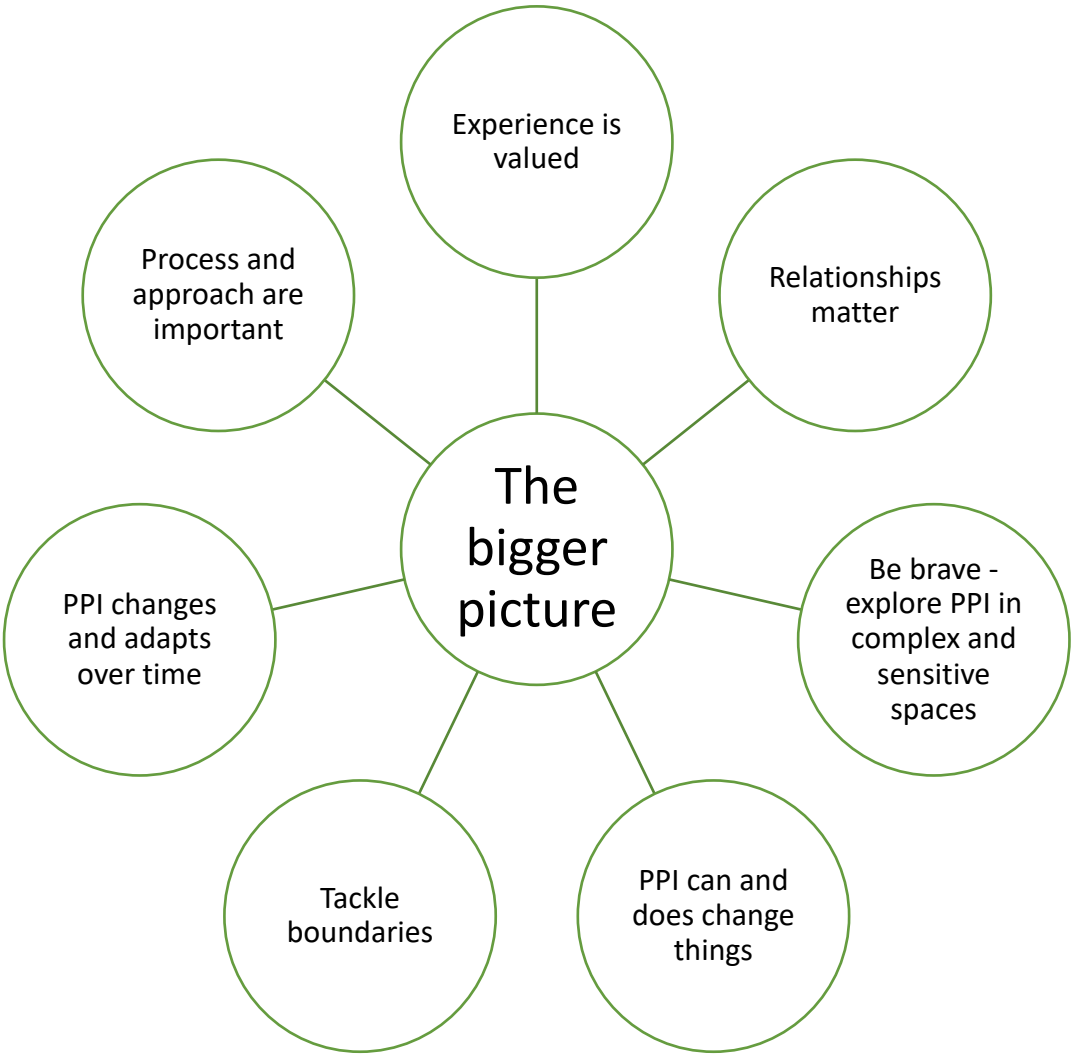
- Summaries of each monitoring to learn review were written and analysed.
- The summaries were reviewed in relation to the UK Standards for Public Involvement (see Table 2), and the NIHR PPI Strategic Commitments (see Table 3).
- Key messages were discussed and agreed.
- The key messages were thematically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

The full text of the summaries is in the Appendix IV of this report.

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.

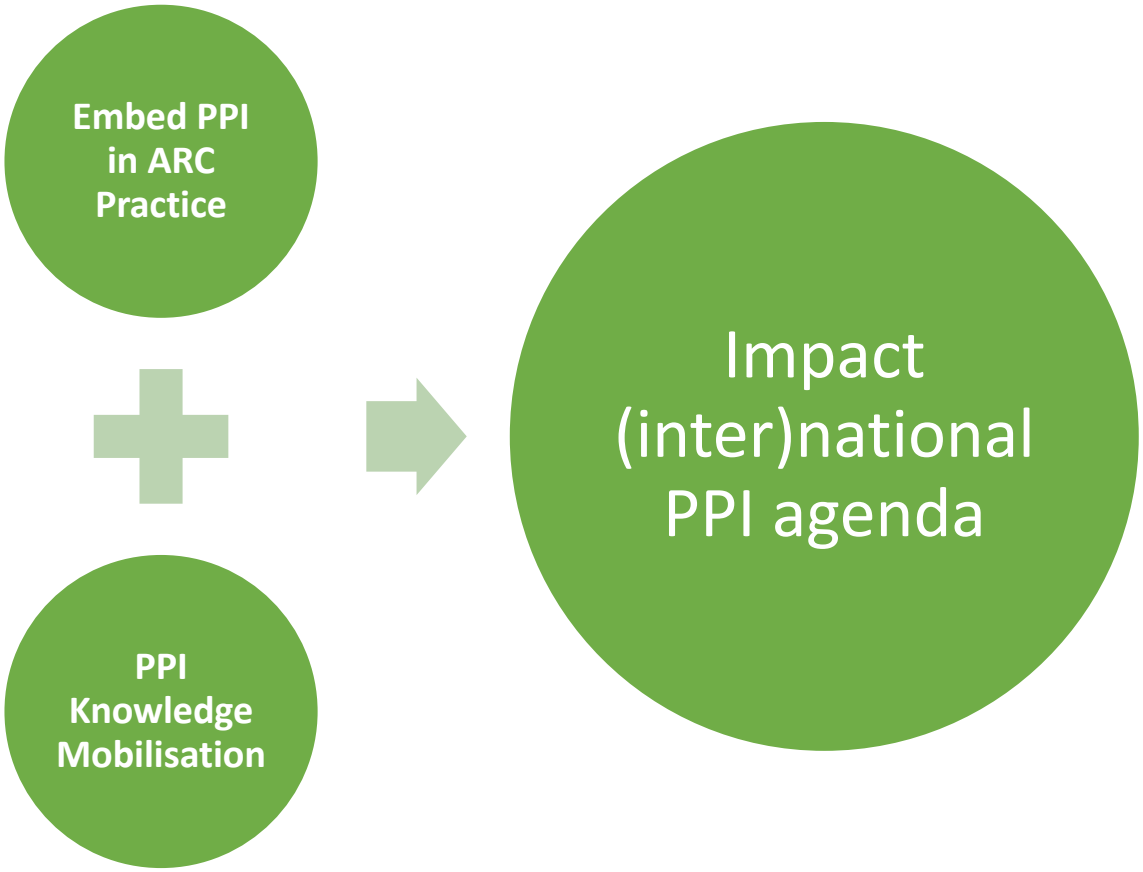
PPI Monitoring to Learn Resources:

- **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.

Section 4: Appendices

I	**Monitoring to Learn process and guidance**	page 17-19
II	**PPI Monitoring to Learn planning and monitoring form**	page 20-26
III	**PPI Monitoring to Learn PPI impact and evaluation guidance**	page 27-36
IV	**PPI Monitoring to Learn review summaries**	page 37 -55
V	**UK Standards for Public Involvement**	Page 56
VI	**NIHR PPI Strategic Commitments**	Page57-58

Appendix I: PPI Monitoring to Learn process and guidance

Please note:

- ***This document currently uses the term "PPI Champion" to refer to public contributors linked to Themes.***
- ***The document is also written based on the ARC OxTV structure.***
- ***Terminology will need to be amended for ARC TV and other PPI infrastructure.***
- ***This document is primarily written for ARC OxTV and therefore suggests a way of doing PPI Monitoring to Learn. It is not intended to be directive or prescriptive and should be adapted for the context in which it is being implemented.***

Aims

The PPI Monitoring to Learn approach is intended to:

- Encourage planned and meaningful PPI involvement across all ARC-funded (or closely ARC-connected) research.
- Develop a clearer understanding of the PPI activity taking place within ARC research, including challenges, adaptations, and emerging learning.
- Offer constructive advice and guidance that may help strengthen PPI practice.
- Facilitate the sharing of learning and good practice across the ARC.
- Highlight learning needs and opportunities that could support ongoing PPI development.

Roles

PPI Team

It is suggested that:

The PPI Team take responsibility for:

- Helping ensure PPI Champions have access to current research lists for their Themes.
- Providing support to PPI Champions as they engage with research teams in planning PPI and considering monitoring activities.
- Creating spaces for regular conversations among PPI Champions about PPI work within each Theme.
- Summarising PPI activity within Themes and across the ARC.
- Collating feedback for each Theme or project and supporting PPI Champions in sharing this feedback.
- Enabling the exchange of learning and examples of good practice.
- Identifying potential PPI learning or development opportunities and exploring how these might be taken forward.

PPI Champions

It is suggested that:

PPI Champions can choose to contribute to this work. While participation is voluntary, it would be helpful for at least one PPI Champion within each Theme to take on this role.

PPI Champions who opt in will be supported by the PPI Team to:

- Work alongside Theme leads and researchers in shaping PPI plans for ARC-funded or ARC-linked research.
- Contribute to the development of broader PPI approaches within their Theme (e.g., involvement in decision-making, reporting processes, and learning opportunities).
- Help ensure PPI plans are recorded for all projects and, where relevant, for the Theme as a whole.
- Explore PPI monitoring plans and timelines with researchers as part of PPI plan development.
- Support monitoring activity within the Theme's projects.
- Share reflections on PPI activity and what is happening in their Themes at PPI Champion meetings.
- Collaborate with the PPI Team to consider feedback for individual projects or Themes.

Process

It is suggested that:

- PPI Champions can liaise with Theme leads and the PPI Team to clarify which projects sit within their Theme.
- Champions can work with their Themes to shape Theme-level PPI plans, recognising that approaches may vary and should be agreed early in the process.
- Research teams will be encouraged to create their own PPI plans, with the option of seeking support from a PPI Champion.
- PPI Champions will share updates on Theme-level and project-level PPI planning with the PPI Champions group and the PPI team.
- PPI plans will be reviewed and 'signed off' by the PPI Team prior to a project beginning.
- PPI Champions should keep an overview of monitoring schedules and share updates with the PPI Champions group and PPI Team.

Support

It is suggested that:

Champions taking on this role will have access to support, which could include:

- Payment for time (to be agreed individually, with flexible use for tasks as needed).
- One-to-one discussions to help plan their approach.
- Group training or reflective discussion sessions.
- Exploration of different models of PPI.
- Guidance aligned with the UK Standards for Public Involvement.

Tasks

Possibilities include:

Collecting Data

- For each Theme, information about Theme-level and project-level PPI activity will be documented.

Discussing Data

- PPI Champions will have opportunities to present and reflect on PPI within their Theme at PPI Champion meetings.
- As projects and Themes engage in formal review and monitoring, PPI Champions may report back any insights to the PPI Champions group and PPI Team.

Analysing Data

Presentations and discussions aim to deepen understanding of PPI activity by exploring:

- Appropriateness, quality, and possible enhancements.
- Examples of good practice and learning that could be shared.
- Challenges, adaptations, and lessons emerging from monitoring.
- Broader insights about PPI across the ARC.

Learning From and Using Data

After discussions:

- The PPI Team and PPI Champions will shape feedback for each project or Theme and consider effective ways to share it.
- With support from PPI Champions, the PPI Team may summarise PPI across Themes and the wider ARC for reporting and knowledge-sharing.
- Particularly valuable examples of practice or learning—ranging from early steps in PPI to more innovative approaches—may be highlighted for wider dissemination.
- Learning gathered collectively may inform potential training or development opportunities.

Potential Outputs

- ARC annual PPI report
- Annual ARC report to NIHR
- PPI case studies or stories
- Blogs

Appendix II: PPI Monitoring to Learn planning and monitoring form

PPI in projects: This form is to help plan PPI in ARC projects/studies. You will then review this plan at regular intervals during the life of the project/study.

Please tell us about where you and this project fit in the ARC family:			
Theme		Project Name	
Brief description of project			
Study PI		PPI Contact (if not PI)	
Email		Email (if not PI)	

<u>Project/Researcher Overview</u> – include any existing PPI experience and any notable impressions.

Links for useful resources for planning PPI: UK Standards for Public Involvement, Public Involvement in Research Impact Toolkit (PIRIT) - Marie Curie Research Centre - Cardiff University,

Topic	**Questions & Examples**	**PPI Plan/Ideas – Date developed**	**How we did – Date reviewed**			
STAKEHOLDERS	• What do you think PPI is/can be? • Who are your key stakeholders? • Why are they important? ***Examples:*** *patients, carers, parents,*		**<u>Prompts for review:</u>** ***Did you identify the right stakeholders? Have you identified new stakeholders? What impact have any changes to your plans had? What have you learnt? What would you do differently? What are your PPI plans moving forward?***			
			Changes	**Challenges**	**Learnt**	**What will you do differently?**

<table>
<tr><td></td><td>particular community, clinical staff, commissioners etc?</td><td></td><td colspan="4"><u>Summary of activity:</u></td></tr>
<tr><td>INCLUSION</td><td>• What can you do to make sure your PPI is inclusive?
• How will you support the people you involve?
Examples: inclusive recruitment practices, fees, expenses, where will people be recruited from (e.g. communities, geography, conditions), training/learning opportunities, support, accessible language, feedback to PPI members, venues & communication, link to (ARC) PPI networks etc</td><td></td><td colspan="4"><u>Prompts for review:</u> Were you able to recruit the appropriate people in the timeframe you expected? Has the support you planned been appropriate? What impact have any changes to your plans had? What have you learnt? What would you do differently? What are your PPI plans moving forward?</td></tr>
<tr><td></td><td></td><td></td><td>Changes</td><td>Challenges</td><td>Learnt</td><td>What will you do differently?</td></tr>
<tr><td></td><td></td><td></td><td colspan="4"><u>Summary of activity:</u></td></tr>
<tr><td>INFLUENCE</td><td>• What is the aim of your PPI?
• How will you ensure ‘a strong stakeholder and/or public voice’ in decision making?
• Are there limitations to how PPI can change or influence your study?</td><td></td><td colspan="4"><u>Prompts for review:</u> Has your PPI influenced parts of the research? Have there been any surprises? What impact have any changes to your plans had? What have you learnt? What would you do differently? What are your PPI plans moving forward?</td></tr>
<tr><td></td><td></td><td></td><td>Changes</td><td>Challenges</td><td>Learnt</td><td>What will you do differently?</td></tr>
<tr><td></td><td></td><td></td><td colspan="4"><u>Summary of activity:</u></td></tr>
</table>

<table>
<tr><td></td><td>• What can (have) they influence(d) or shape(d) in the study?
Examples: question(s); agreeing outcomes measures; study design; dissemination etc.</td><td></td><td colspan="4"></td></tr>
<tr><td rowspan="3">APPROACH</td><td rowspan="3">• How will people be able to get involved in the study?
• What methods or approaches will you use?
• Will there be opportunities for involvement at different levels (engagement through to co-production)?

Examples: set up a group, independent activities, peer researchers, multi stakeholder group, in person/online, working with an existing group, crowdsourcing via social media or public events etc</td><td rowspan="3"></td><td colspan="4"><u>Prompts for review:</u> Have the approaches you planned to use been effective? Have these activities changed your research? What impact have any changes to your plans had? What have you learnt? What would you do differently? What are your PPI plans moving forward?</td></tr>
<tr><td>Changes</td><td>Challenges</td><td>Learnt</td><td>What will you do differently?</td></tr>
<tr><td colspan="4"><u>Summary of activity:</u></td></tr>
</table>

<table>
<tr><td rowspan="3">ACTIVITY</td><td rowspan="3">What activities will your PPI take part in?

Examples: reviewing patient information; considering impact or burden on participants; interpreting data; dissemination activities and outputs etc.</td><td rowspan="3"></td><td colspan="4"><u>Prompts for review:</u> Have you been able to involve people in activities as planned? Have there been multiple ways to get involved? What impact have any changes had? What have you learnt? What would you do differently? What are your PPI plans moving forward?</td></tr>
<tr><td>Changes</td><td>Challenges</td><td>Learnt</td><td>What will you do differently?</td></tr>
<tr><td colspan="4"><u>Summary of activity:</u></td></tr>
<tr><td rowspan="3">RESOURCES</td><td rowspan="3">How many public contributors do you plan to involve?
How often will they be involved?
How much PPI Budget will you need to do what is planned?
How much staff hours and resources do you need to facilitate the PPI plan?</td><td rowspan="3"></td><td colspan="4"><u>Prompts for review:</u> Have resources been sufficient (people’s time, money, frequency of activities etc)? Have your planned activities taken longer than expected? What impact have any changes had? What have you learnt? What would you do differently? What are your PPI plans moving forward?</td></tr>
<tr><td>Changes</td><td>Challenges</td><td>Learnt</td><td>What will you do differently?</td></tr>
<tr><td colspan="4"><u>Summary of activity:</u></td></tr>
<tr><td></td><td></td><td></td><td colspan="4"><u>Prompts for review:</u> Please tell us about:</td></tr>
</table>

SIGNIFICANT CHANGES	What difference do you think the PPI will make and to whom/what? ***Examples:*** *change in knowledge, skills, or confidence; affected relevance, design, delivery, or dissemination; for PPI members, Researchers, Wider community, or the research study*		***One significant change to the study.***
			One significant change to the PPI members you have involved.
			One significant change to the research team.
			If there has (have) been no change(s) please explain why you think that is.
PPI IMPACT & EVALUATION	• How do you plan to capture the impact or evaluate the PPI? • When will you review this PPI plan? ***Examples:*** *meeting minutes; PPI numbers and outputs; before and after patient information developed; lay summary; recruitment and retention rates; PPI impact and evaluation tools such as The Cube, Impact log/'You said we*		**<u>Prompts for review:</u>**
			Please tell us about the PPI impact/evaluation tools you have been using.
			Please tell us how your PPI members (will) contribute to the PPI impact/evaluation you are undertaking.
			Please tell us about how your PPI members have contributed to this monitoring.
			If you haven't already done so elsewhere, please tell us about how you feedback to your PPI members?

	did' tools/feedback, Piiaf, PIRIT or GRIPP2 ***We recommend:*** • *PPI plans should be formally reviewed at least twice during a project unless it is two years or less in length.* • *that projects build in regular 'internal' reviews to make sure PPI is working well for the project and the public contributors.*		

SUPPORT TO DEVELOP THE PPI PLAN/REVIEW	• Please record any help or support you have received while developing your PPI plan or doing the review? • How helpful was the support? • Could you have done it without the support? • What was the most important aspect of the support you received? • Would you need that support in the future? • How will it affect future PPI you do? ***Examples:*** *PPI funding, guidance about how to plan PPI, another team member, PPI Champion, Public contributor with/without lived experience etc*		**Prompts for review:** ***Please tell us about any additional PPI support you have received since developing your PPI plan.***

Appendix III: PPI Monitoring to Learn PPI impact and evaluation guidance

Why is it important to evaluate PPI and understand the impact it has?

Better for PPI

The more we understand the impact of PPI and evaluate it the better we will understand what we are doing, what works for who and when.

The same process or method will not always work for all settings. For example, the method you use for involving adults will not work as well when you want to involve young children or those living with dementia or learning difficulties. You might need to tweak what you do or completely redesign what you do.

Evaluating your PPI process and understanding the impact and how things worked or didn't will hopefully help you to plan future involvement. Sharing your evaluation also helps others embarking on PPI in research, consider it a 'library of starting points'.

Ethical Aspects

We are viewing ethics in a broad sense, including the moral and cultural issues of working with different people and communities, and the need to avoid waste in PPI and research more generally.

Things may appear to have gone well but unless you ask people about how it felt for them you might not know why and what the issues were. For example, the public members might have really enjoyed the experience but the team facilitating the PPI might have had a dreadful experience due to the extra time and effort to make the PPI so good. This knowledge helps to either be proportionate or to ensure additional resources are built in to facilitate the PPI in future projects.

Alternatively, through the evaluation process and looking at the impact PPI has had it might seem that nothing in the research changed. The review process should also help identify why this is: Have suggestions been ignored? Were people involved too late to influence anything? Were they involved in the wrong way/time?

Recording and evaluating what was done will help to avoid 're-inventing the wheel' and even more importantly help to avoid using approaches that don't work, or improve approaches by 'tweaking' them, so they work better.

Return on investment

Funders and funding panels are becoming increasingly astute about assessing PPI plans in applications. They are looking for evidence that the planned PPI is appropriate, meaningful, and effective. Building this evidence into applications will hopefully assist research plans in securing future investment.

Overall, PPI impact and evaluation work should help you to develop PPI plans for future research that are evidenced by what you have learnt from previous activities. Alongside this you should also be referencing good practice standards and guidance. Thus, showing that you are aware of national guidance and standards for PPI and that you understand the wider PPI context and PPI 'direction of travel'. The evaluation of your PPI can help you to show how you are reflecting on, developing, and improving your own PPI practice.

What do we mean by 'PPI Impact' and 'PPI Evaluation'?

In 2019 the NIHR defined the impact of PPI in NIHR health and social care research as: '*The changes, benefits and learning gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiatives.'*

PPI impact is all about what impact the PPI you have done has had on the 'who' and the 'what'.

The 'who' and the 'what' might be:

- your public contributors
- the research team
- individual researchers
- support staff
- the research or specific parts of the research
- the methods or design of the research
- recruitment and retention
- the organisation
- how you disseminate the work etc.

It is important to remember that it is difficult to separate out the specific impact of PPI on all of the research or even individual components as the PPI (if it is not tokenistic) will be an integral part of the research in the same way other parts of the research are (such as methodology, analysis, statistical results etc) as they are all affected by the context and what came before and what happened after.

What is important is to investigate what happened, how people felt and can you connect changes to inputs (whether they are specific or general). This is where making use of the resources identified in the tables that follow is important. Gather your evidence as you go and try and track it where you can to see what impact it has.

PPI evaluation is all about evaluating your PPI practice to make sure you continually improve your practice in terms of impact and experience.

PPI evaluation can be ongoing (e.g. continually 'doing, reflecting and reviewing' what you do) or it can be time specific (e.g. the beginning, middle and end of a research project).

Both involve reflecting on what went well and what went less well and thinking about how this understanding can help you adapt your PPI practice either as you move forward in the research you are doing or as you move towards a new project. It is probably best if you can do both.

So how do we do all of this?

What should we be looking at? Many of the resources listed below explore some of the things to consider when evaluating PPI and its impact. One way to think about it is to consider the different types of potential impact, the following examples are taken from Lammons et al, 2025.

- Impacts on People
- Impacts on Researcher
- Impacts on Services and Systems
- Impacts on PPIE Processes

Resources already exist in abundance. You do not need to 're-invent the wheel' but you might need to adapt something to work for you, the research, the community you are working with and the PPI you are planning.

This is a webinar from NIHR that explores some of the resources detailed below: Evaluating the Impact of Patient and Public Involvement in Research.

The following tables provide a list of some of the examples that are already out there. There will be others that are not listed here and it is unlikely that something will fit your research exactly, but that's OK, you can adapt or search for other examples once you have an idea of the kind of resources that others have found helpful and what might be helpful for your project.

Table 1 PPI Planning resources

Resource name	Description	Potential use	Useful links
PPI Monitoring to Learn	NIHR ARC OxTV developed a planning and monitoring resource to help ARC researchers develop and monitor their PPI plans.	All ARC research can be supported to use the Monitoring to Learn resources to develop an appropriate PPI plan and to monitor it throughout the course of the research.	https://www.phc.ox.ac.uk/files/arc-impacts/2026-arc-oxtv-ppi-monitoring-to-learn-documents.docx This resource might also be useful: Monitoring to Learn Tools - PEM Suite
UK Standards for Public Involvement	These are a set of PPI Standards co-designed with the PPI community in the UK. They explore what to aim for in PPI to 'do it well'.	A useful resource that uses questions to help you explore each of the six standards. The standards can be used as a framework to present your PPI plan. A number of funders now expect PPI plans to at least reference the standards.	UK Standards for Public Involvement - The UK Standards
The Four Pi National Involvement Standards	Developed and co-created by the National Survivor User Network. The 'P's reference: • **Principles**: the underlying values of involvement • **Purpose**: defining why people are being involved and specific goals • **Presence**: ensuring the right people are involved • **Process**: defining how involvement happens **'I'** is for Impact of PPI	These standards were developed to support work in PPI in healthcare services and support, especially mental health. They can also be used in healthcare research. There are resources available to support using the 4Pi standards.	https://www.nsun.org.uk/projects/4pi-involvement-standards/
Charter for Public Involvement and Engagement	The Charter sets out best practice for fully embedding public involvement and engagement (PPIE) specifically in public mental health research. It covers definitions, principles, and values as well as information about resources and support.	The charter provides 12 guiding principles for effective public involvement and engagement. They provide a framework to explore PPIE.	https://sphr.nihr.ac.uk/public-involvement/charter-for-public-involvement-and-engagement/

PIRIT (Public Involvement in Research Impact Toolkit)	PIRIT is designed to support researchers in planning and tracking public involvement in research. It includes two main tools: • Planning Tool: A checklist of potential public involvement activities and relevant UK Standards, guiding researchers through the research pathway. • Tracking Tool: A simple spreadsheet to record when and how public contributions occurred, along with what changed and why it matters.	This resource can help you plan your PPI and then track it. It is helpful as it is closely linked to the UK Standards for Public Involvement so can help you to use the standards as a framework for your PPI plan.	PIRIT download form - Marie Curie Research Centre - Cardiff University
Equality Impact Assessment (EqIA)	An Equality Impact Assessment (EqIA) is a systematic approach designed to evaluate how proposed policies, practices, or research activities may affect different groups of people, particularly those with protected characteristics under the Equality Act 2010. The primary goal is to ensure that all individuals have equal access to opportunities and that any potential negative impacts are identified and mitigated.	Doing an EqIA can help with the thinking around developing inclusive PPI. It can help you think about who you should be involving and how you can make the process of involvement inclusive.	Equality Impact Assessment (EqIA) Toolkit | ARC EM

Table 2 PPI Evaluation resources

Resource name	Description	Potential use	Useful links
The Cube	'The Cube' is an evaluation framework that uses a digital tool to support PPI. The framework consists of four questions which allow for sliding scale responses with the addition of contextual text-based comments. 'The Cube' evaluation framework can be used with or without the digital tool.	This resource is useful for evaluating PPI across the course of a research project. It can help to improve PPI during a project. It can be delivered digitally using the digital tool or in person using a flipchart and post it notes.	The Cube Evaluation Framework - for researchers.docx - Google Docs
Impact Log	An impact log is a simple method of recording PPI impacts and outcomes (in real time). There are many examples of this. The example we have provided is from People in Health West of England.	This is a useful resource for basic evaluation and identifying impact of PPI.	Patient and public involvement impact log - ARC West
PPI Monitoring to Learn	See above	The monitoring element of the tool allows you to track progress against plans over time. You can also adjust plans as appropriate.	https://www.phc.ox.ac.uk/files/arc-impacts/2026-arc-oxtv-ppi-monitoring-to-learn-documents.docx
PIRIT (Public Involvement in Research Impact Toolkit)	See above	The tracking tool allows you to track progress against plans over time.	PIRIT download form - Marie Curie Research Centre - Cardiff University

Table 3 Reporting PPI resources

Resource name	Description	Potential use	Useful links
GRIPP2 (Guidance for reporting involvement of patients and the public)	GRIPP2 is guidance for reporting PPI. The aim of GRIPP2 is to improve the quality, transparency of the PPI evidence base to ensure practice is based on best evidence.	Gripp2 is specifically designed to support reporting of PPI by using a co-designed list of items to report on.	GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research | The BMJ
PPI recording tool	The purpose of this tool is to provide researchers with a comprehensive and usable recording checklist to document patient and public involvement in research. The tool was designed by researchers to map on to the GRIPP2 reporting checklist.	This resource is useful to help gather the information needed to use the GRIPP2 framework to report on PPI.	Reporting tools — Nuffield Department of Primary Care Health Sciences, University of Oxford then click on the relevant link.
REPRISE Reporting Tool	This reporting guidance helps researchers reflect on PPI when reporting their Research Priority Setting exercises. The tool has 10 sections for priority setting (context, governance, framework, stakeholders, identification, prioritization, output, evaluation, translation, funding/conflict).	Helps structure writing about PPI in Research Priority Exercises as well as detailing who was involved (patients, carers, professionals), how they were engaged (methods), what priorities emerged, and how these were used.	https://link.springer.com/article/10.1186/s12874-019-0889-3
Monitoring to Learn tools	A co-created agile tool for identifying the right measurements for patient engagement practices. • Learning based on meaningful and measurable metrics • Increased impact of patient engagement initiatives through monitoring and evaluation	This resource can help assess the process, outcome, impact and results of a PPI initiative, activity, or strategy, and then set new goals and objectives for PPI work.	Monitoring to Learn Tools - PEM Suite

	• Exploration of new ways of improving patient engagement processes • Dialogue facilitation between stakeholders • Better decision-making in medicines development, healthcare management and beyond		

Table 4 – Papers and other resources

Resource name	Description	Potential use	Useful links
Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot, Greenhalgh et al 2019	This is a review of different ways of approaching PPI in research – 65 separate examples were reviewed and evaluated using a tool called Canadian Centre for Excellence on Partnerships with Patients and Public (CEPPP). Five types of frameworks were identified; Power Focussed, Priority Setting, Study Focussed, Report Focussed and Partnership Focussed. They are explained in Table 1.	There was limited evidence of transferability of the frameworks, with authors concluding that 'off the shelf' generic frameworks often needed adapting. This paper offers an evidence base of approaches to start from.	https://onlinelibrary.wiley.com/doi/10.1111/hex.12888
Guidance document: Evaluating public involvement in research, Kok et al 2018	This guide assembles four different approaches to evaluating PPI providing summaries and pros and cons for each approach. Two approaches are already described in Table 1, Impact Log and Cube. Public Involvement Impact Assessment Framework (PiiAF) and Realist Evaluation are not.	Each example benefits from a context section, what the approach comprises (methods and tools) and how it can be used. Authors helpfully describe Key Points relating to each approach helping users to decide which one to use, or not.	https://uwe-repository.worktribe.com/output/866884/guidance-document-evaluating-public-involvement-in-research
Measuring impacts of patient and public involvement and engagement (PPIE): a narrative review synthesis of review evidence, Lammons etc al, 2025	This review collected and reviewed 27 published accounts of impact and PPI, covering UK, US, Canada, and Australia. Authors found that reporting on impact in PPI was variable. The considered four types of impacts: on people (patients, researchers	Before deciding how to approach measuring impact in PPI this review provides a helpful overview that is evidence based. Table 4 provides summary information of all the included studies. Authors invite readers to use their four	https://link.springer.com/article/10.1186/s40900-025-00748-6

	etc); different phases of the research; services and systems in research; and the PPI itself. They report positive and negative impacts.	categories to consider impact in PPI.	

Appendix IV: PPI Monitoring to Learn review summaries

Review Reference Number	Type of review	Page number
Review 1	Project	38
Review 2	Project	39
Review 3	Project	40
Review 4	Project	41
Review 5	Project	43
Review 6	Project	44
Review 7	Project	45
Review 8	Project	46
Review 9	Project	47
Review 10	Project	48
Review 11	Project	50
Review 12	Theme	51
Review 13	Theme	52
Review 14	Theme	53
Review 15	Theme	54
Review 16	Theme	55

NOTE: Theme level reviews are, in the main, from a PPI Champion Perspective

Project title	ACT-UP – a randomised trial for gestational diabetes (GD) and REMIND – the annual check-up after birth.
Reference	Review 1
Academics/Researchers	Associate Professor Nerys Astbury
Project description	ACT UP is a trial for gestational diabetes and REMIND is an annual diabetes check-up after birth. ELOPE was a longer term study used to provide information on managing gestational diabetes and support to women affected by it. The project was community based in Tower Hamlets and designed so that mothers could bring children and attend at a convenient time for them. Participants were diverse, and included black and Asian mothers. The women were looking for greater support in managing their diabetes risk. The idea is to create a 'passport' which the gestational diabetes patient takes to primary care, after discharge from the hospital, and has periodic well-mum checks. Uptake for well-mum checks is currently low. A wide gap was noted between what should happen and what does happen.
Patient Public Involvement (PPI) in the project:	ACT-UP recruitment came from Art through Medicine, a project in collaboration with the Welcome Trust. 20 women with Gestational Diabetes, plus researchers, created art to explain Gestational Diabetes. The group were able to suggest ways to communicate to help with the uptake of check-ups. It was challenging to do innovative PPI as it can be expensive. The best way to reach underserved groups is to go into the community, not only on 'working' days and times. Stigma in some communities can take time to overcome. There is never a tidy border around PPI – it has to be fluid, flexible and responsive to needs.
Key messages	• This project and its PPI focussed on improving accessibility to knowledge about GD in marginalised communities. • It also used art as a vehicle for communicating about GD, rooted in the community. • PPI needs to be fluid and flexible.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Communications
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion; Strengthening partnerships

Project title	DAPHNY study
Reference	Review 2
Academics/Researchers	Dr Lucy Goddard
Project description	App based around clients with high blood pressure in high risk pregnancies looking at diet and activity. The stakeholders: Action on Preeclampsia (a charity), women, pregnant women, obstetricians, midwives, community midwives and support workers.
Patient Public Involvement (PPI) in the project:	Recruitment was via an online platform and face-to-face in clinical settings (most productive) and used questionnaires. The PPI planned at the outset included on-line surveys and in-person discussions, group meetings and involvement throughout. The PPI undertaken was mainly as planned, making sure that there was constant communication so that the public contributors did not feel side-lined at any point. This worked well and they continue to work with the lead researcher on current projects. This success is put down to good communication, explaining what is going on especially re delays i.e. keeping them in the loop so they do not feel abandoned and did feel valued, proper payment for their time and a good selection process at the outset so they would be well motivated, understand the concept, and are keen to contribute. The PPI had limited influence in the project due to the nature of the study but it did keep the lead researcher grounded. The contributors did come up with facts and ideas that had not been thought of, and offered a different perspective. The impact and value have been captured in the thesis, a published manuscript and the NIHR report. PPI challenges included project delays (but kept communicating), technical glitches or restrictions (e.g. internal security issues), people with limited IT skills, the level of feedback being low. Where there are differing views, occasionally professional perspectives are more pragmatic. Important learnings included: Getting the right payments to people so they do not jeopardise any benefits thresholds. Quick and informal information gathering which did not need emails/Teams but would be just a very quick reference (maybe pay for a couple of hours ad hoc communication which includes 'quickies'). Ensuring those involved understand research from the outset.
Key messages	• Whilst PPI did not influence the study, it seemed to influence the researcher – keeping her 'grounded', and providing a sounding board and context. • A need identified in this study was the challenge of educating people about research. • Getting the process and approach right is important.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Impact
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion; Feedback; Strengthening capacity and capability

Project title	Keep on moving: A mixed-methods development of a monitoring tool to detect decline from changes in regular activity in older adults with multiple long-term conditions.
Reference	Review 3
Academics/Researchers Involved	Ishbel Henderson
Project description	Noting changes in physical activity in order to determine physical and cognitive decline in older adults by using technology, designed around their needs, to measure this. Key Stakeholders: Patients, carers, healthcare professionals and it would have been better to include policy-makers.
Patient Public Involvement (PPI) in the project:	The PPI plan was to review and get feedback on questions to be asked as well as to ensure phraseology was used correctly (eg differentiating between functional decline and changes in ability to carry out an activity). It went as intended but slightly less formally, using the 'think aloud' technique in interviews (ie informal response to questions) before formalising questions. Helpful as feedback on the little things like use of emojis and also carer recruitment. PPI was useful for trial interviews so as to get the order and phrasing of the questions right for the target audience. Also to add in questions which were missed out. PPI helped with practise interviews and with respect to the use of the technology. Recruited approximately ten public contributors via conferences for older people and useful technology (in Oxford). Therefore, didn't use the same PPI members consistently so relationships that might have been built perhaps weren't but differing perspectives useful. Used different public contributors for different parts of the project. This was due to poor planning which may be an area to improve upon. Lots of training in how to use PPI from the department - PPI at first seemed complicated, but everyone in the department and the university were supportive and helpful. There was plenty budget and enough time to cope with the PPI demands. Although was no formal PPI evaluation undertaken the changes PPI influenced were included in the write up of the research. They are considering a reflection on PPI at the end of the report.
Key messages	• Direction of research and interview focus slightly changed for the better as a result of PPI feedback, as well as smaller things such as dyslexic mistakes and the question flow so as to use interview time better. • It was a more iterative, natural process than they had initially thought, this was a relief as the seeming formality was daunting.
UK Standards for Public Involvement	This project evidenced: Working together; Support and Learning; Impact
NIHR PPI Strategic Commitments	This project contributed to: Feedback; Strengthening capacity and capability

Project title	FORUM Implementation
Reference	Review 4
Academics/Researchers Involved (name/s, title/s)	Howard Ryland Prof Seena Fazel
Project description	The FORUM implementation was designed to improve measurement of forensic mental health outcomes. This is done by comparing responses over time of both the patient and clinician, and discussing if and how they compare to inform care planning. It is now incorporated into True Colours, an Oxford Health platform that links to the electronic patient record. The key stakeholders were patients, carers, clinical staff, nurses, social workers and support workers. NHS England, as the commissioners of forensic mental health services, were also involved, because they have a longstanding interest in using outcome measures, which form part of a dashboard to measure service quality.
Patient Public Involvement (PPI) in the project:	Patient Public Involvement (PPI) was used to co-design the study. Public contributors were kept informed throughout the process and one person co-authored a paper. PPI has made a difference at all stages but specific impact included developing the topic guide for the patient and clinician interviews, and refining the FORUM questionnaire, including item selection and wording, response options, instructions and overall presentation. The FORUM was co-designed through one-to-one interviews and focus groups including both patients and carers. There was no starting point for what outcomes were important, which were identified by analysing participant feedback. A PPI group was set up from scratch. The plan was for a group of five. Membership has changed over time (ten in total). They were recruited via the Royal College of Psychiatrists, Rethink, McPin and word of mouth. There were ten in-person meetings lasting up to half a day, in addition to some online meetings. The group are regularly asked for feedback about how they are working. The group have received training and suggested diversifying those involved. Originally there was limited funding for PPI, but additional funding was secured from different sources. PPI advice and support was provided via an ARC experienced public contributor. A key insight is that changes to the planned contributors have involved natural turnover of original members, often replaced by people, widening the diversity of the group. The group and researcher are continuing to work together and are discussing future projects.

Key messages	• PPI made the output of the study more user friendly (a tool for measuring progress in forensic mental health services). • The project adapted and flexed for different PPI contributions and incoming funds. • An experienced public contributor supported the ongoing development of the PPI plan. • PPI was developed from scratch and has been iterative. • As PPI was involved from the early stages it has made a difference in all stages of the project.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Communications; Impact
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion; Strengthening partnerships, Feedback; Strengthening capacity and capability
Further information	www.forensicoutcomemeasure.com https://innovation.ox.ac.uk/outcome-measures/the-forensic-outcome-measure/

Project title	Barriers and facilitators to seeing and accessing professional mental health support among Indian and Filipino health and social care workers in England: Qualitative interview study
Reference	Review 5
Academics/Researchers	Jasmine Laing
Project description	The study focuses on exploring barriers and facilitators that may prevent or allow health and social care workers from Indian and Filipino ethnic backgrounds in England to seek and access professional mental support services. All PPIE representatives worked in NHS health and social care services and/or mental health research in England. Four of the five members identified as Indian or Filipino. All five members were involved throughout the study.
Patient Public Involvement (PPI) in the project:	Patient Public Involvement (PPI) planned was to be involved at all stages. The ARC awarded a £1200 grant. A group of five contributors were recruited and six meetings planned. Seven meetings took place. Changes to the planned PPI have included meeting with some individuals separately rather than always as a group. The challenges included involvement of the quieter members and budgetary constraints. PPI has assisted with the design of the study, reviewing the ethical and protocol applications, feedback on documents aimed at patients and recruitment. They will also be involved with future data analysis and dissemination of the study. PPI support from the ARC OxTV was helpful re planning meetings, payments and how to involve PPI and how to go about this generally as someone who was new to using PPI. PPI has helped greatly with confidence in running the study sensitively and with asking the right questions. PPI has helped a lot with recruitment. PPI impact has been captured through an impact log. Key learnings are that a larger budget would have been better, smaller meetings to ensure everyone's voice is heard and some in-person meetings or make it mandatory to have cameras on.
Key messages	• Flexibility (with meetings and interactions) with stakeholders enabled influence on the study design and documents. • The support given for PPI from the ARC was valued and maximised use of PPI and resources. • Developed PPI skills/knowledge. • PPI Expert support was helpful.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Communications; Governance
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion, Improve Reward and recognition; Strengthening capacity and capability

Project title	Developing Novel Methods to Capture Health and Well-Being Outcomes of Community-Based Support: Testing Moodscope with Vulnerable Families
Reference	Review 6
Academics/Researchers	Mary Zacaroli (Public co-lead) Dr Caroline Potter (Senior Researcher)
Project description	This project explored the use of Moodscope – a mood-tracking tool – to measure the impact of community-based activities on health and wellbeing. The key stakeholders included Mary Zacaroli, Dr Caroline Potter, Children Heard and Seen (CHAS – charity), participating parents/carers, Moodscope and ARC (OxTV) who funded the project.
Patient Public Involvement (PPI) in the project:	The idea was conceived by an ARC public contributor who partnered with an experienced researcher to secure funding for the pilot project. They worked closely with a local organisation and Moodscope allowed the project to use some of its resource. Feedback was sought from partners on the research questions and ethical guidelines. Parents were briefed on the activities. Partners were able to decide how/if to share Moodscope data and how the information would be collated. The main challenges were with accessing ethics training and using the software (Nvivo) for the public co-lead. Payment processes were also challenging due to administrative difficulties. Key learnings were about running a project where a co-lead is a public contributor.
Key messages	• This project was conceived by a public contributor, with the charity partner choosing the activities to do. • Projects initiated and led by public contributors can struggle with access to tools and training to help facilitate the project. • Consistent involvement of the same PPI Champion in a particular theme facilitated a public contributor's idea becoming a funded project.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Communications; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion; Strengthening partnerships, Feedback; Strengthening capacity and capability
Further information	https://www.arc-oxtv.nihr.ac.uk/research/TestingMoodscope

Project title	SARAH
Reference	Review 7
Academics/Researchers	Esther Williamson (PI for implementation work) Professor sally Lamb (PI for trial) Cynthia Srikesavan
Project description	SARAH is a project that has been running since 2009. It is a programme of work developing hand exercises for people with rheumatoid arthritis. The key stakeholders were patients with RA, clinicians, NHS managers and commissioners.
Patient Public Involvement (PPI) in the project:	The Patient and public Involvement (PPI) started with the study in 2009. The clinical team developed the programme with only one patient's input. In 2014 implementation began. PPI was more integrated with the implementation than the trial. The National Rheumatoid Arthritis Society's local group helped form a PPI group. This group helped develop training, an implementation study, and the patient course. They were involved in videos demonstrating exercises and gave the study credibility. The challenges have included making the study more diverse and focussed on including underserved communities. It will be more broadly rolled out within the NHS and patient feedback will be sought and incorporated. Key insights include how PPI can grow during the course of a long programme of work. PPI was essential for the patient course to ensure it was suitable. Need to think more about how to include underserved communities.
Key messages	• This example of PPI concerns an implementation project whereby PPI was instrumental in refining and testing the programme for rollout in the NHS. • PPI seemed to help the 'middle man' element of ensuring that an intervention is refined for patients and health professionals alike.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Impact
NIHR PPI Strategic Commitments	This project contributed to: Strengthening partnerships, Feedback; Strengthening capacity and capability

Project title	MMOST Maximising Mobility and Strength Training
Reference	Review 8
Academics/Researchers	Esther Williamson (Esther Williamson) Alana Morris (Study manager)
Project description	MMOST was a feasibility study seeing if it was possible to run a study looking at the benefits of protein supplements taken alongside exercise for older, frail people with walking problems and a low protein intake. All participants got the exercise and half of them got the supplements. The key stakeholders were older people, dieticians, clinicians involved with frail, older people and a food manufacturer, which provided the supplements.
Patient Public Involvement (PPI) in the project:	The Patient Public involvement during the study, which lasted from March 2022 to August 2024, involved a group the project lead had previously worked with and they recruited through other avenues. The PPI group had six public contributors, one who became the lead contributor and a co-applicant on the grant. The lead contributor attended monthly study management meetings and was an active contributor to these meetings. The team have highlighted the need to increase diversity in the PPI group. The PPI group met every six months, as planned. They looked at the feasibility study design. They suggested changes to the plans to make the study more acceptable to participants. They also helped with revising the recruitment strategy. One contributor helped re-write the explanatory leaflet for the patients. They have captured PPI impact in the report of the project. The plan is to continue working as a group to develop a main trial.
Key messages	• PPI in this project was effective at changing study parameters and was broad, deep, and integrated. • The objective of a feasibility study was met and a full trial is being developed with PPI.
UK Standards for Public Involvement	This project evidenced: Working together; Communications; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion, Strengthening partnerships, Strengthening capacity and capability

Project title	BLOod Test Trend for cancEr Detection (BLOTTED)
Reference	Review 9
Academics/Researchers	Sufen
Project description	The BLOod Test Trend for cancEr Detection (BLOTTED) project is a nation-wide study using blood tests to predict cancer risk by building an algorithm which can be used by GPs. Key stakeholders are patients with electronic patient records at risk of cancer, and their GPs. Influence in the study is hard to determine as it is anonymous and part of a huge (27 million) study.
Patient Public Involvement (PPI) in the project:	The Patient Public Involvement (PPI) planned and carried out involved: recruiting a cancer patient panel and hearing their views on the idea and methodology of the project. It was part of the on-going national study and included updating findings, two meetings a year and PPI inclusion at conferences. There were five PPI sessions over the two years involving approximately 70 people. The focus was on discovering whether they felt there might be a better way of implementing the work. Finding the optimum number of times blood tests could be carried out and how they felt about the application of this study. As a result of the PPI the researcher felt there could be more monitoring of specific indices in the blood so as to get a fuller picture. Challenges to public involvement were few as this was set up nationally with local help from a patient involvement professional. PPI contributors included individuals with personal experience of cancer, which enriched discussions around early detection and risk prediction. However, as the group was not intended to be fully representative of the general population, future engagement could include a wider demographic mix to reflect perspectives from those without prior cancer experience.
Key messages	• As the intended application of the model is within general primary care, it is important to note that the PPI group was weighted towards individuals with cancer experience. Future involvement could incorporate a broader primary care population to ensure views reflect the full implementation context. • PPI in ethical discussions, especially in big data and algorithmic projects, is important and helpful.
UK Standards for Public Involvement	This project evidenced: Working together; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Strengthening partnerships, strengthening capacity and capability

Project title	Digital Guided Self-Help for Binge Eating: Devising an Effectiveness Study
Reference	Review 10
Academics/Researchers	Dr Rebecca Murphy
Project description	The project is evaluating a novel digital treatment programme, delivered entirely via smartphone and website. It is a programme-led intervention, meaning all therapeutic content and expertise are embedded within the programme rather than delivered by a specialist therapist. This project is a five- to six-year project that began in 2021 and is expected to be completed in 2026/27. The central component is a randomised feasibility-controlled trial. Recruitment is around 40% complete. Early feedback from participants has been positive, especially regarding the accessibility and usability of the digital programme and the value of guided support. A qualitative study has also been completed and published as part of this project. This provided insights into stakeholder perspectives and informed refinements to the design of any future randomised control trial. The key stakeholders were people with lived experience of binge eating, family members and significant others, and healthcare professionals who specialise in eating disorders. In addition, primary care practitioners, commissioners, and service managers, have been engaged to help to assess feasibility, scalability and alignment with NHS service delivery and resource priorities.
Patient Public Involvement (PPI) in the project:	Patient Public Involvement (PPI) has been embedded throughout the project, including the application stage, and has shaped several key aspects of the design and delivery. The PPI structure includes: • A core PPI group of around ten contributors (primarily white women), including individuals with lived experience and family members. • A separate “inclusivity” PPI group (three members) formed to improve representation from marginalised faith-based communities and minoritised ethnic groups. • A one-off young people’s advisory group (aged 16–20 years, without lived experience of eating disorders) to advise on accessibility and engagement. • A wider contributor network of approximately 300 individuals with lived or professional experience of eating disorders, who are consulted on an ad hoc basis. The groups meet online. The main group has met seven times; the inclusivity and young people groups have met once each.

	Public contributors shaped the consent process and the participant information sheets for the feasibility randomised controlled trial and the qualitative research study. Additionally, they helped shape the feasibility study design, helped define the outcome measures and developed the topic guide for interviews. PPI has improved the relevance, design and dissemination of the research and therefore its quality. In addition, the project lead is now engaging with experts by experience in other aspects of her work (e.g., teaching and training). The challenges have included navigating Covid when meetings went from in-person to on-line and recruitment of a separate inclusivity group. Given the sensitivity of binge eating, the project lead has paid careful attention to ensuring that involvement is supportive and meaningful, and not triggering. Contributors have reported positive experiences of participation. PPI support and help was from the department, the Research Design Service and from a training event on PPI. The PPI budget was sufficient A key learning has been that PPI is even more valuable than initially thought. Planned PPI is to involve members in writing and reviewing research papers and include members in conference presentations as well as having public co-applicants on future research projects. In the future, a large scale trial to test the programmes clinical and cost effectiveness is planned.
Key messages	• PPI in this project was broad, deep, and impactful on study design and more useful than the researcher initially thought. • PPI will continue as the project goes forward in writing papers, conference presentations, and training. • Being alert to potential sensitives or triggering situations.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Strengthening capacity and capability

Project title	DEM - COMM
Reference	Review 11
Academics/Researchers Involved	Padraig Dixon
Project description	The first part of The DEM-COMM project has been completed. The project works exclusively with existing or new data and has used existing data to access cost and quality of life for people with dementia. There are several ideas for new research activity focusing on use of data.
Patient Public Involvement (PPI) in the project:	In the initial project PPI was not considered. Although they have done PPI before in other projects they did not think it was appropriate in this work. This was a *data analysis* research project so options for PPI seemed limited. It was interesting, however, how the results 'landed' with the PPI Champion doing the interview (as a carer for someone with dementia). There was possibly a missed opportunity to reflect on the results with those with lived experience. They were very interested in the possibilities of PPI and discussed this in relation to the new research ideas. They will consider PPI for future projects.
Key messages	• Even in data driven projects it can be an option to reflect on the results with people affected by dementia. • Such activities can be added this as a reflective piece to the research. • The Monitoring to Learn interview stimulated a conversation about PPI in big data research.
UK Standards for Public Involvement	
NIHR PPI Strategic Commitments	

Theme Level report	**Reference:** Review 12
Patient Public Involvement (PPI) in the theme:	The Theme embraced PPI positively, finding it both useful and rewarding. Barriers to using PPI have typically focussed on: • a time issue (is the time invested in recruiting, briefing public contributors worth the pay-off?) • an influence issue (the PPI input will not change the project findings very much, so how can we ask people to give up their time as public contributors where their impact is minimal or zero?) • or a combination of both. Considerations such as these are weighed in advance. One idea to counter the second barrier would be to describe up-front to the public contributor the likely impact of their contribution and let them decide if this is a stumbling-block or not. Examples of levels of PPI use can vary from a couple of 'experienced' public contributors through to larger groups of people from backgrounds where their opinions are rarely asked for. Contributions from the contributors ranged from re-phrasing questionnaires (often to de-medicalise terms) through to suggesting that the public may perceive some interventions to be scams unless otherwise reassured. All useful feedback was incorporated into the projects and helped them work better, were 'less clunky' in operation and with fewer errors. Study recruitment was also improved. PPI seems to follow a 'U' shape throughout the duration of a project. Initially, there is quite a high level of input, when the project is up-and-running this tails off to very little or nothing and, as the project comes to an end, involvement peaks again. Mostly, this is the nature of how things work, although touching base with the in the middle section might yield useful gains.
Key messages	• The need for transparency about what is possible for individuals/communities to make their own decision about getting involved. • Are there useful ways to continue involvement/connections during the middle of projects?
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Impact
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion

Theme Level report	**Reference:** Review 13
Patient Public Involvement (PPI) in the theme:	• The PPI Champion(s) had an introductory session with the Theme Lead. • The PPI Champion brought national experience of PPI which was valued by the Theme. • The PPI Champion was always invited to the Theme meetings, which were set in advance. • PPI was always on the Theme meeting agendas but it was a bit unclear what the purpose of this was – to inform the Theme about what was going on in the world of PPI, discus project or theme PPI? • There was PPI in all the projects within the Theme – what this looked like varied from project to project but did include those who tend to be less involved in research and built relationships with stakeholders. • The PPI Champion was invited to get involved in other research – the choice about whether to engage was personal. • There were opportunities to contribute to decision making eg recruitment, suggestions about additional research. • Whilst the PPI Champion contribution was valued it tended to only get discussed if raised by them, for example in presentations about projects it was rare to see PPI included. • As with all the Themes there was no opportunity for the PPI Champion to influence the research programme for the Theme as they were recruited to the role after the work had been agreed. • The original PPI Champion for this theme later went on to become a PPI Lead for the ARC.
Key messages	• An introduction and close working relationship with the Theme lead was important to the ability to contribute. • Encouraging researchers (especially early career researchers and PhDs) to automatically report on PPI in presentations would help to ingrain this practice. • Researchers value the PPI expert experience. • Providing public contributors to build their own knowledge and experience can support personal development.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Communications; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion, Strengthening partnerships, Strengthening capacity and capability

Theme Level report	**Reference:** Review 14
Patient Public Involvement (PPI) in the theme:	• The original PPI Champion had an 'email' welcome but no other introduction. • There was a willingness to build relationships with the PPI Champion from the deputy theme lead but not really anyone else at the beginning. This was during Covid and included the move to online meetings alongside this people were also 'feeling' their way into new roles. • The PPI Champions role was not clear from the outset. • There was, however, positive feedback on their contribution. • The PPI Champion suggested that Theme members should talk about their PPI and going forward PPI was added to the agenda for meetings but this was more about what was happening in PPI in the ARC rather than about Theme project PPI. • PPI was not intrinsically discussed or included in project discussions unless raised by the PPI Champions. • The original PPI Champion supported the integration of the second PPI Champion into the Theme. • There were a couple of occasions when the PPI Champions were invited to contribute to a project. • The community links of the PPI Champions was seen and valued by the Theme. • There was no involvement in wider Theme decision making to begin with, but this changed in terms of planning meetings towards the end of the ARC. • The PPI Champion did work with a Theme researcher to develop a project and get it funded.
Key messages	• Roles need to be clear. • At a Theme level involvement in wider decision making activity is essential for meaningful involvement. • The opportunity for consistent involvement and to build relationships can lead to positive outcomes. • Researchers value the community knowledge and links public contributors can bring.
UK Standards for Public Involvement	This project evidenced: Inclusive Opportunities; Working together; Support and Learning; Communications; Impact
NIHR PPI Strategic Commitments	This project contributed to: Embedding research inclusion, Strengthening partnerships, Feedback; Strengthening capacity and capability

Theme Level report	**Reference:** Review 15
Patient Public Involvement (PPI) in the theme:	• The Theme was already set up and working together before the PPI Champion joined the group. • They came as someone experienced in PPI and also in the Theme focus but still found it difficult to become embedded in the group/work. • They have over the course of the ARC been able to contribute to individual and Theme related work/projects.
Key messages	• Regardless of experience levels, when public contributors 'join' after everyone else there needs to be special attention paid to integration. • Public contributors want to be able to engage with research that is of interest to them.
UK Standards for Public Involvement	This project evidenced: Working together; Impact
NIHR PPI Strategic Commitments	

Theme Level report	**Reference:** Review 16
Patient Public Involvement (PPI) in the project:	• PPI Champions joined this Theme after the ARC PPI review in 2022. • These were very experienced and confident public contributors who could use their skills and strengths to build effective working relationships within the Theme. • Accessing online meetings was not always easy due to the platform being used. • The original PPI Champion was encouraged and financially supported to take active steps to learn about the focus of the Theme including independent learning and external meetings. • The PPI Champion had experience of facilitation and coaching and developed and delivered workshops to support the theme to explore PPI in their specific context. • The PPI Monitoring to Learn process provided a structured way for the PPI Champion to really engage with Theme researchers about their PPI experience. • Limited PPI but curiosity and some knowledge and/or experience. • The process provided opportunities for the PPI Champion(s) to provide structured opportunities to discuss PPI (workshops and PPI Surgeries). • Monthly PPI 'surgeries' organised by the experienced PPI Champions provided a sounding board for research ideas and hypotheses, researchers refining research questions, parameters, research design, information, and recruitment. • There were other opportunities to be involved with progressing research ideas and projects.
Key messages	• Review and reflection on PPI in 2022 led to a positive change in direction. • Providing public contributors with autonomy (within limits) can enable and facilitate meaningful involvement. • PPI Monitoring to Learn can help create a safe space to explore PPI. • The Monitoring to Learn interviews stimulated a wider conversation about PPI in data and methodological research. • PPI Monitoring to learn facilitated learning opportunities for researchers. • There is enormous value in involving highly experienced public contributors in Theme level activities. • Researchers valued the sensitivity and proactive nature of the PPI Champions. • Where there was limited PPI, there was researcher curiosity and some PPI knowledge and experience to build from.
UK Standards for Public Involvement	This project evidenced: Working together; Support and Learning; Communications; Impact; Governance
NIHR PPI Strategic Commitments	This project contributed to: Strengthening partnerships, Improve Reward and Recognition; Strengthening capacity and capability

Appendix V: UK Standards for Public Involvement



UK Standards *for* Public Involvement

Better public involvement for better health and social care research

INCLUSIVE OPPORTUNITIES
Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

WORKING TOGETHER
Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

SUPPORT AND LEARNING
Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

COMMUNICATIONS
Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

IMPACT
Seek improvement by identifying and sharing the difference that public involvement makes to research.

GOVERNANCE
Involve the public in research management, regulation, leadership and decision making.

NIHR | National Institute for Health Research · CHIEF SCIENTIST OFFICE · Ymchwil Iechyd a Gofal Cymru Health and Care Research Wales · HSC Public Health Agency

Reference: UK Standards for Public Involvement

Appendix VI: NIHR PPI Strategic Commitments

1. Embed research inclusion

Make sustained progress in widening research participation, embedding research inclusion and increasing the diversity of the public and communities who participate in, shape and deliver research.

Priorities:

- ensure that studies and trials have inclusive designs, so that recruitment reflects the diversity of the populations they are intended to benefit
- increase the diversity of public contributors working with the NIHR, including those from groups which are underrepresented on committees and advisory groups, building on existing learning
- develop and embed consistent support arrangements, aligning with the NIHR Research Inclusion Strategy, so that a more diverse range of public contributors experience inclusion
- make it easier for people to access opportunities to be involved through improvements to NIHR's digital channels
- ensure all these improvements are underpinned by data, in line with NIHR's broader Research Inclusion Strategy

2. Strengthen partnerships

Strengthen and grow mutually beneficial partnerships between researchers and communities, and their community-based organisations, to better reflect the diversity of the population.

Priorities:

- increase funding for pre-application researcher-community partnership building and ensure that this is easily accessed by charities and community groups
- build on current best practice to strengthen and join up NIHR's engagement with communities, in ways that work for them, collaborating with statutory agencies and the voluntary and community sector
- fund and grow targeted partnerships with people and communities who face the most deprivation, experience inequalities or have the worst health outcomes, and with relevant voluntary and community sector organisations
- ensure those who undertake and support research have access to training on community engagement and guidance on how to report on it

3. Improve reward and recognition

Make systems of reward and recognition for the involvement of people and communities more equitable, efficient and consistent across NIHR coordinating centres, infrastructure and research.

Priorities:

- establish a minimum set of requirements for reward and recognition that embed consistency across academic, NHS, and other sites
- review NIHR payment rates
- strengthen requirements for organisations with NIHR funding to have systems that consistently enable easy and quick payments for diverse public contributors
- ensure community organisations receive appropriate and timely recognition and remuneration

4. Require feedback

In response to consistent demands from patients and the public, require those who commission, undertake and support research to provide feedback to the public and communities on their contributions.

Priorities:

- clarify and strengthen NIHR's expectation that members of the public shaping research receive accessible and inclusive feedback on the research progress and outcomes, and on the impact their contributions made
- clarify and strengthen NIHR's expectation that research teams must feedback study and trial results to participants in accessible and inclusive ways
- improve reporting of public partnerships in NIHR-funded activities and research to capture and share best practice and identify what does and does not work

5. Strengthen capacity and capability

Improve access to evidence, materials, training and peer support so that research teams can conduct effective and meaningful public partnerships.

Priorities:

- work with partners (in health and care research, delivery, and the voluntary and community sector) to provide resources and support for public contributors and the public partnerships workforce to strengthen shared learning and peer support
- invest in and develop the 'Learning for Involvement' website as the primary destination for resources, good practice and fora to support public partnerships learning and development
- clarify and strengthen NIHR's expectation that people who commission, undertake and support NIHR-funded research will complete induction and training in involving and engaging the public and communities
- provide guidance and training on public partnerships for early career researchers

Reference: Improving how we partner with patients, carers and the public | NIHR