GUIDANCE DOCUMENT:
Evaluating public involvement in research

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I. Introduction

Public involvement (PI) in research has been steadily advancing in recent years. It has therefore, become increasingly important to evaluate PI in research to:

- improve the quality of PI, and hence the quality of research
- evidence the impact of PI and encourage stakeholders to commit to having PI in research
- justify funding and other resources for PI, especially in times of financial constraint
- inform members of the public of the difference that they have made
- facilitate planning for future projects, e.g. taking steps to avoid harm or limitations

It is possible to evaluate both the *process* and *impact* of PI to achieve these objectives. The approaches to evaluating PI in research are wide-ranging, from simple to in-depth, depending on the level of robustness required i.e. greater robustness requires a more in-depth approach.

This guidance document will present and discuss four approaches to evaluating PI. Figure 1 provides brief descriptions of each approach to help you select the one that is most appropriate for your research.

Figure 1: Approaches to evaluating PI in research

Impact log	'Cube' framework	Public Involvement Impact Assessment Framework (PiiAF)	Realist evaluation
• A simple method of recording outcomes of PI in research • Useful for basic evaluation of the impact of PI	• Used to evaluate the process or quality of PI • Particularly useful when immediate results are needed, e.g. to identify areas of concern and take remedial action	• A two-part planning tool or problem-solving mechanism • Part I: planning PI in a research project • Part II: designing a plan to evaluate the impact of PI • Comprehensive method, requiring more time to execute	• Identifies what works for whom (*outcome*) in what circumstances and in what respects (*context*), and how (*mechanism*) • Complex, but useful when it is important to understand the factors shaping the impact of PI

The term 'public' used in this document includes patients (past, current, and potential patients), carers, parents/guardians, and people who use health and social care services (or the organisations that represent them).

This guide to evaluating PI is primarily for principal investigators, research team members, and public contributors.

II. Impact log to record the outcomes of PI

Proper documentation of the various PI activities carried out during the course of research is useful for monitoring and evaluating PI. Table 1 shows how the outcomes of PI can be recorded in an impact log. In cases where PI consultations are conducted via email instead of a face-to-face meeting, you may prefer to record the start and end dates as it may take several days for the outcome to become apparent.

This simple log, however, does not necessarily constitute an 'evaluation'. A realist evaluation, described in section IV, may be more appropriate if you require a more robust evaluation of the impact of PI. Whichever method you choose, evaluating the impact of PI in research is important, not only to contribute to the PI evidence base but also for reporting to research funders, and patient and public contributors.

Table 1: Example of a research project impact log for PI

Date	Attendees	Discussion	Impact (Outcomes)	Other comments
dd/mm/yy	Prof. AB Prof. CD Mrs. EF Mr. GH Mr. IJ KL MN Apologies: Mrs. ZY Mr. XW Mr. VU	The existing *[project name]* questionnaire was made available and patient panel members were asked to rate each question based on how important/relevant the issue was to them. Patient panel members were invited to provide their responses anonymously if preferred. The panel was also asked to comment on the domains or themes each question related to. Comments were gathered from the panel.	[From notes of dd/mm/yy] There was some discussion on why certain questions deemed "definitely important" in this patient panel exercise were not included in the final questionnaire, whilst others voted only "quite important" were instead used. CD explained that psychometric and statistical analysis helped to distinguish what questions performed most effectively. This information was used alongside the panel input to decide on which questions to take forward. These results were then used to refine the questionnaire for the next cycle, and help make a decision on which questions to put forward for the final version of the questionnaire.	Copies of the draft questionnaires before and after the panel meetings as evidence of the impact of the panel's contribution.

III. The 'cube' framework for PI process evaluation

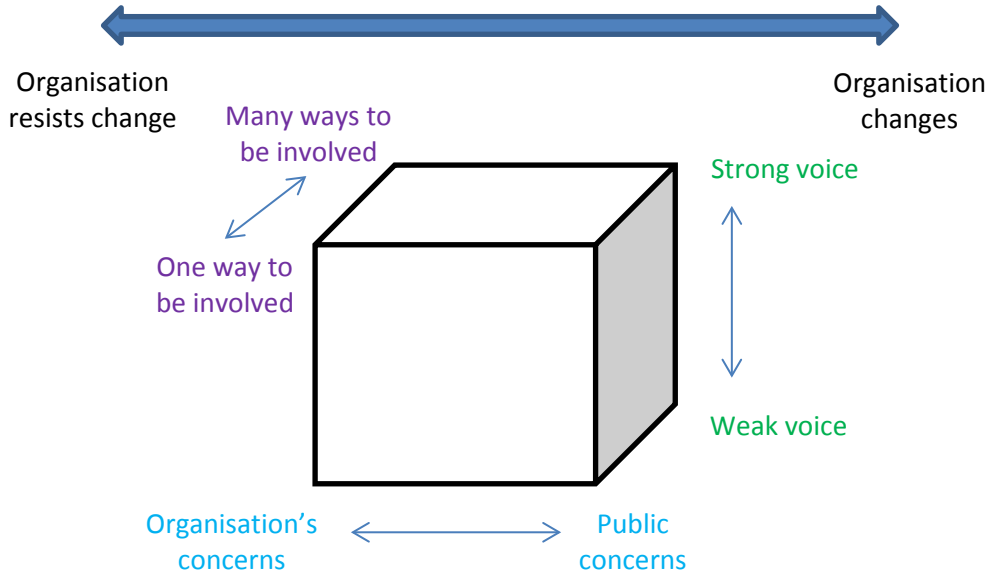
PI is variable and highly dependent on context i.e. the environment in which PI is undertaken, that may include funding, policy, physical environment and the attitude of those involved (Staley, 2015; Brett *et al.*, 2014). Staley (2017) suggests that it is helpful to think of PI as a *conversation*, where the exchange of ideas, values, assumptions and experiences that takes place between researchers and the public. This exchange or interaction of different forms of knowledge (public, professional or scientific) has also been termed a *knowledge space* (Elliott and Williams, 2008).

Gibson *et al.* (2017) developed a theoretical model to describe the four fundamental elements for successful knowledge exchange, taking into account the dynamic and fluid nature of interactions within knowledge spaces. The four dimensions of the framework are described in Table 1 and illustrated in Figure 2.

Table 2: The four key dimensions of a knowledge space (Gibson *et al.*, 2017)

i.	Weak voice or strong voice	Strong voices discuss issues and influence decision-making. Weak voices may discuss issues, but have little influence on decision-making.
ii.	One way to be involved or many ways to be involved	Knowledge can take on different forms, which may not be equally valued. A single involvement approach is likely to privilege one social/cultural group over another, thus perpetuating inequality.
iii.	Organisation's concerns or public concerns	Public concerns are in the context of social action, e.g. public opinion, norms and values, as well as individual experiences and behaviours. Organisation's concerns are, e.g. bureaucracies and markets.
iv.	Organisation changes or organisation resists change	Decision-makers' willingness and ability to respond to issues raised by participants in knowledge spaces depend on contextual factors, e.g. economic resources and national policies.

Figure 2: The four-dimensional 'cube' depicting a knowledge space (Gibson *et al.*, 2017)

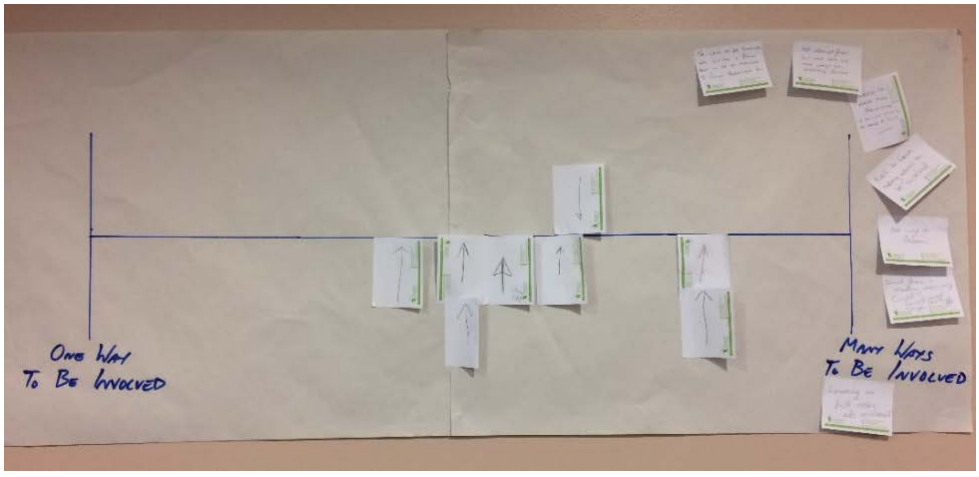


The ‘cube’ framework can be used both as a useful tool for planning PI and to evaluate the process of PI in research. To use the framework for PI process evaluation, members of a PI group will be required to participate in a workshop with the format as laid out in Table 3.

Table 3: Proposed workshop format to evaluate PI using the ‘cube’ framework (Gibson *et al.*, 2017)

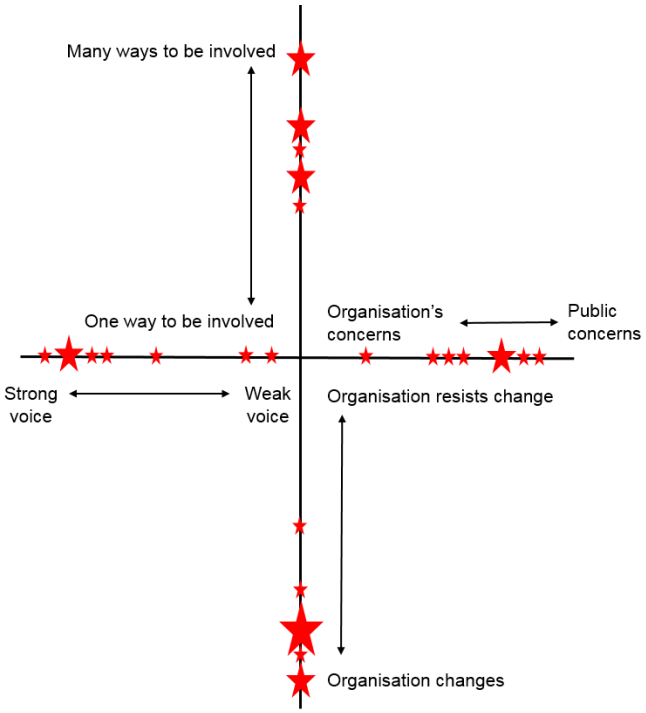
Approximate timings	**Activities**
30 minutes	Introduction to the framework and its origins, including time for questions and answers
1 hour	Exercise to anonymously map experiences of involvement along the four dimensions – these may include experiences of being involved as members of a public panel within a parent organisation and/or involvement in specific research projects as PI representatives: • Each dimension is separately represented on a wall chart • Ask participants to use a sticky note with an arrow on it to indicate where along the dimension they feel best represents their own PI experience • Invite them to also write comments on other sticky notes explaining or supporting their arrow placement (illustrated in Figure 2)
1.5 hours	Discussion and interpretation of the results from the mapping exercise: • Ask participants for comments or reflections, taking each dimension in turn • Have a general discussion about the group’s responses and future directions, and obtain feedback on what worked well and what could be improved

Figure 3: Example wall chart from workshop showing the dimension ‘one way to be involved or many ways to be involved’



Workshop data is presented in a crosshair design, which provides a simple, accurate and easily interpretable method to plot data from all four dimensions in one diagram (Figure 4).

Figure 4: Example mapping of workshop data into a crosshair diagram – the dimension 'one way to be involved or many ways to be involved' corresponds to Figure 3



Interpretation of the diagram:

- Responses clustered around the centre of the cross represent a group with a weak voice, limited ways to be involved, little consideration of public concerns and limited opportunities for organisational change.
- Responses towards the extremities of the cross represent a group with a stronger voice, perceived ability to exert organisational change and so on.
- The size of the symbol used is proportional to the number of responses at the same point on a dimension, i.e. a symbol size of 0.5 point is used to represent one person's response, while a 1.5 point symbol would represent three people's responses.

Benefits of using the 'cube' framework:

- Enables cross-sectional comparisons between PI groups in different organisations, or between different involvement activities within a single group; also allows longitudinal evaluation of changes in PI interactions over time.
- Results of the mapping exercise are immediately available, allowing areas or activities where there is cause for concern and require appropriate remedial action to be identified in real time. It is useful to note that any lack of responses may be important indicators of a breakdown in PI interactions and highlight opportunities to develop more embedded PI.
- Encourages public contributors to reflect about their involvement experiences and interactions from a more holistic, long-term perspective, and also in relation to the views of other group members and PI leads.
- The workshop creates a space for collaborative reflection on the purpose and strategic direction of individual and group involvement in the organisation or specific project, and planning of future PI activities. Its participatory nature helps develop a sense of group cohesion and co-production. (Gibson *et al.*, 2017)

IV. The Public Involvement Impact Assessment Framework Guidance

The Public Involvement Impact Assessment Framework (PiiAF) was developed to help researchers, in collaboration with patient and public contributors, consider how best to involve the public in their research and develop a plan to evaluate PI. It is therefore, more of a problem-solving mechanism rather than a method. The PiiAF should ideally be used at the early stage when research ideas and funding proposals are being developed, but may also be used in ongoing research projects.

The guidance comprises two parts:

- Part 1 focuses on the planning of PI in a research project, including setting out clear aims and objectives for the involvement.
- Part 2 focuses on designing an impact assessment plan to evaluate, for example, whether aims set in Part 1 have been met.

A record card (Figure 5) is provided to capture key points arising from discussion of each element in Part 1, which can then be used as building blocks for developing an impact assessment plan in Part 2.

Figure 5: The PiiAF record card (Popay and Collins, 2014)

Recording key points from your discussion	
Values	
Approaches to PI	
Research Topic and Study Design	
Practical Issues	
Identifying the Impacts of PI in Research	

Part 1: The PiiAF

The PiiAF identifies the main elements that influence PI in research and the impact this involvement can have – these are depicted in Figure 6.

Figure 6: The elements that can shape the impact of PI in research (Popay and Collins, 2014)

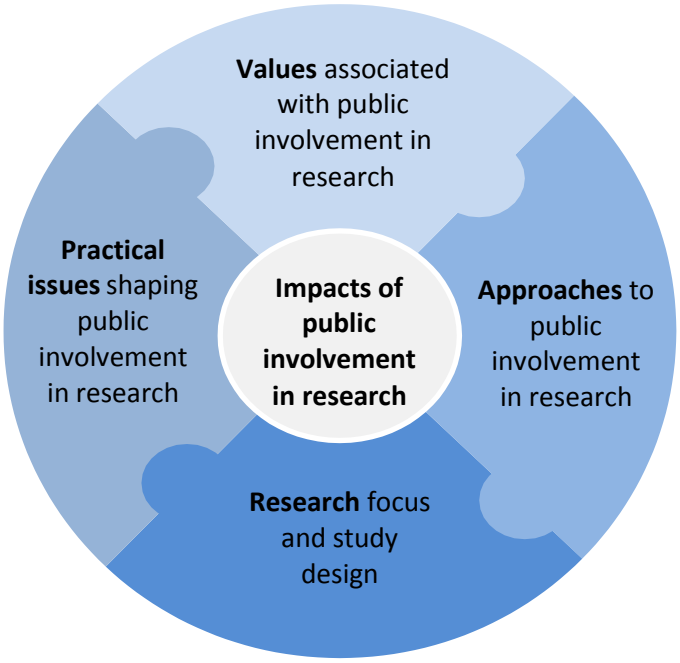


Table 4 provides a summarised description of each element, identifying key issues associated with it, and poses questions to help you explore the implications of these issues for your approach to PI and the types of impacts you can reasonably expect. More detailed information on Part 1 is available on the PiiAF website.

Table 4: Description of the PiiAF elements, key issues, and explorative questions (Popay and Collins, 2014)

ELEMENT 1: Values associated with public involvement in research	
Description	• *Normative values*: Ethical and/or political concerns associated with PI in research • *Substantive values*: Concern with the consequences of PI in research • *Process values*: Issues associated with the conduct of PI in research
Issues	Academic values that conflict with the needs and aspirations of public contributors may lead to negative experiences of PI and reduce its beneficial impact. Tensions between different values might disrupt relationships during the research process and affect the impacts of PI and the outcomes of research. It is important to acknowledge the values associated with PI as early as possible in the research process to enable the development of strategies for managing potentially conflicting values both within the project team and the wider organisational or funding context.
Questions	1. What values about PI are held by you and other members of your research team? 2. What values about PI can you identify in the organisation(s) in which your research will be based?

	3. How might these values shape your approach to PI, the involvement processes and the impacts PI can have? 4. Do you think there is any potential for conflict over the values associated with PI in your team and/or the organisation(s) in which the research will be based? 5. What processes can you put in place to manage divergent values? - Within your team - In the organisation(s) where PI will take place - In the organisation funding your research or from which you intend to apply for funding 6. How might an impact assessment be designed to take into account the values you have identified in your team and the potential for conflict between values?
ELEMENT 2: Approaches to public involvement in research	
Description	• *General approach*: Consultation, collaboration, or control • *Specific methods*: E.g., service user researcher, public members of a project advisory group, or a consultative panel • *Activities undertaken*: E.g., commenting on a research proposal, or peer interviewing
Issues	Different research projects may require different approaches to PI as well as different kinds of lay expertise. PI needs to be designed to suit the particular research study and may involve more than one approach and/or different PI approaches, methods and/or activities at different stages in the research. The evidence base on PI can be improved if researchers are clear and transparent about their approach to PI, the impacts they hope to have, and the pathways linking these two.
Questions	1. What do you consider your overarching approach to PI to be and what specific methods will you adopt? 2. Which aspects of your PI approach and methods might potentially act as barriers and/or facilitators to achieving the impacts you hope for? 3. How might you address these barriers?
ELEMENT 3: Research focus and study design	
Description	**Research focus** • *Discipline or field of work*: E.g., health services research, public health, infectious disease • *Population*: E.g., people with experience of a particular health problem • *Research question*: E.g., effectiveness of a new antimicrobial medicine **Study design** • *Macro level research methods*: E.g., randomised controlled trial, qualitative ethnography • *Micro level data collection methods*: E.g., clinical tests, face-to-face interviews
Issues	Different populations may have different experiences of being involved in research, different reasons for getting involved, and different expectations of involvement. This may affect their willingness, or the extent to which they wish, to be involved. There may be particular ethical or practical issues with involving particular groups e.g. children or people with dementia. Careful consideration needs to be given to how best to involve these groups.

Questions	1. What is your research topic and what will your study design be? 2. What are the main implications of your research topic and study design for the general approach(es) to PI you plan to adopt and the specific method(s) you will use? 3. At what point in your research process do you anticipate PI will have an impact? 4. How will you address any potential barriers to PI that result from your research topic and design? 5. How will your research topic and design shape the type of PI impacts you might expect to see?
ELEMENT 4: Practical issues that can influence public involvement and its impacts	
Description	*Practical issues relevant to PI*: - The availability of training - The level and type of resources to support PI - Issues associated with the payment of fees and expenses - Access to information - Travel and accommodation
Issues	Practical issues may: - make it more difficult for some groups to get involved, e.g. people with disabilities - affect PI processes, reducing the beneficial impacts on the research and the people involved - interact to produce a cumulative impact on PI, e.g. insufficient funding for PI may increase inequality in access to involvement for some groups Practical issues associated with PI need to be reported in sufficient detail in an impact assessment process to allow judgements to be made about whether they acted as barriers or facilitators. The context in which PI takes place may change throughout the course of a research project (e.g. members of the project team may change affecting the level of involvement expertise, resources may be reduced, or changes to the tax and benefit systems may create problems with paying people for their involvement).
Questions	1. What are the most important practical issues that might influence your PI and what consequences could they have for the impacts you wish involvement to have? 2. How will you address the potential barriers to your PI that might be caused by practical issues? 3. How might you design an impact assessment to take into account the practical issues you have identified and potential changes in the context for your research?
ELEMENT 5: Impacts of public involvement in research	
Description	• Impacts related to the research or to the people involved • Short-term (e.g. patient information documents) or long-term (e.g. recruitment and/or retention) impacts • Impact on all stages of the research process, from topic prioritisation to dissemination • Positive or negative impacts • Intended or unintended impacts
Issues	Some pathways between PI and particular impacts are more difficult to establish than others, e.g. the public's choice of topics or outcome measures may be easier to identify when involvement is through consultation rather than collaboration.

	Good quality reporting of PI impacts should include both positive and negative impacts**.** Expectations about the kinds of impacts PI may have on a study should form part of a dialogue between research project team members and the public involved.
Questions	1. Which impacts for PI do you wish to prioritise in your research? 2. Are there any potential negative impacts and how will you identify these? 3. How will you acknowledge and address the different impacts that might be expected by the different project stakeholders (including members of your project team, advisory groups, funders)? 4. How can divergent views (if any) within your project team about the impact of PI be resolved? 5. How might an impact assessment be designed to take into account any unintended impacts of your PI that may occur?

Discussion of impacts of PI in research concludes Part 1 of the PiiAF guidance. If the record card was used to capture the key outcomes of these discussions, it will be useful to refer to this as you work through Part 2 of the guidance, which focuses on designing an impact assessment plan. An example of a completed record card after discussions about the five PiiAF elements in a clinical trial research is available here.

Part 2: Developing a plan to assess the impact of PI in research

This part of the guidance aims to support you in developing an impact assessment plan for PI in your research. The four development phases are shown in Figure 7.

Figure 7: The development phases of an impact assessment plan (Popay and Collins, 2014)

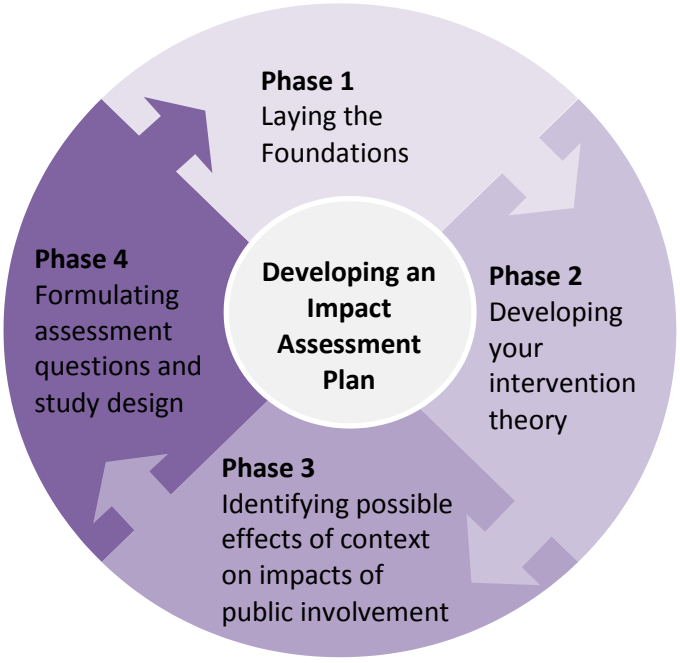


Table 5 describes the key questions to consider at each phase of the impact assessment plan development. Refer to the PiiAF website for a complete discussion of Part 2.

Table 5: Key questions to consider in developing an impact assessment plan (Popay and Collins, 2014)

Development phase	Key questions to consider
Phase 1: Laying the foundations	**a) Why are you carrying out an impact assessment?** • *Formative assessment*: Focuses on improving PI processes; findings are fed back to the team regularly to enable process improvements • *Summative assessment*: Aims to demonstrate the impact of PI, e.g. on recruitment to a trial; findings are reported at the end of the trial • *Process assessment*: Aims to identify factors affecting the PI processes that may subsequently affect the impacts; can be formative or summative These types of assessment are often used in combination. **b) Who should be involved in the impact assessment?** Everyone should be involved in discussions at an early stage. Consider the following in particular: • How members of the public will contribute to the impact assessment, e.g. in designing the assessment. • Whether the assessment should be carried out by members of the project team or by people independent of it. Consider possible issues of bias and potential conflicts of interest, and the feasibility of having an external assessor.
Phase 2: Developing your intervention theory	**An intervention theory: How will your approach to PI lead to the impacts you want?** Issues to consider include: • The likelihood of multiple pathways between PI and specific impacts • That different members of the team may have different ideas about these pathways • Designing your impact assessment to test more than one 'theory' Relevant literature on PI may provide support for your ideas (see Further Reading on the PiiAF website). See pages 46-47 of the guidance document for an example of how an intervention theory might be developed using a completed record card.
Phase 3: Identifying how context may affect the impacts of PI	**How might the context in which your research will take place affect the process of PI and/or its impact?** A completed record card could help you identify key aspects of context relevant to your situation, including: The research itself, its focus and the study design • Are your desired impacts realistic in the context of your research? • Are members of the public involved at appropriate points in the research process? E.g., to impact on recruitment to trials by contributing to patient information leaflets, members of the public will need to be involved at an early stage of a study. Values and behaviours in the research team and in wider settings or organisations How might the support, or lack of it, from key people, particularly senior members of your institution/funders, influence the impact of your PI activities? Constraints imposed by your organisation or funders may lead to tokenistic involvement and reduced impacts.

	Practical issues including structures, procedures and resources • Do you have appropriate financial resources to support the public who are involved to deliver the desired impacts? The availability of these resources can reassure members of the public that their contribution is valued and will be taken seriously. • Are your financial and/or administrative systems fit for purpose? Referring to existing guidelines or principles for best practice in PI, such as PiiAF's draft standards, may help to ensure that your PI has the impacts you are hoping for.
Phase 4: Formulating assessment questions and designing the assessment	**a) What specific questions do you want your assessment to answer?** **b) What challenges will you need to address and which might limit what is feasible?** **c) What approach to impact assessment will you use?** **d) What specific data will you need to collect and how will you do this?** See pages 51-54 of the guidance document for more information and resources to help you answer these questions.

Once these questions have been worked through, there are several other final considerations before the impact assessment plan is complete, including deciding on how data will be analysed, and who the findings will be disseminated to and how. It is also important to identify how your work links with and builds on the existing body of work on PI and assessments of its impact, to ensure that the evidence base on the impact of PI in research is strengthened (Popay and Collins, 2014).

V. Realist evaluation

PI in research is a complex social process whose impact is highly dependent on the specific context and the precise nature of the mechanism of involvement (Staley *et al.*, 2012). Realist evaluation is a particular approach that acknowledges the importance of context in influencing outcomes. For this reason, some people have found it a useful method for evaluating PI. The approach is based on identifying three key elements:

- *Context*: What conditions exist that may facilitate or hinder the effectiveness of a particular approach to PI?
- *Mechanism*: How does a particular approach to PI produce specific outcomes in a given context?
- *Outcome*: What are the effects of PI (intended and/or unintended) produced by particular mechanisms in a given context? (Pawson and Tilley, 1997)

These elements are explored in realist evaluation using both, quantitative and qualitative methods. Together, they form what realist evaluators call context-mechanism-outcome (CMO) patterns. It is important to remember that different stakeholders may have different ideas about how PI works. Therefore, different stakeholders may identify different CMO patterns.

Realist evaluation is about theory testing and refinement. It asks what works for whom in what contexts and how, and collects evidence to answer this question. Findings can be fed back into further development of the theory that might lead to a new CMO pattern that can be tested in future studies (Staley *et al.*, 2012). In this way, a series of studies, each building on previous findings, helps to develop an increasingly refined understanding of which CMO patterns lead to the greatest benefit for all involved, and thus support the development of more strategic approaches to PI (ibid).

Example: ReseArch with Patient and Public invOlvement: a RealisT evaluation (RAPPORT) study

The RAPPORT study "aimed to identify what PI approaches have applicability across all research domains, which ones are context specific and whether or not different types of public involvement achieve different outcomes for the research process, findings, dissemination and implementation of PI" (Wilson *et al.*, 2015). As the name suggests, the study was underpinned by realist evaluation and focused on six example areas: arthritis, cystic fibrosis (CF), dementia, diabetes mellitus, intellectual and developmental disabilities (IDDs), and public health. It involved three stages – the first two stages comprised a scoping exercise and online survey to chief investigators to assess current PI activity; the third stage consisted of an in-depth realist evaluation of 22 case studies tracked over 18 months through interviews and document analysis.

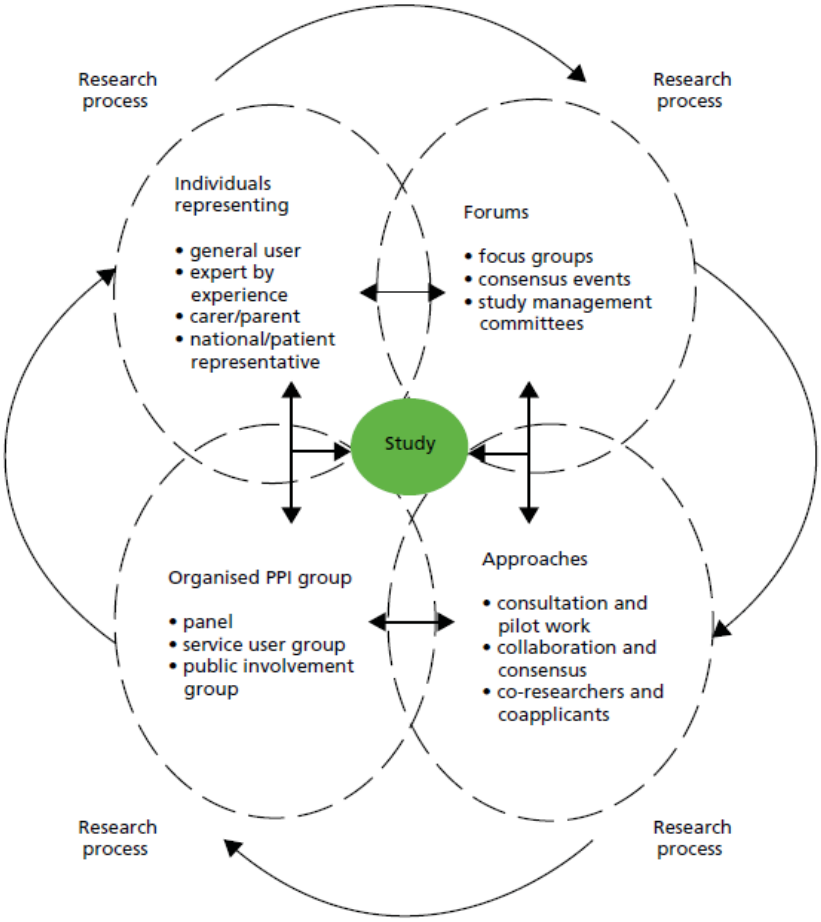
Six CMO patterns based on the case studies' main actions were tested: (1) a clear purpose, role and structure for PI, (2) ensuring diversity, (3) whole research team engagement with PI, (4) mutual understanding and trust between the researchers and public contributors, (5) ensuring opportunities for PI throughout the research process, and (6) reflecting on, appraising and evaluating PI within a research study. Results of the realist evaluation are detailed in Table 6.

Table 6: Context-mechanism-outcome patterns of PI in research (Wilson *et al.*, 2015)

(a) Key enabling contexts that influenced mechanisms for PI	
i. Research funder	Funders' preferences of either the methodological (to improve research quality) or the moral (PI as a right) arguments influenced the operational requirements for PI in grant applications and their focus in developing PI processes.
ii. Topic and study design	Established ways of working in PI influenced how PI was operationalised, e.g. the commitment to include end-users with IDDs indicated that PI was embedded within studies.
iii. Host organisation	Availability of resources to support PI, and whether research was core business or sporadic projects varied considerably between host organisations. Research conducted within the clinical setting had easier access to the target population and potential public contributors.
iv. Organisation of PI	A dynamic framework for PI recognises that PI approaches, forums and public contributors change over time and during research processes (Figure 8). Three models of PI sat within this framework: • *One-off model*. Public contributors were brought into the study for a limited researcher-identified task, often through an established external PI panel. • *Fully intertwined model*. Public contributors often set the research agenda and worked alongside researchers as partners throughout the research process. This model had strongly embedded PI, but was resource-intensive. • *Outreach model*. Public contributors had regular points of contact with researchers throughout the research. Although often fewer in number, they had strong links and networks with the target study population. This model was effective, less resource-intensive and found in a range of study designs. However, it required finding public

	contributors able to provide this link and is unsustainable without appropriate funding.
v. Positive experience of PI	A positive experience created a good cycle for both researchers and public contributors, whereby PI became increasingly embedded.
(b) Mechanisms to embed PI as normal practice (Normalisation Process Theory)	
i. Coherence: making sense of PI	Higher levels of agreement on the purpose of PI usually led to more embedded PI. This may take time to achieve in newly formed groups of researchers and public contributors.
ii. Participation: relational work to build and sustain a community of practice for PI	An assigned, resourced PI coordinator role was important in sustaining PI. It was equally important for the rest of the research team to be fully committed to PI.
iii. Collective action: the operational work to enact PI practices	• Flexible approaches to enable use of public contributors' individual skill sets and personal circumstances • Establishing and maintaining good relationships between researchers and public contributors through regular communication (preferably in person), addressing power imbalances in meetings, and providing opportunities for informal engagement.
iv. Reflexive monitoring: the appraisal work to evaluate PI	Limited systematic appraisal within the case studies revealed that the majority of researchers and public contributors felt that PI is worthwhile but its impact difficult to prove.
(c) PI outcomes	
• In all case studies: research priority/question setting, study marketing, changes to design including interventions, ensuring participant safety and recruitment. • One case study reported increases in recruitment rates following changes to participant information sheets made by public contributors. • Case studies with the most embedded PI were likely to demonstrate the greatest number of PI-related outcomes, and these outcomes were likely to be from the moral perspective, e.g. increased self-worth for public contributors.	

Figure 8: Dynamic framework for PI (Wilson *et al.*, 2015)



The study concluded that six prominent actions were required for positive outcomes/impact of PI:

- Researchers and public contributors share an understanding of the moral and methodological purpose of PI
- A dedicated individual to coordinate PI
- Public contributors have a strong connection with the target study population
- The whole research team is positive about PI input and fully engaged with it
- Efforts to develop relationships of trust and mutual respect established and maintained over time
- PI is evaluated in a proactive and systematic approach (Wilson *et al.*, 2015)

KEY POINTS

- An impact log is a basic way of recording and evaluating the outcomes of PI in research.
- The *'cube' framework* provides a quick and non-onerous way for evaluating the process of PI in research based on four key dimensions:
  - Weak voice or strong voice
  - One way to be involved or many ways to be involved
  - Organisation's concerns or public concerns
  - Organisation changes or organisation resists change
- The *Public Involvement Impact Assessment Framework (PiiAF)* provides a two-part guidance on how best to involve the public in research and develop a plan to evaluate PI.
- *Realist evaluation* explains the factors that shape the impact of PI in research by exploring the links between context, mechanism, and outcome.

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