# Co-Developing a Public Involvement Plan

## A Toolkit with resources to help plan public involvement activities

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## GUIDE TO CO-DEVELOPING A PUBLIC INVOLVEMENT PLAN

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## WHAT IS PUBLIC INVOLVEMENT?

It's important that everyone involved in the project understands what public involvement is. A definition of 'public involvement' from the National Institute of Health and Care Research (NIHR) is given below:

> NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an ***active partnership*** between patients, carers and members of the public with researchers that influences and shapes research.

When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Here are examples of how members of the public might get involved in research:

- as joint grant holders or co-applicants on a research project;
- identifying research priorities;
- as members of a project advisory or steering group;
- commenting on and developing patient information leaflets or other research materials;
- undertaking interviews with research participants;
- carrying out research as user and/or carer researchers.

Public involvement as defined here is also sometimes referred to as Patient and Public Involvement (PPI).

[Taken from: https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371]

## WHAT IS A PUBLIC INVOLVEMENT PLAN?

**A Public involvement Plan is a document that describes the ways in which you will work with patients and members of the public (public contributors) at different stages of your research project.**

Here are some key things you need to know about **co-developing** your Public Involvement Plan:

- You should work **in partnership** with public contributors to develop ideas and plans for involving them throughout your research project. Ideally, you should work with people that have lived-experience of the subject area that is the focus of your project.
- You can try and find studies that have published papers that report previous examples of public involvement to give you some ideas and help you plan what you might do. Some key journals include Research Involvement and Engagement Research Involvement and Engagement | Home page (biomedcentral.com) and Health Expectations, Health Expectations - Wiley Online Library. Other journals also publish PPI studies.

- Your Public Involvement Plan should be **realistic**. You need to make sure that your plans are achievable with the time and resources available to you and your public contributors.
- Your Public Involvement Plan should be a **living document**. Research plans evolve and your relationships with your public contributors will develop over time. You should create spaces to re-visit your Public Involvement Plans to ensure that you maximise your ways of working with public contributors.
- When you have a draft of the Public Involvement plan that you are happy with, it is possible to develop and publish this as a protocol. Examples of protocols are given below.
- Your public involvement plan can become part of a research protocol, where you detail you aims and methods.

## FURTHER RESOURCES

**How to engage patient partners in health service research: a scoping review protocol.** (2021) Tscherning, S.C., Bekker, H.L., Vedelø, T.W. *et al.*

Res Involv Engagem **7**, 20 (2021). https://doi.org/10.1186/s40900-021-00268-z

PROTOCOL

How to engage patient partners in health service research: a scoping review protocol

BMC

**A protocol for co-creating research project lay summaries with stakeholders: guideline development for Canada's AGE-WELL network**. (2020). Wada, M., Sixsmith, J., Harwood, G. *et al.*
Res Involv Engagem **6**, 22 (2020) https://doi.org/10.1186/s40900-020-00197-3

PROTOCOL

How to engage patient partners in health service research: a scoping review protocol

BMC

## WHY IS PARTNERSHIP WORKING WITH PUBLIC CONTRIBUTORS IMPORTANT?

**Working in partnership with people with lived experience of a particular condition, or who access particular services, is fundamental to any research project. Their insights and perspectives can shape a research project to make it a success.**

Public contributors should be at the heart of any research project because:

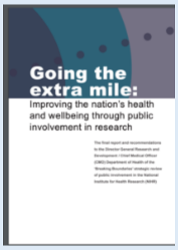
1) They ensure the research project is ***relevant*** to them and meets their needs. They can help understand why the project needs to be done now, why the project is an appropriate use of public funds, and the difference it will make to patients'/service users' lives.

2) Public contributors can bring ***new knowledge and insights*** to your work, for example aspects of health that should be included in a quality-of-life questionnaire.
3) They will ensure that you ***undertake research in the right way***. Any research project should be designed in ways that are acceptable to patients and members of the public. In addition to *ethical considerations*, your public partners will help you design research that considers any *practical considerations*.
4) They will help you ***share the findings***. Public contributors can play a key role in ensuring that research evidence is communicated in the most effective ways to relevant audiences. Public contributors can also have an important role in ensuring that research evidence is implemented and used to continually improve the experience of health and social care for patients, their families.
5) There is a growing **evidence base** that demonstrates the beneficial impacts of public involvement in research. Public involvement can be an evidence informed and an evidence generating activity, with researchers and public contributors often publishing their work.

## FURTHER RESOURCES

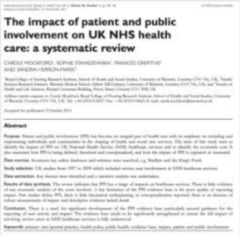
**Going the Extra Mile**
https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf

The National Institute for Health Research (NIHR) completed a review of Public Involvement in Health and Social care in 2015, the 'Breaking Boundaries' review. The report from the review, 'Going the Extra Mile' was published in 2015. This report sets out a clear vision for involving patients and the public in health research.


Going the extra mile:
Improving the nation's health and wellbeing through public involvement in research

**Systematic Review of the impact of Patient and Public Involvement in on UK NHS health care (2011) Mockford et al**
International Journal for Quality in Health Care, Vol 24, Issue 1, February 2012, Pages 28 -38. https://doi.org/10.1093/intqhc/mzr066

This systematic review looked at the ways in which involving patients and the public has an impact on the NHS and consider the economic costs of public involvement. The review included 48 papers, representing 28 studies.


The impact of patient and public involvement on UK NHS health care: a systematic review

Abstract

**Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future (2018) Staniszewska et al.**
BMJ Open 2018; 8:e017124. Doi: 10.1136/bmjopen-2017-017124

This paper reports the findings of the 'Breaking Boundaries' review, which was commissioned by the Department of Health and was the first review of public involvement. The paper considers barriers and enablers to achieving the strategic vision, including attitudes, resources, infrastructure, training and support and leadership. Co-production is identified as a concept that is central to strengthening public involvement. Four areas, Reach, Relevance, Refinement and Relationships, are identified as key measures of success.


Open access
Research
BMJ Open
Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future

6)

## GETTING STARTED

To maximise the benefits of involving patients and the public in your research, you need to be prepared to commit time and resource. Careful planning and preparation are essential to any public involvement activity. Time spent early on in thinking about your public involvement is time well-spent!

Before you get stuck into co-developing your public involvement plans with public contributors, it's important that *you* take some time to think about the following important areas. There is a resource available to support this activity:

1) **Why you want to involve patients, service users and the public in your research**. For many researchers, this might be the first time they speak to people outside an academic environment about their research. Think about what experiences/knowledge/insights they can bring to your research project, and how their perspectives can make a difference to your project. Take time to consider what **values** you attach to public involvement – it's important you think about these so you can then discuss with public contributors what values are important to them. The values you consider important can really shape the approach to public involvement.
2) **Who you want to involve**. It's important to think about the different people you can involve to contribute to your research project. Although you might instinctively think of patients or people that use and access a particular service, it's important to think of broader networks. This can include carers, family members, members of the public or communities. It's important to try and get a range of perspectives providing input to your project.
3) **What resources you have available.** Public involvement requires resource. This includes money – so you can offer refreshments at meetings and pay public contributors for their input – and time.
4) **How long you have to develop your Public involvement Plans.** Co-developing public involvement plans can be a lengthy process. You will have some initial meetings with your public partners and there is likely to be some back-and-forth whilst you refine your plans. You need to be realistic about what you can achieve with the resources available to you.
5) **What the evidence tells you already.** Search the published literature to explore what is already known about public involvement in your area of research. You may find some studies that will help you shape your thinking.

## FURTHER RESOURCES

**NIHR Briefing Notes for Researchers**

https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

A series of ten briefing notes for researches to support public involvement in research. The notes are brief and accessible with very practical advice for researchers embarking on public involvement activities.

Briefing notes for researchers - public involvement in NHS, health and social care research

Published
05 April 2021

Version
1.0 - April 2021

Briefing note one: introduction

Briefing note two: what is public involvement in research?

Definitions of involvement, engagement and participation

**Values associated with public involvement in health and social care research: a narrative review (2013) Gradinger F et al.**

**Health Expectations 2015 Oct; 18(5): 661-75. Doi: 10.1111/hex.12158**

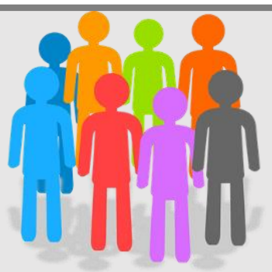
Values underpinning public involvement can shape approaches to public involvement. This paper identifies 3 value systems associated with public involvement (normative, summative and process) and five clusters for each system.

Values associated with public involvement in health and social care research: a narrative review

Abstract

## YOUR PUBLIC INVOLVEMENT PLAN: THINGS TO CONSIDER

### 1. INCORPORATING THE PUBLIC VOICE



"Nothing about us without us"

Anything we do in health and social care research needs to involve the insights and perspectives of people that use and access health and social care services. In many ways public involvement is about the democratisation of research.

The first step in co-developing your Public Involvement Plan is taking time to consider **what perspectives/insights** you need to ensure are at the heart of your project.

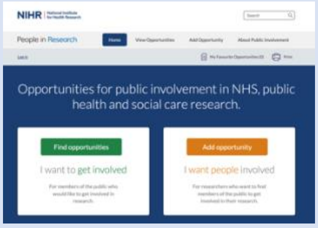
Things you need to consider include:

- *Whose insights/perspectives are most important to shaping your project?*
- *What perspectives and insights would add most value to your project?*
- *How can you ensure that all voices are heard (and not just those that shout loudest)?*
- *Are there any groups/networks/organisations that bring together people with perspectives that are important to your project? Are these groups organised locally/nationally?*
- *Do you have any contacts that can help you gain access to patient/public perspectives?*
- *Is there anyone that can support you to gain access to the people you would like to work alongside in your study?*
- *Do the papers you have read suggest key groups or types of individuals you should involve?*

### FURTHER RESOURCES

**People in Research**
https://www.peopleinresearch.org/

This resource, facilitated by the National Institute for Health Research, is a mechanism for linking researchers with public contributors interested in involvement in Health and Social Care Research.



Opportunities for public involvement in NHS, public health and social care research.

**Reaching Out – A practical guide to being inclusive in public involvement in health research**

Reaching Out – A practical guide to being inclusive in public involvement in health research

https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/NIHR-Reaching-Out_-A-practical-guide-to-being-inclusive-in-public-involvement-in-health-research-Lessons-learnt-from-the-Reaching-Out-programme-April-2021.pdf

NIHR | National Institute for Health Research

A practical guide to being inclusive in public involvement in health research

Lessons learnt from the Reaching Out programme

April 2021

Foreword

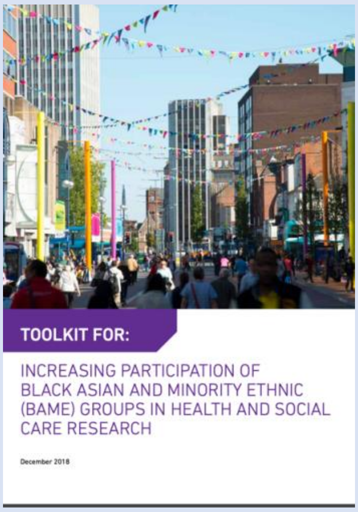
National Institute for Health Research (NIHR) is committed to focusing research effort on populations and areas where there is greatest need. It is also committed to carrying out more health and care research in the locations where the relevant populations live and work and beyond clinical settings. The purpose of the Reaching Out programme – a partnership between INVOLVE (NIHR's national advisory centre on public involvement until April 2020) and the NIHR's Research Design Service (RDS) - was to encourage the development of new public involvement and engagement (PPIE) relationships, and new or more effective approaches to building relationships, within communities in RDS localities leading to new and improved research partnerships. The emphasis was on parts of the community who are not usually, or consistently, involved in health, social care and public health research. In doing this work, the partnership hopes to enable PPIE workers across NIHR and other health and care settings to work together more to achieve common objectives and not duplicate engagement approaches. Developing relationships with different communities and addressing power differentials are key challenges for all of us with an interest in ensuring a variety of communities are involved in our research. These relationships are the building blocks to involvement in research and ensuring that research reflects the needs of communities. This guide, which draws on the four projects which make up the Reaching Out programme, provides information on what researchers and organisations can do to enable a cultural change and lay the foundations for more inclusive

**NIHR INCLUDE**
https://sites.google.com/nihr.ac.uk/include/home

A suite of resources developed by the NIHR Clinical Research Network do address the lack of representation in health and care research with a vision to: provide better health and care through more inclusive research

**Toolkit for increasing participation of Black, Asian and Minority Ethnic (BAME) Groups in Health and Social Care Research**

This Toolkit captures best practice and provides a framework on how to improve the participation of BAME groups in research.



TOOLKIT FOR:

INCREASING PARTICIPATION OF BLACK ASIAN AND MINORITY ETHNIC (BAME) GROUPS IN HEALTH AND SOCIAL CARE RESEARCH

December 2018

## 2. RATIONALE FOR THE STUDY

**Speak to different audiences to understand why your research topic is important to them and how the evidence you generate will make a difference.**

**Why are you doing your research project**? It's important that your research project is ***relevant:*** it needs to address a clear need or priority in health and social care. Working with patient and public partners can help you think about the focus of the study and how it will make a difference.

Thinking about the **rationale** for the study, things you might consider include:

- *What are the problems/issues you are addressing through your research?*
- *Are they of importance to patients or the public?*
- *How will this research improve the quality and experience of health and social care for patients and their families or advance an area of research?*
- *Is this project an appropriate use of public funds?*
- *Has there been any work previously to identify the need for your research project?*
- *Has there been work previously that involved patients or public contributors that you can draw on, for example published studies?*

## FURTHER RESOURCES

James Lind Alliance
[https://www.jla.nihr.ac.uk/priority-setting-partnerships/](https://www.jla.nihr.ac.uk/priority-setting-partnerships/)

The James Lind Alliance is a non-profit organisation that brings together patients, clinicians and carers to considers priority areas in different areas.

## 3. PUBLIC INVOLVEMENT AIMS

**Take time to consider what you want to achieve through your Public Involvement activities.**

We know that working with patients, carers and communities can really enhance the quality of a research project. Systematic revies have demonstrated this (Brett et al 2014, 2012).

Thinking about your aims for public involvement, things you might consider include:

- *What do you hope to achieve through working in partnership with patients and the public in your study? Sometimes exploring the aims of published studies can help you develop your aims.*
- *What are the key aims for public involvement at the start of the journey? Do you think any of these aims might change over time? How will you record them?*
- *Do you have any ambitions for public involvement that go beyond your research project?*
- *Are there any barriers that might prevent you from achieving your aims? What are these and how can you overcome them?*
- *Are there any areas that might add complexity to your Public Involvement plans? How can you explore these further?*
- *What do you think might help you achieve your aims?*
- *What would 'success' in public involvement in your project look like?*

## 4. CONSIDERING THE EVIDENCE BASE

**Ground your Public Involvement plans on existing evidence of 'what works' to avoid research waste.**

Our knowledge on 'what works' in public involvement is expanding thanks to increased reporting of public involvement.

To avoid research waste (when PPI is done but then not reported or published), it is Important to search for any evidence on public involvement in your research area. If there is evidence available, it is important to draw on findings in developing your research plans. If there is a lack of evidence, consider the ways in which your project team can contribute to understanding in this area. Sometimes this means you can create new knowledge.

In addition to searching in subject-specific journals, there are some journals that have a focus on public involvement research. These include 'Health Expectations', 'Research Involvement and Engagement' and 'Research For All'.

Things to consider:

- *Is there an existing evidence-base to draw on to inform approaches to public involvement in your study?*
- *Where will you search for evidence?*
- *Is there any support available to you to signpost you to relevant sources?*

## FURTHER RESOURCES

**Health Expectations**
https://onlinelibrary.wiley.com/journal/13697625

**Research Involvement and Engagement**
https://researchinvolvement.biomedcentral.com/

**Research for All**
https://www.publicengagement.ac.uk/nccpe-projects-and-services/research-all-journal

RESEARCH FOR ALL

## 5. METHODS FOR PUBLIC INVOLVEMENT

**There are many different approaches to public involvement and there is no 'right' or 'wrong' approach. What is most important is developing ways of working that are achievable and work best for all parties involved.**

When considering what methods to use to work with public contributors, you need to consider carefully the specific ways you will involve public contributors to achieve your public involvement aims.

- For researchers, it is important that methods for public involvement enable the research team to get the most out of public contributors' insights and perspectives.
- For public contributors, it is important that they can gain benefits from working with the research team and that they feel valued for their contributions.

There is no hard and fast rule to thinking about how you will work with public contributors. What is most important is ensuring that your Public Involvement Plans are acceptable to all members of the research team and that they can be achieved with the resources available.

There are some UK Standards for Involvement, which offer a great starting point to think about the different things you might need to consider when working with public contributors. Papers reporting PPI sometimes describe how they went about their PPI which can be helpful to read to inform your work.

**Co-Production** is one approach to working with public contributors, which is often seen as the 'gold standard'. Co-Production is defined by the NIHR as 'An approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.' The NIHR have developed some principles and values to Co-Production. True co-production requires a large amount of time and resource, but even if this approach is not achievable within the resources available to you, it might we worth considering with your public partners how you can align to the principles and values.

We have developed a checklist for things you may need to consider during discussions with public contributors about your methods for involvement (see **Resource 2**). It is important that you consider the resources available to you (time and money) to ensure approaches to involvement are realistic.

## FURTHER RESOURCES

**UK Standards for Involvement**
*https://sites.google.com/nihr.ac.uk/pi-standards/standards*

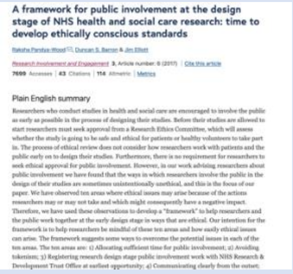
These Standards are a great place to start when thinking about your approaches to public involvement. There is a Standard on 'Working Together', which can help you think about ways you work with public contributors.

**NIHR Guidance on Co-Production**
https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
This accessible document provides guidance on co-producing a research project. Principles and key features of co-production are introduced on p.4.


INVOLVE
NHS National Institute for Health Research
Guidance on co-producing a research project

**Framework for Ethically-Conscious Standards for Involvement. Pandya Woods et al**
https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0058-y

This article encourages thinking on how to involve public contributors in an ethical way throughout a research project.


A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards

Rakhshi Pandya-Wood, Duncan S. Barron & Jim Elliott

Research Involvement and Engagement 3, Article number: 6 (2017) | Cite this article
7699 Accesses | 43 Citations | 114 Altmetric | Metrics

Plain English summary

Researchers who conduct studies in health and social care are encouraged to involve the public as early as possible in the process of designing their studies. Before their studies are allowed to start researchers must seek approval from a Research Ethics Committee, which will assess whether the study is going to be safe and ethical for patients or healthy volunteers to take part in. The process of ethical review does not consider how researchers work with patients and the public early on to design their studies. Furthermore, there is no requirement for researchers to seek ethical approval for public involvement. However, in our work advising researchers about public involvement we have found that the ways in which researchers involve the public in the design of their studies are sometimes unintentionally unethical, and this is the focus of our paper. We have observed ten areas where ethical issues may arise because of the actions researchers may or may not take and which might consequently have a negative impact. Therefore, we have used these observations to develop a "framework" to help researchers and the public work together at the early design stage in ways that are ethical. Our intention for the framework is to help researchers be mindful of these ten areas and how easily ethical issues can arise. The framework suggests some ways to overcome the potential issues in each of the ten areas. The ten areas are: 1) Allocating sufficient time for public involvement; 2) Avoiding tokenism; 3) Registering research design stage public involvement work with NHS Research & Development Trust Office at earliest opportunity; 4) Communicating clearly from the outset;

**Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. Greenhalgh et al (2019)**
https://onlinelibrary.wiley.com/doi/10.1111/hex.12888

This paper looks at 65 frameworks for Public involvement. Frameworks are grouped into five categories: power focused; priority-setting; study-focused; report focused; partnership focused.

The paper includes evidence-based facilitator notes for a 'build your own framework' co-design workshop


ORIGINAL RESEARCH PAPERS
WILEY

Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot

Trisha Greenhalgh MD, Professor[1] | Lisa Hinton PhD, Researcher[1] | Teresa Finlay PhD, Researcher[1] | Alastair Macfarlane MA, Clinical Academic Trainee[2] | Nick Fahy PhD, Researcher[1] | Ben Clyde PhD, Researcher[1] | Alan Chant MBA, Patient Adviser[1]

## 6. EVALUATING AND CAPTURING THE IMPACT OF PUBLIC INVOLVEMENT

**Set aside time and create spaces to reflect on ways in which partnership working with patients and members of the public makes a difference to your research project.**

We know that partnership working with public contributors can improve the quality of research projects. Interactions with public contributors, which may be in a meeting, in an email exchange, or even a conversation over coffee, may alter or change the direction of thinking on a project. Although there may be some 'light-bulb' moments, where a research project may change significantly, it's also important to capture the more subtle examples where contributions have impacted on the research.

With public contributors, try and think about different ways you can capture impact. Some ideas include creating spaces at the end of a meeting to capture impact, keeping reflective diaries, recording meetings to make sure you have complete notes, or using forms to capture impact at the end of meetings. It's important that all members of the team are involved in this activity: each person will have a different perspective on the ways in which public involvement has 'made a difference'.

There are a number of frameworks available to help you evaluate your public involvement activities and consider the ways public involvement has made a difference to your research project.

Things to consider include:

- *Who should be involved in evaluating and capturing the impact of your involvement in your project?*
- *What mechanisms could you use to capture the impact of involvement?*
- *How can you bring together examples of 'impact' on involvement?*
- *How can you use examples of impact to further develop your public involvement plans?*
- *How can you report and share the examples of impact?*

## FURTHER RESOURCES

Kok M (2018) ***Guidance Document: Evaluating public involvement in research***. UWE Bristol. [UWE Bristol e-prints repository].

Available online: http://www.phwe.org.uk/wp-content/uploads/Guidance-on-evaluating-Public-Involvement-in-research.pdf

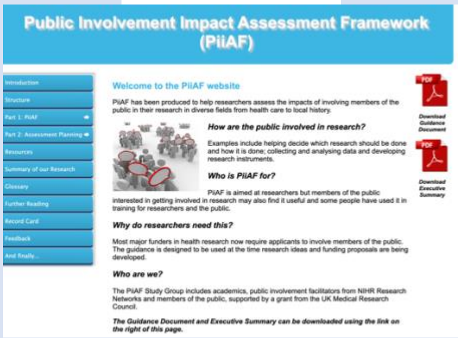
GUIDANCE DOCUMENT:
Evaluating public involvement in research

May 2018

PIIAF

**Popay J. and Collins M. (editors) with the PiiAF Study Group (2014). The Public Involvement Impact Assessment Framework Guidance**. Universities of Lancaster, Liverpool and Exeter [Online]

Available at: http://piiaf.org.uk/documents/piiaf-guidance-jan14.pdf



Public Involvement Impact Assessment Framework (PiiAF)

Welcome to the PiiAF website

PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.

*How are the public involved in research?*

Examples include helping decide which research should be done and how it is done; collecting and analysing data and developing research instruments.

*Who is PiiAF for?*

PiiAF is aimed at researchers but members of the public interested in getting involved in research may also find it useful and some people have used it in training for researchers and the public.

*Why do researchers need this?*

Most major funders in health research now require applicants to involve members of the public. The guidance is designed to be used at the time research ideas and funding proposals are being developed.

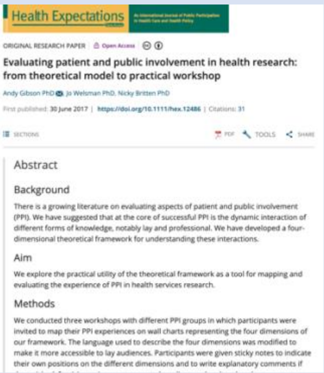
*Who are we?*

The PiiAF Study Group includes academics, public involvement facilitators from NIHR Research Networks and members of the public, supported by a grant from the UK Medical Research Council.

***The Guidance Document and Executive Summary can be downloaded using the link on the right of this page.***

**Gibson's Cube of Involvement**
https://onlinelibrary.wiley.com/doi/10.1111/hex.12486

This research paper describes an approach to evaluation using a visual diagram of a cube.



ORIGINAL RESEARCH PAPER | Open Access

Evaluating patient and public involvement in health research: from theoretical model to practical workshop

Andy Gibson PhD, Jo Welsman PhD, Nicky Britten PhD

First published: 30 June 2017 | https://doi.org/10.1111/hex.12486 | Citations: 31

Abstract

Background

There is a growing literature on evaluating aspects of patient and public involvement (PPI). We have suggested that at the core of successful PPI is the dynamic interaction of different forms of knowledge, notably lay and professional. We have developed a four-dimensional theoretical framework for understanding these interactions.

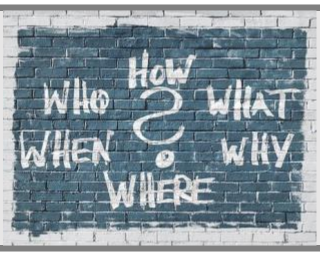
Aim

We explore the practical utility of the theoretical framework as a tool for mapping and evaluating the experience of PPI in health services research.

Methods

We conducted three workshops with different PPI groups in which participants were invited to map their PPI experiences on wall charts representing the four dimensions of our framework. The language used to describe the four dimensions was modified to make it more accessible to lay audiences. Participants were given sticky notes to indicate their own positions on the different dimensions and to write explanatory comments if

## 7. REPORTING PUBLIC INVOLVEMENT



**Reporting public involvement activities and the impact of public involvement on your research projects adds to the evidence-base on 'what works' with regard to involving patients and the public.**

Throughout the course of your research project, it is likely that a lot of resource will be invested in public involvement activities. This will not only be financial resource (e.g. payment of public contributors, meeting costs), but also time contributed by all project team members to public involvement activities.

It is important that you consider, early on, how you will report your public involvement activities. Capturing involvement activities and reporting public involvement is everyone's responsibility but it is useful to have one person with designated responsibility for this task. It is considered best practice to capture activities as you go along – it will save time in the long run. Remember to be honest about reporting public involvement. Not everything will go smoothly, and it's just as important to consider what didn't go well as well as what did go well.

Increasingly, health and social care journals and reports require information about public involvement activities. The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) is the international framework for reporting Public Involvement activities. There are two forms of GRIPP2: a Long-Form (GRIPP2-LF) and a Short Form (GRIPP2-SF). GRIPP2-Long -Form is used when Patient and Public Involvement is the main focus of a study and GRIPP2-Short Form is used where there are some elements of public involvement in a study but where public involvement is not the main focus.

For most research teams, GRIPP2 Short Form is the most appropriate framework. Public Involvement is reported in the following areas: Aims; Methods; Study Results; Discussion and Conclusions; Reflections and Critical Perspectives.

Things to consider include:

- *How are you going to report public involvement in your project?*
- *Who will be involved in reporting public involvement activities?*
- *Who will have ultimate responsibility for reporting public involvement?*
- *What mechanisms can you use to enable accurate capture of public involvement activities that aren't too burdensome?*

## FURTHER RESOURCES

**Guidance for Reporting involvement of Patients and the Public (GRIPP2)**
**https://www.bmj.com/content/358/bmj.j3453**

The publication describes how GRIPP2 was developed using the EQUATOR method for developing guidance. This included a 3-stage Delphi survey and a face-to-face collaborative meeting to develop consensus on the guidelines.

The paper includes an example of how GRIPP2 Short Form can be used to report public involvement activities.

Research Methods & Reporting

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

**Cochrane International PPI Network Training videos**
[https://training.cochrane.org/resource/developing-our-international-PPI-evidence-base-GRIPP2](https://training.cochrane.org/resource/developing-our-international-PPI-evidence-base-GRIPP2)


Developing our international PPI evidence base through high quality reporting: The ev n and use of GRIPP2

This webinar was delivered in November 2021 and includes a presentation from Professor Sophie Staniszewska, the academic who led the development of GRIPP2, and Richard Stephens, who reflects on GRIPP2 as a journal editor and a patient involved in research. The session includes a Q&A session on future developments of GRIPP2.

## 8. DISCUSSION

**Create spaces for ongoing dialogue about public involvement in your project.**

Public Involvement plans should not be fixed but should continually evolve as your project develops. Creating safe spaces for an ongoing dialogue about your Public Involvement plans can help ensure that your plans are informed by latest evidence on public involvement and your collective knowledge within the project team of what is working well and where there is room for improvement.

It is important also to remember that you can engage in dialogue about your public involvement plans with people outside your project. This might include colleagues, other public contributors or people with experience of delivering or facilitating public involvement.

Things to consider include:

- *When should you create spaces for dialogue about public involvement within your project?*
- *What actions could you take to ensure that spaces are safe for people to make honest contributions?*
- *Who can you engage with to discuss your Public Involvement Plans and progress?*
- *Who might be a good 'critical friend' to explore your Public Involvement plans with?*
- *Are there any existing spaces where you can engage in dialogue about your Public Involvement Plans?*

## 9. REFLECTIONS

**Ensure you set aside time and space to reflect on your public involvement activities – individually and as a group.**

'If you do what you've always done, you'll get what you've always got.' It is important to create time and space to reflect on your public involvement activities. It's important to consider what is working well – and celebrate the successes, but also consider what is not working so well and discuss potential ways to improve within the resources available. It is also important to reflect on what you are learning through your public involvement activities and how insights and experiences gained through public involvement activities can add to our existing knowledge and the growing evidence-base about public involvement.

Things to consider include:

- *How can you create spaces for honest reflection on public involvement in your research project?*

- *What mechanisms could you use to encourage reflection?*
- *Should you create spaces for individual as well as group reflection?*
- *Could you involve an external facilitator to reflective discussions? What could this add?*

## 10. TRAINING

**Take time to consider where there are gaps in knowledge or experience and how these can be addressed to make sure that your team can maximise the benefits of partnerships working with public contributors.**

Both researchers and public contributors may have training and development needs that should be addressed to help them become as enabled as they would like to be in the research project. There may be a need for development in research skills, but there might also be a need to develop skills in public involvement or ‘soft skills’ such as presentation skills, communication skills, or skills in chairing or facilitating meetings.

It is important to consider, early on in discussions with public contributors, if there are any training/development needs, and how these can be addressed. It’s also important to consider that ‘you don’t know, what you don’t know’. Think about working with someone with experience of delivering public involvement to help you consider if there are any training/development gaps and how these might be addressed.

Things to consider, include:

- *Would members of the research team benefit from any training/development support on aspects of research methods that are used in the study?*
- *Would members of the research team benefit from any training/development on public involvement?*
- *Are there any training/development resources that are available to you to support you and your research team?*
- *Is there anyone available in your organisation (e.g. Public Involvement Lead) that will be able to signpost you to relevant resources to support your development needs and requirements?*

## FURTHER RESOURCES

Getting Started – Guidance for Public Contributors
[https://www.nihr.ac.uk/documents/Starting-Out-Guide/30145](https://www.nihr.ac.uk/documents/Starting-Out-Guide/30145)

Guide for public contributors on getting started with public involvement in research.

NIHR Briefing Notes for Researchers
[https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/NIHR-Briefing-Notes-for-Researchers-April-2021.pdf](https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/NIHR-Briefing-Notes-for-Researchers-April-2021.pdf)

NIHR | National Institute for Health Research

Briefing notes for researchers

Public involvement in NHS, health and social care research

April 2021

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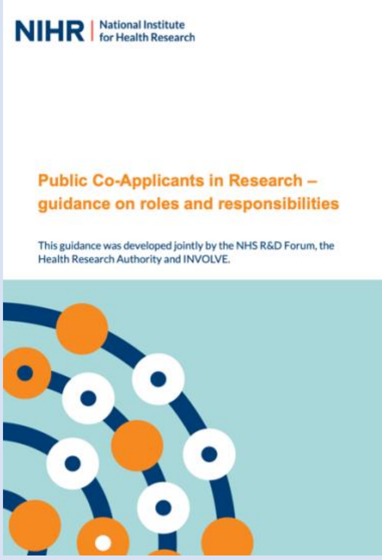
**NIHR Public Co-Applicant Guidance**
https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf



NIHR | National Institute for Health Research

Public Co-Applicants in Research – guidance on roles and responsibilities

This guidance was developed jointly by the NHS R&D Forum, the Health Research Authority and INVOLVE.

**Cochrane International Learning Live International PPI Network**

https://training.cochrane.org/international-ppi-network-learning-live-webinar-series

## 11. SYSTEM SUPPORT

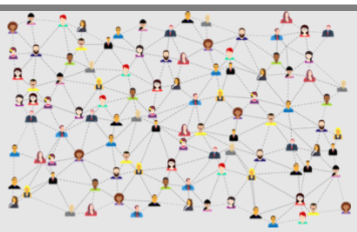
**Make best use of people and infrastructure support available to your project to support your public involvement plans and ideas.**

Many organisations have invested resource to support public involvement activities. This resource can include dedicated staff, with expertise and knowledge about working with patients and public contributors and resources to support public involvement activities. Find out whether there are any training opportunities or funds you can apply to that can support your plans.

Things to consider include:

- *Are there resources available to you in your organisation to support engaging and involving public contributors? How can you access these? It might be an idea to ask colleagues or start by searching your organisation webpage.*
- *Is there anyone in your organisation that can signpost you to resources that may support your public involvement plans and ambitions.*
- *Are there any resources outside your organisation that may support your public involvement and engagement activities?*

## 12. COMMUNITY ENGAGEMENT



**It's important to think beyond your research team. What communities do you need to engage with and what are the best ways of reaching out to them?**

In addition to working with public contributors, it's important that you take time to reflect on what communities would benefit most from knowing about your research and how. Working with communities from the start of your project can be important in helping make sure that you remain grounded in what is most important to communities as you plan and undertake your research but can also be important in ensuring that key messages from your research take root. Thinking about relevant communities to engage with should be an activity that takes place throughout your project, not just at the end. You should not underestimate the resources required to establish, develop and maintain relationships with relevant communities.

Important things to consider include:

- *Which communities would benefit from knowing about your research project and its findings?*
- *What are the most effective ways you can reach out to communities to engage and involve them in your research?*
- *Do you have any existing links/contacts you can use to gain access to these communities?*
- *Are there any contacts in your organisation that facilitate and support community engagement (e.g. University Public Engagement officers, hospital Patient Advice and Liaison services)?*
- *Are there any events you can attend where you can meet with relevant communities (e.g. health condition awareness events, community events, conferences)?*
- *How can you continue to keep communities engaged?*
- *Are there any resources/funding streams available to support community engagement activities?*

## 13. KNOWLEDGE MOBILISATION/IMPLEMENTATION

Knowledge mobilisation can be important in making sure the knowledge and evidence created in research is then used by people, either health or care professionals or public contributors.

It's often good to start thinking about what impact you want your project to have as you start working on it and to discuss this with your patients or public contributors. They are likely to have important creative ideas about how you can take the knowledge from your project and make a real difference.

Things to consider:

- *Explore what role can public contributors play in ensuring that research evidence from your project is taken up and used in practice?*

## **14.** EVIDENCE GENERATION

Patient and public involvement is a ‘doing’ activity, but it can be evidence informed. By ‘evidence’ we mean published peer reviewed papers and grey literature that may be more informally published but can still be helpful. There is a large and growing evidence-base and many researchers are keen to publish their PPI to contribute to this evidence base and avoid the waste of doing PPI but not telling our wider community about it. Papers about PPI help build our knowledge for practice and they provide a strong foundation for documenting the impacts we make.

### Things to consider:

- *How will you work with public contributors to share the evidence of your project?*
- *Do you aim to publish the public involvement of your project?*
- *How will you involve public contributors in academic publications/conference presentations?*
- *Start thinking about what you need to do to publish a paper about PPI as early as you can.*

## RESOURCES TO SUPPORT DEVELOPING YOUR PUBLIC INVOLVEMENT PLAN

### RESOURCE ONE – GETTING STARTED

Spend some time thinking about Public Involvement in your project. Consider the following areas.

| 1. Why should I involve public contributors? | 2. Who should I involve? |
|---|---|
| ***Think about the focus of your research project.***<br>- *What insights/perspectives do you need?*<br>- *What experiences can public contributors bring to your project?*<br>- *What are the ways public contributors can add value?* | ***Think about the patients/communities that will benefit most from your project.***<br>- *Who can you invite to be involved in your project?*<br>- *What experiences/perspectives? would be most valuable to your project.*<br>- *Are there specific communities you want to target?*<br>- *How can you be inclusive in your approaches?*<br>- *Are there any charities/third sector rganisations you can involve?* |
| 3. What resources do I have available? | 4. What deadlines am I working to? |
| **Think about resources you need to co-develop your Public Involvement Plan.**<br>- *How much time can you commit to developing your public involvement plans?*<br>- *Do you have any funding to support co-development of your public involvement plans?*<br>- *Are there any ways you can get additional funding to support your public involvement plans?*<br>- *Is there anyone that can support you to develop your Public Involvement Plans? How can you access them?* | **Think about when your project is going to start. Do you have any initial deadlines you are working towards?**<br>- *How much time do you have for the initial planning of your public involvement plans?* |

**Key Actions**
Note down any key actions you are going to take

| Zone | Action | Date to be completed by |
|---|---|---|
| | | |
| | | |
| | | |

## RESOURCE 2 – METHODS FOR PUBLIC INVOLVEMENT

In developing ways of working, you need to think carefully about the following considerations:

| | |
|---|---|
| 1. Who will lead public involvement? | *This person(s) will be the main contact for public contributors and other researchers for all matters relating to public involvement. They will have overall responsibility for the project, including reporting.* |
| 2. Who will be involved? | *Think about who you will involve in the project. It is important to think about what lived experiences/perspectives would be most valuable to your study and also consider diversity.*<br>*Think about how many people you can involve. This will depend on resources available to you.* |
| 3. Who will facilitate public involvement? | *Think about who will be responsible for ensuring public involvement runs smoothly. This may be the PPI Lead, another member of the team, or a public contributor.*<br>*Things that need considering include: arranging and setting up meetings, recording meetings, sending out communications, processing any payments.* |
| 4. How will you work together? | *Strong relationships are critical to successful relationships. It is important to think about how you can develop strong relations with public contributors.*<br>- *Will you have a core group of public contributors?*<br>- *How will you incorporate the public voice in your project? Will you have meetings? What will the frequency of meetings be?*<br>- *How will public contributors be involved in making decisions about your project*<br>- *How will you provide feedback to contributors on their involvement?* |
| 5. How will you communicate with public contributors? | *Keeping public contributors 'in the loop' is really important. How will you make sure that they are kept informed about the project? What methods will. You use (regular emails, newsletters, blog, telephone calls, video messages?)* |
| 6. How will you value public contributors for their input? | *Will you offer an honoraria for public contributors time? How much will you offer? Are there existing processes for honoraria payments?* |