NIHR | National Institute for Health and Care Research

Involving patients and members of the public in research

A guidance document for researchers working with NIHR Exeter and South West Peninsula at the University of Exeter

Contents

What is patient involvement in research?

The NIHR defines public involvement in research as research being carried out ‘with’, ‘by’ or 'in partnership with' members of the public rather than ‘to’, ‘about’ or ‘for’ them.

This means that, as well as being participants, people with relevant lived experience of the condition or topic your research relates to are about to input into the design, research, analysis and dissemination of the research.

In this guide we use the term patient and public involvement in research (PPI). In line with the NIHR definition, we use the term ‘public’ to include patients, carers, family members and people who use health and social care. This can also include people with one or more health conditions, regardless of whether or not they are current patients.

Participation, engagement and involvement

The terms participation, engagement and involvement have different meanings but are sometimes used interchangeably. In this guidance we use the terms to mean the following:

Participation: where people take part in a study as research subjects, for example interviews, questionnaires or recruitment to a clinical trial. Participation is often conflated with involvement and engagement and these activities may complement one another but these are distinct.

Involvement: 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. This should be a meaningful, active partnership.

Engagement: Where information and knowledge about research is provided and disseminated, for example at a science festival, community event or seminar.

User design: User design or user experience (UX) in technology design refers to making an app or product user friendly and acceptable to the target audience. This is different to, and should not be confused with, involving patients and people with lived experience within the conception, design, development and evaluation of the product.

Image from Versus Arthritis Patient and Public Involvement Guidance

Why is it so important to involve patients in research?

The right to be involved

Working with patients and members of the public can improve the quality of research by ensuring it is relevant and acceptable to people. Fundamentally, patients have a right to be able to influence and shape the research that will impact them.

Patients, carers, family members and people with relevant lived experience of a condition can help to identify research priorities to ensure that research looks at the aspects of experience which are most relevant and important to patients.

Facing illness, disease or navigating disability can be challenging and traumatic. Sometimes research – especially data-based research or research without human participants – can become disconnected and decontextualised from the realities of this. Working with people who have lived experience of the subject matter you're researching can help to ensure this reflects, and is sensitive to, the real-life experience of the subject.

Different perspectives and ways of looking at things

As well as becoming experts in the conditions they experience through the need to self-advocate and self-manage illness, patients, carers and families have an intimate understanding of a condition through their lived experiences. This is invaluable for research and can bring new insights and ways of looking at things.

Experiences of the topic you're studying will also intersect with, and be shaped by, the other identities and experiences people hold - for example, by living in poverty, experiencing structural racism or having multiple long-term conditions. Considering these intersecting experiences will help to understand the nuance and complexity of the topic you're studying and highlight areas you might not have considered.

Improving the quality of research and pre-empting limitations

Through the research process, researchers may face many challenges such as recruitment and retention of participants; acceptance of a technology or intervention to the target population; or ensuring that study documents are easy for participants to understand.

Working with patients and members of the public from the beginning means they can help spot some of these issues ahead of time, saving time and the risk of ineffective research down the line. Patients and members of the public can help with a range of things, including:

- Reviewing study materials such as participant information sheets, consent forms, recruitment adverts to ensure that these are accessible and easy to understand.
- Considering how a research study, product or intervention might be perceived by a range of patient groups.
- Considering the design of the study, for example whether the outcomes measured will cover the things that are important to patients.
- Considering how the research design may fail to meet the needs of marginalised and underserved groups.
- Considering the feasibility of participation for potential participants.

Supporting the impact of the research

Working with patients and members of the public from the beginning can increase the impact of the research, including implementing a technology or intervention into clinical care and sharing the results of the research.

Patients and the public can also be involved in creating the information and methods that you use to share the outcomes of your project and disseminate your findings. This can help to improve the adoption and implementation of your research.

At a very practical level, meaningfully involving patients from the beginning is important when applying for research funding and grants as funders are increasingly requiring applicants to demonstrate that they have worked with patients on the research.

Working with patients and members of the public on your application can help demonstrate the importance of the topic to the funding panel.

What is patient and public involvement and why does it matter?

Healthtalk

Video: getting involved in research

Getting involved in research - YouTube

Involving the public in research engagement and communication

Involving the public 5 steps guide.pdf (nihr.ac.uk)

Levels of involvement

There are different ways to involve patients and members of the public within research. These are all valuable in some situations and can help you to involve different groups. However, it is useful to be clear about the different types to avoid confusion, or overstating the amount of involvement people have had.

We encourage true co-production and collaboration with patients and members of the public where possible.

There are different methods and ways of involving people in your project. Which you choose will depend on what works best in your project, and will need to take into account resources such as budgets.

Choosing your patient involvement method

Choosing your patient involvement method | Cancer Research UK

Consultation

Consultation activities are usually one-off opportunities for patients or members of the public to provide feedback or input on an activity.

Some examples of these activities are:

- Someone reviewing a lay summary and commenting on the language.
- Someone reviewing the design of the study and providing suggestions about how to improve the recruitment strategy.
- Someone attending a workshop to provide a lived experience perspective on a health technology.

Collaboration

In collaborative ways of working, patients and members of the public are involved throughout the project and give input at multiple stages. They have input on the project and are given updates but are at the periphery of the research team and may not be involved with all decisions.

Some examples of these activities are:

- Involving people on an advisory board throughout a project to have input at each stage.
- Someone is involved with designing a health app. They provide feedback at different stages.

Co-production

Patients and members of the public are involved as true equals in projects that use co-production techniques. This addresses the power dynamics and helps to support a true equal partnership.

Patients should be involved from the beginning and involved with setting the questions.

Co-production activities might include:

- Designing a resource with a local charity group, you work together as equal partners.
- Someone helps to develop a health app; they are involved as a colleague and all decisions are jointly made.

Ladder of co-production. This resource describes a series of steps towards full co-production in health and social care.

Ladder of Coproduction | TLAP | social care (thinklocalactpersonal.org.uk)

NIHR guidance on co-production

NIHR Guidance on co-producing a research project (learningforinvolvement.org.uk)

Co-Production Collective: the value of co-production

63925edd5a30c19953d90fed_ValueCoPro_InteractiveSummaryFinal.pdf (website-files.com)

Co-production Collective and People's Voice Media: Co-Pro Stories

Co-Pro Stories: Exploring Lived Experiences of Co-production | UCL UCL Public Engagement Blog

Supporting lived experience leadership

As well as involving patients and members of the public in your research, it's also vital to support and provide resource for communities and people with lived experience to move into leadership roles, as insider or lived experience researchers, and to undertake initiatives that meet their own aims, goals and priorities.

I don't want a seat at your table

I don't want a seat at your table: co-production in mental health services - NSUN website

Lived experience leadership

Lived Experience Leadership - Mapping the Lived Experience Landscape in Mental Health (2021) - NSUN website

Putting people with lived experience in the lead - NPC (thinknpc.org)

How the NIHR South West PPIE teams can help you

The University of Exeter host a number of NIHR funded research centres and infrastructures. To support the mutual benefit of each of these, their research, and to benefit patients and members of the public, we have a model of close collaboration between teams.

We place patients and the public at the heart of what we do, ensuring that people have a right to help shape publicly funded research and have the opportunity to make decisions, shape, and learn about research. We need you to help us make sure that research is the best and most relevant it can be.

PenARC PPIE strategy

PenARC Public Engagement strategy 2019-24 draft v2.0 (nihr.ac.uk)

BRC and CRF PPIE strategy

PPIE strategy - Exeter Biomedical Research Centre (nihr.ac.uk)

Our Involvement Groups

The NIHR BRC, PenARC and HRC all have core involvement groups and include patient representatives in their governance structures. These groups are primarily involved with core aspects of the running of the centres as well as being involved with specific projects and ad hoc opportunities. There are also other involvement groups across the University, involving people with specific experiences or supporting particular types of research.

PenPEG (involvement group for the Applied Research Collaboration, PenARC):
PenPEG - PenARC (nihr.ac.uk)

BRC Involvement Group (involvement group for the Biomedical Research Centre): Contact involvement@exeter.ac.uk

HRC Involvement Group (involvement group for the HealthTechnology Research Centre): Contact involvement@exeter.ac.uk

APEx (involvement group for the School of Primary Care): Contact involvement@exeter.ac.uk

PPIE Groups at the University of Exeter: PPI Groups at the University of Exeter (exeter.ac.uk)

RDUH Genomics Service group: Contact here: rduh.swgmsaadmin@nhs.net

PPIE in the Clinical Research Facility: https://exetercrfnihr.org/public-and-patients/patient-and-public-involvement-ppi/

Ideas Cafes

Ideas cafes are online meetings held with public collaborators to give researchers an opportunity to present their research to a group of members of the public and seek feedback on elements of the research. These are helpful at the early stages of developing a grant application.

The research ideas presented may cover a wide range of topics and methods. As a result, the public collaborators may not have experiences which directly relate to your research and therefore provide more general feedback. These ideas cafes shouldn't be the only patient involvement you do but are a useful starting point to learn more about working with patients and members of the public.

More information and booking onto an Ideas Café: PPIE Support - Exeter Biomedical Research Centre (nihr.ac.uk)

Advice and guidance

Please contact a member of the PPIE team if you have a query you would like to discuss. The PenARC and APEx teams also offer advice clinics, which are meeting with a member of PPIE staff to discuss questions you have about patient involvement and give feedback and advice on developing you plans for patient involvement for your research project or grant application.

Please contact us on **involvement@exeter.ac.uk**

You can book an Advice Clinic slot here: APEx PPI Advice Clinic Tickets, Multiple Dates | Eventbrite

PPIE advice clinics - PenARC (nihr.ac.uk)

Training and events

Throughout the year we offer some training opportunities and events, please keep an eye on our websites for updates on upcoming events.

Previous events and training have included:

- PPIE summer school
- Introduction to PPIE
- PPIE in health economics
- Lay summary training

The practicalities: how do I involve patients in research?

This section covers some of the basic, practical questions we are regularly asked, including:

- How to find the right people to be involved with your research
- How to hold public involvement meetings
- How to make payments
- How to measure the impact of patient and public involvement

When in the project can I involve patients?

You can (and should) involve patients and members of the public throughout your research or product/technology development, including from the early stages.

The image on the next page shows the research cycle and NIHR provide guidance for working with patients and members of the public at each of these stages here: Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR

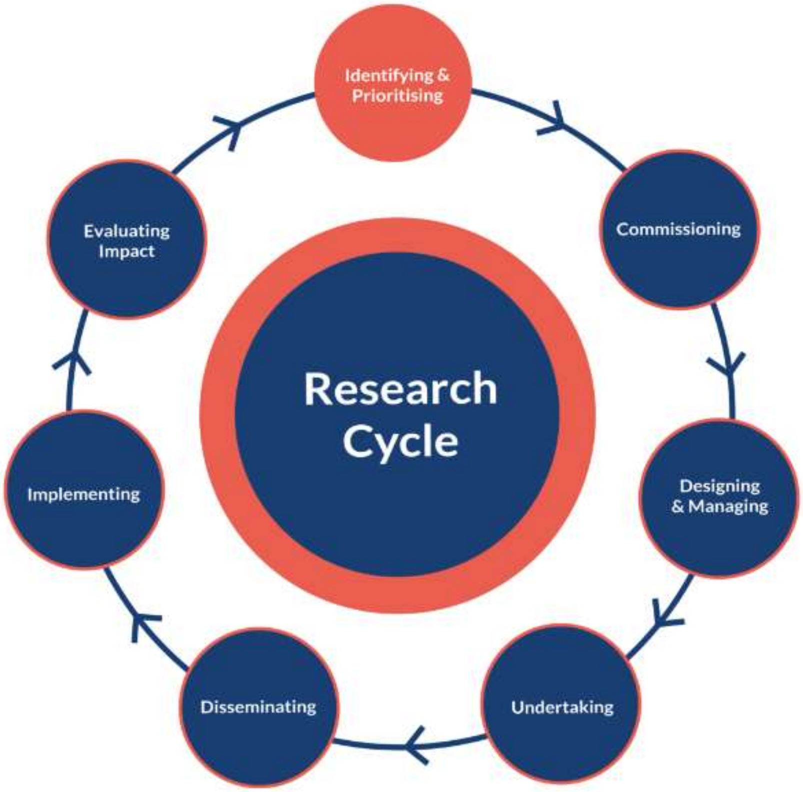

Image from: [Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR]

Planning involvement in your project

Before involving patients and members of the public in your research, you will need to plan who you are going to involve, how and when.

You may benefit from attending an initial PPIE Ideas Cafe (see page 9), or speaking with a member of the PPIE staff team (see page 9 for information on how to book an Advice Clinic with the ARC or APEx teams, or contact involvement@exeter.ac.uk).

PPIE planner

PPIE Planner (plan4ppie.com)

How do I find people to be involved with my research?

Who to involve

- Think about the patient group(s) your research relates to. Are there specific people within this population you'd especially like to hear from? For example, people living in rural areas, people from ethnic minorities or LGBTQ people?
- Think about how you can make the opportunity accessible for a wide range of people.
- Try to ensure that you work with people with a range of perspectives and experiences.
- You may want to make sure you are working with people with different types of perspectives, for example working with family carers as well as individuals with a specific condition.

Approaches to recruitment

You can use a formal recruitment process or an informal process. A formal process would be more akin to a job role with a role description, person specification and interview process.

These each have strengths and benefits. For example, a more formal process may be off-putting for people, but a less formal process may make it hard to ensure that people have the type of experience you require or be difficult if you receive high levels of interest.

If you receive multiple responses, there needs to be a clear and transparent process for selection. For example:

- "First come, first served"
- Based on (informal) interview
- Random selection
- Selection based on need (e.g. representing particular groups).

How to advertise

- We have a large mailing list and we can share adverts for you.
- Speak with colleagues who may already have links and connections with patient or community groups.
- Work with patient advocacy or support groups related to the topic.
- Plan ways to advertise online and in-person. Using a few different methods to advertise can help respond to the limitations of each route.
- Remember, it can take time to build trust, but investing time into building relationships with patients and members of the public can reduce barriers to involvement.

What to include in the advert

- A clear outline of what the project is.
- Outline what the commitment is (e.g. 4, 2-hour meetings per year or approx. 2 hours per week) .
- The duration of the project (e.g. 5 years)
- What lived experience(s) are you looking for people to have?
- What skills and experience do you require applicants to have?
- Outline what you are offering in terms of payments and expenses.
- Be clear about how people can get involved and who to contact with applications and for questions. Include a deadline.
- Outline how you will select applicants, will there be an interview or formal process?

Example recruitment poster for a workshop

Example role description for a lay member of project steering committee

Example email request for an involvement activity

Working with patient advisory groups

Working with a patient advisory panel in your research | Cancer Research UK

What to do next

Once people have applied for the role you can have interviews or informal meetings to select who to work with. (You need to be clear about how you will select people when you advertise).

- Respond promptly to thank them for their input. If you don't think they would be suitable, be clear about this and if possible direct them to where they can hear about other opportunities.
- It is helpful to have an initial informal meeting with public collaborators to enable you to establish a relationship with them and ensure that they understand what is being requested.
- Ask people about any accessibility needs and communication preferences so you know how to support them and best facilitate their involvement.

Training for public collaborators

https://www.learningforinvolvement.org.uk/wp-content/fancygallery/Mod3_2020/story.html

How do I hold patient involvement meetings?

Before the meeting, make sure you have thought about what you hope to get out of it. It's important to have some structure so people know what they are being asked to do.

Providing information ahead of time can help people to prepare for the meeting. If you would like people to do preparation or follow-up outside a meeting, make sure the payment rates you offer reflect this.

Should I have a meeting online, in-person or hybrid?

There are advantages and disadvantages of online and in-person meetings. You should think this through carefully so you know which option is most appropriate.

Hybrid meetings can give you 'the best of both worlds' but require additional considerations to ensure that both online and in-person attendees can get the most out of the meeting.

Advantages of online vs in-person meetings

Online	**In-person**
You can reach people nationally or across a wider area. Can be more accessible for people living in remote areas with poor transport connections. These can be simpler to organise logistically and lower cost.	In-person events can be more accessible for people without access to internet or with low digital skills. You may be able to build a stronger connection with participants. It can be easier to ensure that attendees are safe and managing difficult conversations if your research is on a sensitive topic.

A combination of online and in-person meetings is often beneficial. If you hope to reach a large group, you may be able to reach different attendees for each forum or you could alternate between online vs in person meetings to get the benefits of each.

When to hold meetings

Evening meetings may work for public collaborators who work full time but may be more difficult for those with caring responsibilities. Try to find the most suitable time for your attendees. Again, alternating times can help to ensure that different people are able to attend.

What to consider before, during and after a PPIE meeting

It's important to give people enough notice before the date of the event as people have busy schedules alongside their involvement. We encourage researchers to leave at least 3 weeks before the event to advertise or longer for in-person events.

Before	During	After
Consider whether to hold the event online or in-person. Consider timings and location. Ensure the venue is accessible*. Ask about access needs and dietary requirements. Provide pre-reading materials well in advance.	You may want to start the meeting with some ice breakers and outlining some 'ground rules' or meeting etiquette. Has everyone had a chance to speak? Have someone to take notes and keep track of the discussions. Ensure there are sufficient breaks. Keep to time.	Ensure payments and expenses are processed promptly. Thank attendees for their input and provide feedback about how their involvement has helped. Provide opportunities for them to provide feedback on what went well and what could go better.

***Venue accessibility toolkit:**

Venue accessibility checklist - Shaping Our Lives

Additional considerations for online meetings

- Will you have support for people with limited access to technology or limited skills?
- How many people will be in the meeting, will everyone get chance to speak?
- Will you use features such as breakout rooms?
- Will you record the meeting? You will need consent to record and should only record the meeting if you have a clear and specific reason for doing so.

Additional considerations for in-person meetings

- Be aware that you may exclude people who aren't able to travel.
- Think about the accessibility of the space, e.g. wheelchair access, toilet facilities, lighting and acoustics, transport access or access to parking.
- Think about timings to help with travel requirements.

- Consider where you are holding the meeting. It may be off-putting for people to come to the university (or a nice experience for others). Can you meet people where they are within their local communities?

See the NIHR Exeter BRC events toolkit for other tips and considerations for event planning: NIHR Exeter BRC and CRF EDI Event Toolkit | exeterbrc.nihr.ac.uk

How to make meetings interesting and engaging

Meetings might not always be the best way for people to contribute and share their experiences, or there may be barriers for people to engage, such as:

- Being unsure about speaking in front of others.
- Finding it difficult to express thoughts in words, preferring creative ways of expressing themselves.
- Finding formal meetings intimidating.

You can make meetings more interesting and engaging by using creativity to help people feel at ease and be more engaged with discussions.

Ideas for creative ice breakers and session plans:

Liberating Structures - Introduction

Innoplay training, using play in research, education and engagement

Innoplay

What happens after the meeting?

Offer a follow-up after the meeting to thank attendees for their involvement and outline the processes for claiming payments and expenses (see page 18).

Make sure people know how their involved impacted the project. It is helpful to feed back to people after each activity to let them know what you changed as a result of their involvement, or how it has impacted the project. Regular feedback can help people to understand the importance of their involvement and the difference that it has made to your research. This can keep people engaged and make them more likely to get involved with research in the future.

What do I do at the end of the project?

At the end of a project it's important to make sure you thank those who have contributed and consider ways you can feed back on how their involvement improved the research.

You may also want to ask for your public collaborators' input in the development of your next project, and involve them in future work as well.

NIHR guidance on giving feedback to public collaborators

Guidance-for-Researchers-PPI-Feedback_2018.pdf (nihr.ac.uk)

Consider using one of the reporting tools available (see page 19) to record the impact of the patient involvement.

How do I pay members of the public for their involvement?

We advise that patients and members of the public are offered remuneration for their involvement. This recognises the labour put in and demonstrates the value of public collaborators' inputs. Covering expenses and offering payments also ensures that opportunities are open to more people.

We advise researchers to always ensure that they have adequate budgets to pay for public collaborators' time, however, you should also consider other ways that the experience can be mutually beneficial by helping collaborators to develop skills, confidence and experience or providing a platform to highlight local community and patient led work.

NIHR guidance on payments

Payment guidance for researchers and professionals | NIHR

How to budget for patient involvement in a project

When applying for a grant, it's important that you ensure you have adequately budgeted for your PPIE plans. It will be harder to try and access this funding later. This will include payments for public collaborators as well as expenses such as travel, room hire and refreshments.

Budgeting for public involvement

Payment guidance for researchers and professionals | NIHR

Budgeting for your patient involvement | Cancer Research UK

How much should I pay people?

The amount you choose to pay individuals may vary depending on your budgets. Ensure that you have a clear and consistent agreement with the people you're working with about what you are offering.

You may want to align your payment offer with the NIHR South West payment policy: PenARC Participation Payment Policy | arc-swp.nihr.ac.uk

NIHR rates for public collaborators

NIHR public contributor payment policy | NIHR

NHS England guidance on payments for public involvement

Payment for public involvement in health and care research: a guide for organisations on employment status and tax - Health Research Authority (hra.nhs.uk)

What if I don't have the funds to pay people?

The NIHR Research Support Service (RSS) (replacing former Research Design Services) have a number of regionally based services that focus on specific themes. They offer support to researchers in England. You can contact an RSS to request support with funding pre-application PPIE.

Research Support Service

Research Support Service | NIHR

The NIHR South West teams also host Ideas Cafes, which can provide some initial input from members of the public (see page 9).

How do I make payments?

The University of Exeter have processes for making payments to external people as well as options to send physical or electronic gift vouchers if the person prefers this option. There is also an option for payments to be made directly to a charity on behalf of the individual.

If you work for the NHS or another institution, please contact the relevant department for payment processes.

University of Exeter payments guidance

Payments | Finance Services | University of Exeter

Measuring the impact of patient involvement in research

It's important to consider how you will measure the impact and influence your public collaborators have on the research. This helps to evidence the value of public involvement as well as ensuring that you are meaningfully involving people with real opportunities to influence the research. There are a number of useful tools designed to help you monitor and evaluate your public involvement.

For NIHR grant applications, you will be asked to consider how you will record and evaluate your patient involvement.

Evaluating public involvement in research

Guidance on evaluating PPI in research. (.PDF)

Assessing impact of PPI in research

Public Involvement Impact Assessment Framework (PiiAF)

Reporting PPI

GRIPP2 reporting checklists (tools to improve reporting of PPI in research).

Public Involvement in Research Impact Toolkit (PIRIT)

Public Involvement in Research Impact Toolkit (PIRIT) - Marie Curie Research Centre - Cardiff University

Doing patient involvement well

Whilst it's important to involve patients within research, it's also important that this is meaningful. Patients and members of the public should have real opportunities to influence the research. Their feedback should be valued and heard.

Avoiding tokenism

As involving patients in research becomes more of an expectation of research funders or ethics boards, there is a risk that patient involvement is approached as another procedure or 'tick-box' to complete.

Tokenistic patient involvement can look like asking patients to share their experiences without any intent or possibility to use these to influence the research. For example, asking patients to review documents after these have been finalised, without intent to incorporate their feedback.

Tickboxes and Tokenism? Service User Involvement Report 2022

Tickboxes-and-Tokenism-Feb-2022-1.pdf (shapingourlives.org.uk)

Working together against faux-production

Working together against faux-production | Co-Production Collective (coproductioncollective.co.uk)

Avoiding exploitation

Being involved in research can be challenging for patients especially where it requires reflection on or sharing difficult and traumatic experiences. Patient involvement can be unethical or exploitative where people are asked to share intimate details about their experiences without considering the impact this has on them, or taking the time to develop trust and mutually beneficial relationships.

Doing co-production and patient involvement ethically

649c97e8567bf402f07b01f5_Research ethics - A project report.pdf (website-files.com)

Emotional labour

Methodological Issues and Emotional Labour in Co-Produced Research – Urban Transformations (ox.ac.uk)

Giving people enough time to have meaningful input

Researchers often work to tight deadlines and need to work overtime to get applications in for deadlines. However, it's essential to give public collaborators sufficient time when asking them to review documents or input on a project. People will often be involved alongside busy lives, jobs, other roles, health and/or caring commitments.

We recommend giving people a minimum of two weeks to review documents. We will not usually be able to share requests for involvement with less time than this.

Working with a diverse range of people

It's important that you work with a diverse range of people as experiences and perspectives will vary between people. However, if you've spoken to one LGBTQ person, for example, then you've spoken to one LGBTQ person, and you cannot assume that their views are representative of a whole population.

Consider how the way you have designed your public involvement approach may exclude people. For example, if you have only used one method of recruitment, then the advert will not be reaching many people.

Being inclusive in public involvement in health and care research

Being inclusive in public involvement in health and care research | NIHR

Inclusive patient involvement

Reaching Out: A guide to being inclusive in public involvement (learningforinvolvement.org.uk)

EDI Toolkit | RSS Leicester

EDI Toolkit | rssleicesterresources.org

How to incorporate Equality, Diversity and Inclusion (EDI) in Patient and Public Involvement (PPI)

How to incorporate Equality, Diversity and Inclusion (EDI) in Patient and Public Involvement (PPI) | YouTube

Frequently asked questions

Do I need ethical approval for patient involvement?

Patient involvement is not research and therefore you do not need to obtain ethical approval. If you want to do formal research, conduct interviews and analyse the responses, this is qualitative research and you will need ethical approval.

Although you don't need ethical approval to work with patients and members of the public you do need to work with people in an ethical and supportive way.

Do I need ethical approval for my project tool:

40900_2024_617_MOESM2_ESM.pdf (springer.com)

The difference between patient involvement and qualitative research:

Qualitative research and public involvement: What are the differences? (learningforinvolvement.org.uk)

I am not collecting primary data, do I still need to involve patients?

If your research looks at data which has been previously collected (for example an epidemiological study using data from a longitudinal study or a systematic literature review) you may be less sure about how to involve patients. However, there are still many ways you can work with patients in your study. There are also many ways to explain research in simple plain language.

PPI guidance, including on lab-based research

https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home

PPI Guidance for Researchers.pdf (parkinsons.org.uk)

How do I manage difficult situations with public collaborators?

Sometimes difficult situations can arise when working with patients and members of the public. These situations can often be resolved through informal discussions but leaving these unresolved may risk the issues developing further.

It can be helpful to pre-empt issues by outlining some 'ground rules' or commitments and expectations at the beginning of the project.

- Facilitate discussions with the people involved, listen and openly discuss the matter.

- Allow reflection, acknowledge mistakes and use the situation as a learning process.
- Keep people updated about actions, changes and decisions in relation to the concern.

If you are unable to resolve the issue, you are welcome to contact involvement@exeter.ac.uk to discuss the matter further and explore solutions.

Resources

UK standards for public involvement

UK Standards for Public Involvement (google.com)

What is patient involvement in research?

Healthtalk

Video: getting involved in research

Getting involved in research - YouTube

Involving the public in research engagement and communication

Involving the public 5 steps guide.pdf (nihr.ac.uk)

Levels of Involvement

Choosing your patient involvement method | Cancer Research UK

Co-Production in Research

Ladder of co-production. This resource describes a series of steps towards full co-production in health and social care. Ladder of Coproduction | TLAP | social care (thinklocalactpersonal.org.uk)

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Co-production Collective and People's Voice Media: Co-Pro Stories

Co-Pro Stories: Exploring Lived Experiences of Co-production | UCL UCL Public Engagement Blog

Lived Experience Leadership

I don't want a seat at your table: I don't want a seat at your table: co-production in mental health services - NSUN website

Lived experience leadership: Lived Experience Leadership - Mapping the Lived Experience Landscape in Mental Health (2021) - NSUN website

Putting people with lived experience in the lead - NPC (thinknpc.org)

How the NIHR South West Peninsula PPIE team can help you

NIHR Southwest PPIE Strategies

PenARC PPIE strategy

PenARC Public Engagement strategy 2019-24 draft v2.0 (nihr.ac.uk)

BRC and CRF PPIE strategy

PPIE strategy - Exeter Biomedical Research Centre (nihr.ac.uk)

NIHR Southwest Involvement Groups

PenPEG (involvement group for the Applied Research Collaboration, PenARC)

PenPEG - PenARC (nihr.ac.uk)

PPIE Groups at the University of Exeter: PPI Groups at the University of Exeter (exeter.ac.uk)

RDUH Genomics Service group: Contact here**:** rduh.swgmsaadmin@nhs.net

PPIE in the Clinical Research Facility**:** https://exetercrfnihr.org/public-and-patients/patient-and-public-involvement-ppi/

Ideas Clinics and Advice Cafés

Ideas Café: PPIE Support - Exeter Biomedical Research Centre (nihr.ac.uk)

Book an Advice Clinic slot here: APEx PPI Advice Clinic Tickets, Multiple Dates | Eventbrite

PPIE advice clinics - PenARC (nihr.ac.uk)

NIHR guidance on PPIE

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

How do I involve patients in research?

Recruitment

PPIE Planner (plan4ppie.com)

Example recruitment poster for a workshop

Example role description for a lay member of project steering committee

Example email request for an involvement activity

Working with patient advisory groups

Working with a patient advisory panel in your research | Cancer Research UK

Training for public collaborators

https://www.learningforinvolvement.org.uk/wp-content/fancygallery/Mod3_2020/story.html

Meetings and Events

Venue accessibility toolkit:

Venue accessibility checklist - Shaping Our Lives

NIHR Exeter BRC events toolkit for other tips and considerations for event planning: NIHR Exeter BRC and CRF EDI Event Toolkit | exeterbrc.nihr.ac.uk

Ideas for creative ice breakers and session plans:

Liberating Structures - Introduction

Innoplay training, using play in research, education and engagement

Innoplay

NIHR guidance on giving feedback to public collaborators

Guidance-for-Researchers-PPI-Feedback_2018.pdf (nihr.ac.uk)

How do I pay members of the public for their involvement?

NIHR guidance on payments

Payment guidance for researchers and professionals | NIHR

Budgeting for public involvement

Payment guidance for researchers and professionals | NIHR

Budgeting for your patient involvement | Cancer Research UK

You may want to align your payment offer with the NIHR South West payment policy: PenARC Participation Payment Policy | arc-swp.nihr.ac.uk

NIHR rates for public collaborators

NIHR public contributor payment policy | NIHR

NHS England guidance on payments for public involvement

Payment for public involvement in health and care research: a guide for organisations on employment status and tax - Health Research Authority (hra.nhs.uk)

Research Support Service

Research Support Service | NIHR

University of Exeter payments guidance

Payments | Finance Services | University of Exeter

Measuring the impact of patient involvement in research

Evaluating public involvement in research

Guidance on evaluating PPI in research. (.PDF)

Assessing impact of PPI in research

Public Involvement Impact Assessment Framework (PiiAF)

Reporting PPI

GRIPP2 reporting checklists (tools to improve reporting of PPI in research).

Public Involvement in Research Impact Toolkit (PIRIT)

Public Involvement in Research Impact Toolkit (PIRIT) - Marie Curie Research Centre - Cardiff University

Doing patient involvement well:

Tickboxes and Tokenism? Service User Involvement Report 2022

Tickboxes-and-Tokenism-Feb-2022-1.pdf (shapingourlives.org.uk)

Working together against faux-production

Working together against faux-production | Co-Production Collective (coproductioncollective.co.uk)

Doing co-production and patient involvement ethically

649c97e8567bf402f07b01f5_Research ethics - A project report.pdf (website-files.com)

Emotional labour

Methodological Issues and Emotional Labour in Co-Produced Research – Urban Transformations (ox.ac.uk)

Being inclusive in public involvement in health and care research

Being inclusive in public involvement in health and care research | NIHR

Inclusive patient involvement

Reaching Out: A guide to being inclusive in public involvement (learningforinvolvement.org.uk)

EDI Toolkit | RSS Leicester

EDI Toolkit | rssleicesterresources.org

How to incorporate Equality, Diversity and Inclusion (EDI) in Patient and Public Involvement (PPI)

How to incorporate Equality, Diversity and Inclusion (EDI) in Patient and Public Involvement (PPI) | YouTube

Frequently asked questions

Do I need ethical approval for my project tool:

40900_2024_617_MOESM2_ESM.pdf (springer.com)

The difference between patient involvement and qualitative research:

Qualitative research and public involvement: What are the differences? (learningforinvolvement.org.uk)

PPI guidance, including on lab-based research

https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home

PPI Guidance for Researchers.pdf (parkinsons.org.uk)

NIHR involving patients in research training modules

Mod 1_Mod text enabled (learningforinvolvement.org.uk)

NIHR Academy | NIHR