



# A Rough Guide to Public Involvement

Produced by the NIHR Imperial BRC Patient Experience Research Centre (PERC)

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## 1. INTRODUCTION

This Rough Guide had been designed to supplement our online [Public Involvement Resource Hub](#) and the overall public involvement process (**see p 5**) by providing more practical guidance on the following:

### WHEN

Identify an opportunity where you can involve patients and/or the public in your research project.

- Public involvement can provide benefits at all seven stages of the research cycle (**Fig 1**) – see the summary table of public involvement opportunities on **p 8-10** of this guide.



*Fig 1. Adapted from National Institute for Health and Care Research (NIHR)*

### WHY

Be clear about what you are hoping to get out of involving the public in your research – what difference or impact do you want it to have?

- The National Institute for Health and Care Research (NIHR) provides a useful overview of [why researchers should involve members of the public in their research](#).
- The summary table on **p 8-10** highlights some of the key benefits reported by people who have involved patients or the public at the different stages of the research cycle. These may help you decide what it is you want to achieve from public involvement. Read [Section 3](#) of this guide for more.

### WHO

It's essential to know who you want to involve, how you're going to reach them and why they're the appropriate people to do the task or role you have in mind.

- Read [Section 4](#) of this guide for further insight on this.

### HOW

Once you know the context in which your public involvement is going to be set and who you'd like to involve, you now need to plan how people will be involved and what they'll do.

- Read [Section 5 & 6](#) of this guide for more practical tips. Example public involvement activities for different stages of research can be found in the summary table on **p 8-10** and online.

### EVALUATE

Understanding the impact of public involvement on your research, and those involved, allows you to learn and progress from the benefits and the challenges.

- Read [Section 7](#) of this guide for more details. Remember: it's good practice for the public involved in the project to have an active role in the evaluation process too.

## **SHARE**

Sharing your public involvement work and its impact with those you involved and your colleagues not only helps your efforts and impact go further, but it makes those involved feel valued and adds to the growing evidence base from which others can learn and progress.

Read [Section 8](#) of this guide for more information.

For more detail on any of these sections, visit the online [Public Involvement Resource Hub](#).

## **2. GETTING STARTED WITH PUBLIC INVOLVEMENT**

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### **2.1 A Recap of Key Definitions**

The difference between ‘Public Involvement’ and ‘Public Engagement’ can be confusing, and different funders also use these terms to mean different things. ‘Co-production’ is being used more commonly in research and although not appropriate for all projects, you should know how it differs from public involvement and public engagement.

Officially the [NIHR](#) define these as follows:

**Patient and public involvement (PPI) now referred to as ‘public involvement’:**

*‘An active partnership between patients and the public and researchers in the research process, rather than the use of people as ‘subjects’ of research.*

*Patient and public involvement in research is often defined as doing research ‘with’ or ‘by’ people who use services rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on, and developing research materials, and undertaking interviews with research participants.*

*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 organisations that represent people who use services.’*

**Public engagement:**

*‘Ways in which research can be shared with the public in a two-way process. Engagement encourages researchers to listen and interact with the general public, for example, via science festivals, open days, media coverage.’*

Both public involvement and public engagement are distinct from...

## Participation:

*'Taking part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.'*

## Co-production:

This is a term which you will increasingly hear in relation to involving the public in research.

*'Co-producing a research project is 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.'*

There are five key principles for co-production: sharing power, including all perspectives and skills, respecting and valuing the knowledge of all, reciprocity, and building and maintaining relationships.

For further information, see [PERC's webpage on co-producing research](#) and for inspiration see the [co-production case studies](#) on the PERC blog.

## Other co-production guidance and resources

- NIHR Learning for Involvement: [Co-production resources](#)
- NIHR's Guidance on [co-producing a research project – April 2021](#).
- [PERC's peer research training resource](#): A training resource developed by PERC to train people with lived experience to become co-researchers in qualitative/interview-based research studies
- [Participatory research study on COVID-19 experiences among people living with HIV](#)
- [Improvement Science Snapshot – Co-production of applied health and research \(NIHR ARC Yorkshire and Humber\) \(video\)](#)
- [CCopeY: A Mixed-Methods Coproduced Study on the Mental Health Status and Coping Strategies of Young People During COVID-19 UK Lockdown \(paper\)](#)
- [Co-production in research: co-researcher perspectives on its values and challenges \(paper\)](#)
- Example of co-production project: [Could bird songs help boost engagement with hearing tests? \(blog\)](#)
- Example of co-production project: [Why did nobody ask us?! Reflections and findings from co-produced research into children's vaccine uptake. \(blog\)](#)
- Example of co-production project: [HIV Co-production Showcase: Sharing learning from a participatory research project \(blog\)](#)

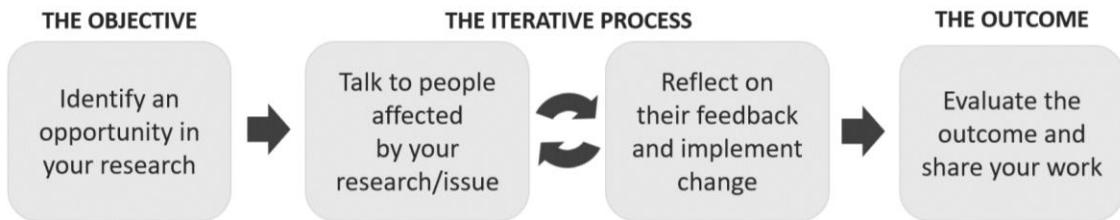
### A small note on: DEFINITIONS

'Patient and Public Involvement' is now more commonly called '**Public Involvement**'. This is because the term '**public**' is considered by the NIHR to include: '*patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services*'. They also note that, '*Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.*'

## 2.2 An Overview of the Public Involvement Process

Public involvement in research doesn't need to be complicated. The key thing to remember is that involvement is a mechanism that fosters communication with people who have experience of, or are affected by, specific health issues. This ensures their voice and insight helps to inform translational research.

In its most basic terms, the public involvement process looks like this:



There are many opportunities throughout the research cycle to involve people although these may differ slightly between research projects. It is up to you as a researcher to plan how you will involve people, identify who will provide insight into these aspects of your research so you can involve them, find them (we can help but building relationships with members of your research population from a very early stage is integral), plan how you'll go about getting started, and how you'll evaluate the impact and share your outcomes at the end.

All the content provided on our [Resource Hub](#), in the [case studies on our blog](#), and within this Rough Guide have been designed to help you get going with this process.

### A small note on: the Data Protection Act 2018

When collecting names, contact details (and perhaps even “sensitive data” in the form of the health condition they live with) of members of the public for future use (i.e. to invite them to other involvement opportunities) or continuing public involvement activities, these need to be kept securely and the use to which they are put made clear.

The policies which apply to the retention and use of this data may vary depending on your department.

Please be aware that the Data Protection Act 2018 came into force and replaced the Data Protection Act 1998 on 23 May 2018. The provisions of the EU General Data Protection Regulation (GDPR) have been incorporated directly into UK law as the UK GDPR. For most organisations, the UK GDPR is the law to turn to first however, the Data Protection Act 2018 supplies a lot of the detail about how privacy law will apply to the UK specifically and sectors / types of activity. PERC has a Privacy Notice on our Resource Hub which has been created to cover people consenting to sign up to public involvement and engagement activities.

See [Imperial's data protection guides](#) for guidance.

## 2.3 Funding Public Involvement

Public involvement is now a requirement of almost all funders. Therefore, any costs associated with public involvement (e.g. activity costs, rewarding people for their time – (see **6.4 Rewarding People for their Time**) should be budgeted for within your research grant, or funded through alternative sources.

### 2.3.1 NIHR Payment Guidance for Public Involvement

Launched in 2020, the National Institute for Health and Care Research's (NIHR) [Centre for Engagement and Dissemination](#) released payment guidance for both [researchers](#) and [members of the public](#) that are regularly updated and can be accessed on the NIHR website. This guidance also addresses the impact of members of the public [receiving payment while on benefits](#), for which further advice should be sought on a case-by-case basis.

### 2.3.2 Top tips for writing about public involvement plans in funding applications:

1. Check the definition of 'public involvement' and 'public engagement' used by the funder and use the same one. Some funders use 'public engagement' to capture 'public involvement', such as the Economics and Social Research Council and the Wellcome Trust. As of 27 November 2024, the NIHR funding applications now use 'Working with people and communities' as one collective term encompassing public involvement; public and patient involvement; and community engagement and involvement.
2. Make sure the plain English summary *is* plain English. Invite a member of the public to check it for readability. If you're unsure or need more guidance, visit [NIHR's Plain English summaries](#). [Remember that 1 in 7 adults in the UK have a literacy level of a 9 to 11 year old](#)<sup>1</sup>.
3. Make sure your proposed public involvement plans are relevant to your research and remember to include anything you have already done that contributes to your plan and how it informed or changed the plan and be specific (e.g. '...held initial discussions with patients with scope for further involvement'; '...discussed the acceptability of research methods...').
4. Don't be over ambitious in your planning – there's nothing wrong with keeping it simple, especially if this is your first-time involving members of the public!
5. Highlight why the people you wish to involve are appropriate to give insight into the project (e.g. they reflect your target population, have lived experience of your research area or are a carer for someone who does), how you plan to promote diversity and inclusivity in those you involve and how you will support those you involve (e.g. offering relevant training and other support).
6. Work out the costs and include them in your budget, i.e. rewarding people for their time, travel expenses, childcare and carer expenses (if applicable) refreshments, Wi-Fi costs (if involvement is virtual) and room hire. It may be useful to look at NIHR's advice on '[Budgeting for Involvement](#)' for guidance and categories of expenses.
7. Refer to any planned public involvement in other parts of your application so that it is clear you consider that public involvement is part of, and integral to, the whole research process (e.g. in

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<sup>1</sup> <https://literacytrust.org.uk/parents-and-families/adult-literacy/what-do-adult-literacy-levels-mean/>

your dissemination plans, how you will achieve impact, etc.). It will usually be linked to research inclusion which is not a requirement for NIHR applications from November 2024 (see below).

8. Only name a member of the public as a public co-applicant if they are aware of what this role involves and have agreed to act in this role a
9. -you are expected to involve them throughout the project as you would involve an academic co-applicant, not just at a certain point in the project. For more information on public co-applicants read the NIHR's "[Public Co Applicants in Research Guidance](#)"
10. Be authentic because members of the public experienced in public involvement sit on funding panels too.
11. Never cut and paste from public involvement websites – the reviewers will recognise plagiarism.

### **2.3.3 Research inclusion as a condition of NIHR funding**

As of 27 November 2024, applicants to all NIHR Domestic Programmes and Career Development Awards are now required to demonstrate how inclusion has been built into all stages of the research cycle and costed for as a condition of funding. Public involvement is one way in which your approach to research inclusion should be informed.

## 2.4 An Overview of Public Involvement Opportunities in Research

[Content source: [PERC](#), [NIHR](#) and [PiiaF Database](#)]

Ideally researchers will be able to involve patients or the public at every stage of their research project, however depending on the project and its complexity, involvement may not be possible at all stages. First understand what you want to achieve with public involvement, and then work out the most appropriate way to meet your goals effectively and efficiently. Evidence suggests that involvement has the greatest impact when people are involved throughout the entire research project rather than at one discrete stage. Being involved from the start creates a sense of ownership over the research, which often translates into greater commitment. Even if involvement is not possible at any other stage, the public can always be involved in providing advice on the plan for dissemination of results and the best ways and places to ensure the research population hears about these in ways accessible to them.

WHEN: Research stage	WHY: Reasons to involve people	HOW: How to involve people	HOW: Real-life examples
<b>1: Identifying &amp; Prioritising</b>  <a href="#">See more online</a>	<ul style="list-style-type: none"> <li>Identify unmet needs and novel research areas</li> <li>Align research focus with patient/public interest</li> <li>Sense check theories and ideas</li> <li>Increase likelihood of funding</li> <li>Maximise your 'pathway to impact' from the start of your project</li> </ul>	<ul style="list-style-type: none"> <li>Contact local user groups or patient forums to help inform your research priorities</li> <li>Listen to people's own experiences and unmet needs to inspire novel research questions</li> <li>Adopt a published model or approach for involving the public in agenda setting research, e.g. James Lind Alliance Priority Setting Partnership (JLA PSP)</li> <li>Check whether priorities have already been set in a published model e.g. JLA PSP</li> </ul>	<ul style="list-style-type: none"> <li><a href="#">James Lind Alliance Priority Setting Partnership</a></li> <li><a href="#">The Dialogue Model</a></li> <li>The Delphi Method <a href="#">case study</a></li> <li>See the <a href="#">Action Catalogue</a> for more inspiration</li> <li>Paper: <a href="#">Beyond the role of participant: a first-hand account of the experiences of a patient-oriented research team</a></li> </ul>
<b>2: Funding &amp; Commissioning</b>  <a href="#">See more online</a>	<ul style="list-style-type: none"> <li>Help explore clinically important research areas</li> <li>Align research with public interest/patient need</li> <li>Speed up the funding process</li> <li>Give greater credibility to your research proposal</li> <li>Open-up funding opportunities from patient organisations and charities</li> </ul>	<ul style="list-style-type: none"> <li>Involve the public in reviewing lay summaries, research proposals and public involvement plans, making sure appropriate costs are allocated</li> <li>Invite people to identify possible ethical issues and the acceptability of the proposal</li> <li>Offer an active role in developing the research grant application</li> <li>Connect with organisations representing patient groups or conditions who commission research</li> </ul>	<ul style="list-style-type: none"> <li>Online public involvement discussion on a '<a href="#">Healthy Homes Hub</a>' proposal to UKRI/NIHR</li> <li>Online public involvement session on <a href="#">proposed cardiovascular research programmes</a>.</li> <li>See the <a href="#">Action Catalogue</a> for more inspiration</li> </ul>
<b>3: Designing &amp; Managing</b>	<ul style="list-style-type: none"> <li>Improve the relevance, clarity and feasibility of your research design and outcome measures</li> <li>Improve the reliability of your research tools</li> </ul>	<ul style="list-style-type: none"> <li>Invite people to review your research protocol for potential challenges, as well as highlight new areas for further patient/public involvement</li> </ul>	<ul style="list-style-type: none"> <li><a href="#">Case study: The Healthy Start, Happy Start Study</a> (PERC's blog)</li> </ul>

- Improve the diversity of participants
- Improve the recruitment plan & process, participant experience and response/retention rates
- Speed up the research and ethics approval process

[See more online](#)

- Give the public/patients an active part in developing and reviewing your research tools for accessibility and relevance, including questionnaires, information sheets and consent forms
- Work with the public on your recruitment and dissemination strategy
- Give the public relevant roles in governance i.e. monitoring and managing elements of the research process or project.

- [Case study: Young People in Psych Research Group \(iMAGine study\)](#)
- [Case study: Involving women to design and develop research into early onset pre- eclampsia \(PERC's blog\)](#)

#### 4: Undertaking & Analysing

- Improve the quantity, quality and relevance of data collected
- Improve the honesty, reliability and depth of responses or patient insight
- Enrich and improve the quality of your interpretations and conclusions
- Increase the likelihood of publication in a peer-reviewed journal

[See more online](#)

- Involve the public/patients in performing library-based research or reviewing documentary evidence
- Involve the public/patients in carrying out interviews and surveys or running focus groups
- Get the public/patients to code interview transcripts or assist you in developing missing themes from your data
- Consult the public/patients to see if they interpret the data differently to the research team

- [Case Study: Involving teenagers in research about the environment and mental health](#)
- [Paper: Patient involvement in qualitative data analysis](#)
- See the [Action Catalogue](#) for more inspiration
- From research idea to interpreting findings: [How young people have shaped the Behaviour in Schools Study](#)

#### 5: Disseminating

- Improve the translation of the research by using language and messages that are more easily understood by a public audience & in languages accessible to them
- Help reach wider, more diverse scientific and public audiences
- Increase the power and credibility of your message and raise the profile of your research
- Improve the likelihood of your research being continued, adopted or implemented

[See more online](#)

- Involve the public/patients in developing/reviewing the dissemination strategy and plain language summary of findings to ensure they are clear and accessible to all, including languages into which these should be translated for your research population
- Invite those you involve to speak at conferences, or to patients, groups or service providers, as well as assist the process by distributing results in accessible formats relevant to them through their informal networks
- Give those you involve an active part developing print and digital content accessible to those it is targeted

- [Case study: You and your hormones \(PERC's blog\)](#)
- Paper: [CCopeY](#)
- See the [Action Catalogue](#) for more inspiration

**6: Implementing**[See more online](#)

- Help your project's results be implemented and have greater impact
- See your work reach and be adopted by more diverse groups
- Improve public opinion, acceptance or insight into your research area
- Raise your team/organisation's profile, which may improve future funding opportunities
- Get assistance from public/patient groups in lobbying for change or funding of an intervention
- Encourage patient organisations to register as stakeholders with regulators such as the Medicines Healthcare Regulatory Authority (MHRA) and National Institute for Health and Care Excellence (NICE) who licence and approve payment for new drugs and devices
- Ask people you involve for ideas on creative ways to implement or maximise impact of work
- [Case study: Developing the iKnife](#) (PERC's blog)
- [Case study: Developing MatImm – an immunisation smartphone app](#) (PERC's blog)
- See the [Action Catalogue](#) for more inspiration
- Paper: [Patient advocacy group involvement in health technology assessments: an observational study](#)

**7: Evaluating**[See more online](#)

- Gain a wider range of perspectives on the research process and impact
- Demonstrate the power of societal and multi-disciplinary collaboration
- Improve the evidence base for best practice in undertaking public involvement
- Identify challenges in undertaking public involvement to assist in finding solutions
- Allow a more critical evaluation of the research project and public involvement activities
- Involve public contributors in determining how you will monitor and evaluate the research project, and their involvement in this
- Collaborate with the public/patients to evaluate the research process, including any barriers that arose
- Get those you involved to reflect on their role, what they have learned and what impact they feel they had
- Oxford BRC [Evaluating PPI Framework](#)
- [Public involvement in research: assessing impact through a realist evaluation](#)
- See the [Action Catalogue](#) for more inspiration
- [Public involvement in research impact toolkit \(PIRIT\)](#)
- [GRIPP2 reporting checklists](#): tools to improve reporting of patient and public involvement in research
- [Patient and public involvement impact log](#)

## 2.5 Top Tips for Successful Public Involvement

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**TRY TO INVOLVE AS DIVERSE A GROUP OF PEOPLE AS POSSIBLE**

  - Involving people from diverse backgrounds gives the greatest insight into the public perspective of your research and is integral to ensure your research is as representative of your research population as possible – **See p 14 for more**
- 

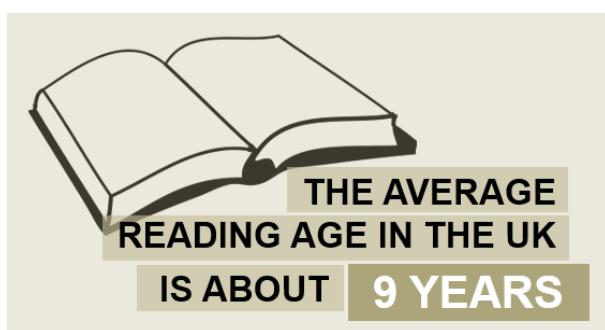
**DO YOUR BEST TO ACCOMMODATE DIFFERENCES**

  - Involving people from diverse backgrounds also means ensuring your involvement activities can accommodate the diversity of needs that they may have

**See p 22 for more.**
- 

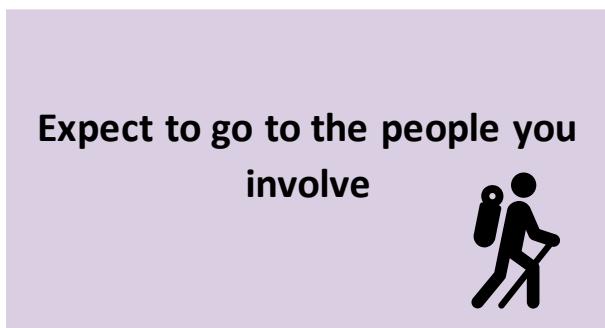
**BE PREPARED TO MANAGE PEOPLES' EXPECTATIONS**

  - People get involved in research for various reasons so make sure you understand what they hope to gain from the experience, but also make sure they understand their role and how you hope they will contribute

**See p 23 for more.**
- 

**THE AVERAGE READING AGE IN THE UK IS ABOUT 9 YEARS**

  - Consider the words and grammar you use when preparing reading and visual materials for patients and members of the public

Visit [NIHR website](#) for help on writing in Plain English.
- 

**Expect to go to the people you involve**

  - You may need to run activities in the evening or at weekends so as to not disadvantage those who are in full-time employment
  - Assess the appropriateness of going to the people you want to involve vs. asking them to come to you

### **3. WHY INVOLVE THE PUBLIC IN YOUR RESEARCH**

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#### **3.1 Understanding Your Aims for Public Involvement**

The rationale for involving the public in research has been well-documented by many researchers and organisations ([see NIHR's Briefing note three: why involve members of the public](#)) and it's important you understand the unique challenges of your own project if you're going to achieve meaningful public involvement. .

**Ask yourself these questions:**

1. “What am I hoping to achieve?” or “What outcome am I looking for?”
2. “What issue or challenge in my research or research plans could the perspective of the public or experiential knowledge of patients help to overcome?”
3. “What difference or impact do I want this involvement to make?”

This will not only help to focus your public involvement plans and guide your choice of approach but will enable you to plan your evaluation process too. See [Section 7](#) – Evaluating the impact of your public involvement work – for ideas and tools to help with this.

**Find out why and how other Imperial researchers involved the public in their work, by reading their [case studies on our blog](#).**

## 4. DECIDING WHO TO INVOLVE

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### 4.1 Know your audience

Who to involve in your research will depend on:

1. **The insight or perspective you need** – typically the population on which your research is based (e.g. specific patient groups), but it may also simply be a perspective that you don't have yourself (e.g. general public/patient)
2. **The purpose of your public involvement plans** – what you want to achieve and what people will be asked to do

#### 4.1.1 Diversity is key

Ideally you want to involve a range of people, from a variety of different backgrounds, who reflect the population the research is likely to impact. Remember, the greater the diversity of people you involve, the richer the opinions you will get in return. This is of vital importance in order to address underrepresentation in research of many groups in the population who have historically and continue to be [underrepresented and underserved by research and health services](#).

#### 4.1.2 Where to find people to involve

No one person should be thought of as being confined to a specific group, but if you want to reach people with a certain type of insight, here are several approaches to consider.

Target audience	Ways to reach them
Experts by lived experience (i.e. condition-specific patients or carers)	<ul style="list-style-type: none"> <li>• Through healthcare professionals – Do you know anyone working in the field? Will they let you put up posters or hand out flyers in an outpatient clinic or ask patients if they wish to be involved on your behalf? (N.B. this does not require ethics approval when it's for public involvement)</li> <li>• Third sector organisations and charities – these groups will often have a large network of patient contacts however you will need to establish relationships with them in advance. Be mindful that some may have limited capacity and resources and may not be able to prioritise your request especially if they don't know you. Start building these relationships early and before you need to ask something of them.</li> </ul>
General public	<ul style="list-style-type: none"> <li>• Personal connections, social media (this should be used with caution as there is a risk of those motivated only by remuneration (and not having the required lived experience) applying through this medium), public engagement events or even people on the street/in a café</li> <li>• Posters on noticeboards, bus stops, libraries.</li> <li>• Neighbourhood websites like “Nextdoor”</li> <li>• NIHR Imperial PERC’s mailing list. PERC sends out an email newsletter with public involvement opportunities taking place at Imperial or Imperial College Healthcare NHS Trust approximately every 3 months.</li> </ul>
Community groups	<ul style="list-style-type: none"> <li>• The <a href="#">Community Champions programme</a> brings local people and services together to improve health and wellbeing and to reduce inequalities</li> </ul>

	<ul style="list-style-type: none"> <li>Consumer health groups such as <a href="#">Healthwatch</a> or <a href="#">The Advocacy Project</a>. Some are membership organisations that distribute opportunities to their members. There are a number of local Healthwatch covering the Imperial North West London geographical area including: <a href="#">Healthwatch Westminster</a>, <a href="#">Healthwatch Kensington and Chelsea</a>, <a href="#">Healthwatch Brent</a>, <a href="#">Healthwatch Hounslow</a>, <a href="#">Healthwatch Ealing</a>, <a href="#">Healthwatch Hillingdon</a>, and <a href="#">Healthwatch Hammersmith &amp; Fulham</a>.</li> </ul>
People with public involvement experience	<ul style="list-style-type: none"> <li><a href="#">VOICE</a> is an online platform for advertising and hosting public involvement, engagement and certain participation (excludes clinical trials) opportunities. Members of the public can sign up for free and choose subjects they wish to hear about and are sent a newsletter based on these choices every Friday. It aims to capture the public's vast experience, ideas, opinions and expectations about the research, innovations and policy developments affecting their lives. Established by Newcastle University, Imperial College London joined as the first external collaborator in January 2019 giving Imperial and Imperial College Healthcare NHS Trust researchers the ability to post a range of public involvement opportunities on the platform, undertake polls, host discussion forums as well as share news and feedback amongst other things. Find out more about <a href="#">VOICE at Imperial here</a>.</li> </ul>
Imperial Young Person's Advisory Network (17 to 25 years)	<ul style="list-style-type: none"> <li>The network enables and empowers young people (17-25 years old) to shape and influence current and future health and services research taking place at Imperial or the Imperial College Healthcare NHS Trust. The network is sent an email newsletter with public involvement opportunities approximately every 3 months.</li> </ul>

## 4.2 Addressing inclusivity and underrepresentation in research

People recruited into health and social care research often do not represent those most in need. Those who are underserved often have demographic and socioeconomic factors that increase the health inequalities they experience. Due to their underrepresentation, findings from the research may not apply to all groups of patients. This in turn limits treatment options for under-served people, increases health disparities and perpetuates the cycle of inequalities.

### 4.2.1 What does underrepresented and underserved mean?

People who are [underrepresented and underserved](#) in research describe groups of people whose perspectives are often missed from healthcare evaluation and research, and are underrepresented in healthcare decision-making. Improving the openness and inclusivity of research (both participation and involvement) will be one of the key ways to counteract health inequalities in health services and research.

Depending on the field, underrepresented groups may be anyone. But often they include people who identify as having 'protected characteristics' (as defined by the [Equality Act 2010](#)). This may relate to their geographical location, age, disability (e.g. people with a learning disability), gender reassignment, marriage or civil partnership, pregnancy and maternity, ethnicity, religion or belief, sex, sexual orientation (e.g. people who identify as lesbian, gay, bisexual, transgender, queer, questioning, intersex, and asexual (LGBTQIA+)), socio-economic status and access to health or social care. The NIHR has recently included a requirement in their funding applications as part of their equality, diversity and inclusion (EDI) guidance for researchers to document how they are collecting information on equality, diversity and inclusion characteristics, how these have been addressed in their research

proposal including steps taken to ensure the research sample is representative of the population at which the study is targeted. This includes explaining how the recruitment is planned to ensure inclusivity of study participation and justify and explain any exclusions.

#### **4.2.2 What does the NIHR mean by research inclusion?**

In November 2024, [NIHR officially launched a new requirement](#) that all applicants must demonstrate how their research will address existing inequalities in health and social care as a condition of funding. Applicants will now be required to demonstrate how inclusion is being built into all stages of the research lifecycle to ensure that research is intentionally designed, conducted and communicated inclusively, and to ensure that the researchers can be held to account for delivering on their plans. NIHR has developed:

- [Inclusive research funding application guidance](#) and
- a [Webinar: Research inclusion as a condition of funding](#) to advise applicants (further resources linked below).

#### **4.2.3 Who is representative?**

As it is not appropriate for researchers to representatively sample their target population for public involvement purposes, inclusion of people from **diverse backgrounds is what's key**. Remember that no one person can ever fully represent a disease area or group of people, but they can contribute a valuable non-research perspective. This is why we also call members of the public who are involved in research “public contributors” rather than “public representatives” as no one can represent anyone but themselves unless they have a mandate to do so e.g. a representative of a charity.

#### **4.2.4 Easy to ignore?**

The idea of inclusivity originates from us often only reaching out to those who are easiest to find or engage with, e.g. those who are already involved in research or who attend science engagement events. Previously, communities that were not typically engaged were called ‘hard-to-reach’ or ‘seldom heard’, but these phrases are no longer used after acknowledgement that it is research processes and approaches that create the barriers to engagement. People don’t consider themselves ‘hard-to-reach’ but perhaps ‘easy to ignore’. Creating “inclusive opportunities” for people to be involved in research is one of the six [UK Standards for Public Involvement](#).

#### **4.2.5 Be proactive!**

Proactive efforts should be made to involve as diverse a range of relevant communities, backgrounds and perspectives as possible in both research participation and involvement in research. This will often involve taking your research to people and communities at a place where they feel comfortable, rather than expecting them to come to you at a venue of your choice. PERC works with a number of communities in Northwest London who may be open to providing feedback on a research project at one of their community meetings. Contact PERC to find out more.

## 4.3 Resources for addressing underrepresentation in research participation

### **NIHR Inclusive Research:**

- [NIHR Inclusive research funding application guidance](#)
- [Webinar: Research inclusion as a condition of funding](#) (YouTube) and [slides](#) on NIHR Learn (you will need to create an NIHR Learn login to access the slides)
- [Research inclusion toolkit hub](#) on NIHR Learn (you will need to create an NIHR Learn login to access these resources)

### **NIHR INCLUDE Project:**

- [Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project](#) - examples of good practice and resources to guide teams seeking to engage with, and improve inclusion of, under-served groups in health research.
- NIHR Inclusive research funding application guidance
- [INCLUDE webpage](#) – updated with relevant training and resources
- [INCLUDE Ethnicity Framework](#) - aims to help research trial teams think carefully about which ethnic groups should be included in their trial for its results to be widely applicable, and what challenges there may be to making this possible.
- [INCLUDE Impaired Capacity to Consent Framework](#) – a tool for researchers to ensure that their trial is designed to be inclusive of people with impaired capacity to consent, as well as improving the quality of the trial design and funding application.
- [INCLUDE Socioeconomic Disadvantage Framework](#) – designed to aid researchers, who are designing clinical trials, to consider barriers to including patients from socioeconomically disadvantaged backgrounds in their trial.
- "Ensuring that COVID-19 research is inclusive: guidance from the NIHR INCLUDE project" (<https://bmjopen.bmj.com/content/10/11/e043634>)

### **Centre for Black and Minority Ethnic Health:**

- [Ensuring ethnic diversity in research](#) – advice for researchers
- [Increasing participation of Black Asian and Minority Ethnic \(BAME\) groups in health and social care research](#): a toolkit – Applied Research Collaboration East Midlands
- [Equality Impact Assessment \(EqIA\) Toolkit](#) – designed to ensure that equality considerations apply to all stages of the research process

### **Training:**

- [NIHR INCLUDE online course](#) - accessible online through NIHR Learn. For new users, you will be prompted to register at the login page. Upon completion of the registration form, you will then have access to the course

## 4.4 Further resources for addressing underrepresentation in research participation

- Pan D, Sze S, Minhas JS, et al. The impact of ethnicity on clinical outcomes in COVID19: a systematic review. [EClinicalMedicine 2020; published online June 3.](#)

- Treweek S, Forouhi NG, Narayan KMV, Khunti K. [COVID-19 and ethnicity: who will research results apply to?](#) *Lancet*. 2020;395(10242):1955-1957. doi:10.1016/S0140-6736(20)31380-5
- "Developing a roadmap to improve trial delivery for under-served groups: results from a UK multi-stakeholder process"
- Marmot Review report – 'Fair Society, Healthy Lives | Local Government Association
- [Mind-the-Gap-A-handbook-of-clinical-signs-in-Black-and-Brown-skin.-first-edition-2020.pdf \(litfl.com\)](#)
- [Racial Bias in Pulse Oximetry Measurement | NEJM](#)
- [Developing a roadmap to improve trial delivery for under-served groups: results from a UK multi-stakeholder process"](#)
- [NHS Race & Health Observatory Terminology Consultation Report – The Power of Language: A Consultation Report on The Use Of Collective Terminology at The NHS Race and Health Observatory, November 2021](#)). Through a combination of survey and focus groups, insights were used to inform the creation of five principles to follow when writing and talking about race.
- [NHS England – Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups](#). This document provides practical insights for researchers on how to engage more diverse participants in health research and its associated blog [Not 'hard to reach' – increasing diversity in research participation](#).

#### 4.5 Resources for addressing underrepresentation in public involvement:

- [NIHR Being Inclusive in Public Involvement in Health Research](#)
- [NIHR Reaching Out: A practical guide to being inclusive in public involvement in health research – Lessons learnt from the Reaching Out programme](#)
- [NIHR: A guide to creating inclusive content and language](#)
- [NIHR Race equality in public involvement](#)
- [NIHR Race Equality Framework: a practitioner's guide for public involvement in research to improve racial equity in health and care research](#)
- Bevan, C., Alderdice, F., Darby, S. et al. ['The Listening Series': increasing equity, diversity and inclusion in patient and public involvement and engagement for policy research by listening to and learning from under-represented groups](#). *Research Involvement and Engagement* 10, 71 (2024). <https://doi.org/10.1186/s40900-024-00601-2>.

## 5. CHOOSING YOUR PUBLIC INVOLVEMENT APPROACH

### 5.1 More Guidance on Public Involvement Activities

There is no ‘one size fits all’ way of involving people in research. It will depend on the needs of the people you are involving, your research project, the time and resources you have available and what you want to achieve.

To help you get going here's a list of some involvement activities, starting with the simplest, along with links to where you can find more information:

Public Involvement Activity	Source for more information
<b>Informal chat</b> <ul style="list-style-type: none"> <li>Listen/talk to someone (patient/public) with experience of the research topic or issue, e.g. in a hospital outpatient clinic, over the phone, via patient forums or social media</li> </ul>	Just get started, you'll learn more by doing.
<b>Survey</b> <ul style="list-style-type: none"> <li>Run a survey in a setting where your target audience may be found, e.g. waiting rooms. If the results of this survey are being used to inform your research this is public involvement and does not require ethics approval.</li> </ul>	Imperial staff and students have free access to the <a href="#">Qualtrics survey tool</a> . Make sure you have turned off the automatic collection of IP address and GPS coordinates which the system is set to automatically collect as these are not covered in the PERC Privacy Notice as they are not considered necessary to collect.
<b>Discussion Groups and Workshop</b> <ul style="list-style-type: none"> <li>Discussion groups are similar to informal chats except that you bring a range of people together and hold open discussions as a group. Discussion groups are similar to focus groups which are a qualitative research methodology which require ethics approval..</li> <li>Workshops are often used to explore ideas, generate new perspectives, and put forward guidelines on a given project or technological development. Workshops are useful for broader technological and scientific topics with no prior consensus</li> </ul>	For more, visit: <a href="#">actioncatalogue.eu/method/7418</a>  <a href="#">CRUK how to run a focus group. Cancer Research UK Patient Involvement Toolkit for Researchers</a>  <a href="#">Open Learn: Facilitating group discussions</a>  <a href="#">Facilitation tools for meetings and workshops</a>  <a href="#">Mind UK: Discussion and focus groups</a>
<b>Research Buddies</b> <ul style="list-style-type: none"> <li>Research buddies are patients or community members who provide links between the researcher, and</li> </ul>	For more, visit: <a href="#">Types of Community Involvement   Consumer and Community</a>

<p>community members, organisations or the research funder</p>	<p><a href="http://cciprogram.org">Involvement Program (cciprogram.org)</a></p> <p><a href="http://www.pipdr.org">Patient and public involvement in doctoral research: Impact, resources and recommendations</a></p>
<p><b>Patient/Public Panel, Network or Reference Groups</b></p> <ul style="list-style-type: none"> <li>Public panels or reference groups can be referred to throughout the course of a research project. They provide advice at a specific stage or throughout a project. This may be more relevant for projects where continuous and varied involvement can be adequately managed</li> </ul>	<p>For more, visit:</p> <p><a href="http://www.pipdr.org">Types of Community Involvement   Consumer and Community Involvement Program (cciprogram.org)</a></p> <p><a href="http://www.ukcic.org">Patient and Public Involvement Panel: UK Coronavirus Immunology Consortium (UKCIC)</a></p> <p><a href="http://www.cancerresearchuk.org">Cancer Research UK   Working with a patient advisory panel in your research</a></p> <p><a href="http://www.youngperson.co.uk">Young person's advisory group   online toolkit</a></p>
<p><b>Public contributors in research governance e.g. members of study steering committees, data access committees etc</b></p> <ul style="list-style-type: none"> <li>A Study Steering/management Committee has a supervisory and advisory role. It has overall oversight of the trial or research study and provides advice to the study/trial management group, funder and sponsor of the research.</li> <li>It is accepted practice that patients/public should be members of these committees to ensure the patient/public voice is included in these committees.</li> </ul>	<p><a href="http://www.nihr.org">NIHR Good Practice Guidelines</a> on the recruitment and involvement of public contributors on Trial Steering Committees and Study Steering Committees</p>
<p><b>Public Co-Applicant</b></p> <ul style="list-style-type: none"> <li>Public co-applicants offer a different perspective from other members of the team during the development and delivery of a study.</li> <li>The inclusion of public co-applicants can increase the breadth of experience, knowledge and skills within a research team. Although many NIHR funding application forms have a space for a "Public Co-Applicant" to be named, this does not mean including one is mandatory. Please read the NIHR guidance on Public Co-Applicants to decide if this is appropriate for your project and the proposed Public Co-Applicant.</li> </ul>	<p>For more, visit:</p> <p><a href="http://www.nihr.org">Public Co Applicants in Research Guidance (NIHR)</a></p> <p><a href="http://www.uwe.ac.uk">Discovering the role of public co-applicant (University of the West of England)</a></p> <p><a href="http://www.peterbatesandevelynkoon.com">How to engage people as research co-applicants (Peter Bates and Evelyn Koon)</a></p>

## 5.2 Further Public Involvement Resources and Guidance

For more public involvement resources and guidance, visit our [Public Involvement Resource Hub](#) or the following online sources and reports:

- [\*\*Navigating digital health\*\*](#)

A guide for the public involved in/interested in being involved in, research using data and artificial intelligence. Developed by Kelly Gleason (Cancer Research UK (CRUK) Senior Research Nurse at Imperial, Department of Surgery & Cancer) in partnership with public contributors and Imperial researchers.

- [\*\*Public Involvement Front Door\*\*](#) - these resources combine a values-based approach with practical tips and resources with a patient safety lens funded through [SafetyNet](#), the NIHR Patient Safety Research Collaboration Network

- [\*\*Patient and public involvement trauma informed guidance for organisations and healthcare professionals \(March 2024\)\*\*](#)

This document offers guidance on how to work with patient and public involvement partners in a way that is both psychologically and trauma informed. It is split into key phases for any patient and public involvement activity.

- [\*\*Public involvement toolkit – a guide to involving members of the public in your research \(Aug 2022\)\*\*](#)

A toolkit created by Health and Care Research Wales, along with researchers, which has everything you might need to involve members of the public in your research.

- [\*\*Cancer Research UK Patient Involvement Toolkit for Researchers\*\*](#)

Cancer Research UK provides free access to their patient involvement toolkit for researchers. Hosted within 'planning your patient involvement' is detailed information on how you prepare, deliver, and evaluate many of the methods listed above.

- [\*\*A practical guide to patient and public involvement in lab-based research \(Feb 2020\)\*\*](#)

This guidance has been co-produced by staff, patients, public and researchers involved in Parkinson's UK, Alzheimer's Society and NIHR UCL Hospitals BRC.

- [\*\*The Action Catalogue\*\*](#)

This is an online decision support tool that is intended to enable researchers, policymakers and others wanting to conduct inclusive research, to find the method best suited for their specific project needs. The Engage2020 Action Catalogue is an outcome of the Engage2020 project, which is funded by the European Commission (DG Research).

- [\*\*A research handbook for patient and public involvement researchers \(Oct 2018\)\*\*](#)

This handbook is written for patients and members of the public who want to understand more about the approaches, methods and language used by health-services researchers.

## 6. HOW TO SUPPORT THE PEOPLE YOU INVOLVE

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### 6.1 Providing Training

Evidence suggests that public involvement is more likely to have a positive impact if those you involve first receive appropriate training and then continued support. If the people you are involving in your research are representative of your research population then they will come with a mix of skills and needs. Providing training both on the process of public involvement and on the basics of research and its stages is all part of involving people.

#### 6.1.1 Training by whom?

If you are involving patients and members of the public in your research, then it is expected that you provide them with some training. Whether it's organised by you or someone else, the training should meet the specific needs of those you are involving and take place at the outset of their involvement. You should have a discussion with the people you are involving in your research to help you understand their training needs, as some may be more familiar to public involvement and research processes than others.

#### 6.1.2 Training on what?

Training involves taking the time to explain the project, its general stages, and the timeline, as well as providing more specific details of your research, protocol and methodology in simple terms. It would be useful to also cover any background to the project, such as where your funding comes from, when you must report to your funder and what you must provide. Depending on the needs of the group, ongoing training or mentoring could be provided throughout the course of the project.

### 6.2 Training Resources for Patients and Members of the Public

Imperial has a free online introductory course on public involvement in research which is suitable for both researchers and some members of the public - visit our [Public Involvement Training page](#). Certificates of completion are free for those with an Imperial email and public contributors should have the cost of these covered (should they wish to receive one). There are also other online training courses available including the NIHR's [Public reviewing with the National Institute for Health and Care Research \(NIHR\)](#) which are suitable for members of the public and researchers and covers writing and reviewing research funding applications. However, you will still need to provide background and explanations about your project to those you involve.

If your department holds research symposiums, you could also invite your public involvement contributors along. This is a great opportunity for public engagement if the content is made accessible to the public and is not too scientific.

Visit our [Public Involvement Training page](#) for more links to:

- Training and resources
- Downloadable public involvement guides
- Plain English public involvement glossaries

## Supporting Diversity and Inclusion

Embracing differences between people is very important to ensure you gather a rich range of perspectives, and that they enjoy the experience. The NIHR provides [guidance](#) on how to optimise the inclusiveness of your involvement and covers a number of key considerations, such as payment and communication requirements. Your communication with people needs to be appropriate to their circumstances, e.g. using the phone or WhatsApp for someone who doesn't use email or adapting your communication style to accommodate people with learning difficulties, or a hearing, visual or physical disability. One of the UK Standards for Public involvement is "[Communication](#)" (see page 27).

### 6.3.1 Identify needs early

Ask people when you recruit them to be involved if they have any specific needs, so you can cater for them appropriately. You can capture this information, as well as other demographics, by including equality monitoring questions in your 'Expression of Interest' Qualtrics form that you ask people to complete to sign up to your public involvement.

### 6.3.2 Language

The language we use is also important for better accessibility and to make sure we appeal to the widest audience possible. NIHR's "[A guide to creating inclusive content and language – Sept 2021](#)" is a good starting point.

It's also worth noting that if your organisation provides NHS care or adult social care, they are legally required to follow the [Accessible Information Standard](#). This ensures that people who have a disability, impairment or sensory loss can communicate effectively with health and social care services. For more information, visit [england.nhs.uk/ourwork/accessibleinfo/](http://england.nhs.uk/ourwork/accessibleinfo/).

### 6.3.3 Learning Disabilities

According to [Mencap](#), there are 1.5 million people with a learning disability in the UK. But with the right support, which is tailored to their needs, most of them can lead independent lives.

[Easy Read](#) is one way of making information more accessible to people with learning disabilities. Easy Read versions use simple, jargon-free language, shorter sentences, and supporting images to depict the main points of a document so that people with learning disabilities can understand the main issues and make decisions if necessary. Here are some websites with health information and resources available in Easy Read:

- [www.apictureofhealth.southwest.nhs.uk/](http://www.apictureofhealth.southwest.nhs.uk/)
- [www.sth.nhs.uk/patients/patient-information/find-a-leaflet/view-all-easy-read](http://www.sth.nhs.uk/patients/patient-information/find-a-leaflet/view-all-easy-read)
- [www.changepeople.org/blog/december-2016/free-easy-read-resources](http://www.changepeople.org/blog/december-2016/free-easy-read-resources)

This publication explains how people with learning disabilities were involved in research, and has been written in an accessible way too:

- [Accessible article: involving people with learning disabilities in research \(pdf\)](#)

In addition, there is:

- [Photosymbols](#) – a library of photos, symbols and templates for use in the development of Easy Read Information. There is a charge to use them, but if your research is linked to the Imperial College Healthcare NHSTrust they should have access to an Easy Read library as they are required to comply with the Accessible Information Standard

- Photovoice – a visual method that focuses on participant-led photography. The method gives participants a way to voice their worlds visually, opening the method to people who may not be able to articulate themselves verbally. For more, read the publication from Cluley (2017): [Using photovoice to include people with profound and multiple learning disabilities in inclusive research.](#)

#### A note on: MANAGING DIFFERENCES

When collaborating with any group of people, regardless of their background, steps should be taken to understand their individual circumstances and needs, and to offer appropriate support where needed, e.g. pre-booking travel on their behalf. See [Section 6: How to Support the People You Involve](#) for more.

## 6.3 Managing Expectations

Managing the expectations of those you involve as well as the research team is very important. Everyone needs to understand what their role is and what they are required to do. To help with this process, feel free to use our *Terms of Reference* and *Role Descriptions* templates, which we've developed for you to adapt – accessible from our online [Public Involvement Resource Hub](#).

### 6.4.1 Plan your public involvement as early as possible

Public involvement is much more effective and valuable for all those concerned if it is planned from the beginning of a project, or even before (so that you identify the research question with those most affected). Most funding applications now require you to include a public involvement plan in the submission. Just make sure your involvement plans have been thoroughly thought through and prepared before starting. Poor planning leads to delays and unforeseen barriers, which can spoil the experience for all involved, and limit the opportunity for impact.

### 6.4.2 What if the project has already started?

If your project has already started, it will usually be possible to incorporate public involvement activities throughout the remaining project and at the very least, it is always possible to incorporate public involvement at the “Dissemination” stage.

#### A note on: TRANSPARENCY

Transparency and accountability are key to successful public involvement. You will lose goodwill by not being open about the research, its progress and problems and the results. Where needed, Terms of Reference and Role Description documents should be co-produced by the public and the research team, rather than the research team providing people with a *fait accompli*. It is fine to provide a draft document as a starting point for discussion, but you need to ask people if they are happy with it – and the expectations being asked of them – whether the information is clear, and if anything is missing. If people feel they've taken part in developing these types of documents, they're more likely to feel ownership over their involvement and comply with what's been agreed.

## 6.4 Rewarding People for Their Time

It has been accepted practice for some time that patients and members of the public be rewarded for their time when involved in research. Your team/department may have a policy in place which governs payment and reimbursement of expenses, including the amounts paid for different levels of involvement. If not, we recommend following the [Recognition payments for public contributors](#) developed by the NIHR Centre for Engagement and Dissemination (CED).

### 6.5.1 Travel and other expenses

When recruiting patients and the public to involve in your project, you should consider where they live as your public involvement budget will need to cover their travel expenses. Depending on the circumstances of the person and the public involvement budget, accommodation, carer costs and childcare may also need to be paid for. If a meeting is first thing in the morning or late in the evening, they may need to stay over the night before or after the event. In accordance with NIHR payment guidance, when attending virtual meetings, public contributors are paid a £5 contribution towards data/Wi-Fi costs.

### 6.5.2 Benefits and public involvement payments

It is important to note that, if someone is receiving benefits, being paid (including receiving vouchers) as a reward for public involvement, they may put their benefits at risk. Payment for involvement may be considered taxable income, based on the individual's circumstances. Vouchers may have previously not been considered income in the past, however, HMRC now consider receipt of vouchers to be equivalent to income. Those receiving benefits are advised to seek expert, personalised advice before accepting payment for involvement. The NIHR has engaged a Citizen's Advice Bureau to provide individualised advice for those receiving benefits about whether public involvement payments have an impact on their personal situation.

For more information about rewarding people who are receiving benefits, see:

- the NIHR Centre for Engagement and Dissemination's: '[Payment guidance for researchers and professionals – Welfare benefits](#)'.
- Guidance written for the public can be accessed via '[Payment guidance for members of the public considering involvement in research](#)'
- Guidance written for the public can be accessed via '[Payment for public involvement in health and care research: a guide for members of the public on employment status and tax](#)'.

## A note on: EXPENSE PROCEDURES

### *Payment for peoples' time*

There are two ways people can be paid for their time and involvement at Imperial.

1. **Non Payroll Fees form:** If your public contributors will receive payment of £1,000 or less annually altogether from Imperial teams, then you may pay them using a Non-Payroll Fees (NPF) form. The form must only be used for low-value payments of professional fees and similar payments for services rendered by individuals ("freelance workers") not acting in a formal employment relationship with Imperial. They must not already be on Imperial's payroll (i.e. they must not have received, at any time since April last, a payslip from the Imperial payroll office). More guidance is on the form itself. People who have previously been paid by Imperial as staff or a temporary worker are required to be paid using a different method. Please ask your finance contact for further details.
2. **Consultancy agreement/Invoice:** If public contributors have been paid, or will be paid, more than £1,000 in one calendar year, the best way of paying them should be discussed with your finance department and may involve a consultancy agreement where they submit an invoice (see the Public Involvement Resource Hub for a template) with details of the activity they are claiming for, their time spent and amount claimed. They will be treated as a supplier and be approved as such on the finance system.

Please note, patients and members of the public are responsible for disclosing their own income and benefits to HMRC and this responsibility is solely theirs.

### *Reimbursement of expenses*

Regardless of how people are paid for their time, reimbursement for travel and subsistence expenses should be itemised separately on both a NPF and invoice. Those on benefits are able to receive reimbursement for expenses even when they are unable to receive payment. These expenses are not included in the £1,000 limit mentioned above.

## 6.5 UK Standards for Public Involvement

The [UK Standards for Public Involvement](#) are designed to improve the quality and consistency of public involvement in research. They were developed over three years by a [UK-wide partnership](#), and are a description of what 'good' public involvement looks like and encourage approaches and behaviours that are the hallmark of good public involvement such as flexibility, sharing and learning and respect for each other. The six standards are:

1. [Communication](#)
2. [Working Together](#)
3. [Inclusive Opportunities](#)
4. [Impact](#)
5. [Governance](#)
6. [Support and Learning](#)

These standards provide guidance and reassurance for those using them to work towards best practice in public involvement.

## 7. EVALUATING THE IMPACT OF PUBLIC INVOLVEMENT

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To be able to properly evaluate your public involvement activities, you will need to give it some thought **BEFORE** you start. You will note that one of the UK Standards for Public involvement is “Impact” (see page 27).

We suggest thinking about:

- How will you know if your public involvement activity achieved the outcome you, and those involved, were hoping for?
- What will be your measure of success? How will this be measured – both for impact on research and those involved? Who will be responsible for capturing/measuring this?
- Have you developed your objectives and evaluation approach together with the people you wish to involve?
- How will you monitor and evaluate the public involvement approach you took?
- How will you reflect, feedback and learn from your evaluation/assessment of the outcomes, impact and/or process?

Where possible, the people you hope to involve in your research should be involved in both this planning stage and its assessment at the end.

As a minimum, we recommend using a public involvement log (link below) or pre- and post-public involvement evaluation forms (example templates are available on the [Public Involvement Resource Hub](#)), but other approaches may be possible too, such as:

- [Public involvement impact log for researchers](#)- This template (adapted from People in Health West of England (PHWE)'s template) should be completed following each public involvement activity throughout the project to record key areas of input and discussion with the public and any associated impact (positive and negative) on the research, the research team and those involved. This is important in order to collect impact of your public involvement.
- The [Public Involvement Impact Assessment Framework \(PiiAF\)](#) (funded by the Medical Research Council) is a very comprehensive site that was produced in 2013 to help researchers plan and assess public involvement. The PiiAF Guidance Document may be too detailed for many of your needs, but as it is meant to only act as a framework, you can pick and choose elements that you think may be useful.
- The [Public and Patient Engagement Evaluation Tool \(PPEET\)](#) (created by McMaster University) is a series of three questionnaires to evaluate public and patient engagement. The tool was developed primarily for use within health system organisations but has also been used to evaluate engagement within other contexts (e.g. health research). Engagement in this context could include public involvement.
- [The Public Involvement in Research Impact Toolkit \(PIRIT\)](#) (created by the Marie Curie Research Centre at Cardiff University) is a resource to help researchers plan meaningful public involvement, track and demonstrate the difference it makes.
- [Evaluating PPI training: a resource for facilitators](#) (created by members of the PPI Ignite Network) is a practical set of materials to support facilitators of public involvement training activities to evaluate their training sessions and events, with the ultimate goal of improving PPI

training provision across Ireland. The resource includes a question bank of potential survey questions, a facilitators guide and checklist, and editable templates to support evaluation efforts.

### **7.1 Why is assessing impact of public involvement important?**

By assessing the impact of involving the public, you can help build an evidence base of public involvement activities in research, which lets others know what works well for different types and stages of research, and what can be improved. Your funders will also be interested to hear about your experience and may ask you to report on this. Many people also find it a useful exercise for their own personal and research career development.

It's also important to provide feedback to the public contributors involved in your project so they know that their contributions and comments have been considered, how they have been used and whether they've been beneficial to the research. The '[Guidance for Researchers: Feedback](#)' was co-produced by public contributors, public involvement leads and researchers in the East of England was developed to provide guidance around how to feedback to public contributors.

## 8. REPORTING PUBLIC INVOLVEMENT

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All researchers who incorporate patient and public involvement in their work should find ways to share their experience so that others can learn from their approaches, methods and outcomes – just as we do by publishing our research.

Below we outline two formal approaches to publishing, but there will be many more ways this could be done, including writing up what was done (as an example of public involvement) or a blog posts (see [PERC's blog](#)), developing [posters/infographics/videos](#) or running workshops. The people you involve may also have some interesting ideas on how to share your experiences. Please get in touch with PERC so we can send you the template questions to answer.

### 8.1 Publishing in a Peer-Reviewed Journal

#### "Patient and Public Involvement Statement"

A number of British Medical Journal publications require authors to include a ["Patient and Public Involvement Statement"](#) in their submissions.

The following questions are required to be addressed in a Patient and Public Involvement Statement:

- At what stage in the research process were patients/public first involved in the research and how?
- How were the research question(s) and outcome measures developed and informed by their priorities, experience, and preferences?
- How were patients/public involved in the design of this study?
- How were they involved in the recruitment to and conduct of the study?
- Were they asked to assess the burden of the intervention and time required to participate in the research?

### 8.2 Report your Public Involvement in your Paper

When submitting a research paper to other journals for publication, make sure you include a few lines on your public involvement activity. Ideally public involvement will have been part of your research design, methodology and/or interpretation of results and should be acknowledged appropriately.

To improve the consistency and quality of public involvement reporting, a checklist known as GRIPP ([Guidance for Reporting Involvement of Patients and Public, pdf](#)) was published in 2011 which aimed to help researchers prepare research manuscripts. However, a revised version, [GRIPP2](#) (Fig. 2), was published in 2017 to simplify the reporting process and accommodate research where public involvement is not a primary purpose of the research. GRIPP2 questions are included in Part 2 of the Public Involvement Planning and Impact Tool.

**Table 2** GRIPP2 short form

Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	
2: Methods	Provide a clear description of the methods used for PPI in the study	
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	

PPI patient and public involvement

Fig 2. The GRIPP2 short form (SF) checklist for reporting studies where public involvement is a secondary purpose

### 8.3 Patient/public Reviewers of Manuscripts

As well as the above checklist, you should also consider who will be reviewing the manuscript. Many journals now include patient reviewers in the peer review process.

One example is the British Medical Journal (BMJ) which asks [patient reviewers](#) to both review the public involvement elements of the research/project, as well as comment on the following:

- Are the questions the paper addresses relevant and important to patients and/or carers?
- Are there topics or issues that are missing, or need to be highlighted more?
- Is the treatment or intervention suggested or guidance given something which patients/carers can readily take up? or does it present challenges?
- Are the outcomes described/measured in the study important to patients/carers? Are there others that should have been considered?
- Do you have any suggestions that might help the author(s) strengthen their paper and make it more useful for doctors to share and discuss with patients/ carers?
- Do you think the level of patient/carer involvement in the study could have been improved? If there was none, do you have ideas on how they might have done so?

You could therefore invite your own patients or members of the public to review your manuscript using the same guidance before you submit. In this way, if the public haven't been involved in writing the manuscript, you've still managed to involve them in the dissemination of your research.

Please see Workgroup of European Cancer Advocacy Network (WECAN)'s [online course](#) for patients and the public involved in writing publications.

### 8.4 Publishing in a Public Involvement-Focused Journal

This option may be suitable where public involvement was a primary goal of your project, and/or you've developed or completed a particularly interesting public involvement project and monitored and tracked its impact too.

We've listed below four well-respected journals that have a strong focus on public involvement:

#### 1. Health Expectations

[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1369-7625/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1369-7625/homepage/ForAuthors.html)

**2. The Patient Experience Journal**

<http://pxjournal.org/journal/aimsandobjectives.html>

**3. Research Involvement and Engagement**

<http://researchinvolvement.biomedcentral.com/submission-guidelines>

**4. The Journal of Participatory Medicine**

<http://participatorymedicine.org/journal/submissions/>

A long form checklist of GRIPP2 is also available to guide the development of papers where public involvement was the main purpose of the project – see [Table 1 of the GRIPP2 paper](#).

## 9. FURTHER READING AND KEY RESOURCES

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### 9.1 NIHR Centre for Engagement and Dissemination (CED)

Established in 2020, the CED replaces NIHR INVOLVE and is part of and funded by the National Institute for Health and Care Research. It has kept many of INVOLVE's policies and information both on the previous [INVOLVE website](#) and the new [NIHR Evidence website, which publishes plain language summaries of selected NIHR-funded research studies to help inform decisions about health and care.](#)

NIHR's [Learning for Involvement](#) – this website hosts former INVOLVE guidance and resources which have been retained and allows resources to be shared for public involvement.

### 9.2 NIHR Learning for Involvement

Run by the National Institute for Health and Care Research, to support active public involvement in the NHS, public health and social care research. It hosts public involvement information, resources (such as guidance, websites, videos, articles and blogs) and training from the NIHR and other organisations. Users are invited to upload their own resources and training to share with the public involvement community too.

### 9.3 Health Research Authority (HRA)

In its role to protect and promote the interests of patients and the public in health, the Health Research Authority manages the research and ethics approval process for the NHS in England – [watch this HRA Approval animation](#), for a quick introduction. Public involvement is therefore central to their own work and the approval process, and they have provided useful guidance and templates specific to this on their website.

Relevant HRA web links and resources:

- [HRA Participant Information Quality Standards](#) (Oct 2024) requires people with relevant experience (patients, family members, carers or members of the public) to be involved in the development of all participant information sheets.
- [HRA: Public involvement in research \(web page\)](#)
- [\(web page\)](#) – provides examples of how public involvement can help to make research more ethical and produce better outcomes
- [HRA: Informing participants and seeking consent \(web page\)](#)
- [HRA: Preparing study documentation \(web page\)](#) – templates for applying for approvals

## 9.4 Imperial College

Patient and public involvement is central to several departments at Imperial. Many of these have their own patient and public involvement websites and contacts, with additional information tailored to the research field:

- [NIHR North West London Patient Safety Research Collaboration](#)
- [NIHR Imperial Clinical Trials Unit](#)
- [NIHR Imperial Clinical Research Facility](#)
- [Imperial College Healthcare NHS Trust](#)
- [NIHR Health Protection Research Unit in Respiratory Infections](#)
- [NIHR Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance](#)
- [NIHR Applied Research Collaboration North West London](#)

## 9.5 NIHR Research Support Service (RSS)

The NIHR Research Support Service (RSS) provides support to researchers to develop applications to national, peer-reviewed research programmes. The service is delivered by eight 'Hubs' categorised by region and research expertise. In addition, there are two Specialist Centres for Public Health and Social Care, which provide more context-specific expertise. The Hubs and Specialist Centres are open to researchers based anywhere in England, or those working in collaboration with English partners. Selected Hubs offer small pre-funding grants which can be used to plan involvement in a project before the project has been funded. This may be useful if you wish to bring together a group of patients or members of the public to discuss appropriate ways for involvement in your proposed research project. The funds could be used to cover room hire costs, refreshments, travel expenses and paying for peoples' time to discuss the proposal. Each Hub has its own guidelines which should be referred to for further details and required timelines. Researchers are advised to contact the Hub as early as possible – ideally several months before the funder deadline.

## 9.6 World Health Organization (WHO)

Guidance for best practices for clinical trials. Geneva: World Health Organization; 2024. Licence: CC BY-NC-SA 3.0 IGO – see 2.3.1 (Working in partnership with people and communities)

## **10. GETTING IN TOUCH**

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NIHR Imperial Patient Experience Research Centre (PERC) is available to support and advise on public involvement activity within individual research projects or larger programmes of research funded by or affiliated with the NIHR Imperial BRC.

If this applies to you and you have a query or would like general advice, please contact us on [publicinvolvement@imperial.ac.uk](mailto:publicinvolvement@imperial.ac.uk).

If you work outside of Imperial and/or the NIHR Imperial BRC, please visit Imperial's public involvement list of advisors tab to find the appropriate person to support you.