

## A Rough Guide to Patient & Public Involvement

Produced by the NIHR Imperial BRC [Patient Experience Research Centre \(PERC\)](#) team

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# 1. INTRODUCTION

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This Rough Guide had been designed to supplement our online [PPI Resource Hub](#) and the overall PPI process (see p4) 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.

- PPI can provide benefits at all seven stages of the research cycle – see the summary table of PPI opportunities on p6–7 of this guide



Fig 1. Adapted from NIHR

## WHY

Be clear about what you are hoping to get out of the PPI – what difference or impact do you want it to have?

- The NIHR organisation INVOLVE provide a useful overview of [why researchers should involve members of the public in their research](#)
- The summary table on p6–7 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 PPI. Read [Section 3](#) 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 right 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 PPI 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 and 6](#) of this guide for more practical tips. An overview of example PPI activities for different stages of research can be found in the summary table on p6–7 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 lay people involved in the project to have an active role in the evaluation process too

## SHARE

Sharing your PPI work not only helps your efforts and impact go further, but it 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 [PPI Resource Hub](#) online.

## 2. GETTING STARTED WITH PPI

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### 2.1 A Recap of Key Definitions

The difference between ‘Involvement’ and ‘Engagement’ can be confusing, no less so because different funders use these terms to mean different things.

Officially, [NIHR INVOLVE \(www.invo.org.uk/\)](http://www.invo.org.uk/) define them as follows:

#### **Patient and public involvement (PPI):**

*‘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 would include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.’*

#### **Patient and public engagement (PPE):**

*‘Where information and knowledge about research is provided and disseminated, for example: science festivals, open days, media coverage.’*

Both PPI and PPE are distinct from...

#### **Patient and public participation (PPP):**

*‘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.’*

#### **A small note on: DEFINITIONS**

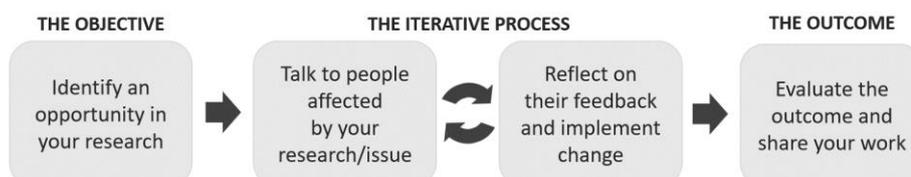
Sometimes, ‘Patient and Public Involvement’ is simply called ‘**Public Involvement**’.

This is because the term ‘**public**’ is considered 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’* according to the [NIHR](http://www.invo.org.uk/). 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 PPI Process

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

In its most basic terms, the co-creation process looks like this:



But it is up to you to decide where the best opportunities lie in your research, who you'd like to involve, 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 [PPI Resource Hub](#), in the [case studies on our PPI blog](#), and within this Rough Guide have been designed to help you get going with this process.

### A small note on: DATA PROTECTION

When collecting names and contact details of members of the public for future use (i.e. to invite them to other involvement opportunities) or continuing patient and 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. You will need to check with your [Data Protection Co-ordinator](#).

## 2.3 Funding Public Involvement

Patient and public involvement (PPI) is now a requirement of almost all funders. Therefore, any costs associated with PPI (e.g. activity costs, rewarding people for their time – see p18) need to be budgeted for within your research grant, or funded through alternative sources.

There are small PPI grants available from the [Research Design Service London's 'Enabling Involvement Fund'](#), which can be used to plan PPI in a project before the project has been funded, i.e. paying for venue hire, refreshments, travel expenses and peoples' time where a group of patients or members of the public are brought together to discuss appropriate ways to include PPI in a project.

Public involvement proposals would also be eligible to apply for the [Wellcome Trust's Public Engagement Fund](#) because Wellcome's definition of 'public engagement' includes 'public involvement' (as defined by NIHR's INVOLVE).

In addition, the NIHR Imperial BRC (in conjunction with PERC) runs an annual PPI grant scheme. The scheme is intended to support researchers and their teams to undertake meaningful patient and public involvement linked to current or planned research activity within the Imperial BRC. For more information on the next call for applications, contact PERC at [ppi@imperial.ac.uk](mailto:ppi@imperial.ac.uk).

Top tips for funding applications:

1. Check the definition of 'public involvement' and 'public engagement' used by the funder and use the same one accordingly. Some funders use 'public engagement' to capture 'public involvement', such as the Economics and Social Research Council and the Wellcome Trust.
2. Make sure the plain English summary *is* plain English. Invite a lay member to check it for readability. If you're unsure or need more guidance, visit [INVOLVE's Plain English help page](#)
3. Make sure your proposed PPI plans are relevant to your research and remember to include anything you have already done that contributes to your plan, e.g. '...held initial discussions with patients with for further involvement'; '...discussed the acceptability of our 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 doing PPI.
5. Highlight why the people you wish to involve are right for the project (e.g. they reflect your target population), how you plan to promote diversity and how you will support those you involve, e.g. relevant training.
6. Work out the costs and include them in your budget, i.e. rewarding people for their contribution, travel expenses, refreshments, room hire. Try out INVOLVE's [involvement cost calculator](#) for guidance.
7. Refer to any planned public involvement in other parts of your application, e.g. in your dissemination plans, pathways to impact etc.
8. Only name a lay member as a co-applicant if they have agreed and you will involve them throughout the project, not just at a certain point.
9. Be authentic because lay people often read funding applications too.
10. Never cut and paste from PPI websites – the reviewers will recognise plagiarism.

## 2.4 An Overview of PPI Opportunities in Research

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

Some people may be able to involve patients or the public at every stage of their project, while for others involvement may be limited to one or two stages. First understand what you want to achieve with PPI, and then work out the most appropriate way to meet your goals effectively and efficiently. Evidence suggests that public 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.

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 peoples' 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</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> and <a href="#">video</a></li> <li>The Delphi Method <a href="#">case study</a></li> <li>See the <a href="#">Action Catalogue</a> for more inspiration</li> </ul>
<b>2: Funding</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 PPI plans, making sure appropriate costs are allocated to involvement</li> <li>Invite people to identify possible ethical issues</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><a href="#">Duchenne Parent Project</a></li> <li><a href="#">Mental Health Awards</a></li> <li>See the <a href="#">Action Catalogue</a> for more inspiration</li> </ul>
<b>3: Designing &amp; Managing</b>  <a href="#">See more online</a>	<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> <li>Improve the diversity of participants</li> <li>Improve the recruitment process, participant experience and response/retention rates</li> <li>Speed up the research and ethics approval process</li> </ul>	<ul style="list-style-type: none"> <li>Invite people to review your research protocol for potential difficulties, as well as highlight new areas for further patient/public involvement</li> <li>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</li> <li>Work with the public on your recruitment strategy</li> <li>Give the public relevant roles monitoring and managing elements of the research process or project</li> </ul>	<ul style="list-style-type: none"> <li><a href="#">PPI case study: Health Start, Happy Start</a> (PERC's blog)</li> <li>Imperial's <a href="#">My Medication Passport</a></li> <li>See the <a href="#">Action Catalogue</a> for more inspiration</li> </ul>

#### 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
- 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 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
- [Imperial's IMPRESS study](#) (video)
- [Macmillan Listening Study](#)
- [INVOLVE's Public as Peer researchers case study](#)
- See the [Action Catalogue](#) for more inspiration

[See more online](#)

#### 5: Disseminating

- Improve the translation of the research by using language and messages that are more easily understood by a lay audience
- Help reach wider more diverse scientific and lay 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
- Involve the public/patients in developing/reviewing the dissemination strategy and lay summary of findings to ensure they are clear and accessible to all
- 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 their informal networks
- Give those you involve an active part developing print and digital content
- [PPI case study: Lol-Lab](#) (PERC's blog)
- See the [Action Catalogue](#) for more inspiration

[See more online](#)

#### 6: Implementing

- Help your project 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 you team/organisation's profile, which may improve future funding opportunities
- Get assistance from public/patient groups in lobbying for change
- Ask people you involve for ideas on creative ways to implement or maximise impact of work
- [PPI case study: Developing the iKnife](#) (PERC's blog)
- See the [Action Catalogue](#) for more inspiration

[See more online](#)

#### 7: Evaluating

- 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 PPI and best practice in undertaking PPI
- Identify challenges in undertaking PPI to assist in finding solutions
- Allow a more critical evaluation of the research project and PPI activities
- Involve lay representatives in determining how you will monitor and evaluate the research project, and their involvement
- Collaborate with the public/patients to evaluate the research process, including any barriers that arose
- Get those you involve to reflect on their role, what they have learned and what impact they feel they had
- [INVOLVE's continuing development case study](#)
- See the [Action Catalogue](#) for more inspiration

[See more online](#)

## 2.5 Top Tips for Successful Public Involvement

 <p><b>TRY TO INVOLVE AS DIVERSE A GROUP OF PEOPLE AS POSSIBLE</b></p>	<ul style="list-style-type: none"><li>Involving a diverse group of people gives the greatest insight into the lay perspective of your research</li></ul> <p>See <a href="#">p10–11</a> for more.</p>
 <p><b>DO YOUR BEST TO ACCOMMODATE DIFFERENCES</b></p>	<ul style="list-style-type: none"><li>Involving a diversity of people also means ensuring your involvement activities can accommodate the diversity of needs that they may have</li></ul> <p>See <a href="#">p15–16</a> for more.</p>
 <p><b>BE PREPARED TO MANAGE PEOPLES' EXPECTATIONS</b></p>	<ul style="list-style-type: none"><li>People get involved in research for various reasons so make sure your recruits understand what their role is and how they are expected to contribute</li></ul> <p>See <a href="#">p17</a> for more.</p>
 <p><b>THE AVERAGE READING AGE IN THE UK IS ABOUT 9 YEARS</b></p>	<ul style="list-style-type: none"><li>Consider the words and grammar you use when preparing reading and visual materials for patients and members of the public</li></ul> <p>Visit <a href="http://www.invo.org.uk">www.invo.org.uk</a> for help on writing in Plain English.</p>
 <p><b>CONSIDER THE TIMING &amp; LOCATION OF MEETINGS</b></p>	<ul style="list-style-type: none"><li>You may need to run activities in the evening or at weekends so as to not disadvantage those who are in full-time employment</li><li>Assess the appropriateness of going to the people you want to involve vs. asking them to come to you</li></ul>

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

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#### 3.1 Understanding Your Aims

The rationale for involving the public in research has been well-documented by many researchers and organisations (see INVOLVE's overview of [why researchers should involve members of the public in their research](#)). But, it's really important you understand the unique challenges of your own project if you're to achieve PPI that's impactful.

Ask yourself these questions:

- What am I hoping to achieve? Or What outcome am I looking for?
- What issue, challenge or activity could the lay perspective of the public or experiential knowledge of patients help with?
- What difference or impact do I want this involvement to make?

This will not only help focus your PPI 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 PPI work – for ideas and tools to help with this.

**Find out why other Imperial researchers did PPI, by reading their [case studies on our blog](#).**

## 4. DECIDING WHO TO INVOLVE

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### 4.1 Know your audience

Who you choose to involve will depend on:

1. **The population on which your research is based**, e.g. specific patient groups or public health; and
2. **The purpose of your involvement plans**, i.e. what you want to achieve and what people will be asked to do

Ideally you want to talk with a range of people, from a variety of backgrounds and over a period of time, 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.

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 a number of approaches to consider:

Target audience	Ways to reach them
Experts by experience (i.e. condition-specific patients or carers)	<ul style="list-style-type: none"><li>• Healthcare professionals – Do you know anyone working in the field? Will they let you put up posters in an outpatient clinic? (N.B. this does not require ethics approval when it's for PPI)</li><li>• Third sector organisations and charities – these groups will often have a large network of patient contacts, and be happy to support you getting in touch</li><li>• Your research teams' website and/or Twitter handle – this could be an easy way to advertise opportunities; however, it's best not to rely on this approach, especially if you're unsure whether a good proportion of the people you want to involve are active followers</li></ul>
General public (aka. Lay members/partners)	<ul style="list-style-type: none"><li>• Personal connections, social media, public engagement events or even people on the street</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><li>• Consumer health groups such as <a href="#">Healthwatch</a>. Some are membership organisations that distribute opportunities to their members. The Healthwatch covering the Imperial College area is <a href="#">Healthwatch Central West London</a></li></ul>
PPI-experienced people	<ul style="list-style-type: none"><li>• <a href="#">People in Research</a> allows researchers to advertise opportunities for involvement to interested members of the public. Its reach is UK-wide, but tends to be used by those who are quite experienced in PPI</li><li>• <a href="#">Voice</a> is a Newcastle-based organisation that aims to capture the public's vast experience, ideas, opinions and expectations about the research, innovations and policy developments affecting their lives</li></ul>

## 4.2 Addressing inclusivity in PPI

Nobody expects researchers to establish a full ‘representativeness’ of their target population among the people they involve. Diversity is what’s key. This idea of inclusivity stems from the fact that too often we only reach out to those who are easiest to find or engage with, e.g. those who are already involved in research, or who come to science engagement events.

You may have heard the term ‘seldom-heard’ used to describe groups of people whose perspectives are often missed from healthcare evaluation and research, and are under-represented in healthcare decision making. These groups were previously called ‘hard-to-reach’, but this has been changed in view of the fact that it’s our own processes and approaches that create the barriers to engagement. They don’t consider themselves ‘hard-to-reach’.

Depending on the field, seldom-heard groups may be anyone. But often they include people from ‘protected characteristic’ groups (as defined by the Equality Act 2010), for example people who identify as lesbian, gay, bisexual or transgender (LGBT); people with a learning disability; or people from ‘inclusion health’ groups, such as homeless people, sex workers, and Gypsy and Traveller communities.

Where possible, positive efforts should be made to involve as diverse a range of relevant communities, backgrounds and perspectives as possible. This will often involve taking your research to them rather than expecting them to come to you or a venue of your choice.

The following three case studies may prove useful reading as they describe how to involve certain seldom-heard groups in research and the benefits this can bring:

- [Involving seldom-heard groups in a PPI process to inform the design of a proposed trial on the use of probiotics to prevent preterm birth: a case study](#)
- [Combining PPI with qualitative research to engage ‘harder-to-reach’ populations: service user groups as co-applicants on a platform study for a trial](#)
- [Engaging and involving Gypsy and Traveller communities](#) – a podcast produced by the East Midlands Academic Health Science Network

### A small note on: MANAGING DIFFERENCES

When collaborating with any range 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.

## 5. CHOOSING YOUR PPI APPROACH

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### 5.1 More Guidance on PPI Methods

There is no 'one size fits all' method of involving people. It will depend on your research project, the time and resources you have available and what you want to achieve.

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

PPI Method	Source for more information
<p><b>Informal chat</b></p> <ul style="list-style-type: none"> <li>Listen/Talk to someone (patient/public) with experience of the research topic or issue, e.g. via patient forums or social media</li> </ul>	<p>Just get started, you'll learn more by doing.</p>
<p><b>Survey/Interview</b></p> <ul style="list-style-type: none"> <li>Run a survey or interview in a setting where your target audience may be found, e.g. waiting rooms</li> </ul>	<p>Imperial staff and students have free access to the <a href="#">Qualtrics survey tool</a>.</p>
<p><b>Focus Groups and Interactive Workshop, e.g. a Perspective Workshop</b></p> <ul style="list-style-type: none"> <li>Focus Groups are similar to informal chats and interviews except that you bring a range of people together and hold open discussions as a group</li> <li>Perspective workshops follow a SWOT (strengths, weaknesses, opportunities and threats)-inspired method. They're often used to explore myths, generate new perspectives, and put forward guidelines on a given project or technological development. The method is especially applicable for broader technological topics with no prior consensus</li> </ul>	<p>For more, visit:  <a href="http://actioncatalogue.eu/method/7418">http://actioncatalogue.eu/method/7418</a></p>
<p><b>Research Buddies or Patient Reps</b></p> <ul style="list-style-type: none"> <li>Research buddies are patients, consumers or community members who provide links between the researcher, other consumers and community members, organisations or the research funder</li> </ul>	<p>For more, visit:  <a href="http://www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/research-buddies">www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/research-buddies</a></p>
<p><b>Patient/Public Panel or Reference Groups</b></p> <ul style="list-style-type: none"> <li>PPI Panels can be referred to throughout the course of a research project. They provide advice at a particular stage or throughout a project. This may be more relevant for large-scale projects where continuous and varied involvement can be adequately managed</li> <li>Reference groups are like Patient Panels except they are groups of consumers or community members</li> </ul>	<p>For more, visit:  <a href="http://www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/reference-groups">www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/reference-groups</a></p>

<p><b>Steering groups/user committees</b></p> <ul style="list-style-type: none"> <li>• These are groups of stakeholders who steer and influence the research project. It will have more influence and involvement than a reference group, which only provides advice</li> </ul>	<p>For more, visit:  <a href="http://www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/steering-groups">www.involvingpeopleinresearch.org.au/researchers/how-to-involve-consumers/steering-groups</a> and  <a href="http://actioncatalogue.eu/method/744">http://actioncatalogue.eu/method/744</a></p>
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For more PPI ideas and guidance, visit the following online sources and reports:

- [Cancer Research UK PPI Toolkit for Researchers \[cancerresearchuk.org\]](http://cancerresearchuk.org)  
Cancer Research UK provides free access (using the login and password provided on the website) to their PPI toolkit for researchers. Hosted within 'Methods of Involvement' is detailed information on how you prepare, run, and evaluate many of the methods listed above.
- [The Action Catalogue \[http://actioncatalogue.eu/\]](http://actioncatalogue.eu/)  
This is an online decision support tool that is intended to enable researchers, policy-makers 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).
- [The Health Foundation 'Evidence scan: Measuring patient experience \(June 2013\)](#)  
This report sets out the pros and cons of various methods of involving people, including when one method may be more appropriate than another. In particular, surveys are covered in detail.
- [Bagley et al. \(2016\) 'A patient and public involvement \(PPI\) toolkit for meaningful and flexible involvement in clinical trials – a work in progress'](#)  
This publication describes a developing toolkit that aims to support clinical trials teams to undertake effective and meaningful PPI.

## 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 users 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 PPI and on the basics of research and its stages is all part of involving people.

If you are involving patients and members of the public in your research, then it is expected that you provide them with some training. This doesn't mean using your research grant to send them on a course. 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 the involvement. You can use this [‘Training/Support questionnaire \(word\)’](#) template to help you understand the training needs of those you involve, as some may be more familiar to PPI and research processes than others. The questionnaire is also accessible from our online [PPI Resource Hub](#) [scroll down to ‘Further PPI Resources > ‘PPI member documents’].

Training involves taking the time to explain the general stages of your project, 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 have to report to your funder and what you have to provide. Depending on the needs of the group, ongoing training could be provided throughout the course of the project.

For some resources to help you put together training for the people you involve, see the ‘Training Resources for Patients and Members of the Public’ section below. Alternatively, some pre-arranged training modules coordinated by PERC may be available – visit our [PPI Training page](#) online for upcoming dates.

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

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

- Training and resources
- Downloadable PPI guides
- Plain English PPI glossaries

## 6.2 Accommodating Differences

Embracing differences between people – whether in age, culture, personality or ability – is very important to ensure you gather a rich range of perspectives, and they enjoy the experience. This document '[Strategies for diversity and inclusion in public involvement \(pdf, 2012\)](#)' from INVOLVE covers a number of considerations, such as payment and communication requirements, and provides guidance on how to optimise the inclusiveness of your involvement.

Your communication with people needs to be appropriate to their circumstances, e.g. using traditional mail 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. It's best to ask at the beginning whether people have any specific needs, so you can cater for them appropriately. For this, you can use our template recruitment questionnaire: '[Background information form \(pdf\)](#)', also accessible from our online [PPI Resource Hub](#) [scroll down to 'Further PPI Resources > 'PPI member documents']]. Alternatively, you can design your own.

It's also worth noting that if your organisation provides NHS care or adult social care, they are now 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/).

### Learning Disabilities

According to [mencap.org](http://mencap.org), there are 1.4 million people with a learning disability in the UK. But with the right support, i.e. support that's tailored to the individuals' needs, most people with a learning disability in the UK can lead independent lives.

[Easy Read](#) is one way of making information more accessible to people with learning disabilities. Easy Read is not a simple translation of existing documents into easier to understand language. 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)

And 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 NHS Trust they should have access to an Easy Read library as they are required to comply with the Accessible Information Standard

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

## 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 \(word\)](#)' and '[Standard/Chairperson Role Descriptions \(word\)](#)' templates, which we've developed for you to adapt – also accessible from our online [PPI Resource Hub](#) [scroll down to 'Further PPI Resources > 'PPI member documents']].

Involving people early in the process is equally vital. PPI is much more effective and valuable for all those concerned if it is planned from the beginning of a project, or even before. Most funding applications now require you to include a PPI plan in the submission. If your project has already started, it may be possible to incorporate involvement activities half-way through. Just make sure your PPI plans have been thoroughly thought about and prepared for before starting. Poor planning leads to delays and unforeseen barriers, which can spoil the experience for all involved, and limit the opportunity for impact.

### A small note on: TRANSPARENCY

Transparency and accountability is key to successful PPI. You will lose good will by not being open. 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 Patients and the Public for Their Time

It is now accepted practice 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 [‘Policy on payment of fees and expenses’](#) developed by NIHR INVOLVE.

When recruiting patients and the public into your project, you should consider where they live as your PPI budget will need to cover their travel expenses. Depending on the circumstances of the person and the PPI budget, accommodation and childcare may also need to be paid for. And 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 some cases, it may be more appropriate to work with an external organisation who is able to offer expert support that is more directly suited to the needs of the group you are targeting. They may reimburse expenses in cash where individuals do not have a bank account, or help you use petty cash to cover expenses on the day of an event. This can be especially important for children and young people, and for groups who may be socially excluded, such as the homeless.

For more information and guidance (including rewarding children and young people), visit NIHR INVOLVE’s webpage: [Payment and recognition for public involvement](#).

### A note on: EXPENSE PROCEDURES

#### *Payment for peoples’ time*

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

1. **NPF form:** If your lay partners will receive payment of less than £1,000 annually from (any) Imperial College (team), 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 the College. They must not already be on Imperial College’s payroll (i.e. they must not have received, at any time since April last, a payslip from the Imperial College payroll office). More guidance is on the form itself
2. **Invoice:** If lay partners have been paid, or will be paid, more than £1,000 in one calendar year, they should submit an invoice (see the [PPI Resource Hub](#) for 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 claimed separately using an [expense claims form](#). These expenses are not included in the £1,000 limit mentioned above.

## 7. EVALUATING THE IMPACT OF PPI

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To be able to properly evaluate the impact of your public involvement activities, you will need to give it some thought **BEFORE** you start.

Such as:

- How will you know if your involvement activity achieved the outcome you were hoping for? What will be your measure of success?
- What mechanism or tool will you use to measure its impact on your research and those involved?
- How will you monitor and evaluate the approach and process you took?

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 pre- and post-PPI evaluation forms (example templates are available on the [PPI Resource Hub](#)), but other approaches may be possible too, such as:

- Our **DRAFT PPI Impact Assessment Plan** – We've developed this tool to simplify and consolidate the process of planning and assessing the quality and impact of PPI in research. We would like to pilot it with researchers within Imperial so please [get in touch](#) if you'd like to trial it on your project. Ideally, you have a rough PPI plan but haven't yet started
- The [Public Involvement Impact Assessment Framework \(PiiAF\) website](#) (funded by the MRC) is a very comprehensive site that was produced in 2013 to help researchers plan and assess PPI. The PiiAF Guidance Document may be too detailed for many of your needs, but a quick look may still be useful

By assessing the impact of involving lay people, you can help build an evidence base of PPI 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.

## 8. REPORTING PPI

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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 blog posts (see [our blog](#)), developing posters or running workshops. The people you involve may also have some interesting ideas on how to share your experiences.

### Publishing in a Peer-Reviewed Journal

When submitting a research paper to a journal for publication, make sure you include a few lines on your public involvement activity where relevant. It is likely to have been a part of your research design, methodology and/or interpretation in some way and should be acknowledged appropriately.

To improve the consistency and quality of PPI reporting, a checklist known as GRIPP ([Guidance for Reporting Involvement of Patients and Public, pdf](#)) was published in 2011 that aimed to help researchers prepare research manuscripts. However a new version, [GRIPP2](#), was published in 2017 to simplify the reporting process and accommodate research where PPI is not a primary purpose of the research:

**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 PPI is a secondary purpose*

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 \(BMJ\) who ask patient reviewers](#) to both review the PPI elements of the research/project, as well as comment on the following:

- Are the study's aims and the issue and questions that the paper addresses relevant and important to you as a patient? Do you think it would be relevant to other patients like you? What about carers?

- Are there any areas that you find relevant as a patient or carer that are missing or should be highlighted?
- From your perspective as a patient, would the treatment, intervention studied, or guidance given work in practice? Is it feasible? What challenges might patients face that should be considered?
- Are the outcomes that are being measured in the study or described in the paper the same as the outcomes that are important to you as a patient? Are there others that should have been considered?
- Do you have any suggestions that might help the author(s) strengthen their paper to make it more useful for doctors to share and discuss with patients?
- The level of patient involvement in the research described, and if/how it could have been improved. Authors are now required to state if and how they involved patients in setting the research agenda and the design and implementation of the study and include this information in a box within the manuscript. If there was no patient involvement we would welcome your ideas on how this could have been done. We hope this will help authors think of the best ways to include patients in their future research and further progressive patient involvement in the research enterprise

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 lay members haven't been involved in writing the manuscript, you've still managed to involve them in the dissemination of your research.

### **Publishing in a PPI-Focused Journal**

This option may be suitable where PPI 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 five well-respected journals that have a strong focus on PPI:

- 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/>
- 5. Research for All**  
[www.publicengagement.ac.uk/work-with-us/current-projects/research-all-journal](http://www.publicengagement.ac.uk/work-with-us/current-projects/research-all-journal)

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

## 9. FURTHER READING AND KEY LINKS

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### 1. INVOLVE

[www.invo.org.uk](http://www.invo.org.uk)

Established in 1996, this government funded programme is considered the central portal for PPI expertise, insight and research. It is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research.

### 2. Health Research Authority (HRA)

[www.hra.nhs.uk](http://www.hra.nhs.uk)

In its role to protect and promote the interests of patients and the public in health, the Health Research Authority now 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 web links and resources:

- [HRA: Public involvement in research \(web page\)](#)
- [Impact of public involvement in research: impact on the ethical aspects of research, INVOLVE](#) (pdf; May 2016) – evidences how public involvement can help to make research more ethical and produce better outcomes
- [HRA: Informing participants and seeking consent \(web page\)](#)
- [HRA: Involving the public in your research \(web page\)](#)
- [HRA: Preparing study documentation \(web page\)](#) – templates for applying for approvals

### 3. Imperial College London

Patient and public involvement is central to a number of departments at Imperial. Many of these have their own PPI sites, with additional information tailored to the research field:

- [Patient Safety Translational Research Centre](#)
- [Imperial Clinical Trials Unit](#)
- [NIHR Health Protection Research Unit in Modelling Methodology](#)
- [NIHR Health Protection Research Unit in Respiratory Infections](#)

## 10. GETTING IN TOUCH

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PERC is available to support and advise on PPI 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 [ppi@imperial.ac.uk](mailto:ppi@imperial.ac.uk). We may also be able to offer guidance over the phone: +44 (0)20 7594 9774.

If your request is about a forthcoming Fellowship application, please provide the following information with your email so we can provide advice in a timely fashion:

- Name of Fellowship scheme
- Application deadline date
- Lay summary of your research
- Bullet point description of proposed PPI
- Specific issue(s) you wish to discuss

If you work outside of Imperial College and/or the NIHR Imperial BRC, please visit our [Work with us](#) tab to find the best way to get in touch.

In addition, we are always interested in collaborating on new projects related to our areas of expertise. If you have a research idea you would like to discuss, please contact [Prof Helen Ward](#).