

Patient and Public Involvement in Health and Social Care Research

A handbook for researchers by Research Design Service London



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Foreword

Demonstrating the continued involvement of patients and the public in your research plans is an important part of developing a successful grant application and is often a marker of good quality research. Simon Denegri, former Chair of INVOLVE, has previously stated, “no researcher or institution who applies to the NIHR for funding can expect to be successful without a plan for PPI that lay reviewers have scrutinised.” That said, involving patients and the public can seem a time consuming and daunting prospect for new and experienced researchers alike.

We’ve created this handbook to address some of the common questions and misunderstandings about patient and public involvement (PPI) that we have come across over the years helping researchers apply for research funding.

The handbook will give you a firm foundation in the rationale of PPI, providing insights into the contribution that patients and the public can make at different stages of your research. We also cover practical aspects such as involving the right people and where to find them, as well as the financial costs to consider.

We hope this handbook will help you and your research team to better plan, manage and implement meaningful PPI in your research.

From the PPI team
NIHR Research Design Service London

Acronyms

BRC – Biomedical Research Centre

DBS – Disclosure and Barring Service

EIF – Enabling Involvement Fund

NHS – National Health Service

NIHR – National Institute for Health Research

NRES – National Research Ethics Service

PPI – Patient and Public Involvement

RDS – Research Design Service

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The basics



What do we mean by Patient and Public Involvement in research?

Patient and Public Involvement (PPI) in research is the development of an active partnership between patients and/or members of the public and researchers.

PPI is the term used to describe researchers and patients and the public working together to develop research which is relevant and useful to patient and public needs. You can actively involve patients and the public in all stages of the research process; including,

- Inspiration for research ideas/topics/questions
- Prioritisation of ideas and/or research questions/studies
- Design and management of studies
- Data collection and analysis
- Translation of results into health/social care impact
- Dissemination of findings.

PPI is **not** about having patients or members of the public as research participants. It is important that researchers listen to people with personal experience of the conditions or experiences that they are investigating to find out what is important to patients, service users, their families, or members of the public.

In this handbook, we refer to Patient and Public Involvement (PPI). Below you will find a list of people who make up the 'patients' and 'public' in PPI.

Who are patients and the public?

- Past and current users of health and/or social care services
- Members of the public who may be affected by public health interventions
- Formal carers, or informal (unpaid) carers and family members
- Parents
- Members of the general public
- Organisations who represent patients and users
- Patient support groups
- Charities that represent specific health conditions
- Individuals with an interest in the topic being researched.

Why is Patient and Public Involvement important?

The contributions of patients can be extremely valuable, providing alternative views from those of the research team or NHS staff. Patients are able to make judgements based on their understanding and lived experience of their condition. They may have different aspirations and thoughts about health outcomes that health care professionals and researchers may not have considered. PPI is important because it makes interventions more likely to be acceptable in practice. PPI can also help researchers with recruitment of patients for their research, and ensure that research materials are patient friendly.

When should I involve patients and the public in the research development process?

Although PPI can be incorporated at different stages of the process it is generally best to develop links with potential patients and the public at the earliest stages of developing the project. The National Institute for Health Research (NIHR) suggest five key stages in the research process where involvement could take place. These are:

- Design of the research
- Development of the grant application (pre-protocol work)
- Undertaking / management of the research
- Analysis of data
- Dissemination of research findings.

The research cycle in Chapter 5 will provide more detail on the involvement activities at each stage of the research cycle. You **do not** need to undertake all activities described to have suitable, relevant and good quality PPI within your project. You should try and undertake the activities you think will be most relevant to those involved and to your research project. If you are in doubt about where to involve patients and the public in your research project, it is a good idea to ask them to advise you on areas they feel need input from them.



What do I call people who I involve in the research development process?

A wide range of terms are used to describe those people who are involved in the research development process:

- patients
- lay people
- health service/social care users
- PPI members
- research advisers
- research associates
- lay advisers
- lay panel members
- patient advocates etc.

Most importantly, however, they are not research participants.

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Creating links with patients and the public



Before you begin your involvement activities you will first need to find patients and members of the public and make links with appropriate groups. There are many areas where you can locate them about getting involved in your research. You may already have links to suitable patients and/or patient groups. The list below may help you identify the links that you already have or could develop.

In clinic – do you treat any patients you think would want to get involved in your research? While this might be a convenient option, your own patients may give answers and opinions to please you. You may have contacts to other clinics, or a colleague in your institution who might be able to ask their patients whether they would like to be involved.

Patient groups and charities – You may have worked with patient groups or charities in this area previously, either in research or on other projects. You could get in touch with them, and utilise the important contribution that those organisations can bring.

Individuals – do you know of people through your own networks that may be helpful or interested? Consider involving those that took part in an earlier stage of research e.g. pilot study.

RDS London – we may have individual or group contacts that we can put you in touch with.

Clinical Research Networks – are there any networks in your research area that may be relevant and helpful?

Local funders – Clinical Commissioning Groups (CCGs), local councils and voluntary (third sector) organisations

Biomedical Research Centres (BRCs) – There are eight BRCs in London, and 20 nationwide. You could approach these for help.

Public health research – you can ask people at schools, parenting groups, community groups, libraries, churches, leisure centres etc.

People in research – People in Research is a site hosted by NIHR INVOLVE where you can advertise your research opportunities to interested patients and members of the public who can view and reply to your advert: www.peopleinresearch.org

Creating a standing PPI group – You may find that you want to create a regular patient/lay research group for your research topic or team. Setting up a patient group is useful if you, your research team or your department have a particular focus on one research topic or theme.

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Ethics and consent



You do not need to obtain formal consent to involve people in your research as part of your PPI plans. For more information about this, the National Research Ethics Service (NRES) and NIHR INVOLVE have written a statement to clarify the position of ethics and PPI.

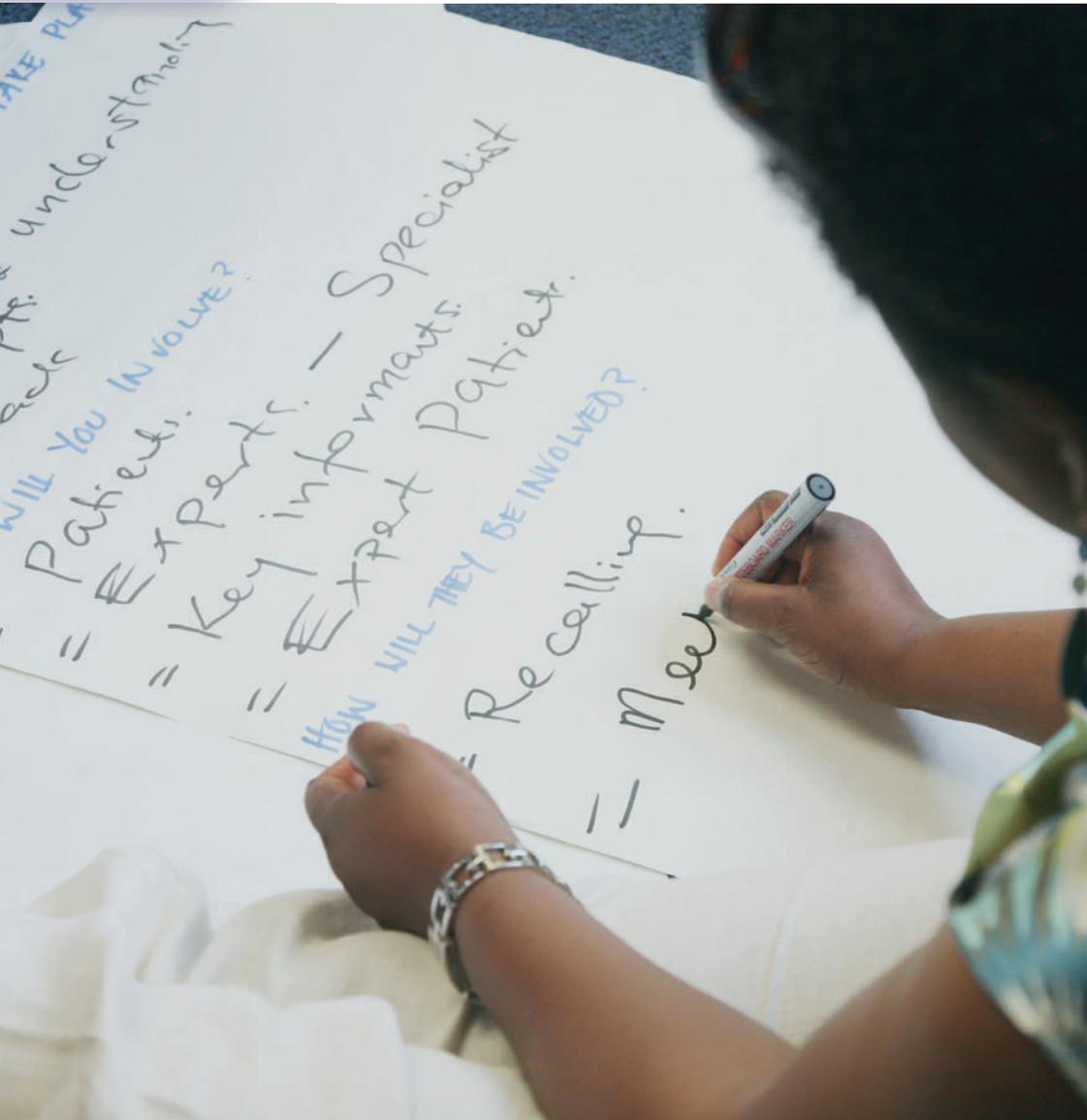
“The active involvement of patients or members of the public does not generally raise any ethical concerns **for the people who are actively involved**, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. They are acting as specialist advisers, providing valuable knowledge and expertise based on their experience of a health condition or public health concern. Therefore, ethical approval is **not needed for the active involvement element** of the research (even when people are recruited via the NHS) where people are involved in **planning or advising** on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group, or co-applicant.”

You can find the full NIHR INVOLVE Statement at their website: www.invo.org.uk

While no formal consent is required for PPI, it is generally recommended to draw up terms of reference for PPI members. This ensures that both parties are fully aware of the level of involvement and the associated expectations towards each party.

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Planning and preparing – what you need to know



Before beginning to involve patients and the public in research, a number of issues need to be carefully considered. The following is a list of questions and factors to take into account. These are suggestions; there are other factors that you may need to consider, which will vary depending on your research.

Needs and expectations

You should consider why you want people involved in your research.

- What do you think their perspective will bring, what can they add?

Think about who you want to involve and where will you find them.

- It may take a long time to engage people and get them actively involved in your study, so it is advisable to start the process of involvement as early as possible

Consider your expectations of those involved.

- What contribution will they be expected to make?
- Are your demands on people's time reasonable?

Contemplate what skills you would appreciate in those you wish to involve.

- Do they need research skills?
- Do they need previous experience in research?
- Will you need to include a glossary of terms to help them?
- Will you provide or find appropriate training for them?
- Maybe patients or members of the public do not need any skills for your project, just experience of a certain condition.

You could write a role description. This may be more suitable for more formal roles or may be something that the research team and patients /members of the public agree on together. You should take care not to be too prescriptive in the role description since the principle of PPI values is the lived experience of patients.

You can access a role description template at our website: www.rds-london.nihr.ac.uk

Planning for PPI costs

You should plan your costs and think about whether the project will cover all reasonable costs, such as:

- The costs of a personal assistant for someone less able
- The costs of providing carer cover if the person you wish to involve is a carer
- The costs of childcare, or
- The costs of taxi fares if the patient or member of the public is less able?

You should consider how you will pay for the expenses incurred by the involvement activities you plan.

Will your project pay an honorarium to those you involve? How might this affect this person's benefit payments?

If you need money to pay for patient and public involvement in the design stage of your research, i.e. before you have funding, you can apply online for RDS London's Enabling Involvement Fund.

For more information on how to apply, see page 32.

For more information on estimating costs for your PPI, see page 24.

Organisation

Some travel arrangements can be made in advance:

- You could book trains, taxis ahead of time.

Who will be the point of contact for those involved?

- It is often better to have one point of contact who will work with patients or members of the public and assist them, if and when they need it.

Think about the duration of meetings with patients or members of the public. They may require more comfort breaks and the freedom to take medication during meetings.

- Should you meet them beforehand and afterwards to ensure they feel comfortable?

Do you need to have a meeting or could you discuss via email or telephone?

It may make sense for you to send reading materials well in advance of meetings in order for people to prepare. If so, the materials should be in plain English.

Consider the location and disabled access of your meeting place. You could organise meetings in a place that is local to your PPI members. This might also make the meeting less formal. Possibilities include:

- Community centres
- Libraries
- Coffee shops (bear in mind that public venues may not be suitable if you will be discussing sensitive, potentially upsetting or confidential information)

Think in advance about how you will distribute information to people:

- Will you use email, post or telephone?
- Remember that some people may need large print. For all written material, it is best to use an Arial font and if possible to print on pastel coloured paper to aid reading for those with visual or neurological impairments.

Training and support

PPI members are likely to need support so that they can contribute to your study in a meaningful way.

How will you support PPI members so that they can understand the terminology you use in your research?

How will you make sure that PPI members have a basic understanding of the research and the methods you are using?

The NIHR Biomedical Research Centre at Guy's Hospital provides training for patients and members of the public who would like to be involved in research.

Find out more at their website: www.guysandstthomasbrc.nihr.ac.uk

PPI members often find it helpful to have a meeting early in the study in which researchers explain the basic research methods and key terminology in accessible language. This allows patients and members of the public to contribute to the research more fully. Such training meetings also help you and the PPI members to get to know each other better.

NIHR key areas of involvement

Designing research, developing a grant application

Many of the PPI activities can overlap in both design and development. It is likely that some of these activities will be happening concurrently as the project develops and the funding deadline approaches.

At design and development stages, you should already have a clear idea of who you are involving in your research and, quite possibly, how. Remember those you involve may also suggest alternative ways of involving people, so there should be flexibility. At this point involvement may be informal and preliminary. This may be a good time to develop an understanding of the support needed by those you have involved. For example, do they need training in order to understand the basics of research or the processes involved in applying for funding? Can you provide this or do you need to seek support from other sources?



As a first step, you should consider discussing your research topic with those you have chosen to involve. You could ask them to review the proposal and offer suggestions for changes. You could use this discussion as a starting point for other involvement activities.

In the development of your project, patients and the public may:

- Help to clarify the research questions and affirm their importance, helping you focus the research questions to reflect the needs and priorities of patients and the public;
- Review and comment on proposed methods and outcome measures, ensure that methods selected are appropriate from patients' perspectives;
- Review and make suggestions on the recruitment strategies;
- Explore the burden on participants – Are there any barriers to patients taking part? This is where a lay perspective is most valuable in ensuring the study is feasible and practical, answering the question whether a patient would agree to take part in the study.
- Explore possible ethical issues from a patient's perspective, e.g. emotional and personal safety issues to participants;
- Be named as a co-applicant; and
- Help to plan subsequent PPI activities.

You may also wish to include patients and the public in helping you to identify priorities for your topic area or research theme. It is worthwhile speaking to patients and the public about topics they would like researched, or about what patient priorities are. Please see the James Lind Alliance website if you would like further information on setting priorities with patients and the public: www.jla.nihr.ac.uk

Undertaking research

Even when your study is underway and you have other priorities, it is important not to forget about your patients and the public. There are many practical ways that PPI can be involved at this point.

Steering groups, data monitoring committees, lay panels, and expert advisory groups

Some research teams invite patients and the public to join the research steering group. However, you should carefully consider whether this is the most appropriate approach to take and whether you think this would be the best setting in which to involve patients in your research. It may be better to set up a separate lay advisory group, focusing on patient and public input to the research.

If you choose to involve patients and the public in the steering group, you should ensure that:

- they have received the relevant paperwork beforehand and have understood it;
- you provide lay summaries/glossaries and omit jargon;
- you meet with them before and after each meeting to ensure they are supported;
- you make them feel part of the group, equal to other group members;
- you explain things to them clearly; and
- you create a meeting in which they can ask questions and seek clarification.

Preparation of patient information sheets and consent forms

Before you submit your proposal for ethical approval you will likely need to produce patient information sheets, adverts and consent forms (depending on your research).

Preparing these documents is often an extremely useful point at which to involve members of your PPI group. They can help you make the information relevant and accessible for people being recruited to the study. Clearer and more accessible study information is likely to help you recruit patients to time and target.

Qualitative research

PPI is different from qualitative research. The aim of PPI is to involve patients and the public as partners in order to improve the design of your study. Qualitative research aims to gain information/opinions from patients and the public about the topic of your research. In qualitative research, patients and the public are subjects of your research, whereas in PPI, they are partners in the design and implementation of your research project. If you are undertaking qualitative research, there is a good possibility that patients and the public will be able to make useful contributions to developing the interview questions and schedule. Additionally, you may wish to involve them in undertaking interviews if this is feasible and would add to the relevance of the research. It may be that you think those being interviewed are more likely to open up and discuss matters with someone who has similar experiences. You may want a researcher and a PPI member to co-interview. If you wish to involve patients in interviewing in any way you must think about the following.

- Their training needs – will they need training in interview skills, techniques or qualitative research?
- If they are interviewing patients, they may need Disclosure and Barring Service (DBS) checks or research passports that will allow them to carry out research. Be sure to discuss this with your local Trust R&D team.

Recruitment

It is worthwhile discussing your trial/study recruitment plans with the members of your PPI group. Patients and the public will have different perspectives and may be able to point out potential issues they see with your plans before you begin the process of recruiting. They may also be able to suggest ways of avoiding issues or of changing elements in your recruitment to suit the needs of the participants. It is important to note, however, that it is not the role of patients to 'solve' any recruitment issues you may have in your study.

Analysing data

Consider whether you want to include patients in your analysis plans. Researchers often find data analysis a trickier area for PPI. If you have involved your patients and the public in undertaking research (and they have the necessary DBS checks, research passport etc.), you can involve them in undertaking the analysis of the data.

Patients and the public can:

- Develop themes from the data and suggest gaps in the data, which can help identify further research questions; and
- Explore the data and provide interpretations, from patients' perspectives, which may differ from that of the research team.



Disseminating research findings

Many researchers like to include PPI in the dissemination plans for their study. They can do this through a variety of ways.

Where to disseminate?

Patients and the public, at this stage, can:

- Provide suggestions about different avenues for dissemination;
- Provide access to relevant local groups and organisations you could use to promote the findings of your research; and
- Help publicise your findings by getting them published on charity and voluntary sector websites.

Writing and presenting

Patients and the public can:

- Advise on and help develop reports on the research findings that are readily understood by the public;
- Participate in presenting the research findings and talk about their experience of being involved in the process;
- Write out the findings for local patient groups, Trusts, etc;
- Present the research findings at conferences, patient group meetings, and to hospital managers and policy makers; and
- Deliver more creative methods of dissemination, e.g. via podcasts, blogs, media & press.

One of the common complaints from members of the public is that they do not hear about research activities. Those involved in your project could identify places to disseminate your results and help create a lay version or summary.

Once the study is complete, ensure that the members of your PPI have been properly thanked and rewarded for their input. Remember you may want to involve them in the future in other studies, in other ways. PPI is about building relationships with your research community.

For examples of PPI in research, please see NIHR INVOLVE's Senior Investigators and Public Involvement publication on their website, which contains many examples.

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Patient and Public Involvement in the research cycle

1. Identifying & prioritising

Patients and the public can

- Help inform research priorities (e.g. through local user groups and organisations)
- Be consulted about research topics and priorities, important to them as service users
- Collaborate with researchers to identify topics for research
- Identify topics for research themselves.

2. Design

Patients and the public can

- Inform the design of the research study,
- Clarify the research question and affirm its importance,
- Ensure the methods selected are appropriate for patients,
- Assist in creating a recruitment strategy, and
- Review and comment on proposed questionnaires and data collection methods.

3. Development of the grant proposal

Patients and the public can

- Help to ensure that the research proposed and methods chosen are ethical,
- Inform on areas where patients and the public might be involved,
- Provide ongoing advice on where patients and the public could be involved,
- Define outcome measures,
- Advise on the appropriateness of the Lay Summary,
- Raise awareness about costs of involvement and expenses, and
- Be named as co-applicants.

4. Undertaking the research

In setting up a steering group to manage / monitor the research, patients and the public can

- Steer the project throughout the research process,
- Assist in writing the patient information and consent forms,
- Help ensure that the research is ethical and acceptable to patients and members of the public,
- Aid in designing the detailed protocol,
- Produce research updates that are patient friendly, and
- Assist in conducting interviews and surveys.

8. Monitoring & evaluation

Patients and the public can

- Have continued involvement with the study to maintain focus and address issues as they arise,
- Collaborate with researchers to evaluate the research process, and
- Reflect on their role and what they have learned.

7. Implementation

Patients and the public can

- Increase the likelihood that results of research are implemented, by adding validity to the findings; and
- Develop patient information for new services/interventions within hospitals, GPs surgeries etc.

6. Dissemination

Patients and the public can

- Advise on different avenues for disseminating results;
- Jointly present the research findings with researchers;
- Write information for local patient groups/hospitals, etc;
- Assist in getting the research findings published on charity or voluntary organisations websites;
- Help distribute the research findings within their informal networks; and
- Produce summaries of the research findings.

5. Analysing & interpreting

Patients and the public can

- Assist the research team in developing themes from data, and
- Be consulted to check understanding whether they interpret the data in the same way as the research team

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Costs and payment for Patient and Public Involvement



PPI is not free; patients and members of the public should be offered payment for their time on the project. Some people may refuse payment. Nevertheless, when submitting a proposal for funding, you should include costs for your PPI activities. Costs for PPI will include payments to patients and the public for their time and effort, and payment for your involvement activities. Funders will be looking to see that you have properly accounted for PPI activities and that you have sought adequate costs.

How do I pay PPI members once I have funding for the project?

There are different ways in which you can pay patients and members of the public for their involvement, should they want to be paid. You can:

- Put them on a university payroll or issue temporary contracts,
- Ask PPI members to invoice for their time,
- Ask them to use timesheets to record their involvement activity, or
- Reimburse PPI members with vouchers.

Payment may affect the benefit status of PPI members. You can access free consultation from the Advisory, Conciliation, and Arbitration Services (ACAS) on employment status and benefits, <http://www.acas.org.uk>

For more information about payment for patients and the public, NIHR INVOLVE offers two publications:

- 1. What you need to know about payment:** An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research. Although this is intended for members of the public it is a useful document for researchers and research teams, too.
- 2. Payment for involvement:** A guide for making payments to members of the public actively involved in NHS, public health and social care research.

Both publications are available on their website.

Besides payment to patients and the public there are other costs associated with PPI. Typical costs and the considerations are outlined on the next page:

Costs of Patient and Public Involvement

The following table is intended to get you thinking about what the costs for your PPI members will be. If you are unsure where is best to meet or what transport costs to include, discuss this with your PPI group. Remember that some may have specific requirements, such as requiring a taxi due to disability, or needs, such as print documents. Be sure to factor in these unseen costs when preparing your funding application.

Evaluating PPI is increasingly viewed as an important activity for those undertaking PPI in research. There are many reasons why you and your research team may want to evaluate your PPI activities. By carrying out an evaluation of your involvement work, you may be able to assess whether your original aims and objectives defined during the planning stages have been achieved. Evaluating your PPI activities may also prove to be important for those you have involved. It can be encouraging for them to understand what value their contribution has had on the research and on their own development.

Cost	Considerations
Meeting room hire	<p>Can you use a free room within the university? Would you be better using and paying for a community location e.g. a Community Centre or Library? How many times a year will you need this room for / need to pay for a room? Do you need rooms with wheelchair or disabled access and access to disabled toilets? If patients have mobility issues, should you hold the meeting close to local transport?</p>
Refreshments	<p>How many patients are attending? What catering should you order? Roughly how much will this cost? Do you need to cater for specific diets (diabetic patients, pregnant women etc)</p>
Photocopying	<p>If you need larger font publications or information materials to print in colour what will these costs be?</p>
Carer cover	<p>Are you inviting carers to get involved? Will you need to pay for professional carer cover? Are you asking mothers or families to get involved? Will you need to provide a babysitter? Will you need to pay for the costs of a personal assistant?</p>
Transport	<p>Do you need to pay for long distance train or petrol costs, what will these costs be? What will the costs for taxis be? Do you need to account for any other travel costs?</p>

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Evaluating Patient and Public Involvement



Evaluating PPI is increasingly viewed as an important activity for those undertaking PPI in research. There are many reasons why you and your research team may want to evaluate your PPI activities. By carrying out an evaluation of your involvement work, you may be able to assess whether your original aims and objectives defined during the planning stages have been achieved. Evaluating your PPI activities may also prove to be important for those you have involved. It can be encouraging for them to understand what value their contribution has had on the research and on their own development.

Evaluating the involvement of patients or members of the public can help to:

- Identify what works (or not), for whom and in what circumstances;
- Identify how the involvement impacted the research process;
- Celebrate success – recognising the achievements of your research team, the patients, and the public;
- Generate evidence and share learning of the value of PPI – your PPI activities could inspire others and help evidence the impact of PPI on the research process?
- Improve the planning of future projects – evaluating what worked and what did not will help you identify how to plan future projects; and
- Determine personal impact.

There are many frameworks for evaluating PPI in research, none of which have been unanimously adopted by researchers, NIHR or NIHR INVOLVE. You could also obtain your feedback informally or in a final debriefing session with those you have involved, looking critically at what worked and what did not.

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How can RDS London help?



Bespoke advice on grant applications

PPI is an important part of developing research grant applications. Many researchers struggle with it and come to the RDS to learn about the funders' expectations and the most appropriate ways in which they can involve patients or members of the public in their project. The general adviser is your first point of contact at the RDS. General advisers explain the importance of PPI and provide some initial guidance on involvement and will introduce you to our PPI advisers when more specialist advice is needed.

To contact a general adviser, you need to complete our online support request form available at: www.rds-london.nihr.ac.uk

Specialist PPI advisers can help you think about the rationale and logistics of involving patients and members of the public in your research project. Depending on the level of input needed, we can provide feedback via e-mail, telephone, or face-to-face meetings.

Fast-track review service

Most major funders ask applicants to provide a plain English summary of their proposed research. This is a summary written for members of the public and non-specialist audiences. It is something which is becoming increasingly important to funders. The NIHR now stipulates that applicants must provide a good quality plain English summary.

Public involvement is key to writing a good quality plain English summary. Patients and members of the public can help to ensure the language used is easy to read and that the information provided gives audiences a full understanding of the research.

We strongly encourage researchers to use their own PPI group to review plain English summaries in the lead-up to submitting their research application. If this is not possible, RDS London's fast-track review service has been set up to help researchers involve patients and the public in the development of their plain English summary. Your summary will be reviewed by two lay reviewers who give feedback, by email, within two weeks. Contact your RDS general adviser to find out if you are eligible for the service.

Enabling Involvement Fund

It is considered good practice to involve members of the public as early as possible in the research design process. Funding public involvement at the grant application stage can, however, be challenging. RDS London's Enabling Involvement Fund can help.

The Enabling Involvement Fund (EIF) facilitates the involvement of service users in the development of research ideas and research grant applications. The fund helps researchers to establish links with relevant patients, carers, service users, service user groups, and individuals. It is intended to get patients and the public involved in research at an early stage where they can be influential and have a positive impact. You can use the fund to reimburse PPI members for their time, and to cover room hire, refreshments and travel costs. If you wish to apply for the EIF, you must be intending to submit a research proposal to a national peer reviewed funding stream (e.g. NIHR and medical charity schemes).

We recommend that you submit a completed EIF application form **at least eight weeks prior** to your funding application deadline. We may still consider an application at a later stage, but you should contact us to find out if you are eligible.

We provide guidance notes, which will give you more information and tell you all you need to know about the process of applying for the Enabling Involvement Fund. You can access this document from the RDS London website.

PPI workshops

RDS London runs workshops on implementing PPI in research with the NIHR Biomedical Research Centre at Guy's and St Thomas' NHS Foundation Trust and King's College London. The workshops are unique in the area of PPI as they are co-designed and co-delivered by patient trainers, and give the opportunity for participants to discuss specific challenges in their own studies with experienced patients and members of the public. The workshops target researchers that are currently in the process of applying to the NIHR or similar funding streams.

What do the workshops cover?

- An overview of what effective PPI is and is not in the context of research
- How patients and the public can be involved at each stage of the research cycle
- Practical planning for effective PPI
- Clarification on what resources and support structures exist in RDS and BRC.

Who can attend?

The workshops are free and open to researchers developing grant applications (or applying for personal fellowships) in applied health or social care research.

We welcome a broad range of researchers at our workshops, including medical doctors, nurses and allied health professionals, academics, and National Health Service and social care managers.

Please check the RDS London website for more details and upcoming workshop dates.

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Writing a plain English summary



What is a plain English summary?

NIHR INVOLVE states that a plain English summary is a brief summary that has been written for members of the public and an interested audience rather than specialists. It should be written clearly and simply, without jargon and with an explanation of any technical terms that have to be included.

Your plain English summary should cover the whole of your research project. When writing it you should take care to:

- avoid acronyms, jargon and technical language where possible
- provide explanations of complicated or uncommon words
- use active rather than passive language, i.e. say 'the research team will investigate this topic' rather than 'the topic will be investigated by the research team'
- use short sentences and short paragraphs
- ask others to check your summary to see whether anything is unclear.

NIHR INVOLVE suggests including the following information in your plain English summary:

Aim(s) of the research

- What are you aiming to find out?
- How will patients/carers/members of the public and services benefit from your research – either directly or in the longer term?

Background to the research

- Why does this research need to be done now?
- What is the scale of the issue? For example:
 - How many patients/members of the public are affected?
 - What are the costs to services?

Design and methods

- What design and methods have you chosen and why?
- Who are your participants? (if appropriate)

Patient and public involvement

- How have patients/the public been involved in developing this research to date?
- How will patients/the public be involved in the conduct/management of the research?

Dissemination

- Who will the findings be communicated to and how?

NIHR INVOLVE has information and resources on their website about writing plain English summaries: www.invo.org.uk



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Resources



The following resources provide a background to PPI and include information and ideas about how you could involve patients and the public at various stages of the research cycle.

Unless otherwise stated, all resources and links can be found at www.rds-london.nihr.ac.uk.

How to do PPI

Briefing notes for researchers

Produced by NIHR INVOLVE this publication provides an introduction for researchers who are new to PPI. Within this document you will find a background to PPI and its aim, as well as a step-by-step guidance on how to incorporate PPI in NHS, public health and social care research.

Payment

We have several resources that explain the payment of patients and members of the public who are actively involved in health and social care research.

Payment for involvement

The guide includes information on covering expenses, payment for time, skills and expertise, and issues you need to be aware of when making payment for public involvement in research.

What you need to know about payment

This introductory guide is for members of the public who are considering active involvement in NHS, public health or social care research.

Benefits advice service for involvement

NIHR INVOLVE created a service offering personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state benefits. More information can be found at their website: www.invo.org.uk

Case studies and examples

The following reports give examples of how other researchers have undertaken patient and public involvement. Through the use of case studies and experiences from others, you may find out new ways of undertaking patient and public involvement in your research.

Senior investigators and public involvement

This report details the work of senior investigators and the different ways they are include the public across all stages of the research process. A copy of the report is available at www.invo.org.uk.

Exploring impact: public involvement in NHS, public health and social care research

This document addresses the difference that public involvement makes to the research process, the impact of involvement on researchers' and the public, and gaps in PPI in health and social care research drawing on the use of case study examples to illustrate the advantages and pitfalls. You can access the report at: www.invo.org.uk.

Identifying and prioritising

Priority Setting Partnership (2009)

If you are planning, or looking to, prioritise research topics or themes with patients and members of the public, have a look at the James Lind Alliance website: www.jla.nihr.ac.uk.

National Research Ethics Service Report

This report summaries a joint study by NRES and NIHR INVOLVE. Specifically, the study assessed the extent and nature of PPI in health and social care research from NRES' routinely collected data as part of the applications process for ethical approval of research projects. You can access the report at: www.rds-london.nihr.ac.uk.

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Patient and Public Involvement checklist



Here are some things you will need to think about when developing your PPI strategy for your research:

- Why do you want people involved?
- Who are you going to involve? (consider diversity, seldom-heard groups)
- How will you find them?
- How will you involve them? (Terms of reference, role description, expectations, regular contact)
- How will you support them? (Training, key contact)
- Do some of your PPI advisers require specific support? (Interpreters, childcare, support for learning difficulties etc.)
- How will you incorporate their feedback into your research?
- How and when will you feedback to them about the progress of your research?
- What is the lifetime of the group and of the research?
- How will you pay for PPI members' time and expenses?
- How will you acknowledge them? (Thanks & recognition)
- Do you have a meeting venue? (How will people get there? Is it accessible? Catering?)
- Meeting times? (frequency, start and finish times, enough time for discussion but not too long!)
- Practical issues (admin, language, directions)

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References on Patient and Public Involvement



Theoretical discussions of PPI and participant in health research:

Arnstein, S. R. (1969). A Ladder Of Citizen Participation. *Journal of the American Institute of Planners*, 35(4), 216–224. <https://doi.org/10.1080/01944366908977225>

Boaz, A., Biri, D., & Mckevitt, C. (2016). Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom? *Health Expectations*, 19(3), 592–601. <https://doi.org/10.1111/hex.12295>

Filipe, A., Renedo, A., & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. *PLoS Biology*, 15(5), 1–6. <https://doi.org/10.1371/journal.pbio.2001403>

Gibson, A., Britten, N., & Lynch, J. (2015). Theoretical directions for an emancipatory concept of patient and public involvement. *Health*, 16(165), 531–547. <https://doi.org/10.1177/1363459312438563>

Ives, J., Damery, S., & Redwod, S. (2013). PPI, paradoxes and Plato: who's sailing the ship?: Table 1. *Journal of Medical Ethics*, 39(3), 181–185. <https://doi.org/10.1136/medethics-2011-10015>

Staley, K. (2013). There is no paradox with PPI in research. *Journal of Medical Ethics*, 39(3), 186–187. <https://doi.org/10.1136/medethics-2012-100512>

On the practice of PPI

Boote, J. D., Dagleish, M., Freeman, J., Jones, Z., Miles, M., & Rodgers, H. (2014). “But is it a question worth asking?” A reflective case study describing how public involvement can lead to researchers’ ideas being abandoned. *Health Expectations*, 17(3), 440–451. <https://doi.org/10.1111/j.1369-7625.2012.00771.x>

Dudley, L., Gamble, C., Allam, A., Bell, P., Buck, D., Goodare, H., ... Barbour, R. (2015). A little more conversation please? Qualitative study of researchers’ and patients’ interview accounts of training for patient and public involvement in clinical trials. *Trials*, 16(1), 190. <https://doi.org/10.1186/s13063-015-0667-4>

Reporting on PPI and its impact

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*, 17(5), 637–650.

<https://doi.org/10.1111/j.1369-7625.2012.00795.x>

Crocker, J. C., Boylan, A., Bostock, J., & Locock, L. (2017). Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. *Health Expectations*, 20(3), 519–528.

<https://doi.org/10.1111/hex.12479>

Dudley, L., Gamble, C., Preston, J., Buck, D., Hanley, B., Williamson, P., ... Walker, A. (2015). What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials. *PLoS ONE*, 10(6), 1–17.

<https://doi.org/10.1371/journal.pone.0128817>

Minogue, V., Boness, J., Brown, A., & Girdlestone, J. (2005). The impact of service user involvement in research. *International Journal of Health Care Quality Assurance*, 18(2), 103–112.

<https://doi.org/10.1108/09526860510588133>

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., ... Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *British Medical Journal*, 358(j3453).

<https://doi.org/10.1186/s40900-017-0062-2>

Wright, D., Foster, C., Amir, Z., Elliott, J., & Wilson, R. (2010). Critical appraisal guidelines for assessing the quality and impact of user involvement in research. *Health Expectations*, 13(4), 359–368.

<https://doi.org/10.1111/j.1369-7625.2010.00607>

Publishing about PPI in your research

You could consider publishing an article about the PPI in your research. This can bring several benefits, including an additional article about your research. Publishing will add to the literature on PPI (a research topic in its own right) and allow other researchers and members of the public to learn from your experience. Additionally, you could write an article with a member of your research PPI group as a lead or co-author.

For further information on PPI in health and social care research, NIHR INVOLVE has many resources available on their website – from reports and studies to examples of PPI: www.invo.org.uk



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For help with your Patient and Public Involvement, please get in touch on 020 7848 6782 or email ppi@rdslondon.co.uk

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