

A brief guide to public involvement in funding applications

How the NIHR Research Design Service (RDS) can help



Acknowledgements:

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1. Introduction

What is the NIHR Research Design Service?

The [NIHR Research Design Service \(RDS\)](#) supports researchers to develop and design high quality research proposals for submission to NIHR [funding programmes](#) and other open, national, peer-reviewed funding competitions for applied health or social care research.

There are [10 regional RDS](#) services across England supporting a broad range of people.

How we can help?

We offer a confidential, free service to support you to develop a high quality research proposal. When you are applying for a research grant, the funding panel will be looking at how you have involved members of the public in developing your proposal and how you intend to involve them in your research study.

Talk to us as early as possible and we will support you to involve members of the public in designing and planning your research.

Our public involvement advisers can contact you by phone, email or arrange to meet you. They will also be able to tell you about other support on offer such as:

- » involvement funds to support public involvement in your application;
- » workshops on public involvement in research;
- » a review of your application by a panel of patients, carers and service users.

How you approach public involvement will be different in each project so contact us to discuss it. We will be happy to help.

i Further information: [Research Design Service \(RDS\)](#)

The planning that takes place now is the foundation for public involvement throughout your research. If it is not properly thought through you risk not allocating enough time and money for public involvement in your research and a study that is not acceptable to the participants. Much of this guidance is relevant to public involvement activities throughout your study.

"...It takes time to establish relationships, to get beyond the superficial to really identify what's important. It's about having ongoing conversations and establishing a dialogue, not just emailing a draft and saying 'What do you think about this?' You also have to listen to people's comments and remain open, not being blinded by what you think as a researcher" (1)

2. What is public involvement in health and social care research?

Involvement and engagement can be fluid and flexible and the different approaches are often linked. Depending on the focus of your research, you might involve and engage with communities, groups, organisations, or individuals.

Public involvement is where members of the public are actively involved in the design and conduct of research. For example, as co-applicants, as a member of the advisory group, or as part of the research team developing the materials, interviewing research participants, analysing the data, and/or disseminating the results.

Public engagement is telling people about your research, why it is important, what it found out and the impact and implications of the results.

Participation is when members of the public take part in a research study

i Further information: [Briefing notes for researchers](#) (INVOLVE 2012)
[Community Planning Toolkit](#)
(Community Places 2014)

Public involvement is also different to **qualitative research** where you are collecting data from patients, service users and carers and finding out their views and opinions, as participants in the study. The distinction is particularly important as you would require ethical approval for participation in a study (see section 5).

Who are the public?

Many terms are used to describe people involved in research; for example, lay people, people with lived experience, research advisers, consumers, patients, carers, service users and members of the public.

INVOLVE, the national organisation funded by the National Institute for Health Research (NIHR) to support public involvement in health and social care research, uses the term 'public' to describe the range of people who can be involved and we use that as a general term in this guide.

Ask the people you are involving how they would like to be identified.

3. Why is it important?

Public involvement is at the **centre** of NIHR health and social care research and the public have a right to have a say in what and how publicly funded research is undertaken.

Involving people in your research can improve the quality of your research, by contributing different perspectives and experiences. As well as the impact it can have on your research, involving members of the public can impact those involved by empowering people and providing a route to influence change and improvement in issues that concern people the most (INVOLVE 2012).

4. Standards for public involvement in research

National standards for public involvement have been developed to improve the quality and consistency of public involvement in research.

They are also designed to:

- » encourage self reflection and learning
- » be a tool to help people and organisations identify what they are doing well, and what needs improving
- » be used with any method or approach to public involvement in research
- » be adaptable to your own situation and used alongside other resources



Further information: [National Standards for Public Involvement](#)

5. Where to start

! Invest in time to develop networks and build relationships

The most important advice that our public involvement advisers give is to think about your public involvement as **early as possible**.

“...If you give people more time and meet with them more than once you can open the floodgate to a whole new set of ideas and possibilities. It will also give you confidence that you have a viable project to take forward...” (2)

Start early and involve people before writing your application. This will:

- » allow you to be open minded about change and offer people choice about **how** they get involved
- » potentially save you from having to rewrite or resubmit your application
- » help you to ask the right questions
- » give you the opportunity to build relationships, speak to people more than once and find out if they are interested in being co-applicants or continuing to be involved if you get funding

Ideally, you will have involvement from the beginning. However, there might be reasons why this is not possible. For example, there may be limited time to submit your proposal or you may have had difficulty finding people to get involved. Contact your **[regional RDS](#)** for advice on how to involve the public in the time available.

6. Planning and Preparing for public involvement

Ethical approval

You do not need to apply for ethical approval to involve the public in the planning or the design stage of research.

INVOLVE and the **[Health Research Authority \(HRA\)](#)** have published a **[statement](#)** on public involvement in research and research ethics committee review.

How to involve people.

Think about why you want to involve people and how they can influence and add value to your application. This will help you to consider the different ways that they can be involved. For example, as:

Part of a collaborative approach: holding meetings or workshops to find out the views of people with lived experience on your topic and working with either individuals or the group to develop your application.

i Further information: [Briefing notes for researchers](#) (INVOLVE 2012)

A public co-applicant: as an equal member of the team, a public co-applicant has the same level of responsibility as other co-applicants. There is no formal requirement to include a public co-applicant in NIHR funded research. However, public co-applicants can bring different perspectives and experience to the development of your application and research. Their role will be different in each project depending on their knowledge, experience and the time they have available. It is important that you provide funders with:

- » a clear, jointly agreed, role description
- » your reasons for having a public co-applicant on the team
- » a budget that includes support and training for the public co-applicant role

i Further information: [Public co-applicants in research – guidance on roles and responsibilities](#) (NHS R&D Forum, Health Research Authority & INVOLVE 2019)

As members of a co-produced study: where researchers and members of the public have an equal partnership in the study, working together from the beginning to the end. The Social Care Institute for Excellence states that co-production “starts from the idea that no one group or person is more important than any other group or person. So everyone is equal and everyone has assets to bring to the process” (3).

i Further information: [Guidance on co-producing a research project](#) (INVOLVE 2018)
[What is co-production?](#) (Social Care Institute for Excellence; SCIE)

You might choose a mixture of these approaches, but whichever one you choose, be flexible and offer a range of opportunities for involvement. Some people might be happy to attend a meeting whilst others might prefer to read a document at home and talk to you by phone or email comments back to you.

Who to involve

Think about your project, who the research is for, and the range of experience that you need. For example:

- » individuals or people from organisations
- » older people
- » children and young people
- » parents or carers
- » seldom heard communities
- » people with learning disabilities
- » people from different communities or geographical areas

Balance the various perspectives that you need with the resources and support that you can offer, but involve at least two people so you have different views and experiences. You might find that including both people with involvement experience and those that are new to research brings a variety of skills and views that can complement each other.

Consider if you need to involve additional stakeholders such as health and social care managers or practitioners.

i Further information: [Diversity and inclusion](#): what's it about and why it is important for public involvement in research? (INVOLVE 2012)

i **Involve people with a range of different perspectives and experiences**

How to find people

You might already have networks of people with the experience that you need. If not, talk to colleagues with experience of public involvement to see if they have any ideas. How you approach finding people will depend on your project. For example, social media might work for some groups but not others and you might need to try more than one approach.

Consider making contact and developing relationships with relevant:

- » support groups, patient groups, charities or voluntary organisations
- » health and social care practitioners such as community development workers, social workers or health visitors

Advertise your opportunity through:

- » online social media and Facebook
- » local libraries or GP practices
- » community initiatives
- » outpatient departments
- » **People in Research**: a website hosted by INVOLVE where you can advertise your research opportunities

i Further information: [The use of social media for active public involvement in research](#) (INVOLVE 2014)

i Contact your [regional RDS](#) to find out about networks and public involvement groups and panels that you can approach

“For the first project I drew on RDS PPI [public involvement] expertise for support but less so now because we have our own [public involvement] panel that we set up 8 or 9 years ago across the hospitals involved in specific spinal projects - department wide. The Panel are our ‘go to’ people and have been invaluable in everything we do. We meet them very regularly and give updates about on-going projects and discuss ideas for new projects” (RDS Yorkshire and the Humber (Y&H)).

How to prepare

It is important that people are given enough time and feel that they have made a difference to your application.

Be clear:

- » explain what writing a funding application involves and tell people that they can opt out at any time. The RDS has developed a leaflet for patients, service users and carers on [getting involved in research grant applications](#)
- » check with the people involved that they understand the proposed research or whether they need further information
- » develop role descriptions together so that both sides know what is expected of each other
- » have a clear timetable showing when decisions will be made and deadlines for completion
- » discuss what will happen if the application is successful, opportunities for further involvement and what will happen if the application is not successful.

Communicate well and offer support:

- » consider the different perspective of everyone involved in the process and the mutual respect this requires
- » provide details of a named person for people to contact
- » assess the learning needs of both your research team and the people you are involving
- » do not make assumptions; ask what support people would like to receive
- » think about what support you will offer if it is a challenging or sensitive topic
- » use simple, clear language without jargon
- » provide feedback so that people know their involvement is valued and has made a difference
- » thank people who have been involved

! Hold meetings in a place that people will feel comfortable and at times that are good for them; don't expect people to come to you

i Further information: [Planning a meeting: briefing notes for researchers](#) (INVOLVE 2012)
[Learning and development resource](#) (INVOLVE 2019)

Payment and recognition

Funding public involvement to develop an application before it has been successful can be difficult. However, it is important to reimburse travel and other expenses such as childcare or personal assistance as a minimum.

- » Contact your regional RDS to find out if you are eligible to apply for their involvement fund
- » Check if your department or organisation has funds to support public involvement in research applications
- » Find out if your department or organisation has guidance or processes for paying people

Paying people if they are receiving state benefits is complex and it is important that people get advice before accepting any payment as it might impact on their benefits.

i Further information: INVOLVE latest advice and information on [payment and recognition](#) including access to a free, confidential [benefits advice line for researchers and members of the public](#).

“Some of the patients took part in informal discussion groups with tea and cake. But some of them didn’t want to take part in a group meeting, so we met them one-to-one and captured their ideas. We funded this work through a patient and public involvement grant from [the RDS] and from funds within our own department. We had to apply for this money...” (4)

i Make it easier for people to be involved; if possible, pay for their travel in advance so they are not out of pocket

Public involvement in the research process

People with lived experience, patients, service users and carers can work with you at all stages of the research cycle; for example:

Identifying and prioritising - working together to:

- » inform research priorities
- » identify topics that are important and relevant
- » highlight new research areas

Design - working together to shape and develop:

- » the research question
- » the outcome measures most important to people
- » research methods to make sure they are sensitive, ethical and appropriate for participants
- » the recruitment strategy
- » research materials and data collection methods
- » to define outcome measures that are important to people

Developing the funding application - working together:

- » to advise on how members of the public can be involved in the study
- » how to record the impact of public involvement will be recorded
- » as co-applicants on the study
- » to comment on the plain English summary
- » to review the budget and costs for public involvement

Undertaking the research - working together to:

- » guide how the research is carried out and managed
- » develop and review participant information and consent forms so they are acceptable and accessible
- » support the development of the research protocol
- » help to carry out interviews and surveys
- » write research updates in plain English

Analysing and interpreting - working together to:

- » interpret the results and explore any trends
- » check if the research team's understanding is the same as that of people with lived experience
- » identify key recommendations

Dissemination - working together to:

- » make sure that the results are widely disseminated through formal and informal networks
- » jointly present findings
- » co-author journal articles
- » ensure articles, blogs and information are in plain English and accessible to a wide audience

Implementation - working together to:

- » increase the likelihood of the research being put into practice by adding real-life perspectives to the findings
- » influence and raise awareness of the findings for the voluntary sector and health and social care practitioners

Monitoring and evaluation - working together to:

- » evaluate the research process and record and report public involvement in the study
- » make sure that the study remains focused on the issues for people with lived experience of a condition or service

7. Writing your grant application

Report how people have been involved in developing your application and clearly highlight any changes that have been made as a result of their involvement. Outline your plans for public involvement in your study if the application is successful. If your application has several stages, it is important to demonstrate this throughout the text at each stage (see Diagram 1).

Costing public involvement in your application

NIHR funding panels will expect to see a realistic budget for public involvement in your study.

i Further information: [INVOLVE budgeting guide and involvement cost calculator](#)

i All NIHR funding panels have members of the public reviewing public involvement in research applications

A plain English summary of your research

It is important that people understand what your research is about. The plain English summary is often the very first section of your application that academics, clinicians and public panel members read.

Ask people with no knowledge and experience of research to read your summary and tell you if it is clear and easy to understand.

There is further information on writing your research summary in plain English on the NIHR [Make it Clear](#) website.

i A good quality Plain English summary of your research is a requirement for NIHR funding

Ethics Committees

It is not only funding committees that will ask about your public involvement. The Health Research Authority (HRA) has published [guidance](#) for Research Ethics Committees on what to look for when reviewing public involvement in research ethics applications and top tips for researchers.

8. Recording and reporting public involvement

Recording the difference that public involvement made at this very early stage of the research will benefit you in the future. You might find it helpful to create a public involvement impact log to record the impact on:

- » the research topic/question/application
- » the people involved
- » the research team

If your application is successful you will be asked to report on public involvement in your research at many other stages for example:

The [NIHR Journal](#) asks for a description of your public involvement

The [BMJ Open](#) and [BMJ](#) require authors of all submissions to report on public involvement and how patients and the public were, or will be, involved in [choosing the methods and developing plans](#) to share research findings

The [Research Excellence Framework \(REF\) 2021](#) will include public involvement as a criteria for assessment of impact

“It was a dream process - a co-designed project - they came up with the idea, I refined it with them, they went to the RDS and did much of the legwork and we are now 2 years into the research”. (RDS YH)

i Further information: [Guidance for Reporting Involvement of Patients and the Public \(GRIPP2\)](#)

9. What next?

Whether your application was successful or not:

- » feedback the result to the people you involved and ask them for their comments on the process
- » learn from your experience for your next application

If successful:

- » celebrate your success and recognise the achievement with the patients, service users, carers involved
- » implement your public involvement plans and record and report your public involvement activities

If not successful:

- » contact your regional RDS so we can discuss the feedback from the funding panel
- » discuss the feedback with the people you involved and provide an opportunity for them to ask questions
- » develop and continue to build relationships with the patients, carers and service users so you remain in contact to work with them to develop research in the future

i Further information: [Guidance for researchers: feedback](#) (Centre for Research in Public Health and Community Care 2018)

10. References

1. [Example 4: Decision making about implantation of cardioverter defibrillators \(ICDs\) and deactivation during end-of-life care](#) (INVOLVE 2013)
2. [Example 2: Resources for Living \(R4L\) pilot: Exploring the potential of progressive cuisine for quality of life improvement for head and neck cancer survivors](#) (INVOLVE 2013)
3. [Co-production in social care: What it is and how to do it](#) (Social Care Institute for Excellence 2013)
4. [Example 6: Design and optimisation of a saliva-based point-of-care biosensor for non-invasive monitoring of chronic obstructive pulmonary disease \(COPD\) exacerbations: COPD-SPOC sensor](#) (INVOLVE 2013)

11. Useful resources and organisations

Take a look at your [regional RDS website](#) for a full list of resources and information on public involvement in research.

Organisations

[NIHR INVOLVE](#): national organisation funded by NIHR to support public involvement in health and social care research

[Health Research Authority \(HRA\)](#): protects and promotes the interests of patients and the public in health and social care research

Resources

[Patient and public involvement in health and social care research: a handbook for researchers](#) (RDS London 2018)

[Patient involvement toolkit for researchers](#) (Cancer Research UK)

[Guide for Service Providers and Practitioners Organising Involvement Activities with Disabled People](#) (Shaping Our Lives 2016)

[Top tips for public involvement in research: a short list of tips to help researchers facilitate meaningful public involvement in research](#) (RDS YH)

[Involving children and young people in research: top tips for researchers](#) (INVOLVE 2016)

[Going the Extra Mile: a strategic review of public involvement in the National Institute for Health Research](#) (NIHR 2015)

[Impact of public involvement on the ethical aspects of research](#)
(Health Research Authority & INVOLVE 2016)

Blackburn H, Hanley B & Staley K. Turning the pyramid upside down: examples of public involvement in social care research (INVOLVE 2010)

[Examples of patient and public involvement reported in the Research Excellence Framework 2014 impact case studies](#) (INVOLVE 2014)

[A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards](#) (Pandya-Wood, Barron Elliot, Research Involvement & Engagement, 2017;3:6)

