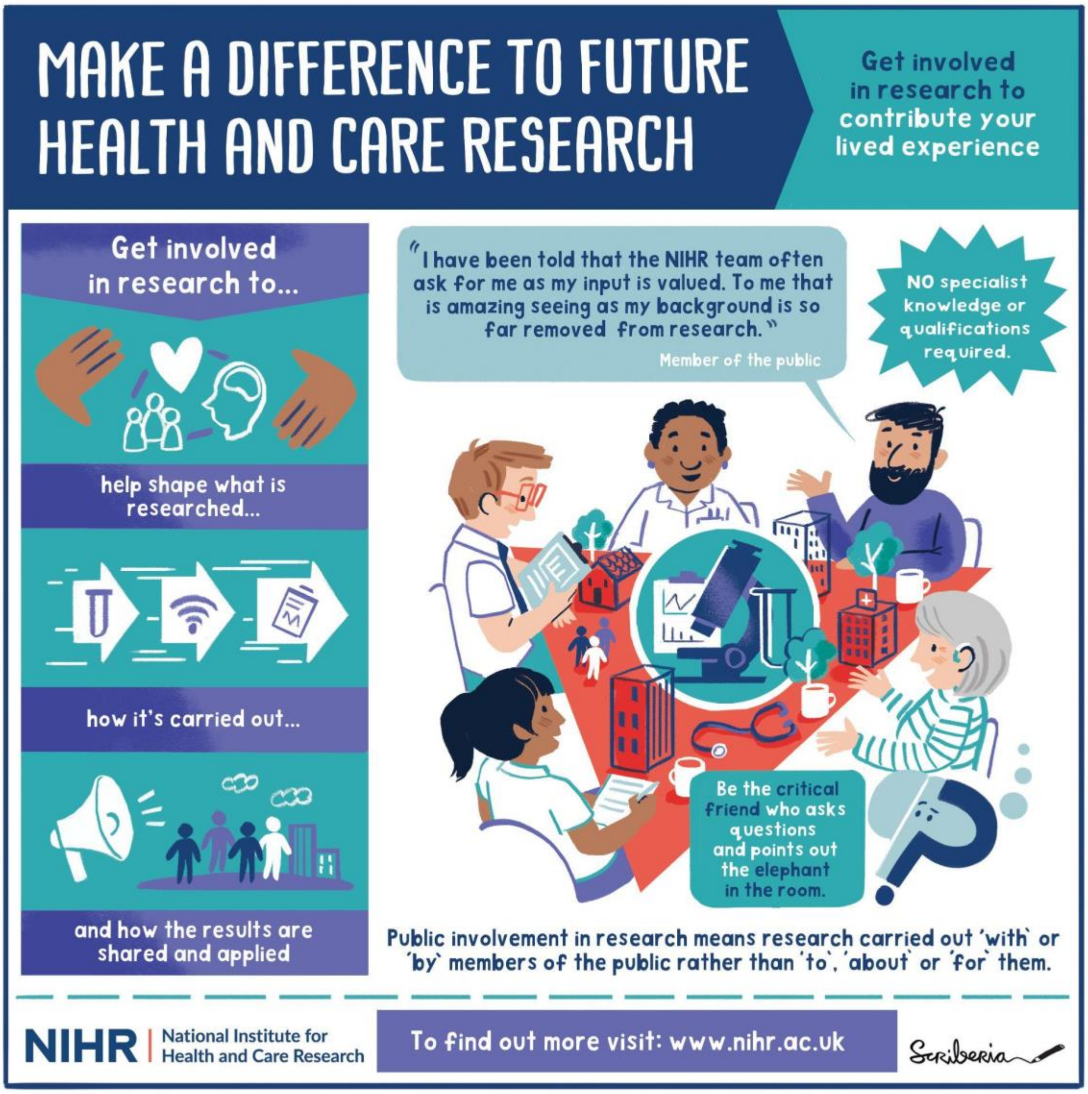
NIHR | National Institute for Health and Care Research

Starting Out Guide

Find out why and how to get involved in research

About this guide

Thank you for taking the time to find out more about getting involved in health and social care research. This Starting Out Guide has been written to help and advise members of the public who would like to get involved, or have recently become involved in research. In this guide you will find key information and principles about getting involved in research, whatever your experience or prior knowledge. We recognise that there are a variety of ways that people are involved, so your experience might differ from the key points given below. The main purpose of this guide is to help you feel valued and supported so that you are able to contribute in a way that works for you.



Definitions

What is public involvement in research?

Public involvement in research is described as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, the public, and researchers in the research process. When the public get involved in research, they work to help shape:

- What research gets done
- How it is carried out
- How the results are shared and applied in practice.

Being involved is not the same as taking part in research as a 'research subject'. It is not about taking part in a trial or study to test a new treatment or care option. We refer to this activity as research 'participation' or being a research 'participant' or 'subject'. Public involvement is about being a member of the team that works together to design and run the study or trial.

"Often common sense gets lost in research. We are needed to help research keep on track."
Public contributor

Researchers will be seeking people with a wide range of experiences including people who have specific conditions or diseases, care for someone with a condition or who have an interest in research more generally. The people involved in research are often called 'public contributors'.

The UK Standards for Public Involvement are a guideline to good public involvement and set out what you can expect from the people who involve you in research.

"Public involvement brings together the voices belonging to members of the public mingled with the voices of academics and clinicians."
Public contributor

What is NIHR?

NIHR stands for National Institute for Health and Care Research. NIHR is the country's largest funder of health and social care research, meaning it gives organisations and individuals the money, support and technology to do research. NIHR is funded directly by the government, and is not a private company. NIHR's mission is to improve the health and wealth of the nation through research.

Why should I get involved in research?

Because you can make a difference to future health and social care research! By getting involved in research, you can help make research more relevant, useful and beneficial to everyone. This can then in turn improve the way health and social care is provided in the future.

There are many different reasons why people get involved in research. For many, it is about making a difference, wanting to ensure that future health and care will be better for the people who come after them. Some people have had difficult experiences and appreciate being able to do something positive with that experience. Others see their involvement as an opportunity to ‘give something back’. Some people get involved to ensure the voice of their community/communities are represented in research. Many people get involved for a number of these reasons combined.

“Getting involved in research is intellectually stimulating, satisfying and interesting”
Public contributor

You have knowledge and insight from being a patient, carer and/or service user. This ‘lived experience’ is invaluable for research. Your experience of health and social care can help to shape how future research is done. However, you do not always need to have a ‘lived experience’ or specific medical condition. You do not need to have any specialist knowledge or qualifications to get involved in research. Public involvement is for anyone who has an interest in health and research.

Read Adele’s blog to hear her journey as a public contributor in research, where she provides valuable suggestions for anyone considering public involvement.

“My caring role and service user experience means something, my views are listened to and enable research to reflect the needs of others like myself.”

“I would ask everyone to consider getting involved in research. It will definitely benefit someone you know and many others that you don't...yet!”

How can I support research?

Sometimes being involved in research can be called being a ‘critical friend’. A critical friend is usually a person who asks the obvious or sometimes difficult questions that nobody else has asked. This is sometimes known as ‘pointing out the elephant in the room’ in a friendly and supportive way. As a critical friend you can help researchers to see things that they have missed or misunderstood. As a critical friend you can look at the research from your perspective. You can offer thoughts, advice and guidance to researchers on whether you feel that their research is true to the wide diversity of needs and values of the people who use health and social care services.

“I have been told that the NIHR team often ask for me as my input is valued - to me that is amazing, seeing as my background is so far removed from research”
Public contributor

You can find a detailed list of types of activities you might get asked to do in the Public Information Pack. These include, for example:

- Giving ideas for new research
- Making sure research focuses on the most important outcomes
- Helping to design projects to make it easy to take part as a study participant
- Making sure written materials are clear and easy to understand
- Helping to share research results with people who want to use them

"Research needs to be accessible to all. I feel my work is helping to make this more of a reality."
Public contributor

Watch this video to hear Mary talk about her experience of being involved in research.

What information might I need right at the start?

The following is a list of the key information that's important to know to decide whether to become involved, or once you have agreed to become involved in research. Please note: the amount of information available will differ from project to project and is often dependent on the role you take on. You might need to ask for this information, as it might not be given to you automatically.

1. Information about how I will be involved

Questions to ask:

- What is my role?
- What am I expected to do?
- What happens in meetings?
- What is the overall time commitment?
- How often are meetings?
- Will meetings be held in person or online?

Researchers are encouraged to develop a role description for involvement activities, which explains clearly what you're expected to do, roles and responsibilities. Where possible, this should be discussed and agreed between you and the research team or organisation.

2. Information about the organisation and research project

Questions to ask:

- What does the organisation do?
- What is the research project trying to achieve?
- What do the researchers and other people in the team do?

Having this information will help you to understand where you and your work, the research team or the research project fits into the big picture.

3. Who else is involved?

Questions to ask:

- Who else is on the Project Team, Steering Committee or Advisory Group?
- Are there other public contributors involved?
- Who might I need to contact during my involvement?

This can include the names of the other people involved, people's job titles and details of the role(s) and responsibilities of the people you are working with (or those people associated with the research). There should be a key contact or public involvement lead whose job it is to support you. This will help you know who you can ask for help. In the rare event of problems arising, knowing who is on the team and their roles can help you understand who you can talk to.

4. Practical information and support

Questions to ask:

- What is the organisation's policy for payments and expenses?
- Is there an access and/ or support policy? Who can I talk to about my needs?
- Can someone help me with paperwork (for example, printing meeting papers) and things like travel arrangements?
- What support will I be given to get involved remotely?
- I can't or don't want to work remotely - in what other ways can I get involved?

It is important that you are sent relevant practical information as soon as possible, and have this explained to you. This will help you make an informed decision about getting involved or continuing your involvement.

It is good practice for organisations to offer to pay you for your involvement in research, and reimburse your expenses. This is one way in which you can be rewarded for the time, skills and expertise that you contribute to the research process. Paying people for their involvement in research helps to support more equal partnerships between researchers and members of the public. With this in mind, it is important to understand the payment policy. This is especially important if you receive state benefits as receiving payment may affect your benefit claim or entitlement. The NIHR has specific guidance on the topic of payment for members of the public considering involvement in research. However it is important you ask how the specific research team and organisation involving you plans to pay you and/or reimburse expenses. They will have specific information relevant to you, for example how long the payment process takes and what receipts you might need to keep.

Relevant travel arrangements, such as train tickets and hotel bookings, can be arranged and paid for in advance by the organisation involving you. If travelling by car, ask about parking arrangements. Before meetings, you might be sent documents to read in advance: you can ask for them to be sent to you electronically (e-mailed) and/or sent as hard copies that are printed and formatted to suit your needs and requirements.

Research teams and organisations value a diverse group of people being involved. If you require specific support requirements, such as a personal assistant, wheelchair-accessible rooms, hearing loops or special dietary needs, you can request that these are taken into account to enable your involvement – but please give plenty of notice of your requirements.

As we are working from home more and more, you might find involvement activities will be either face-to-face meetings or remote (or a combination). Ask about additional support you can get for working from home, for example IT support, or specific training to use online platforms such as Zoom or Microsoft Teams.

NIHR recommends that researchers pay you an additional fee for remote working of up to £5 per meeting to cover the cost of telephone calls, paper, printing ink and paper, internet connection and other home supplies. Ask whether they are paying you this additional fee for remote working, and whether there is a limit to how much you can claim per week or month for remote working costs.

You might not be able to work from home, and this is fine too. Tell the research team about your preferences and see what adjustments they can make to suit your circumstances.

5. A mentor or ‘buddy’

Question to ask:

- Is there anyone else that has been involved in research who I can turn to for help?

Some organisations may have a mentor or ‘buddy’ available. This can be an independent person like you (this could be a patient, carer or service user) who will be able to support and guide you. The buddy could be a professional or member of staff. If a mentor or buddy isn’t offered, you can ask your key contact or public involvement lead if someone might be available to support you.

6. Training and learning opportunities

Questions to ask:

- Are there any training courses that I can attend to support me in my role?
- Are there any easy-to-follow guides on the research process that will help me in my role?
- Is there an induction?

If you think that you would benefit from any specific training related to the activity you are involved in, ask your named contact or buddy. Training might be available in the form of formal training, or through observation and discussion sessions. Training might also be through simply spending a few hours with a relevant member of the research team.

NIHR’s information on training, learning and development can be found on Learning for Involvement.

You can keep a log or record of any training you have done as part of your involvement with research. Often, the best time to begin this is as soon as you start your involvement. Keeping a record of the training you have done, and what new skills you have gained, may also be useful when applying for other involvement activities.

"I have really valued the opportunity to learn to do so many varied tasks."
Public contributor

7. Feedback

Questions to ask:

- How is the research going? What has happened since the last meeting?
- How have my comments and suggestions been used?
- If my comments and suggestions have not been included, why?
- Is my involvement having an impact on the research?
- Is there anything I could be doing differently in my involvement role?

Researchers are told that it is important to give you updates on how the research project is going, and also give you specific feedback on your involvement role. Sometimes there may be long gaps between information updates. When this is the case, this should be explained to you, so that you do not feel left out or out of the loop. If you are not kept updated please see section 8 below on 'Other support'.

"I was a bit sceptical at the beginning, but when I saw some wording I'd suggested repeated in full in their final report, I was like: "Oh, wow – they really did listen to me!"
Public contributor

8. Other support

Questions to ask:

- What support is available if I start to feel distressed or upset when I am participating in involvement activities?
- What do I do if I have a complaint?

Very occasionally it might be difficult or upsetting for you to share your experiences and thoughts with the research team. If that happens, you can turn to your key contact or public involvement lead, as they will be available for you to talk to, or to seek support from.

If you have a complaint, talk to your key contact or public involvement lead in the research team or organisation. If you feel unable to talk to your key contact, ask if the research team's host organisation (often university or NHS Trust) has a complaints procedure you can follow. You can also contact the NIHR for advice: ced@nihr.ac.uk

9. A glossary or jargon buster

Questions to ask:

- Is there a glossary that will explain key terms and acronyms?
- Are there any technical words and concepts that are specific to the research that will need explaining?

You might already find that the NIHR Glossary has explanations of words or acronyms often used in health and social care research. However there might be terms or acronyms specific to the research project or organisation you're involved with. If that is the case you should ask for an explanation.

Don't feel nervous about asking people to explain acronyms, abbreviations or jargon. Often other people in the room are also confused by the language and they might be glad you asked the question.

Further information

For a more detailed introductory guide to public involvement, you can read the NIHR Public Information Pack. For more public involvement guidance, you can browse the Learning for Involvement website.

Sign up to the NIHR newsletter to get quarterly updates about the research opportunities and information that interest you.

To speak to NIHR about public involvement in research, you can call us on 020 8843 7117 or email CED@nihr.ac.uk

Where can I find public involvement opportunities?

The People in Research website is a database of opportunities for members of the public to get involved in research. You can scroll through all the opportunities, or sort through your results by topic, type of involvement or location. If you see an opportunity that interests you, click on 'contact details' at the end of the opportunity to see the name of someone who can provide you with further information.

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This version of the Starting Out Guide supersedes the previous version: INVOLVE (2017), Starting Out – essential information for members of the public who are thinking about getting started in involvement in research.