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Public Information Pack (PIP)

How to get involved in NHS,
public health and social care research

A quick guide



Authors

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The Public Information Pack (PIP)

This guide is the first in a series, all available from INVOLVE:



PIP 1: A quick guide – a brief introduction to involvement



PIP 2: Getting started – explaining involvement and what to expect



PIP 3: Finding out more – the different organisations involved in research



PIP 4: Jargon Buster – explaining common research terms

Introduction

This booklet is one of four booklets in INVOLVE's Public Information Pack (PIP). The PIP has been written for patients, carers and members of the public who are interested in getting involved in health or social care research.

PIP 1 – A quick guide

This guide answers the main questions people ask when they first get involved in research. It explains how you can get involved in research, what you can expect and the difference you can make.

What is public involvement in research?

INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

Everyone benefits from research. This not only includes scientific research in laboratories, but also research into health and social care. Research provides the evidence about what works best. Patients, carers and health and social care professionals all use this evidence to make decisions about treatments and care.

When the public gets involved in research, they work alongside researchers to help shape what research gets done, how it's carried out and how the results are shared and applied in practice. Being involved is not the same as taking part in research. It's not about being the person who takes a new drug in a clinical trial. It's about being a member of the research team that works together to design and run the study.

By getting involved in research, you can help make research more relevant and useful to patients, carers and the public. By working with researchers, you will improve research and therefore make a difference to the way health and social care is provided in the future.

“Today's research is tomorrow's care.” **Maurice, London**

Research is defined as a well-ordered investigation or experiment that aims to find new facts and reach new conclusions. Health and social care research aims to find new knowledge that could lead to changes to treatments, policies or care.

What can I contribute to research?

Your knowledge from having experienced your own care, or the care of others, is of great value to researchers. Researchers may have text book knowledge about different conditions, their treatment and services, but unless they have also lived through it, there will be gaps in their understanding. By contributing your experience and views, you provide valuable expertise that would otherwise be missing.

You won't be expected to have technical knowledge of how research works. The knowledge you have as a patient, carer or member of the public is what's unique about your contribution.

Have I got the right experience to be involved?

There are many different types of research looking at hundreds of different topics. Researchers are likely to want to hear the views of a range of people from a variety of backgrounds. This means your experience might be more relevant for some projects than for others. It's about finding the projects that need people like you, and roles that match your interests and experience.

“Your role is to be a critical friend to researchers. You will see the research from your perspective and advise researchers on how their research could be better. Sometimes this can just seem like common sense to you, but it will be valuable feedback for the researchers.” **Amander, Southampton**

What difference will I make?

You can make a difference at any and every stage of research. Your contributions can help shape the thinking behind the research and the planning and delivery of the project. You have a powerful voice that can influence others beyond the research team, including the people who take part in the research and the people who use the results. Sometimes the involvement of patients, carers and members of the public determines whether a project gets funded, whether it runs successfully and whether the results change practice.

What will I be expected to do?

When you first get involved, you are likely to be asked to share your thoughts and views on the researchers' ideas and plans for their research, and any information written for patients or the public. You might do this in a number of ways, for example by:

- attending meetings with researchers
- joining a group of patients, carers and members of the public attached to a research organisation or a specific project
- becoming a member of a research team
- commenting on written documents sent to you by post or email

Over time you may want to take your involvement further. You can go as far as you want in developing your skills and experience, working at local, regional or national levels, on small or large projects. You may be surprised at the range of opportunities that will be open to you.

What can I expect of the people who involve me in their work?

You can expect:

- clear information about what's expected of you and your role
- a fair and open process of recruitment
- a good working relationship with the people who involve you
- regular feedback on how your input has made a difference
- training and support to enable you to have your say
- payment for any expenses including travel
- practical support, such as working in accessible venues
- a point of contact who can provide information and support on request

You may sometimes be offered payment for your time. INVOLVE has produced guidance on payment for involvement, and advice about how this might affect your tax and benefits (both are available online and in paper copies from INVOLVE).

What training and support might I be offered?

Before you get involved you may be offered training in research or involvement. Depending on your experience, you're likely to find some forms of training more helpful than others. Everyone will have different things they want to learn.

There should always be at least one person, and often a team of people, whose job it is to support patients, carers and the public to be involved. They will support you in the way that meets your practical, emotional and information needs, perhaps giving you extra support at the beginning, and helping you to increase your confidence over time.

“The people who involve you will have invited you to get involved for a reason. They want your input, so they will want to find ways to help you feel able and confident to say what you think. So they will want to support you, to make sure that happens.” **Helen, Keele**

Why do researchers want to involve the public in their research?

Researchers are aware of the benefits of involvement and therefore want to do it well. They want to learn from their conversations with patients, carers and the public. They will listen to what you have to say and will often make changes to their ideas and plans as a result. They have an added incentive to involve people in their work, because when they apply for funding, they are often asked to state how they have involved patients and the public in developing their proposal, and how they will involve them in carrying out the research.

How will I benefit from being involved?

People who have been involved in research say that the experience has been more rewarding and more enjoyable than they ever expected. It has given them:

- a new purpose and a sense of feeling valued
- new knowledge about how research works and the latest findings
- new skills as well as opportunities to use existing skills
- increased confidence
- a different way to cope with their condition
- new friends and a source of support

Why do people decide to get involved in research?

People who get involved in research have different reasons for wanting to do it. Some people have had a difficult experience and appreciate being able to do something positive with it. Others have had very good experiences, and see their involvement as an opportunity to 'give something back'. For most people, it's about wanting to make a difference – so that in the future, care will be better for the people who come after them.

“I still have my condition, but my experiences and other people's experiences can help to change things. I know what we do makes a difference, maybe not to my health, but to someone else's, to future generations. To be able to be part of that journey by being involved is an amazing thing to do.” **Diana, Exeter**

Where can I find out more?

You can find out more about public involvement in research from the rest of the INVOLVE Public Involvement Pack which explains involvement in more detail, introduces different research organisations and explains common research terms.

Contact INVOLVE for further advice and paper copies of any of their publications:

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Thanks

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