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Public Information Pack (PIP)

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

Getting started



Foreword

There's never been a better time to get involved in NHS, public health or social care research and the opportunities are plentiful. A changing society and pressures on health and care services mean that now, more than ever, research is essential to discover and evidence the care and treatments which best meet patients' needs and which genuinely improve services.

Whether you are a patient, or a member of the public, there are many areas of research you can contribute to, and in many different ways. You need not know anything about research to get involved. There are people and organisations that can guide you through it, including INVOLVE. And putting aside the moral arguments, that people who are affected by research are entitled to be involved in it, being part of research makes you an adventurer; it is exciting, thought provoking and allows you to use skills that you might not have realised you had. It can lead you into new experiences or opportunities that you didn't expect. For some, this has led to new careers, qualifications and importantly a sense of being valued.

Making a difference to research so that it genuinely helps patients can be better than medicine itself. To contribute to research aimed at improving life for those with a condition that you share is humbling. It not only feels the right thing to do, it means that you can stretch yourself, learn lots, and be a part of a team who share your passion for making a positive difference for the future. What can be more brilliant than that? You will join an ever growing movement which raises awareness about the importance of research, breaks down barriers and myths, and which contributes to a brighter world of better health and quality of life for us all.

Zoë Gray, Director INVOLVE

Tina Coldham, Chair of INVOLVE Advisory Group

Authors

This document was compiled by Kristina Staley, Director of TwoCan Associates (www.twocanassociates.co.uk) and Sam Goold, Public Involvement Officer, INVOLVE. They drew on the advice and experience of many contributors, including patients, carers and members of the public, as well as staff and researchers with experience of involvement. A full list of everyone who contributed can be found in the Thanks section on pages 29-30.

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The Public Information Pack (PIP)

This guide is the second 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 2 – Getting started

This booklet answers the questions that people frequently ask when they first get involved in research. It explains how and why the public are involved in research, what they can expect and what difference they make. It also includes stories from people who have been involved for a number of years, as well as stories from researchers and research staff who support involvement.

All four PIP booklets and other useful INVOLVE publications are available online and in paper copies from INVOLVE (see back page).

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1. What is public involvement in research?

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

“The treatment you get at your GP or hospital is based on research. The only way we’re going to make that any better is by doing more research. So we’ve all got to help make that happen.” **Kathy, Keele**

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

When the public get involved in research, they work alongside researchers to help make decisions about what research gets done, how research gets done and how the results are shared and applied in practice. Being involved is not the same as taking part in research. It’s not, for example, 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. You can stop money being wasted on research that doesn’t actually help people. 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.

“Research has always seemed to be a mystery, only carried out by very clever people. What I know now, is that it’s a very normal process and everyone should have a say in what goes on, because research affects our lives. The information that comes out from research impacts on me, so for me to have a say in it, is a necessary process.” **Norraine, Manchester**

“At the end of the day, we are the end user of the entire health system. If it’s approved, then we start using what the researchers have been researching – so we’re more important than the researchers in some ways!” **Richard, Exeter**

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.

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.

2. 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. Many researchers are healthcare professionals and will know a lot about treatment and services. They may also have text book knowledge about your condition, but unless they have also lived through it, there may be gaps in their understanding. By contributing your experience and your views, you provide valuable expertise that would otherwise be missing.

“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**

If you get involved in research, you will not be expected to have technical knowledge of how research works. You will pick that up as you go along. You already know all that you need to know, based on your experience of living with an illness or disability, using services or looking after someone else. The knowledge you have as a patient, carer or member of the public is what's unique about your contribution to the research team.

“You’ll be surprised by how much you’ve got to offer researchers – you’ve got a lot to offer.” **Julie, Exeter**

“You’re the most experienced person on what’s happened to you and that experience can really help research. You don’t need to try to speak on behalf of all patients, just give your opinion based on what you know. If you know other patients and can talk about their experiences too, that can sometimes be useful, but it’s not essential.” **Adele, Keele**



Ruth’s story of involvement

Ruth Day

Public Contributor, Research Design Service (RDS) East Midlands

Reviewing research proposals, Scientific Panel Lay Member, speaking at seminars and conferences.

How did you become involved in health research?

My daughter is 10 years old and has Cystic Fibrosis (CF). I am her main carer and advocate and have to manage her condition by ensuring she has all her treatments and medication. Due to this I made sure I was up to date with the current research surrounding CF to ensure I was on top of her condition and that she was on the best treatment possible.

I got into health research during a training course where I met someone who told me about the fact that patients and public can help with reviewing research proposals. This was quite daunting at first as the medical terminology was difficult to understand. However, I soon realised I didn’t have to understand it all, I just had to give my perspective as if it was me or a family member.

My main role is reviewing scientific health research. Within a research summary there has to be what is called a plain English summary which should contain no medical jargon and be easy for a lay person to understand.

I like to find out about the research, what needs to be done and why and also what the benefit of the research is to patients and the

healthcare system. I also like to see that the practicalities and emotional issues are being addressed, such as how the patients and carers may be feeling when they are being asked to take part in a research trial.

What has been your greatest achievement?

There have been quite a few highlights so far. I was asked if I would speak at a conference to tell my story of how I got involved in health research. This was quite a challenge as I am not used to public speaking and I was bit nervous but I think it went down well! Another highlight of my involvement was attending a scientific panel where I was given the opportunity to review three research proposals. I felt valued and listened to, and that my advice was worthwhile coming from a more human perspective.

What would you say to others looking to get involved in health research?

Please don’t be put off by the word ‘research’. Public involvement is about giving a human perspective on what it is like to live with different medical conditions. You do not have to understand the research just give your opinion on how you would feel if you or a family member were asked to take part.

3. 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 input from people like you and roles that match your interests and experience. For example:

- Researchers working on a new insulin pump for pregnant women with diabetes wanted to work with diabetic women who had recently had children.
- Researchers looking at the impact of NHS staffing levels on care wanted to involve anyone with a recent experience of NHS services. They wanted to hear the views of people who had been inpatients or outpatients, or had received emergency care, as well as people who had been caring for a relative or friend in hospital.
- Researchers developing a new screening test for lung cancer wanted to involve members of the public (not patients), who were smokers and ex-smokers, to contribute their views on the research.
- Researchers working on a project to improve the health of people living in damp housing wanted to involve people from a local estate where there were lots of problems with damp housing. These people weren't patients, but they had experience that was relevant to the research.

“When you're thinking about whether to get involved in a research project, it's OK to say 'No, I don't think I fit that project'. It's OK to put yourself forward if you're interested, but your experience might not be what they're looking for, or they might already have someone with that particular expertise. So then it's OK for a researcher to say 'no' to you. Just don't take it personally!” **Andrea, Exeter**

“I got asked to help with a research project looking at thumb splints, because I'd just used a thumb splint for arthritis in my hands. The researchers involved me with my small and delicate hands, and also a man who had big hands, because they needed to hear from all sorts of people. So your experience, no matter how limited it might seem, might be exactly what the researchers need.” **Kathy, Keele**

You don't have to have any kind of qualification to be involved in research. But you may have skills from other parts of your life that will be valuable to researchers, from working, volunteering or family life. The combination of these skills and your knowledge and experience, might make you the ideal person for an involvement role. For example, in a research project involving women with ovarian cancer, one of the women drew on her skills in organising events to help plan a final workshop for patients. She wasn't just a volunteer providing an extra pair of hands on the team. She used her experience as a patient *as well as* her organisational skills to help plan the workshop. She ensured it was easy for women with ovarian cancer to attend, and that the workshop would cover what other patients would most want to hear about.

4. What difference will I make?

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

The following are some of the different ways you could help researchers, as well as examples of how patients, carers and the public have made a difference in previous research projects.

You could help research by...

Giving researchers new ideas for research

A carer working with researchers on a project about support for carers identified a group of 'hidden' carers that the researchers had not known about. The researchers had only been thinking about carers of people with a disability or people with mental health problems. The carer involved had looked after her husband when he had heart disease, but hadn't identified herself as a carer at the time. Sharing her experience led to a new project to look at support services for this group.

Making sure researchers work on the most important questions

While working on a project with a group of women who had experienced domestic abuse, researchers discussed a number of ideas about what to research next. The women said research on how GPs could better identify and support children affected by domestic violence was a high priority for them. This influenced the researchers' decision about which project to work on next.

Helping to write a funding bid

Researchers wanted to work on a project to assess the evidence as to whether people who have different blood pressure measurements in each arm are at greater risk of heart disease or stroke, than people whose blood pressure is the same in both arms. They involved members of the public in writing their application for funding. The feedback from the public made the bid easier to understand by improving the way it was written, and helped the researchers to more clearly describe the group of people who would be affected.

Helping funders to decide which projects are worth funding

A group of people with Multiple Sclerosis (MS) reviewed an application for funding for a trial of a new exercise programme for people with MS. They rejected the application because the programme was targeted at people with mild MS. The patients explained that people with mild MS can usually go to a gym. It's the people with severe MS, who may be in a wheelchair, who find it difficult to know how best to exercise and where to go. They suggested that it would be better to fund research that focused the people who are more severely affected.

Making sure research focuses on the most important outcomes

In a study to improve the care of premature babies, the researchers assumed that parents would be worried about how long their child had to stay in a specialised unit far from home. However, the parents explained they were more worried about delays to their child returning to a local hospital because of lack of transport or an available bed. So as well as measuring the length of stay in specialised care, the researchers also measured these delays in transfer, to see if their research identified ways to reduce them.

Inspiring and motivating researchers

Researchers who meet patients for the first time, often say they are surprised to realise that their research means so much to other people. This gives them the motivation and enthusiasm to keep going, whenever the going gets tough. Working with patients reminds them that their work really matters to the people they most want to help.

Helping to design projects that make it easy to take part

A research project based in central Manchester, expected people with bowel cancer to attend clinic appointments at 8:30 in the morning. The patients involved in the project commented that this would be difficult and expensive, because people would be likely to get stuck in traffic. They suggested scheduling the appointments later in the day.

Helping researchers to avoid causing any distress through their research

A researcher assessing the accommodation needs of Gypsies and Travellers worked with members of the community to design and carry out the research. She recruited members of the community to interview people about their needs. The Travellers who were involved advised her that it would be unacceptable for a male interviewer to interview a woman. The researcher therefore made sure that she paired up female interviewers with women in the study, to avoid causing any offence or upset.

Identifying how best to support people who take part in research

A research project looking at the side-effects of the drugs used to treat Parkinson's disease, needed patients to come to the clinic for tests after not taking their medicine in the morning. The patients involved in the project explained that this would make it very difficult for some people to get up and get out of the house. The researchers therefore provided a professional carer to help the participants attend the clinic appointments while off their drugs.

Identifying potential problems in project plans and coming up with the solutions

Researchers working on a project to develop services to support families whose children had been adopted, involved parents of children who had been taken away by social services. The researchers planned to send out letters inviting parents to take part in the project via local social service departments. The parents who were advising the researchers helped to write the letters and recommended avoiding using the social services' franking machine. They said it would be better to use a stamp, because if they received a letter that was obviously from social services they would be very unlikely to read it and would probably throw it straight in the bin. The researchers followed their advice, and had no problem with recruiting people to their project. Other researchers working in this area had always had problems with recruitment in the past.

Helping to collect the data and working with researchers to make sense of the results

In a project assessing the problem of drug use in prisons, the researchers invited an ex-offender to work on their team. He helped to recruit prison inmates to take part in focus groups. He helped run the groups and to make sense of the findings. He identified issues that the researchers might otherwise have missed.

Making sure that any written materials are clear, easy to understand AND includes the most important information

A group of people with mental health problems reviewed a leaflet that a researcher had written to explain what would happen to the people taking part in her study. The study involved taking scans of the brains of people with experience of psychosis. The group made suggestions about how to improve the wording and the layout to make it easier to read and understand. The leaflet explained that music would be played through headphones while people were in the scanner. One person in the group with experience of psychosis, said that if he was experiencing paranoia at the time, he would need to know exactly what piece of music would be played, in order for him to feel safe.

Helping to share the results with people who want to use them

A patient who was involved in a research project about secondary breast cancer, helped to present the results at a conference. Having the patient speak seemed to 'electrify the audience'. It can be extremely powerful to hear directly from the people who will be affected by the research. They have a perspective that researchers don't always hear, and they can give a realistic view on whether the results are genuinely useful.

Helping to put new evidence into practice

A group of older people, who worked with researchers on a project about how to prevent falls amongst older people, presented the results to senior managers from their local authority. A couple of the older people were then asked to join a working group within the local authority, to look at how to apply the findings to make practical changes in local care homes and day centres.



Stephen's story of involvement

Stephen Dent

Retired Local Government Officer
Research User Group
Primary Care and Health Sciences
Keele University

What was your motivation for getting involved in research?

I have Ankylosing Spondylitis. It is a disease that not many people know anything about and there has not been much research into it. One of my hopes is that I might persuade those who are starting off new areas of research to do a bit more on this.

What studies have you been involved in?

The most recent one we've developed is a pain App for mobile phones. It was actually developed by us as patients working with a GP and this is now available to download. Basically, it is a tool that you can use every day to describe your levels of pain and mark down what medications you are on. It produces a graph which the doctor can look at to get guidance as to whether any new medications are actually making any difference.

How did you feel when you first got involved?

The meetings I had with other patients were great because you are with people the same as yourself. Those sort of meetings I am very comfortable in. When you find yourself on your own with professors or researchers they can talk 'medical speak' and it is very easy to feel a bit lost. But everyone has their own specialities and our speciality is what it's like

in real life. So long as you can understand some of the jargon, it's alright and the more you deal with it, the more you get used their language.

How is it now you have been involved for a few years?

We do influence quite a lot of research and the direction it goes in. Simple things like reviewing questionnaires, they can come out completely different to what the researcher started with. I feel useful and they are forever telling us how they couldn't manage without us now.

Has anything surprised you about being involved in research?

I am really surprised at how long it takes and by the fact that when the research has finished it sometimes isn't implemented. Often the research that Keele produces is used abroad but not in the UK.

What would you say to people who are new to getting involved?

Don't get too scared if it sounds complicated. Because the more you do, the more you will realise where you are useful.

5. What will I be expected to do?

When you first get involved, you will probably be asked to share your thoughts and views on:

- the researchers' ideas and plans for their research
- information that has been written for patients or the public (this includes information used to publicise the project, or to inform people taking part, or to share the final results)

You might do this in any 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 and working with them to give your combined views on different projects
- joining a group to advise on a specific project
- becoming a member of a research team
- commenting on written documents sent to you by post or email

Some meetings may be in person. Some may be held over the phone or online. You will often be able to work in a way that suits you best, choosing roles that match your interests, experience and skills. You can do as much or as little as you want, and can always say 'no' if what's being asked of you feels too much.

"It's important not to do more than you want to. Being involved can be tiring, and you might have an emotional reaction to the discussions. You need to set your limits, especially if you are managing a health condition or have other demands on your time." Heather, Exeter

Over time you may want to take your involvement further. You might want to get involved in actually doing the research and helping researchers to make sense of the findings. You might want to get involved in:

- training and recruiting new researchers
- presenting research results at conferences and workshops
- writing articles for patient newsletters and blogging
- contributing to articles for journals

You can go as far as you want in developing your involvement skills and experience, working at local, regional or national levels, on small or large projects, for only a few weeks or over a few years. You may be surprised at the range of opportunities that will be open to you.

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

INVOLVE has developed a set of values and principles that outline what you can expect from the people who involve you in their work. These include:

- clear information about any opportunity for public involvement
- clear information about any involvement role – what your responsibilities will be and what's expected of you
- a fair and open process of recruitment
- choices about when and how to be involved
- a good working relationship with the people who involve you, based on mutual trust and respect
- regular feedback on how your involvement has made a difference
- access to a range of training and support to enable you to have your say
- payment for any expenses you have as a result of your involvement and clear information about how to claim your expenses
- practical support to make your involvement possible e.g. booking accessible venues for meetings, providing paperwork in large font, easy parking, paying for child care
- a point of contact who can provide information and support on request
- involvement in evaluating how well the process has worked and the impact of the work you have done

"Getting feedback about whether you have helped the researchers is really important. But what I didn't realise is that research can take several years and you might only meet researchers three or four times a year during a project. So while you can get feedback after every meeting, you might not know whether your input has made a difference to the results of the research, until years later." Andrea, Exeter

If you find that the people who involve you are not following this good practice, you can tell them about INVOLVE's guidance, and you could help them think about how they can improve what they do.

Sometimes researchers will offer a payment as a thank-you for your time and contributions to their project. This is likely to be a fee rather than a salary. INVOLVE has produced guidance on payment and reward for involvement and advice about how this might affect your tax and benefits.

Useful links

www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf
www.invo.org.uk/resource-centre/payment-andrecognition-for-public-involvement/
www.invo.org.uk/wp-content/uploads/2016/12/INVOLVE_payment_document_v4-NOV16.pdf



Adele's story of involvement

Adele Higginbottom

Patient and Public Involvement & Engagement
Project Co-ordinator
Primary Care and Health Sciences
Keele University

What is your role?

My role involves working alongside researchers and patients. We have a group of over a hundred Research User Group (RUG) members and they have been involved in over 94 research projects.

How did you first get involved in research?

In 2006, I was invited to be a participant in a study for people living with long-term chronic pain and had to write a daily diary for six months and be interviewed by a researcher, who also interviewed my husband and daughter. I'd never done anything like that before, but I really enjoyed it. I found it quite cathartic to write the diary about living with pain and how it affected me and my family.

Out of the blue in 2006 I had a letter from a professor to say that she wanted to start a RUG and would I be interested in going? So I thought, well, why not?

What sort of projects have you done?

Way back in the beginning I was involved in a project about back pain. I was asked to join a research team on a training course in Oxford and it was just amazing. I'd never done anything like that before. I was very nervous because I hadn't met many of the others, and then there was little old me! But I was

accepted as a member of the team, and I think from then on it gave me the confidence to get more involved with projects, and I realised that the patient voice really did make a difference.

How do you feel now compared to when you started?

Getting involved in Patient and Public Involvement (PPI) absolutely changed my life. It gave me a focus. It gave me something to be very passionate about, and I still am so passionate about the patient voice being heard. It's just absolutely changed my life completely.

What's your greatest achievement?

As a RUG member I was involved in a project that was about a self-management guide book for patients with osteoarthritis. We worked with the researchers for 12 months and now that guidebook is used nationally and internationally. It is one of my proudest moments, making a guidebook that is now out there for patients, making a difference and helping them to self-manage their condition.

Any messages to people new to involvement?

I think I would say, just do it. It can be scary, especially if you have not been involved in research before, but you do make a difference. The researchers have the knowledge of what they are researching, but you have that knowledge of living with that condition. So your experience is absolutely valuable.

7. What advice can you give me for when I first get involved?

This section provides further details of what is likely to be expected of you and what you can expect, when you first:

- go to meetings with researchers
- comment on a research proposal
- comment on information written for patients
- join a group of patients, carers and members of the public

The precise details may vary from project to project, and the researchers or staff will work with you to make clear what your role is and what they expect from you.

"I've been involved a number of times and I've been called something different every time – lay member, service user, patient, consumer representative, public contributor and research partner! There are lots of different words used, but what's most important is that you and the people you're working with have the same understanding of why you are there, and what you are being asked to contribute."
Philip, Manchester

Going to meetings with researchers

When you go to a meeting with researchers, they will be expecting you to contribute your views to the group discussion. You may be sent papers to read in advance and given a list of the topics that will be discussed (the agenda). Doing this for the first time may feel daunting for some people, especially if the research environment is new. It can be helpful to bear in mind that:

- researchers are people too and may be just as nervous about meeting you and getting everything right
- everyone in the room will want to hear what you've got to say – your views have value
- you can draw on your experience and that of other people you know – but you are not expected to speak on behalf of all patients
- it's helpful to ask questions – sometimes the simplest and most obvious question is exactly what needs to be asked
- you might not understand what's being said, especially if people are using jargon – take the opportunity to ask what it means, as you'll be helping other people in the room too
- you might have more freedom to say what you think than other people and that can be very powerful – you can open up discussions that might not have happened before
- there will be people there whose job it is to support you and enable you to have your say, including other patients, carers, members of the public, staff and whoever is chairing the meeting

“I remember going to a meeting and thinking ‘What am I doing here?’, but I was so passionate about what they were talking about. When I went to the next meeting and made a comment, this very highly educated anaesthetist turned round and said to me, ‘Thank goodness someone with lived experience can say what it’s really like. Because you said it, people are listening and you’ve said it much better than we could have done’. That’s when I thought I can really make a difference here. **Heather, Exeter**

“You can’t go into meetings and expect to know everything, so don’t be afraid to ask. Half the people in the room won’t understand either, but they can’t ask because they’re expected to know. As a patient you’re entitled **not** to know, so you can use that. Don’t feel intimidated. I went to a meeting with lots of highly qualified clinicians and I sat there thinking ‘What am I going to contribute to this?’ Now I’ve been there a while, **they ask me**, ‘What do you think Mike? We need to know the patient view’. **Mike, Manchester**

“We can challenge researchers to think outside their box. We can ask what we might think is an obvious question, but they might never have thought of it before. Research is all about asking questions, and we can helpfully challenge researchers by asking them questions.” **Kathy, Stoke**

Commenting on research proposals

When you are asked to comment on a research proposal, you are very likely to be given support and guidance as to what’s needed from you. The researchers may have specific questions they want to ask you or they may ask for any general comments. They will want to know whether the research is important from your point of view and whether it is looking at the outcomes that matter most to people like you.

Sometimes you might be asked to look at a research proposal by a potential funder, a charity or Government funding body, to help make decisions about whether the research should be funded. In this case your feedback might help the funder rather than the researcher.

Sometimes you might be asked whether you think a proposal is ethically acceptable. In this case your feedback might help the researchers to improve their plans, or might be used to inform an ethics committee, which decides whether the research can go ahead. This task includes drawing on your experience to think about:

- whether taking part will cause people any distress or harm and how this could be avoided or reduced to an acceptable level
- whether the practical arrangements for participants could be improved to make it easier to take part
- whether the people taking part might need additional support or care to manage the demands of taking part

Commenting on information written for patients

You may be asked to comment on information that has been written for patients and the public, such as:

- information about research that’s underway to let people know the research is happening
- posters, letters and articles being used to advertise the research project to people who might want to take part
- patient information sheets - these explain what taking part in a research project will mean for the participants, so they can decide whether they want to do it
- articles, reports and press releases that are used to share the results with patients and the public

Your task will be to comment on whether the information:

- contains all the details that people need to understand the research
- contains all the details that potential participants need to decide whether they want to take part
- is written clearly and simply in a way that is easy to understand
- is laid out in a format that is clear and easy to read
- is produced in a format that is accessible to the target audience e.g. in large font, if the target audience is likely to have visual problems

“I was talking to someone who didn’t want to get involved, because he knew that we read research documents. He thought that because he didn’t have a scientific background it wouldn’t be for him. But the whole point is that we’re not supposed to have the knowledge to understand scientific and technical documents. If you read it and say ‘I don’t understand that’, you’ve just done your job!” **Lindsey, Manchester**

Joining a group

Many research organisations are now setting up groups of patients and carers to support them across a wide range of research projects, as well as helping them to develop their own policy and practice in involvement. Some groups are topic specific and involve people who all know about the same condition. Others involve people with experience of different conditions. Each organisation will run its group slightly differently. Before you join a group, you will be given information on the way that the group works and about other relevant local organisations and networks.

Joining a group may not appeal to everyone, but the advantages are:

- being able to learn from members of the group with more experience of involvement
- working with people that you know
- receiving support from your peers
- being supported and trained by staff
- having someone to contact when you need help

“After my first meeting with my group, I remember thinking, ‘I so want to do THAT again, it was such a laugh!’ They got all the work done and it was such a lovely environment and I walked away feeling uplifted. I didn’t think I would feel like that at all.” **Lindsey, Manchester**

“You will feel welcomed and appreciated, that your opinion is valued. And the support you get from the staff is often second to none.” **Stephen, Keele**

Useful links

INVOLVE’s work on induction for members of the public getting started in involvement in research is at: www.invo.org.uk/wp-content/uploads/2018/01/Induction-public-v3.pdf

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

Good quality public involvement has been required for researchers seeking public funding for their research for a number of years. When researchers apply for funding from the National Institute for Health Research (NIHR: a Department of Health funded organisation that promotes and supports research in the NHS) as well as some of the other research organisations, they must include information about how they have involved patients and the public in developing their proposal, as well as how they plan to involve them in carrying out their research. This means most researchers are very interested in doing involvement well.

Many researchers understand the added value of involvement. They want to listen and learn from their conversations with patients, carers and the public. So they want to hear what you have to say and will often make changes to their ideas and plans as a result.

“It was a surprise me to me that we would be valued as equals – every academic I have worked with has been so down to earth.” **Julie, Exeter**

“Being involved changes how you think about researchers. We put them on a pedestal, but when you sit down with them with a cup of tea, they are just like you or I, and they are very willing to listen to you.” **Heather, Exeter**

However, there may still be a small number of researchers who don’t yet understand involvement. When working with them, it may feel like they are simply ‘ticking a box’. If they are open to your ideas, you may be able to change their views about what involvement could achieve, and work with them to increase your influence. If you feel you are not being heard, you could speak to the person who leads on involvement, a member of staff or a researcher. You always have the option to politely decline to be involved any further, and to explain your reasons why.



Sandra's story of involvement

Sandra Jayacodi

Service User Advisor for research studies, policy and governance, service redesign.

Research team member, Research Fellow and speaker at local and international conferences.

How did you get first involved in research?

I like new ideas, so I got interested in research and joined the local Trust's Research and Partnership Group. Every time a local researcher needed someone for their project, they emailed the group. Through that I got involved in a research project about improving physical health for people with severe mental illness. That's where it all started.

What was it like for you at the beginning?

For the first two meetings, I hardly spoke a word! I didn't know what my role was. Although I was asked to give my input, I was anxious, sometimes confused and didn't understand what was said. Then one time, I brought in some leaflets about improving health, which the researchers thought were really good. That increased my confidence and I started to talk and contribute more, and now they can't stop me!

How have you been involved in research since then?

I got involved in other research projects and learnt how much service users and carers can contribute to research, which encouraged me to apply for a one-year research fellowship. That experience really increased my

confidence, which led me to apply for a job as a service user researcher. I hadn't applied for a job for 10 years, so that was daunting. I drew on lots of support from the research team leads and members I'd been working with. One research lead even did a mock job interview with me – they were all so supportive and encouraging.

I've also been doing some work in Malaysia where I come from, giving talks about stigma, recovery and service user involvement, which is completely new to their culture! It's a slow process to get them on board, but if I can help even to make a small change, that feels like a big success for me.

What do you feel is your biggest achievement?

I did speak at the House of Lords and I also spoke at an NHS event with over 200 senior members of staff, where I told my story, which I think went down well. But I think what I'm proudest of is completing the fellowship and getting that job. Now I'm able to think about my own research and the ideas I have about how to improve things. People are listening to me and I can make people pay attention to what service users need.

What would you say to other people that are thinking about involvement?

It's a great opportunity to learn new things and you can take it at your own pace. You'll build up your skills and confidence, and your contributions will change what services look like. Just through asking simple questions, you can help make big changes.

9. What training and support might I be offered?

Training for people who get involved

Before you get involved in a research project, or when you join a group, you may be offered training about involvement and about research. The aim will be to help you understand the research world a bit better, so that you can understand when and how your contributions add value. Depending on your background and experience, you may find some forms of training more helpful than others. Everyone will have different things they want to learn.

As with anything you do in life, you will learn how to do involvement in a number of ways. You'll read about it and you'll learn from others with more experience than you. But you'll probably learn the most from actually doing it – 'learning on the job'. Don't be concerned if everything isn't perfect at the start. Your skills, understanding and confidence will greatly increase over time.

"I came into it with mental health issues and I was quite scared at the beginning, but I've grown and become an extremely confident person and that's amazing. As you can become more confident, you're more able to challenge. Start gently and you will grow and your contributions will get better. You have to find your feet at first, but it doesn't take long." **Julie, Exeter**

Support for people who get involved

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 needs, perhaps giving you extra support at the beginning, and helping you develop your confidence over time. They will aim to meet your practical needs, your emotional needs and your learning and support needs.

"One of our projects wanted to involve a woman with gout - I didn't even know women got gout, but they do and we found one. She would have never have put herself forward, but we encouraged her and gave her a lot of support at the start. One of us went to the meetings with her, but she doesn't need us now! Sometimes people can do a lot more than they realise, but might need a bit of extra support at the beginning." **Carol, Keele**

"Sometimes I've been near to tears when somebody says something. It can just touch a nerve, so you've always got to be sure there is somebody there who will make sure you're alright. That's what I found with the staff team here. They make sure there is no obstacle for me. They always make everything simple and easy for me. All these things make a difference." **Jim, Exeter**

"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**

Useful links: www.invo.org.uk/resource-centre/learning-and-development/top-tips/

10. How will I benefit from being involved?

People who have been involved in research say that the experience has been more rewarding and more fun than they expected. It has given them a renewed **sense of purpose**, from being able to use their experience and knowledge to improve research, and help make the future better for others.

“If I can help just one person so they don’t have to go through the pain that I went through, then my time being involved in research is worthwhile. Coming here you’re thinking of the people who come after you, and how you can improve things for them.” **Stephen, Keele**

It has given people **new knowledge**, from learning about how research works, what researchers are really like, and hearing about the latest research on different conditions. Some people use the knowledge and skills they gain through involvement to better prepare for their interactions with health professionals.

“Now in our yearly, 20 minute appointment with my daughter’s consultant, we come away with the answers to our questions, because we’ve more knowledge from research – it empowers you – armed and dangerous we call ourselves! The good doctors like to be questioned and sometimes you’ve got information they’ve not even read yet!” **Heather, Exeter**

Involvement allows people to develop **new skills** and provides **opportunities to use their existing skills**. People end up doing things they would never have imagined doing before. They sometimes go back to doing things their health had stopped them doing. Sometimes developing and reusing these skills helps people to find work or go back to work.

“We all start this journey with a health condition, and you don’t think you’re ever going to get out of that hole. Involvement gives you a purpose, to stop watching TV all day and going bonkers, to do something to make a difference. I had no problem presenting to people before, but then I had a nervous breakdown and lost all confidence. Getting involved in research gave me the confidence again. I have presented at three conferences and am a co-author on a journal article. These are things I’d never thought I’d be doing.” **Jim, Exeter**

Many people enjoy the **sense of feeling valued** by researchers. People who have lost jobs because of their health, often say they lost confidence in their abilities, but getting involved helped to remind them of what they **can** do, helping them to feel useful again. As they **gain confidence** over time, people improve the quality of their contributions and get involved in more varied and extensive ways.

Talking about their condition with researchers sometimes provides people with a **different way to cope**. They value being able to talk to someone who is genuinely interested in their condition and making good use of what might have been a bad experience.

“Being involved gave me a better handle on my fibromyalgia, rather than going to therapy or talking to a sympathetic friend. I don’t always want a pat on the shoulder or for someone to feel sorry for me. With research you get to talk about it in a very different way, which helps you get your mind around it and gives your experience a value, and you a value, that you don’t get anywhere else.” **Joyce, Manchester**

People who join groups or work with other patients, carers and the public often say they make many new friends over the years, people who provide a much valued source of support.

“I wasn’t aware how exciting involvement would be. It has opened up a new world that I had no idea existed and I’ve met loads and loads of different people. That’s a massive bonus.” **Kay, Manchester**



Mat's story of involvement

Mat Rawsthorne

ESRC PhD Student

Mental Health and Wellbeing Service User Consultant

REBOOT Notts study

What are you currently researching?

We are looking at online support for mental health and comparing two existing solutions. We're asking 'Which one works best and for which people?'

How do you involve patients and the public in your research?

The main way is we have a Lived Experience Advisory Panel, a LEAP, which is good practice. The panel is a mix of people who have experience of seeking help for depression, or experience of looking after somebody else with depression, or experience of using online tools to help manage a long-term mental health condition.

We try and get their input at all the key stages of the research: helping shape the bid for funding, giving feedback on the outcomes that are going to be studied, which questionnaires we use, the information for patients, and the design and testing of the website, because it is an online study.

The area where the panel has been really invaluable has been in providing their knowledge of who is out in the community, to help us prioritise our engagement of people with mental health problems. We are trying to do a kind of 'Heineken effect' on this, which is to reach the parts other studies don't reach!

How do you hope the research to be used?

It depends on the findings, and again the LEAP are going to be helping us to understand the findings, figuring out what they mean and who we should share them with. But what we are hoping is that commissioners, the people who fund NHS services, will have a clear idea about who the websites do and don't work for. And the other hope is that the people who provide this type of service might get an idea of the kind of conversations that help people, and those that maybe aren't so helpful.

What would you say to people who are looking to get involved in health research?

I would say that my voice isn't enough, and that we need other voices. And the other thing I'd say is that it's about respect on both sides - respecting the expertise by experience and the clinical and research expertise. So it is a very collaborative venture.

11. Why do people get involved in research?

People who get involved in research have different reasons for wanting to do it. For most people, it's about making a difference, wanting to ensure that future 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 have had very good experiences, and see their involvement as an opportunity to 'give something back'.

"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**

If you have a particular concern, or a specific change you want to see, involvement in research may not be the best way for you to influence others, unless the research is very specifically about your issue. There may be other ways to help improve services, for example, by working directly with NHS organisations to improve the way care is delivered.

Getting involved in research is about helping to test out ideas of what makes care better, rather than focusing on what went wrong. Finding effective ways to share the most significant parts of your story is important to help researchers understand what matters most to patients, carers and the public.

"It's not about complaining, or always telling the story about your bad experience. You may have to leave your baggage at the door!" **Julie, Exeter**

"You have to think about how to communicate well, how to make someone else listen by phrasing it differently. How you present your views will be affected if you are a patient who is angry with the world, and you may need help to do that in a different way. But once you can do that, then you're away! You can use your experience for positive action!" **Heather, Exeter**

12. Where can I find out more?

If you would like to get involved in research, there are likely to be a number of opportunities that might suit you. The challenge lies in finding them, as they are advertised in different places by a variety of organisations. Some of the places you could look and organisations you could contact include:

- The People in Research website (www.peopleinresearch.org/) that advertises involvement opportunities – you can also sign up to receive alerts of new opportunities
- InvoDIRECT (www.invo.org.uk/communities/invodirect/) – INVOLVE’s online directory of local and national networks, groups and organisations that support involvement in health and social care research
- The news section of the INVOLVE website (www.invo.org.uk/news/)
- Universities working on health research (www.thecompleteuniversityguide.co.uk)
- Research centres and networks supported by the NIHR (listed in PIP 3)
- Local NHS organisations e.g. hospitals and GP practices – ask staff if they know of any involvement opportunities in your area
- If you are a patient or carer, any medical charities supporting people with your health condition
- Newspapers – local and national

If you are in contact with health or social care professionals, they may also be able to identify local and national research organisations that would be relevant to you.

You can also contact INVOLVE for further advice and for paper copies of any of our publications:

Tel: 023 8059 5628
Email: involve@nhr.ac.uk
www.involve.nhr.ac.uk

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