

**INVOLVE**

**NHS**

*National Institute for  
Health Research*

# Starting Out

Essential information for members of the public getting started in involvement in research.

November 2017



# Starting out

Essential information for members of the public getting started in active involvement in research.

This booklet can be used as guidance for members of the public new to involvement in research, or as part of an induction package for public contributors.

# About this booklet

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This booklet was developed as part of the INVOLVE Learning and Development Project.

## Acknowledgements

This booklet was developed with the support of:

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**Abi Dennington-Price**, Patient and Public Involvement in Research (PPIRes), Norfolk

Members of the INVOLVE Advisory Group (especially **Joyce Fox** and **Una Rennard**)

Members of the Induction Subgroup of the INVOLVE Learning and Development Project, led by **Anne Price**.

## This booklet should be referenced as:

INVOLVE (2017), Starting Out – essential information for members of the public getting started in involvement. INVOLVE, Southampton.

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## Who are ‘the public’?

When we use this phrase we mean it to include:

- patients and potential patients
- informal (unpaid) carers
- parents and guardians
- people who use health and social care services
- disabled people.

In fact, anyone who is not employed as a health professional or academic.

## Who and what is INVOLVE?

INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research (NIHR), to support active public involvement in NHS, public health and social care research. It is one of the few government funded programs of its kind in the world.

National Institute for Health Research: [www.nihr.ac.uk](http://www.nihr.ac.uk)

### **The INVOLVE vision:**

“A world of active public research partnerships leading to improvement of health and care for all.”

### **The INVOLVE mission:**

“INVOLVE is the lead for advancement in health and care research across NIHR and beyond. We achieve this by working with others to raise aspirations, drive up standards, provide guidance and facilitate partnerships.”

So to put this simply, INVOLVE is there to support gold standard public involvement and help to make **your** valuable work really mean something, leading to better and relevant healthcare for all.

## So WHY should I do this anyway?

In 2014, an independent panel conducted a review of public involvement in the National Institute for Health Research (NIHR), called 'Breaking Boundaries', which led to a report entitled 'Going the Extra Mile'. The report offered a new vision and called for a set of principles to support public involvement in research, and for public involvement in the NIHR to be focused on six common goals.

Three of these goals show why patient and public involvement (PPI) is important and why we need you to join in:

- it is standard practice for the public and professionals to work together
- the experience of patients, service users and carers is valued
- public involvement is a required part of high quality research.

If you are interested in the full report or its summary, it can be found here:

[www.nihr.ac.uk/news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-nationalinstitute-for-health-research/2739](http://www.nihr.ac.uk/news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-nationalinstitute-for-health-research/2739)

## How can I support research?

**Share the knowledge, experiences and insight you have gained through being a patient and / or carer (this is sometimes called being an 'expert by experience')**

Researchers want to learn from the knowledge you have gained from living with a condition, or through caring for someone with a condition. Your lived experiences of being on the receiving end of health and social care can help to shape how future research is undertaken, and that, in the longer-term, can help to shape and improve how care is provided.

You may be an interested member of the public who can bring a valuable, common sense perspective.

The links below offer two short films on how and why sharing a person's 'lived experience' is important.

May Griffiths: A Carer's Journey of Involvement in Research:

[www.youtube.com/watch?v=rYwlq2fq-EU&feature=youtu.be](http://www.youtube.com/watch?v=rYwlq2fq-EU&feature=youtu.be)

Or how a young man's health condition enabled him to be involved in research. Tom Grew, February 2015:

[www.invo.org.uk/find-out-more/getting-involved/public-information-pack-whiteboard/](http://www.invo.org.uk/find-out-more/getting-involved/public-information-pack-whiteboard/)

## Become a 'Critical Friend'

A critical friend can be defined as: "a person who asks the 'difficult' questions" (and sometimes they can be the obvious questions that nobody else has asked), but in a friendly way.

Many researchers have never been a patient, carer or cared for by somebody else, and so they may miss things from their research plans that seem obvious to you. As a critical friend you can help to make them aware of what they have missed. And as an independent member of the public, you have the freedom to ask the awkward question (sometimes known as 'pointing out the elephant in the room') - in a friendly, supportive way.

**In research there is no such thing as a stupid question, so keep asking questions – get the researchers thinking!**

Your role as a critical friend is to look at the research from **your** perspective, and to offer thoughts, advice and guidance to researchers on whether you feel that this research appropriately reflects the needs and values of the people who use health and social care services.

**You do not need to have specialist / academic / research, knowledge as the others in the room have that!**

# What information might I need when getting started?

The following is a list of key information that you should be provided with once you have agreed to be a public representative in a research project or with a research organisation.

**Please note:** the amount of information available will differ from project to project, and is often dependent on the amount of public involvement in the project so far.

**If you aren't provided with any of this information, you are fully entitled to ask for it.**

- 1. Who else is involved?** Who else is on the project team, Steering Committee or similar group? Who might you need to contact during your involvement?

This can include photographs, job titles and details of the role(s) and responsibilities of the people you are working with. This will help you to get to know who to ask for what advice. In the rare event of problems arising, you should also know who you can talk to. There should be someone whose job it is to support you, often known as a key contact.

- 2. Organisational details and structure.** What does the organisation you are involved with do? What do the various researchers and other people involved do?

Having this information will help you to understand where you and your work, or the research project, fits in the big picture. For example, is the research project part of a bigger research programme?



**3. A Glossary or Jargon Buster.** Who are NIHR, CCF, RDS, CRN, NETSCC, CLAHRCs, HRA?

All these groups, names and abbreviations may seem very complicated until they are fully explained. Make sure you are provided with a **Glossary** which explains what the full names are. For example, NIHR is the National Institute for Health Research.

A Glossary might also explain any 'technical jargon', so that words or terms, such as 'randomised control trial', are explained.

**So, take a deep breath...**and be prepared for getting used to dealing with some technical words, jargon, acronyms and abbreviations. It is almost impossible to understand all these at the start – and each one you come across should be fully explained, either in the footnotes or Glossary of a document.

INVOLVE can help here with their Jargon Buster. You can find it at this link, or ask INVOLVE to send you a paper copy:

[www.invo.org.uk/posttypepublication/pip-4-jargon-buster/](http://www.invo.org.uk/posttypepublication/pip-4-jargon-buster/)

Never feel nervous getting people to explain acronyms, abbreviations or jargon, as often others in the room are also confused by the language.

**4. A role description.** What is your role? What might you be expected to 'do'?

This should offer a clear idea of what your roles and responsibilities are. This could be negotiated between you and the research team / organisation. It may depend upon how much time you have to commit, or what parts of the research you might be involved in.

## 5. Policies and procedures relevant to your role and the organisation.

Is there a car parking policy? A disability access policy? What is the policy for payments and expenses for public participants? You should be provided with all of this kind of information at the start of your involvement. **If you are not – ask for it as soon as possible.**

More help on what to expect regarding payments can be found here:

[www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/](http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/)

Or ask INVOLVE to send you a paper copy.

**6. Relevant learning / training opportunities.** Are there any training courses that you can attend? Are there any easy-to-follow guides on the research process that will help you in your role?

If you think that you would benefit from any specific training related to the activity you are involved in, **ask for it!** Training might be available in the form of formal training, or through observation and discussion sessions, and / or through simply spending a few hours with a relevant member of the Research Team.

If you are in a steering group or formal committee, it may help to have pre-meetings with your key contact so as you can ask questions or be brought up to date with things in advance of the meeting.

In time, you might like to create a 'CV' of the skills you have, and those you have gained while involved. If you do, there is a specific tool which can help you with this: [www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/involvement-portfolio/](http://www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/involvement-portfolio/)

Start this as soon as you start your involvement, as it may be useful to remember what you have done and what skills you have gained when applying for other involvement activities.

INVOLVE's information on training, learning and development can be found here:  
[www.invo.org.uk/resource-centre/learning-and-development/](http://www.invo.org.uk/resource-centre/learning-and-development/)

**7. A mentor or 'buddy'.** Is there anyone else who has been involved in research who you can turn to for help?

Some organisations may have a 'buddy' or a 'mentor' available. This will usually be an 'independent' person like you (often a patient or carer) who has been involved with the organisation, or in research projects, before and who will be able to support and guide you.

**If a mentor or buddy isn't offered, ask your key contact if someone might be available to support you.**

**8. Feedback.** You should be able to find out how you are doing, whether your comments and feedback useful, and how they are being used.

Being kept 'in the loop' is an essential part of being involved in research. The research team or organisation should keep you regularly updated with information, such as:

- What has happened since the last meeting?
- How is the research going?
- How have your comments and suggestions been used?
- Has the research been funded? Was the funding proposal you commented on successful?

**Sometimes there may be long gaps between information updates: when this is the case, the research team should explain this to you, so that you do not feel 'left out'.**

If you are not kept 'in the loop' please see the para below on "What to do if I feel unfairly treated".

**9. Administrative support.** Can a member of the research team or organisation help you with paperwork (for example, printing meeting papers) and things like travel arrangements to help you carry out your role?

Relevant travel arrangements, such as train tickets and hotel bookings, can often be arranged and paid for in advance by the research team. Before meetings, you should be provided with both electronic (e-mailed) and hard copies of papers in good time for you to be able to read and comment on them.

**Specific support requirements**, such as wheelchair-accessible rooms, hearing loops and special dietary needs, should be provided to enable your involvement – **but please remember to give the research team plenty of notice of your special requirements.**

The research team or organisation should ask you at the start of your involvement about any support you might need – for example, whether you require a stand-in carer and / or a personal assistant.

Research teams and organisations often value a diverse group of people being involved, so any reasonable support you might need should be provided, as long as you raise it with the team with enough notice.

**10. Emotional Support.** What happens if you start to feel distressed or upset when you are participating in activities?

Researchers should understand that sometimes it might be difficult or upsetting for you to share your experiences and thoughts with them. When that happens, there should be a supportive person available for you to talk to, or to seek support from.

**Remember to ask for the contact details of that person right at the start, if they are not already provided.**

## 11. What if you feel unfairly treated, or something goes wrong?

You should have your key contact in the research team or organisation. But if you feel that is not appropriate to talk to your contact, the research team's host organisation (often university or NHS Trust) should have a complaints procedure.

You can also contact INVOLVE for guidance:

INVOLVE  
Alpha House  
University of Southampton Science Park  
Chilworth  
Southampton  
SO16 7NS

Telephone: **023 8059 5628**

Email: [involve@nihr.ac.uk](mailto:involve@nihr.ac.uk)

You can also for more information about public involvement standards and how these are being developed

<https://sites.google.com/nihr.ac.uk/pi-standards/about-us>

**12. More guidance for the beginner.** Further information about getting involved in research, the INVOLVE Public Information Pack (PIP) is a good source of information for those getting started.

The PIP is made up of four booklets and is for members of the public who are interested in getting involved in NHS, public health and social care research. The booklets have been produced by INVOLVE with support and advice from members of the public to help us ensure we cover the kind of information people need when first getting involved in research.

[www.invo.org.uk/posttypepublication/the-public-information-pack-pip/](http://www.invo.org.uk/posttypepublication/the-public-information-pack-pip/)

## So what groups and opportunities are out there?

### **To find opportunities to get involved:**

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.

You can also sign up to receive an e-mail alert whenever a new opportunity is added that matches your interests.

[www.peopleinresearch.org/view-opportunities/](http://www.peopleinresearch.org/view-opportunities/)

### **To find local groups in your area, and their contact details:**

The invoDIRECT webpage may help by providing contact details of groups near you that get involved in research, should you wish to join a group to do your PPI work.

[www.invo.org.uk/communities/invodirect/](http://www.invo.org.uk/communities/invodirect/)

**And most importantly, enjoy your time in involvement.**

## **Let us know what you think**

We welcome your comments and feedback on this 'Starting Out' document. If you use this resource, please let us know if it has been useful. And please feedback any comments, suggestions or other information to the INVOLVE Coordinating Centre.



**National Institute for  
Health Research**

This publication is available to download from: [www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)

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