

Starting Out

Essential information for members of the public who are thinking about getting started in involvement in research.



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About this booklet



Starting out

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

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Who? What?

Who are ‘the public’?

When we use this term, we mean it to include:

- patients and potential patients
- informal (unpaid) carers
- parents and guardians
- people who use, or have used, health and social care services
- people with disabilities.

In fact, anyone who is not employed as a health or social care 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

The INVOLVE vision:

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

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

Why?

Why should I get involved anyway?

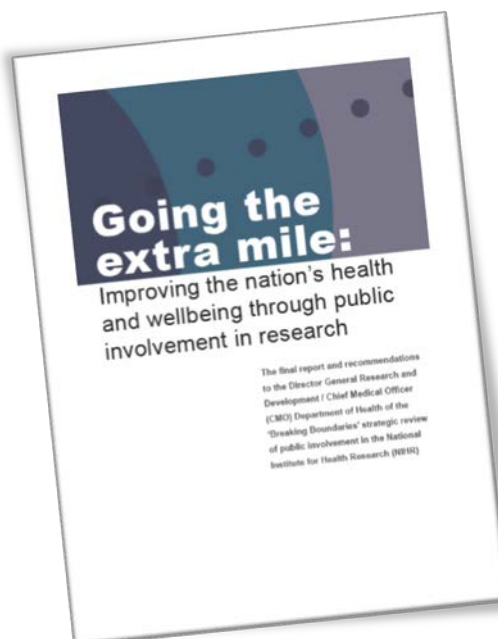
In 2014, an independent panel conducted a review of public involvement in the National Institute for Health Research (NIHR), called 'Breaking Boundaries', which led to a report entitled 'Going the Extra Mile'. The report offered a new vision and called for a set of principles to be produced to support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

Among these are the following three goals, which 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:

https://warwick.ac.uk/fac/sci/med/about/centres/clahrc/ppi/resources/final_published_copy_-_extra_mile_-_march_2015.pdf



How?



How can I support research?

You can share the knowledge, experiences and insight you have gained through being a patient, carer and / or service user (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. Also, you may be an interested member of the public who can bring a valuable, common sense perspective.

The links below offer 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

Public Involvement in the CASTLE study for childhood epilepsy

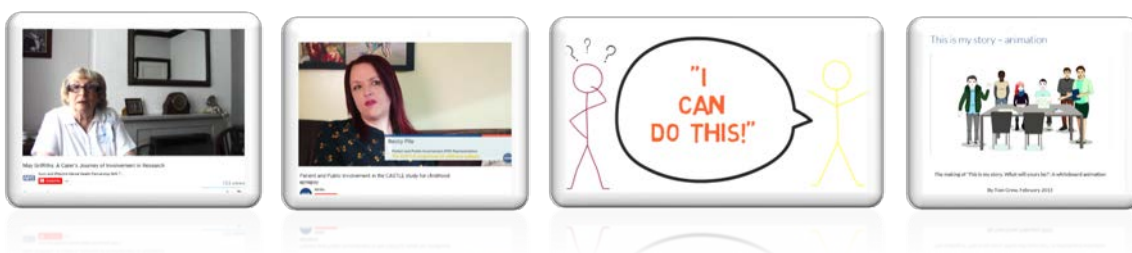
<https://www.youtube.com/watch?v=rXLWrCKGfWI>

Mary's involvement in a Healthy Parent Carer Study:

<https://www.youtube.com/watch?v=SXZduZhkxFE>

How one young man's health condition enabled him to be involved in research:

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 obvious or sometimes difficult questions” that nobody else has asked.

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 knowledge or qualifications, as the others in the room have those.

What?

What information might I need right at the start?

The following is a list of key information that you should be provided with once you have agreed to get involved 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 role you take on.

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

1. Who else is involved?

Who else is on the Project Team, Steering Committee or group? Who might you need to contact during your involvement?

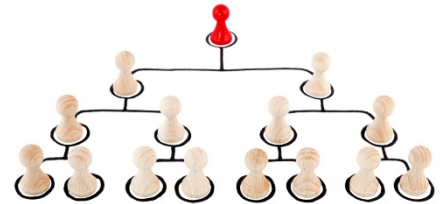
This can include photographs, job titles and details of the role(s) and responsibilities of the people you are working with. This will help you to get to know who to ask for what advice. In the rare event of problems arising, you should also know who you can talk to. There should be someone whose job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



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?



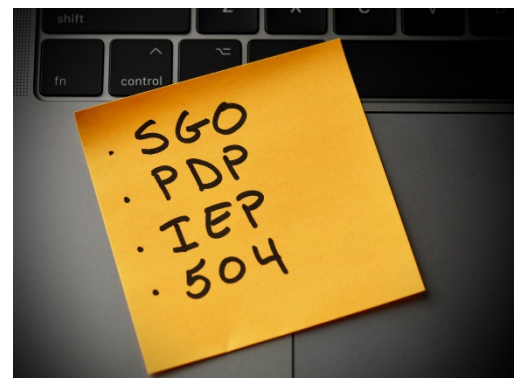
3. A glossary or jargon buster

Who are NIHR, CCF, RDS, CRN, NETSCC, ARCs, 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 controlled 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.



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

INVOLVE can help here with their Jargon Buster. You can find it at this link:

www.invo.org.uk/posttypepublication/pip-4-jargon-buster/

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. Where possible, this should 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

What is the organisation's policy for payments and expenses for public participants? Is there a car parking policy? Is there an access policy for people with disabilities?

You should be provided with these, and all of kinds of information at the start of your involvement. **If you are not – ask for it as soon as possible.**

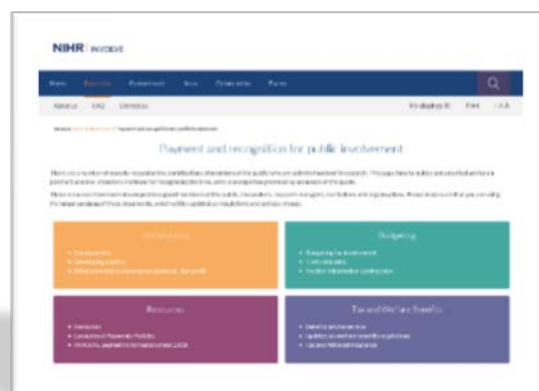
Also, there is a guide covering what you need to know about payment:

www.invo.org.uk/posttypepublication/what-you-need-to-know-about-payment-2/



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

www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/



Or you can ask INVOLVE to send you paper copies of the above documents.

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?

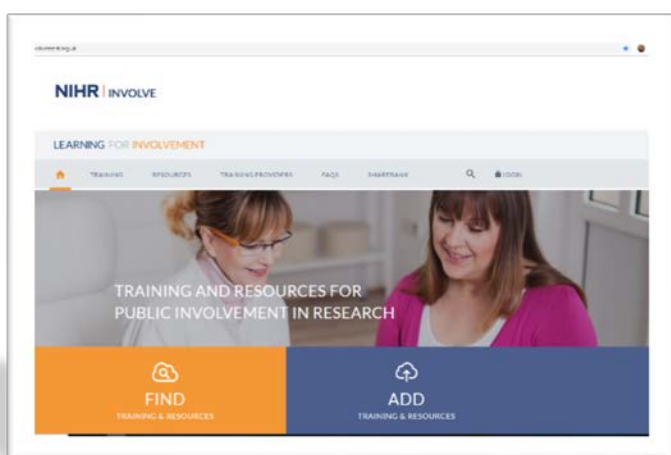
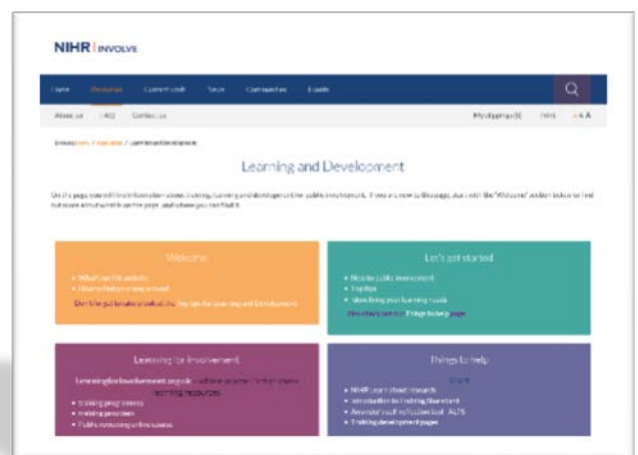
If you think that you would benefit from any specific training related to the activity you are involved in, **ask for it!** Training might be available in the form of formal training, or through observation and discussion sessions, and / or through simply spending a few hours with a relevant member of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

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/

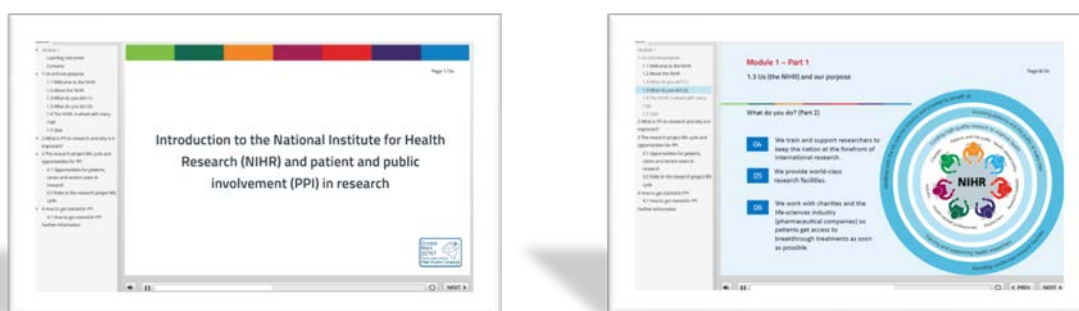


This includes a link to INVOLVE's Learning for Involvement website, where you can find training courses and learning materials:
www.learningforinvolvement.org.uk

Relevant learning / training opportunities (continued)

An interactive course for new and experienced reviewers is highly recommended, even if you are not intending to become a reviewer.

www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/



There is no test at the end of it, but all those completing the course receive a certificate:



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 an 'Involvement Portfolio' tool which can help you with this, which can be requested from the NHS R&D Forum:

www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/involvement-portfolio/

7. A mentor or 'buddy'

Is there anyone else that 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 (this may be a patient, carer or service user) who has been involved with the organisation, or in research projects, before and will be able to support and guide you.

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



8. 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, or versions more suitable to your needs, 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 taken into account to enable your involvement – **but please remember to give the research team plenty of notice of your special requirements.**

The research team or organisation you are involved with 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.



9. Feedback



You should be able to find out how you are doing, whether your comments and feedback are 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:

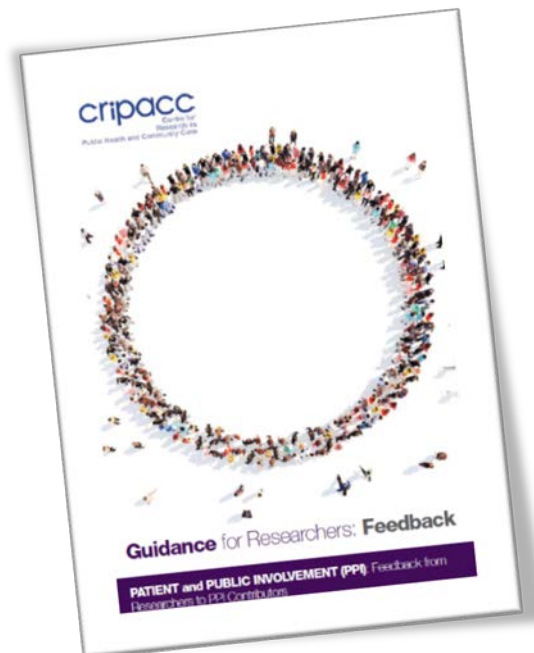
- What has happened since the last meeting?
- How is the research going?
- How have your comments and suggestions been used?
- If your comments and suggestions have not been included, why?
- Has the research been funded? Was the funding proposal you commented on successful?

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'.

There is guidance for researchers about offering feedback during involvement:

www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback-2018.pdf

If you are not kept 'in the loop' please see section 11 over the page on "What if you feel unfairly treated, or something goes wrong?".



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 talk to your key contact or public involvement lead in the research team or organisation. But if you feel unable to talk to your key contact, the research team's host organisation (often university or NHS Trust) should have a complaints procedure.

You can also contact INVOLVE for guidance:

You can also find more information about public involvement standards on the following website:

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

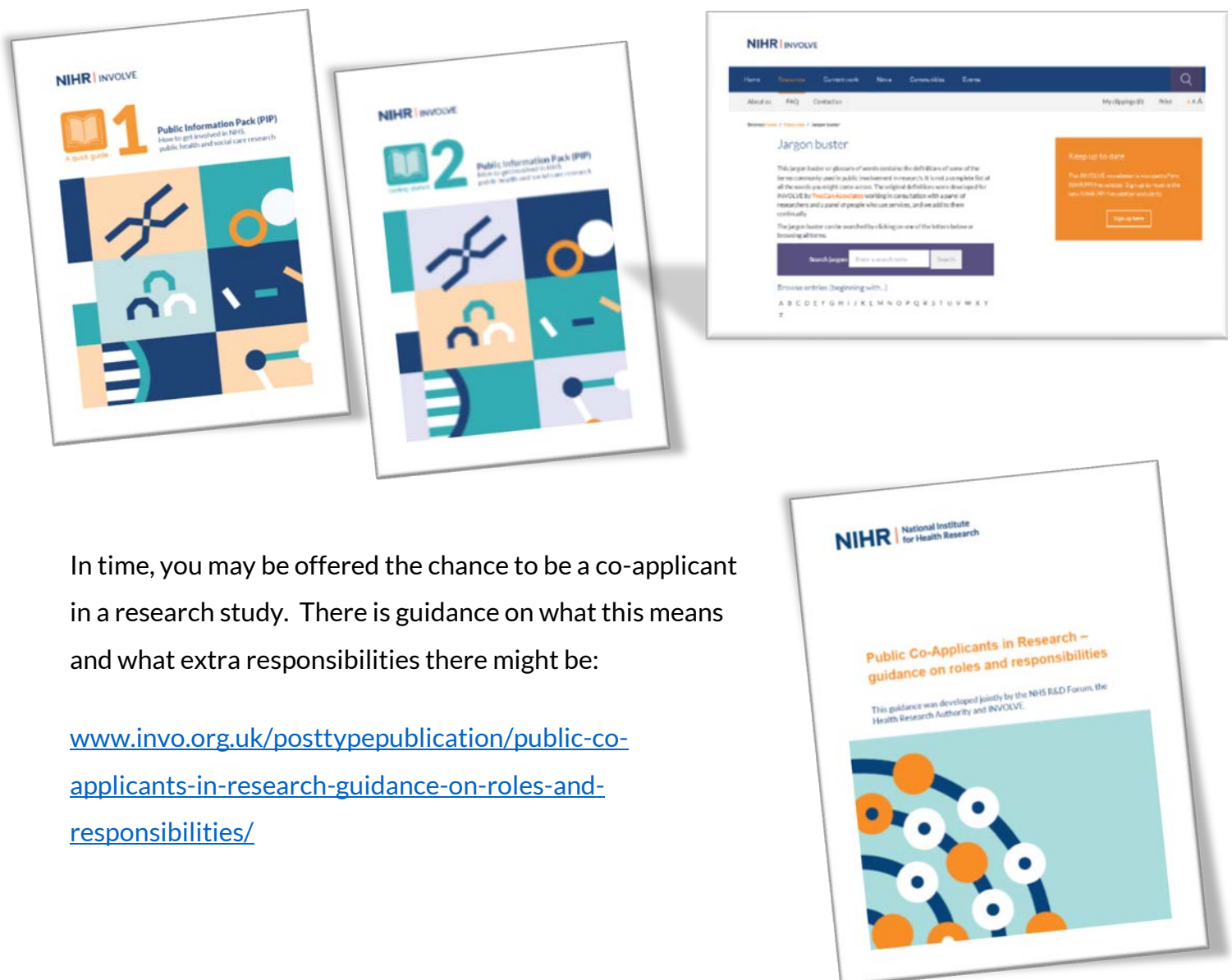
INVOLVE
Alpha House
University of Southampton
Science Park
Chilworth
Southampton
SO16 7NS
Telephone: 023 8059 5628
Email: involve@nihr.ac.uk

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 a series of booklets and online resources 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/



In time, you may be offered the chance to be a co-applicant in a research study. There is guidance on what this means and what extra responsibilities there might be:

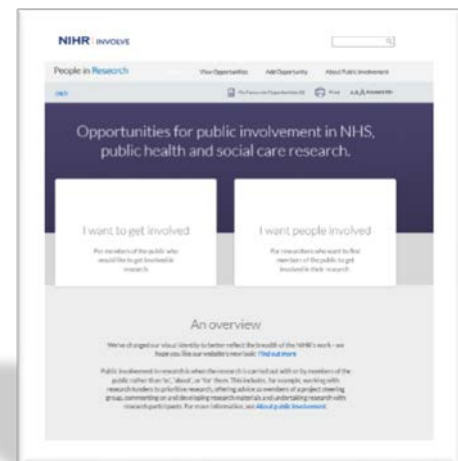
www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/

Where?

Where can I find public involvement groups or opportunities?

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/

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/



And most importantly, enjoy your time in involvement.

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

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!"

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

My involvement work gives me a necessary break from caring. Some me time!

The lead researcher really listened to what I was saying, and understood my concerns (even when some other people tried to shout me down): they wrote a really lovely email which explained why they couldn't make some of the changes I'd suggested, and also where they had been able to make some of the changes I'd suggested for when they interview patients and their families.

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

Sharing my experiences and worries helped to make me feel much more confident and nowhere near as lonely.

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.

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 how it has been useful. And please feedback any comments, suggestions or other information to the INVOLVE Coordinating Centre.

This publication is available to download from: www.involve.nihr.ac.uk

An **audio version** is also available at: www.invo.org.uk/posttypepublication/starting-out/

If you need a printed copy of this booklet, or if you would like to know more about what we do, please contact us at:

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