

A guide to training and support for public involvement in public health research:

A co-produced resource

Everything you need to know and more!

Written by:

Jennifer Bostock, Michelle Collins and Tracey Lee

August 2019

Acknowledgements:

We would like to acknowledge the contributions of all the public advisors involved in the project that led to the production of this resource: Jennifer Bostock, Oliver Coles, Roy Darlison, Mick Lee, Tracey Lee and Tom Marshall. We would also like to acknowledge the involvement of researchers: Jennie Popay, Michelle Collins and Emma Halliday

The project was funded by the National Institute for Public Health Research (NIHR) School for Public Health Research (SPHR).

The views expressed in the resource are the authors' own and do not necessarily reflect those of the NIHR or Department of Health & Social Care.

1. Introduction

This booklet is intended to provide guidance for researchers on training and support for public involvement in public health research. It has been produced as part of the review of public involvement in the first phase (2012-2017) of National Institute for Health Research (NIHR) School for Public Health Research (SPHR). The project's public advisors and researchers have co-produced it.

In this guidance we use the *Involve*¹ definition of public involvement in research which refers to research carried out 'with' or 'by' not 'for', 'about' or 'to' members of the public. We also endorse the *Involve* distinction between members of the public and people who have a professional role in health, social care and public health services. We adopt a broad understanding of what training and support for public involvement in public health research looks like and this is explored in the second section. After this, we include some frequently asked questions that we hope will address many of the queries that both researchers and members of the public might have about public involvement in research and training and support. We then provide a range of collated resources that researchers and members of the public alike might find useful when thinking about, training and support for planning and engaging in public involvement.

1.2 Training and support for public involvement in research

Training and support for both members of the public involved in research and researchers is widely regarded as essential and appropriate to ensure that effective and inclusive public involvement can take place. Training helps enhance the confidence, skills and knowledge of members of the public undertaking public involvement. This knowledge and skill development is valuable in and of itself but it can also help to address power imbalances in the relationship between researchers and members of the public involved.

Training for both members of the public involved and researchers also helps to ensure that public involvement has a positive impact on the research process and that both researchers and members of the public have a good experience of involvement. Where effective training for members of the public involved in research has taken place it has:

- Adopted a practical, hands-on approach in an egalitarian and open environment
- Had clear aims and focused on specific research projects that allow members of the public to draw on their own experiences
- Members of the public have made an active contribution to its development

But there is still work to be done on making sure that training and support is effectively embedded within public involvement in research practice. A lack of availability and accessibility of training nationally has been identified as a problem with most training being developed locally to meet the needs of specific groups or particular research projects.

In addition, some researchers hold negative views about the desirability of training for public involvement in research. There is a concern that training might lead to the professionalisation of members of the public and the essential 'layness' of their contribution might be lost. Other barriers to accessible training and support include the use of technical or jargonny language which members of the public find hard to understand. In addition, a lack of payment for members of the public attending training whilst trainers and employed researchers receive payment for being at the same activity.

We hope this guide will provide enough information and signposts onto further advice and support that training for public involvement in public health research will become more straightforward to put in place. We think this will mean that training and support for public involvement in research is more likely to happen. This guide has been co-produced by members of the public and researchers on the project that reviewed public involvement in the first phase of SPHR research.

2. Training and support

2.1 Training for members of the Public

Training for public advisors can range from introductory courses in research methodology to specific skills-based training, for example on qualitative interviewing techniques for peer researchers. Below is a list of the types of training you might consider dependent upon your resources, time and the requirements of your research

- What is public health research?
- Basic research methods
- Qualitative research methods
- What is expected from a public advisor?
- How to review research literature (e.g. grant applications, protocols etc)
- Ethical review by public research advisors - how to spot and deal with ethical issues in public health research
- Peer Research Interviewing -you may consider it helpful for public advisors to conduct interviews with participants. This is a widely adopted method in qualitative research and can significantly enrich your data
- Chairing skills training – it is often a good idea to have a lay advisor chair advisory panels/groups or participant groups or lay panels to aid objectivity and inclusion
- Writing skills for public advisors – lay summaries, journal articles etc
- Dissemination/Impact – how can you as a public advisor help spread the word once the research is over to ensure it has the greatest impact?

A researcher's view...

It's really important that when members of the public are involved in research, they have a good understanding of what public involvement in general means – what it involves, why it's important, the values underpinning it. This is in addition to understanding the specific roles and expectations around public involvement in the particular project in which they are involved. That's why training in public involvement is key to ensuring the success of public involvement in a project.

I've seen the difference that training in what public involvement is makes to members of the public involved in research: an increased willingness to speak in groups, greater confidence in the views and perspectives they are putting forward and a greater enjoyment of their role.

Dr Michelle Collins, researcher



2.2 Training for Researchers on Public Involvement

Training at whatever stage of your research career can help you get the best from public involvement. Here are some examples of training that has proved helpful to researchers.

- What is public involvement and how can it help my research?
- Creative methods of involving the public
- Lay Panel – what are they and how do I set one up and what are the benefits?
- Practicalities of working with public advisors – eg payment, support etc
- Recruitment and Retention in research – how public advisors can boost recruitment and retention in your projects
- Dissemination & Impact – how public advisors can maximise the publicity of the results of your study – eg co-authorship; conference presenting; community engagement activities.

2.3 Where can I find out about training?

Many of the courses under the heading for public advisors can be done in-house by members of the research team either as workshops, during meetings, as presentations and/or with simple written guides. The best method is usually face to face with short sessions tailored to the specific research project/theme you are working on. The organisations listed below run courses for members of the public.

You may be able to access courses for researchers locally from the Public Involvement teams at your host university. Below is a list of other organisations/individuals known to offer such training.

- Involve – <http://learningforinvolvement.org.uk>
- The Research Design Service (RDS) – there are ten regional design services across England. Find out what support your nearest RDS can offer. For example in the North West the RDS offers a range of support for public involvement: <https://www.rds-nw.nihr.ac.uk/public-involvement/fund/>
- One of the co-authors of this guide provides generic and bespoke training workshops in Public Involvement, Research Ethics, Chairing/communication; Writing skills & Research Dissemination/Impact – contact: Jennifer Bostock at jennifer@jlbostock.plus.com

3. Frequently Asked Questions

3.1 For researchers:

Q. How do I get members of the public involved in my research?

A. You may find it helpful to contact other bodies and colleagues that have done similar research, as they will have lists of people willing to get involved. You may want to contact charities, local community groups, schools, health groups etc. If you are applying for funding outside the School then you can contact your local Research Design Service (RDS) who will have a (Patient and Public Involvement) PPI team with lists of local public advisors. They may also offer advice and financial support to help you achieve involvement at the design stage of your study.

The NIHR/Involve run a website which is free to advertise on where you can post opportunities for public advisors to apply for – it is called ‘People in Research’ and the link is: <https://www.peopleinresearch.org/>

Q. How early should I be involving members of the public?

A. In order to get the most from your research it is advisable to involve members of the public as early as possible – for example coming up with research themes/topics and prioritising research ideas can all be very beneficial and are welcomed especially by funding panels and research ethics committees. By the design stage of the study it is important to get members of the public involved to ensure that the design is feasible and that members of the public are more likely to be recruited in sufficient numbers.

Q. What other forms of training and support are there apart from training courses?

A. Mentoring is an important form of support for members of the public and also researchers undertaking public involvement. Read this article describing the role of a service user research mentor supporting less experienced service user researchers. <http://www.invo.org.uk/mentoring-service-user-researchers>

Q. Is a Focus Group public involvement?

A. If you are going to analyse the data and use it in your findings then it is not public involvement but part of research methodology. If you are getting a group together of members of the public to advise on your study then it is public involvement. In order to avoid confusion do not use the term focus group when describing a public involvement activity.

Q. Should I send the members of the public involved some information on the purpose of the research.

A. Yes. Write a separate short document for this purpose which might include a lay summary or a simple short explanation of the study. Make sure you use plain English and if you have to use acronyms or complex terminology provide a glossary. A full protocol is rarely helpful unless requested by the advisor.

Q. Should I offer a financial incentive?

A. You should at least offer refreshments/lunch and expenses (eg travel). Anything above this would be up to you and your budget. However, it is good practice to offer financial compensation for the time a member of the public spends on the research.

Q. How do I know how much to pay members of the public involved?

A. This is dependent upon 3 things: a) your budget (b) the work you ask the member of the public involved to do (c) good practice – INVOLVE has a simple to use guide on payments which is recommended by the NIHR – see <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/>. There is also an Involvement Cost Calculator you can use to budget for involvement especially when applying for external funding – see <http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>. The accepted day rate for public advisors according to INVOLVE is currently £150 per day & £75 per half day plus expenses.

3.2 For members of the public:

Members of the public will have a range of experiences of public involvement: some might never have been involved in a research project before whilst others might have extensive experience of involvement. Typical questions that members of the public might have during the early stages of involvement include:

Q Do I need any special skills to get involved?

A. This will depend on the research project and your role within it. Sometimes you might be involved because your opinions and life experiences are relevant to the research project. Other times you might be involved because you have a specific skill or expertise. This is something you can talk about with the research team before you decide whether to get involved.

Q. Will I be able to read about the research before the first meeting?

A. Yes. You should be provided with or could ask for a brief summary of the research project and what will be expected of you if you choose to get involved.

Q. Will I get paid?

A. You should receive payment for any out of pocket payments you have made for things like travel and accommodation. In some cases, the research team may be able to organise your travel or accommodation so that you don't have to make any payments.

At the moment there are different approaches to whether payments are made to recognise the time and the experience you bring to the project. Make sure you discuss this with the research team and are clear about whether, how much and how public involvement payments will be made.



4. Understanding the skills, experience and knowledge members of the public bring to public involvement

It can be useful for both the research team and members of the public involved to have a clear understanding of the skills, experience and knowledge that the member of the public is bringing to the research project before it takes place. There are a small number of tools available to help with this.

4.1 Assessing public involvement skills, experience and knowledge before the research project takes place

- *For members of the public:* *Involve* have produced a [resource](#) on carrying out a needs assessment for public involvement training and support. It describes different ways in which needs assessments might be carried out and also provides some case studies.
- *Involve* [Learning Needs Analysis Tool](#) accessed through the *Involve* website: (an on-line version of this resource is to be available in 2018). This resource helps members of the public reflect on the skills and knowledge needed for a public involvement activity, to identify their existing experience and, if there are any gaps in experience, to consider preferred ways of learning new skills or knowledge.

4.2 Reflecting on public involvement skills, experience and knowledge, including any support needs, whilst the research project is taking place

Reflecting on the learning that takes place during the research project can help in identifying any further training or support needs for either the member of the public involved or the research team. It is also a good way of demonstrating the impact of public involvement on the research project and the people involved.

- *For members of the public:* Amander's Levels of Participation Significance (ALPS) tool accessed through the [Involve website](#). A self-reflection tool designed for members of the public involved in research to use after an activity they've been involved in. It encourages the person using it to reflect on what new skills/knowledge etc. they have gained as a result of being involved in the activity and what support they would have found useful. The exercise is framed through the metaphor of climbing a mountain.
 - *For research teams:* National Standards for Public Involvement in Research [Audit Tool Template](#) developed by Health and Care Research Wales. This resource invites research teams to reflect on whether and how well training and support for public involvement in research is made available.

A Public Advisors View

When I first got involved in SPHR research I asked myself:
Do I have the skills to get involved?
What is expected of me?
I wasn't sure if any special skills were needed, or I would have to do anything academic. These questions were answered either before the research started or during the first meeting, which I found very helpful. Once I was properly involved, I really enjoyed it. I felt valued and that my opinions really counted. If I was to give any advice to researchers it would be to make sure that everyone gets a chance to have their say, without pressure.

Mrs Tracey Lee, public adviser

5. Where can I get more Information about Public Involvement?

5.1 Training Course providers

Resource	Location
CLAHRC North West London e-learning resources (requires registration)	http://clahrc-northwestlondon.nihr.ac.uk/what-we-do/learning-and-development/elearning
Jennifer Bostock, one of the co-authors of this guide provides generic and bespoke training workshops in Public Involvement, Research Ethics, Chairing/communication; Writing skills & Research Dissemination/Impact	Contact: jennifer@jlbostock.plus.com
The Research Design Service (RDS) –	Look for your nearest RDS to see what support they offer. For example in the North West: https://www.rds-nw.nihr.ac.uk/public-involvement/fund/
<i>Research and Experience</i> (Bec Hanley and Derek Stewart) – an organisation that offers training courses in public involvement in research	http://www.becandderek.co.uk/
UCL	https://www.uclhospitals.brc.nihr.ac.uk/investigators/ppi-training
University of Salford Continuing Professional Development courses focused on public involvement in research:	http://www.salford.ac.uk/onecpd/courses/patient-and-public-involvement-in-research
Voice North: Citizen Involvement Matters <i>A short MOOC for researchers on actively involving citizens from across the EU to identify innovation needs and research priorities actively involving citizens from across the EU to identify innovation needs and research priorities</i>	https://www.voice-global.org/courses/citizen-involvement-matters/

5.2 Involve resources

Involve is a national advisory body that supports greater public involvement in NHS, public health and social care research and is funded by the National Institute for Health Research (<http://www.invo.org.uk>). It has developed a range of resources and networks for public involvement in research. We focus on resources related to training below:

Resource	Location
Guide to planning training, including case examples:	http://www.invo.org.uk/posttyperesource/planning-training-general-overview/
Guide 'Developing Training and Support for Public Involvement in Research':	http://www.invo.org.uk/wp-content/uploads/2015/06/8774-INVOLVE-Training-Support-WEB2.pdf
Guide about payment for members of the public considering public involvement	http://www.invo.org.uk/posttypepublication/what-you-need-to-know-about-payment-2/
Web page with information about payment and recognition about public involvement in research	http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/

5.3 Video-based resources

<http://www.healthtalk.org/peoples-experiences/medical-research/patient-public-involvement-researchers/training-needs-involvement>

5.4 Articles and blogs

Resource	Location
Horobin, Brown, G, Higton, F, Vanhegan, Wragg, A, Wray, P and Walker, D-M (2017). Co-producing public involvement training with members of the public and research organisations in the East Midlands: creating, delivering and evaluating the lay assessor training programme. <i>Research Involvement and Engagement</i> 3 (7). https://doi.org/10.1186/s40900-017-0056-0	https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0056-0
This blog is a very good resource, it gives advice on what NOT to do in public health research, but also advice on how to go about it. It explores the research criteria compared to volunteer opinion, sometimes helping to better focus the research.	http://sphr.lshtm.ac.uk/2017/02/21/blog-public-involvement-can-make-or-break-your-research-study/

5.5 Examples of Public Involvement in Research Training

Resource	Location
NIHR Building Research Partnerships – information about training workshops on public involvement in research	https://www.invo.org.uk/building-research-partnerships/
Stroke Association	https://www.stroke.org.uk/news/our-patient-public-involvement-ppi-training-day

5.6 Other resources

Resource	Description
Resources from the Plain English campaign with advice on writing that avoids jargon	http://www.plainenglish.co.uk/free-guides.html

References:

1. A national organisation funded by NIHR and focused on increasing the amount of public involvement in NHS, public health and social care research: <https://www.invo.org.uk>