

INVOLVE



*National Institute for
Health Research*

Developing training and support for public involvement in research

Supporting public involvement
in NHS, public health and
social care research

About this report

This report is for people who are planning training and support for public involvement in research. It offers a general overview of the things to think about when developing training and support packages for members of the public, researchers or both. This report is part of a larger online resource about training and support which is available in the Resource Centre of the INVOLVE website www.invo.org.uk/resource-centre/training-resource/

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Let us know what you think

We welcome your comments and feedback on this resource. Please also send us ideas for more case studies and links to other useful resources.

Send your comments, information and ideas to: training@invo.org.uk

Terms used

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. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

In the examples cited in the report, the terms reflect those used by the authors such as research advocate, consumer or lay member instead of public.

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Introduction

There are a number of different situations in which people will need training and support for public involvement in research. These range from large research organisations aiming to train a large number of researchers working across a network, where a formally run training course might be appropriate, through to individual researchers developing informal ‘on-the-job’ approaches to train and support one or two members of the public on a small, low-budget project.

Tailoring training and support for public involvement to each individual situation, if possible, is helpful and constructive.

This publication offers advice and guidance to help you develop your own training and support packages suited to different situations and contexts. It is part of a larger online resource which holds a collection of full case studies and also provides detailed information about planning training and support for five common ways of involving the public in research:

- research panel member
- project advisory group member
- project steering group member
- public reviewer
- peer interviewer.

The information in this report and online resource is drawn from the direct experience of training and support by members of the public, researchers, trainers and public involvement specialists. This might be people’s experience of being a participant in training or support initiatives or experience of providing training or support. Contributors took part in a group conversation or individual interview to identify the key points for the main topics. A list of all contributors is available in the online resource at www.invo.org.uk/acknowledgements-and-contributors

This resource does not offer ‘off-the-shelf’ training programmes or a directory of training courses. This is because:

- There are very few publicly available training courses – most are developed for an internal audience (people working for or with a particular organisation) or they are integrated into individual research projects.
- Most off-the-shelf programmes need to be tailored to the situation – many are developed for a specific audience or situation, so may not be directly relevant to other situations or groups of people.
- Some people are reluctant to share the details of their training programme – quite fairly as they may have invested significantly in developing them and may be dependent on delivering training for their living.

What do we mean by ‘training’ and ‘support’?

What do we mean by ‘training’?

We use the term **‘training’** to describe the wide range of activity that aims to help members of the public and researchers develop their knowledge, skills and experience to prepare them for public involvement in research.

The term training tends to suggest a one-off, one-day event to introduce a new skill but it is not always helpful to view training for public involvement in this narrow way. ‘Training’ in this context describes a multitude of different kinds of learning opportunities including:

- group sessions with a trainer
- providing high quality written materials and guidance
- learning on-the-job
- attending conferences
- networking and shared learning with peers
- online activities
- university or college courses.

Think creatively and be open-minded when planning training for public involvement and try not to be constrained by a limited concept of what training involves. Recognise that those getting involved, whether researchers or members of the public, will come with a wide range of skills and experience. They will also have different learning styles – so individuals may have different preferences as to how they want to be trained and what may help them to learn the most.

What do we mean by ‘support’?

We have used the term **‘support’** to describe a wide range of activity that enables researchers and service users to work together in research. This includes support to address:

- practical and financial issues
- emotional and psychological support
- project supervision to promote professional and personal development.

Support can be offered in a range of different ways including via:

- a user support worker
- a member of the research team
- a mentor with similar experience
- team meetings
- one-to-one meetings with line managers
- informal or formal mechanisms of peer support.

Think about offering support through a variety of mechanisms for both researchers and members of the public when planning public involvement in research.

Essential principles for training and support

Any form of training and support for members of the public, researchers or staff in research organisations should, ideally, be based on the following principles.

Training and support needs to be tailored to the situation. There is no ‘one size fits all’ approach. Training and support need to reflect the nature of the research project, the remit of the group, the specific needs of the individuals involved, and the resources available.

If you’re offering training or support, it is best to be responsive to individual needs – so make sure any ‘off the shelf’, ready-made training courses offer what people have said they want to learn. Training and support also need to be in a style that suits them – for example training for young people may need to be delivered in a different way to training for adults.

Anyone in a research team may need training and / or support to develop their skills. Don’t assume researchers have all the necessary skills and knowledge for public involvement in research. Don’t assume that all members of the public lack the necessary skills and knowledge – they may only need help with adapting their existing skills to the research context. Build on the knowledge, skills and experience that people have already. Training members of the public and researchers together can often be very powerful.

Training and support should not be seen as one-off events. Both may need to continue throughout the life of a project or the life of a group. Learning opportunities should be built into all stages and linked directly to the task in hand.

The success of training and support is often due to the skills and competencies of the person delivering it. Offering training or support requires specific skills and experience. For example, you may be good at something, but that doesn’t mean you’ll be good at training others to understand it or how to do it. If you don’t have the necessary skills or experience, draw on people who do.

Don’t assume that members of the public are only bringing their direct, personal experience of the topic. They bring a much wider variety of skills and knowledge to the research process. They often have as much to teach researchers as researchers have to teach them. The process of working together should be seen as an ongoing, two-way process of mutual learning and personal development.

Who benefits from training?

Members of the public and researchers at all stages of their journey with public involvement in research may benefit from training.

Those **new to involvement** may benefit from an initial introduction, such as what involvement or research is, the principles behind it and some practical information about how they might do it. They need to have a clear understanding of their role, what is expected of them and what to expect from the others in a team.

People who are starting to **undertake involvement** may need training to develop particular knowledge to enable them to be effective in their role. For example, **researchers** might need more detailed information about practical aspects, such as accessibility or payment, and **members of the public** might need more detailed background information on the particular research topic or nature of the role they are undertaking. Researchers and members of the public may also need to develop their skills. For example researchers may value training in facilitation skills or chairing group discussions, while members of the public may wish to develop research skills such as conducting interviews.

People who are **more experienced** may value training to enhance their practice. For example, researchers may wish to find out more about employing service user researchers. Members of the public may need training in taking on roles with greater responsibilities, for example chairing advisory groups.

Anyone in a research team may need some training. For example:

- researchers may not already have the necessary skills and knowledge for public involvement in research
- members of the public don't necessarily lack the skills and knowledge – they may only need help with adapting their existing skills to the research context.

For **researchers**, it may not be necessary for every member of a research team to be fully equipped with all the skills needed to manage the public involvement so identify the person best placed to lead on this and assess their training needs (see the section on carrying out a needs assessment). Other members of the team, for example a statistician or data manager, will need to understand why the involvement is important and what it contributes to the process, but not necessarily how to manage it.

What should training cover?

Preparing **members of the public** for their role should:

- help them understand the role they will be undertaking and the value of their perspective
- explicitly recognise and acknowledge the skills and experience they bring from other areas of life
- help them understand where they fit in the wider research context such as within the research team or host organisation or the wider research commissioning and prioritisation process, for example how decisions are made about research priorities and funding, or how research influences healthcare
- provide opportunities to develop their experience, skills and knowledge in a way that is matched to their role
- when required, include a general introduction to research, covering topics such as the research cycle, overview of different research methods and research terminology
- provide opportunities to discuss further training and support needs.

Preparing for involvement with the Patient Learning Journey Model

Before people with experience of pressure ulcers started contributing to research at the Leeds Clinical Trial Unit, the Patient and Public Involvement Officer, Delia Muir, brought them together for facilitated workshops. The aim was to prepare them for involvement in research. However, instead of focusing on research, this workshop focused on helping people to understand the value of their personal experience, expertise and skills and how this can contribute to research. The participants worked to identify learning points from their personal experiences and how to communicate these to others. They were also helped to think about how much of their personal experiences they were willing to disclose when working with a research team. In the full case study, Delia reflects on how the value of a training approach which starts with the people and their stories, rather than the other things they need to know.

www.invo.org.uk/training-case-study-13-2/

It is important to recognise that **researchers** will need training about public involvement in research.

Junior researchers need training about public involvement in the same way as they need training about any other aspect of research – it can usefully be integrated into standard research training either as individual sessions or for those most interested, postgraduate accredited courses.

Training for researchers – a workshop designed by a virtual working group

This one-day workshop was designed to target early career researchers undertaking their PhD. It was planned by a collaborative group including three public involvement managers, a member of the public and two doctoral students. The workshop aimed to meet the needs of researchers by demonstrating how public involvement could contribute to the conduct of their research and help them fulfil the expectations of funders and sponsors, and by identifying a range of resources and practical approaches to developing involvement in their own projects. An innovative aspect of this workshop was using postcards to complete short action plans and mailing them back to participants three months later to remind them of their ideas.

www.invo.org.uk/training-case-study-one-2/

Senior researchers may benefit from training because public involvement is relatively new and they may have missed opportunities for training earlier in their career. Understanding involvement will help them support involvement across their research group and support their junior colleagues who are developing involvement in research projects. Taking part in short training courses may be helpful, such as that described above or in case study four in the online resource (www.invo.org.uk/training-case-study-four-2/).

Training is particularly useful for researchers at key stages in their careers and/or at different stages of the research cycle including when:

- writing grant applications – particularly when applying to funders who require information about plans for public involvement in research proposals
 - moving to a new workplace – incorporating public involvement into an induction package for new research staff will help people to find out about the standards of good practice in their new organisation, what involvement is happening locally, who is doing it and what training / support is available
 - individuals are promoted and acquire more personal responsibility for planning and managing involvement.
- Preparing **researchers** for public involvement should:
- be clearly linked to public involvement, that is where members of the public are actively involved in research projects and research organisations and not recruiting patients or members of the public as participants in research or raising awareness of research, sharing knowledge or engaging with the public (www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research)
 - develop understanding that public involvement can be a solution to some practical problems in research – rather than a ‘must do’ or ‘add-on’ to heavy workloads
 - explicitly recognise and acknowledge the relevant skills and experience they may already have, in addition to those acquired through their professional training
 - provide opportunities to develop their experience, skills and knowledge in a way that is tailored and linked to their role
 - be matched to their role and responsibilities for public involvement, for example training and support is essential for those who have the lead responsibility for involvement
 - address the practical knowledge and core skills required to work with people, for example facilitation skills and managing group discussions
 - develop knowledge and understanding about the benefits and barriers to involvement
 - provide opportunities to discuss further training and support needs.

Find out more

about what training should cover:

Case studies of training approaches

www.invo.org.uk/developing-training-and-support-case-studies

Training and support for specific roles

www.invo.org.uk/resource-centre/training-resource

Public Information Pack (PIP) for members of the public interested in getting involved in research (Buckland et al 2007) www.invo.org.uk/resource-centre/publications-by-involve

Collaborate and succeed – An evaluation of the Compass Masterclass in consumer involvement in research (Staley/TwoCan Associates 2011)

www.twocanassociates.co.uk/perch/resources/files/COMPASSreportFinal.pdf

Building Research Partnerships

(Macmillan 2012) learnzone.macmillan.org.uk/course/view.php?id=305

Different methods of training

Not all training needs to take the form of a traditional training course. People can learn about involvement and develop new skills in a number of ways. Some approaches can also offer effective sources of ongoing support. The best approach will depend on people's needs and preferences and the resources available. Different approaches to consider are listed on page 5.

Making sense of the evidence in dementia: an interactive online course

The ALOIS community is an engagement project managed by the Cochrane Collaboration Dementia Group, which recruits and trains lay volunteers, specifically targeting carers and former carers of people with dementia, to update and maintain an online register of controlled dementia trials. This trials register is called ALOIS after Alois Alzheimer. The ALOIS community volunteers read reports of dementia research and extract key pieces of information to enter into the trials register, a task referred to as 'coding'.

As well as holding training workshops, the ALOIS community have developed online learning materials for volunteers. These can be used by anyone with a computer and internet connection. The online materials include narration, pictures, other audio clips, links to other websites and short exercises to provide more information about the Cochrane Collaboration, dementia research and the ALOIS community. The modules can be viewed at aloiscommunity.org

See also www.invo.org.uk/training-case-study-15-2

Researchers and **research staff** in organisations may have access to staff development programmes/budgets which can help develop their knowledge and skills. This may be through staff presentations, or more informally, for example by observing colleagues or other researchers 'doing' public involvement. Organisations can therefore promote learning in different ways, for example by running 'study days' or workshops, or helping researchers to find out who else in their department, university or local area is doing public involvement.

It may be possible for researchers to access training from someone working in an external organisation that promotes public involvement – through a Clinical Research Network or a local Research Design Service, for example. Others may have a user support manager, a paid full- or part-time member of staff, who works in their department, unit or university (see case study five in the online resource www.invo.org.uk/training-case-study-five-2/). These staff may be able to offer a range of training and support for a group of researchers including:

- advice when first starting to involve the public
- training courses for researchers and members of the public
- help with finding members of the public to be involved
- support for researchers when they first put their learning into practice, for example commenting on draft job descriptions and person specifications for members of the public
- help with planning and budgeting for public involvement in a grant application.

Members of the public do not always have access to these organisational and informal learning opportunities and might require a more concerted approach to meet their development needs. It might be appropriate to carry out an assessment of their training and support needs. Creative thinking about training opportunities may be needed as in-house budgets and resources may be limited. Training useful for involvement might be available through local libraries, voluntary organisations, universities and higher education colleges.

Find out more

about different methods of training:

Contact public involvement specialists in other organisations

National Institute for Health Research (NIHR) Clinical Research Networks
www.crncc.nihr.ac.uk

NIHR Research Design Services www.invo.org.uk/find-out-more/information-for-researchers/research-design-services-information

NIHR Collaborations for Leadership and Applied Health Research and Care www.nihr.ac.uk/infrastructure/Pages/CLAHRCs.aspx

NIHR Biomedical Research Centres www.nihr.ac.uk/infrastructure/Pages/infrastructure_biomedical_research_centres.aspx

Information about adult learning and skills development

www.learndirect.co.uk

Issues to think about before you start – training

What is the best way to describe the ‘training’ you are offering? It may not always be appropriate to use the term ‘training’. This can suggest people are in some way deficient in knowledge and skills, which may not be true. It may be better to use one of the following terms – ‘briefing’, ‘induction’, ‘introduction’, ‘professional development’. Talk with the people you are going to train about their preferences for how the ‘training’ is described.

Can you offer people a choice about the form of training they take part in? Individuals may have different preferences and ideally for training to be most effective, it should match these preferences. However, with resource and time constraints you may not be able to offer a wider range of approaches.

Be clear about the purpose of training and explain this to potential participants. People need to understand what they are coming to and make an informed choice about whether they want to participate.

Training is integral to involvement. Include sufficient time for training. For members of the public, don’t expect people to give up extra time in addition to their involvement in a project or group. Make it an integral part of their involvement.

Recognise the limits of one-off training courses or conferences. A one-day event is not likely to equip everyone with all the skills and information to either ‘do’ public involvement or get involved – researchers and members of the public may value ongoing training and support. Consider formal and informal mechanisms to enable people to continue to learn about involvement, for example through workshops covering specific topics, internal presentations from experienced researchers and members of the public, use of social media, online discussion forums and so on.

Be creative about access to training. Budgets for training can be limited and training that is useful to involvement might be available through local libraries, voluntary organisations, universities and higher education colleges.

Who is best placed to deliver the training? Think about who is the right person to offer the training and whether you need to bring in people from outside your organisation. Effective training may be offered by:

- people with expertise in the area who can champion involvement based on their experience
- external trainers (see box on next page for things to think about when you want to find a trainer)
- members of the public with training skills and experience of being involved in research.

Shared learning from peers is very powerful and messages ‘direct from the horse’s mouth’ can be more credible. Training delivered by members of the public, either alone or in partnership with researchers, is particularly valued by researchers.

Training researchers and members of the public together. This can help everyone to:

- clarify their expectations
- prepare for new ways of working and help with team building
- gain a shared sense of the purpose of the involvement.

Sometimes it may be better to train the groups separately, for example when people are just starting out and may prefer a group of peers to create a ‘safe’ learning environment.

Things to think about when you want to find a trainer or facilitator

If you plan to commission someone to develop and/or deliver training, it's a good idea to think about the following issues.

- Is the trainer able to demonstrate knowledge and understanding of public involvement?
- Are they prepared to work with you and potential participants to plan and/or deliver the training?
- Do they have a track record in training in the area you want them to cover, or in a closely related area?
- Do they have a track record in delivering the type of training approach you plan to use? (For example, the development and delivery of online training is very different to the development and delivery of face-to-face training.)
- Do they have experience of working with people similar to the potential audience for the training? (For example, if you are training a group of people with aphasia, the trainer will need experience and understanding of working with people with aphasia.)
- Do they work to a core set of values or principles? If so, what are they?
- Do they have appropriate public/professional liability insurance cover?
- Are you confident that you and the trainer/facilitator will be able to provide adequate support to participants both during and after training? This may include practical and emotional support.

This list is available as a checklist to download from the online resource – www.invo.org.uk/wp-content/uploads/2012/07/Finding-a-trainer-things-to-think-about-v1-070312.pdf

Running training events or courses

If you have decided that a formal course will best meet training needs, try to incorporate the following good practice points:

- Use a variety of approaches to be responsive to the variety of learning styles, for example interactive group work, writing and role-play exercises. Case studies can be particularly useful.
- Where possible, training is best carried out face-to-face – even if the people being trained only come together once and then work on their own for the rest of the time an initial meeting is very valuable.
- Face-to-face training also helps people to network, to feel part of a community, to set up informal mechanisms of peer support and can also help to establish teams.
- Check people's expectations of the training beforehand or at least at the beginning of any training session to check the right people are in the room and if necessary to adapt the programme / agenda to meet their needs.
- Build in plenty of breaks to allow a comfortable pace and promote networking.
- Provide handouts / folders so people can record their learning and refer back to this material at a later date.
- Use evaluation forms to get feedback from participants after the training and use their responses to improve your programme / sessions.
- Ensure any training event is accessible and ensure any materials are provided in a format that is suitable for the participants, for example it may need to be offered in large print.

Find out more

about running events:

Briefing note eight: Getting started

www.invo.org.uk/getting-started/

Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers (INVOLVE 2012)

www.invo.org.uk/resource-centre/resource-for-researchers/

Budgeting for training events or courses

The costs of training will vary enormously depending on the precise format that it takes. It's important to build in all the relevant costs in any funding bid for a project with public involvement.

The expenses associated with training events might include:

- trainer / facilitator / speaker costs – fees, travel, accommodation, thank you payment
- travel and accommodation expenses for participants
- payment for participants' time while attending the training
- catering – lunch / tea / coffee
- costs for social media, teleconferencing or webinars for remote access to training
- venue / room hire
- paper / printing handouts
- hire of specialist equipment or support services, for example projector, laptop, internet access, hearing loop, hoist, interpreters or signers
- carer / childcare costs
- costs of certificates or accreditation.

Find out more

about budgeting and payment:

Briefing note five: Resource public involvement in research www.invo.org.uk/resource-public-involvement-in-research/

Payment for involvement: a guide for making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE 2010) www.invo.org.uk/resource-centre/publications-by-involve/

What are support needs?

The support needed by researchers and members of the public will very much depend on the situation. Support is often required to enable people to fulfil their role effectively. Support needs will depend on many different factors including:

- the nature of the research
- the individual's role in the research project/group
- their level of experience
- the attitudes of the people they work with
- their health status.

It is important to recognise that all members of a research team may need support.

Planning support requires thinking about what kind of support might be relevant, who is the best person to offer support and what is the best approach to provide the necessary support. Individual needs are different so approaches need to be flexible and responsive. Requirements change over time as people grow more confident or take on more challenging roles. Ongoing discussion helps to check that people's support needs are being met.

Different types of support

The different types of support that could be useful to researchers and members of the public include:

Project management / supervision – reviewing project progress and addressing issues arising from the research will be relevant to all research team members irrespective of their background.

Personal / professional development – to review people's progress and performance and provide positive feedback and encouragement and / or to see if they need any additional pointers to further develop their skills. For example, **members of the public** who take on research roles such as peer interviewing, may need feedback and guidance when they first put their skills into practice and **researchers** may benefit from the support of a public involvement manager when they first start involving members of the public in their research, to reassure them that they are following best practice.

Practical support – to help people to familiarise themselves with a new research environment, for example all research team members might need help with finding their way around a new location or building. Members of the public may need support with meeting their practical needs, such as payment of fees and expenses, making travel arrangements, parking, and accessing childcare.

Financial advice – paying members of the public for their involvement may, for example, have an impact on their benefits or may mean they have to register as self-employed. Researchers and members of the public may need advice on how to manage payment.

Emotional / psychological support – to help people to cope with any distress that arises as a direct consequence of being involved in research, for example if they become upset after discussing a sensitive or emotional topic, or from hearing about other people's bad experiences, or from returning to an environment that has been traumatic in the past. Some people may also be challenged by others about the benefits of public involvement in research and may be helped by being prepared to cope with personal or professional criticism. Emotional / psychological support is often as relevant to researchers as it is to involved members of the public.

On-the-job support – to allow people to let off steam or raise any concerns after a difficult meeting or frustrating experience.

Some of these types of support can be provided through informal mechanisms that develop organically as colleagues start to work together and form a team. Others may be better provided through a more formal approach that will need to be properly costed and resourced.

Find out more

about different types of support:

Training and support for peer interviewers (INVOLVE 2012) www.invo.org.uk/posttypesource/training-and-support-for-peer-interviewers

Payment for involvement: a guide for making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE 2010) www.invo.org.uk/resource-centre/publications-by-involve/

Different approaches to providing support

All kinds of people can offer support including:

- a public involvement manager working inside an organisation – they may be a researcher or an experienced member of the public
- a peer support worker
- the project principal investigator or chair of a committee
- a peer – a member of the public who is also involved in research, or a researcher with experience in involvement
- a counsellor or psychologist.

Different people may be better placed to provide some forms of support than others. For example, the principal investigator or senior manager may be best placed to offer supervision and project management, whereas a peer, counsellor or psychologist may be better placed to provide emotional / psychological support.

Different approaches to providing support include:

- mentoring
- coaching
- group meetings – annual meetings, support groups, shared learning groups
- virtual support – through telephone or email conversations and the use of social media.

The best approach will be highly dependent on the situation, for example whether you are an organisation seeking to support large numbers of staff or projects or an individual researcher seeking to support a small research team.

Some of these ways of providing support may also be effective at meeting people's learning needs – they can help increase people's knowledge and skills to help them be effective in their role.

National Institute for Health Research Cancer Research Network (NCRN) – support for lay members

The NCRN offers a package of support to lay members of their Clinical Study Groups through the Consumer Liaison Group and Clinical Studies Groups. This package includes coordinating an email group, encouraging peer mentoring between new and existing members and pairing lay members with a scientific mentor. Each method aims to meet different support needs: the email group enables virtual conversations on a wide range of topics with the 100 or so members, the peer mentor offers individual support to new members when bringing patient and public involvement issues to Clinical Study Group meetings, and the scientific mentor helps lay members to navigate through the scientific content of these meetings.

www.invo.org.uk/training-case-study-seven-2

Find out more

about different approaches to providing support:

Case study five: Research User Support Worker – Arthritis Research UK Primary Care Centre www.invo.org.uk/training-case-study-five-2

Case study eight: INVOLVE shared learning groups for public involvement www.invo.org.uk/training-case-study-eight-2

Examples of training and support for public involvement in research: a report from the sharing innovative practice workshop (INVOLVE 2010) www.invo.org.uk/resource-centre/publications-by-involve/

Peer support

Peer support is a valuable way for people to support each other, gain confidence in their role and learn strategies and skills from each other about involvement in research. Many of the examples of support described in this report and in the online resource include an element of peer support, from advisory groups and panels to peer interviewing and support workers.

The key feature of this approach is the exchange of support between people who share a common experience and are on a level with each other. Whether in a group setting or on a one-to-one basis, people are offering each other support on an equal or shared basis. This can be of particular value to people who share experience of a health condition or disability, who can understand each other's circumstances and needs in a way that others without this experience might not.

Peer support can often develop informally and it is possible to encourage people to support each other by creating the right environment or facilitating particular activities. Examples include:

- when holding meetings or events build in time for socialising to encourage informal conversations and sharing experiences
- encouraging members of a group to discuss their own experiences of a particular condition or their training and support needs
- setting up a peer mentoring system between more experienced members of a panel or group and new members just joining
- exchanging contact details, setting up an online forum or email groups.

Peer support: the perspective of a user support worker

Carol Rhodes, Patient and Public Involvement (PPI) Coordinator at the Arthritis Research UK Primary Care Centre, believes that having experience of a musculo-skeletal condition makes a huge difference with the Research User Group she supports. The original group asked to have someone with a musculo-skeletal condition in the role, as they wanted a person who would understand things from their perspective.

“I think it was good that I had no research experience so I could see things from their viewpoint; so when I don't understand what is being said in a meeting then the rest of the group is more likely to admit that they don't. Also I can say that I think we need to stop for a break now as my joints are aching so others must be also.”

www.invo.org.uk/training-case-study-five-2

Peer support: for service user researchers

Rethink Mental Illness has carried out a number of small research projects with service user researchers. One of the features that emerged from early experiences was the need for peer mentoring in the form of support from an experienced service user researcher who was not part of the team. This has now been offered in two projects, most recently an exploration of Recovery for people with a bipolar diagnosis. In this project, the peer mentor was employed for a total of eight days over the course of the project to support the team as and when they wanted. She also attended a few meetings with the group.

The members of the team had different needs and sought support for different issues, including: general debriefing and feedback after interviewing, personal support in a crisis and assistance with analysis. One of the service user researchers described the support offered as ‘invaluable’. She found it useful that the peer mentor had experience both of research and of mental health problems. She valued the opportunity to talk to someone who was outside of the organisation when she had concerns about the research or doubts about her own skills – issues she did not feel able to talk to the researchers about, at least initially.

More information about training for peer interviewers in the Rethink projects is available in case study 16: Training for peer interviewers at Rethink www.invo.org.uk/training-case-study-16-2

Patient and Public Involvement (PPI) exchange – one-to-one peer support for research staff

This approach to peer support was developed by some of the specialist advisors for public involvement in the National Institute for Health Research (NIHR) Research Design Services (RDS). Staff members who lead on public involvement in neighbouring RDS have arranged mutual visits with the aim of sharing experiences of their role and learning from each other. Once specialist advisors have paired up, they plan the visits to each other’s site, arrange to meet with other staff as appropriate and decide on topics for discussion. Reflecting on the experience of an exchange, one specialist advisor noted:

“The value of the PPI exchange was to be able to focus on our PPI practice in greater detail than in the national RDS shared learning group. Face-to-face visits were important in gaining a greater insight into one another’s locations and our intellectual interests. The meeting enabled us to build trust and offer mutual support for some of the challenging aspects of our roles. It was very useful to have pre-planned structure for our discussions – although we did occasionally get excited and wander off topic! The PPI exchange was a good way of gaining support, sharing expertise and developing ideas for future collaborations.”

For more information about the shared learning groups see case study eight: INVOLVE shared learning groups for public involvement www.invo.org.uk/training-case-study-eight-2

Issues to think about before you start – support

Make sure the person providing support has sufficient time and resources to fulfil this role. Ensure that they have the skills and knowledge to either manage different support needs or to refer people to other services.

Be clear about the boundaries to the support you will provide. You could provide this in a written statement so people are clear about the support they can expect.

Be proactive in offering support. It is better to provide more support than is needed and then reduce it, than to not offer any support until a crisis has occurred.

All kinds of people will have the skills and interest to get involved in research. It might seem that involvement won't suit some groups of people, for example those with aphasia, at the end of life, or people whose first language isn't English – but with the right approach, these individuals can make valuable contributions. It is important to match support and the type of involvement to individual needs, so that some of the perceived barriers to involving a wide range of people can be overcome.

Budgeting for support

The costs of support will vary enormously depending on the approach that is used. The key issue is to ensure there is sufficient funding available to cover all the costs, for example time for staff and members of the public, venue / room hire and travel costs for people to attend group meetings.

It's important to build in all the relevant costs for support in any funding bid for a project with public involvement. You need to be clear about which individual is responsible for providing support, how much of their time is being allocated to this role and what resources they will need.

Do not underestimate the time needed to provide support – in a large organisation with lots of involvement activity, it might require a full-time staff member, or in individual projects, frequent meetings with individual members of research teams.

Carrying out a needs assessment for training and support

A needs assessment (sometimes called a needs analysis) is a way to find out what training or support to provide. The aim is to fill any gap between the skills and knowledge people already have and the skills and knowledge they need for their involvement role. Carrying out a needs assessment may be relevant for members of the public and researchers.

There are different ways to carry out a needs assessment for an individual or for a group. It can be as simple as having a one-to-one conversation with someone, or it may involve organising a group meeting or conducting a more formal survey of a large group.

The case studies highlighted in this report and the online resource describe some approaches used for assessing training needs. Identifying support needs is likely to happen in a more informal way, through conversations, as people experience their role. Trying to develop an integrated training and support package is likely to be more effective.

You will need to:

1. Identify what skills, knowledge, experience and support are needed for a particular involvement role – look at the job description where relevant and / or talk to people who have been in that role for some time.

2. Ask people to reflect on the skills, knowledge, experience and support they have that help them to fulfil this role, and aspects of the role they may find challenging – this includes asking people about the activities they carry out, how important they feel these are and how confident they feel in this role.

3. Identify training and support needs – ask people to identify specific areas where they would like to increase their confidence and/or build on their skills or knowledge to help them become more effective.

Informal approach to assessing training needs

The Arthritis Research UK National Primary Care Centre used an annual meeting of their service user group to ask about people's training needs. They designed posters with suggested options for training and space for people to suggest other ideas. People were invited to 'vote', with post-it notes, for their top three choices for training.

www.invo.org.uk/training-case-study-nine-2

It can also be helpful to ask about people's learning styles, for example whether they would prefer in-house training, attending external courses, e-learning, books, or shadowing as a method of learning.

It is likely that a needs assessment will identify more than one training and support need and different preferences as to how this is provided. Making a decision about what training and support to provide and in what format will then require a dialogue between all the stakeholders involved – training managers, budget holders and potential trainees. This can help to prioritise training and support based on the:

- urgency / timeliness of the need
- extent of the need – how many people need training and support
- the resources available and potential sources of training and support.

Training needs assessment of researchers at the University College London Comprehensive Biomedical Research Centre

In one of the Biomedical Research Centres in London, the public and patient involvement manager wanted to find out more about researchers' training needs and what would attract them to training for public involvement, for example topic preferences, time of day, length of sessions and so on. A brief survey was used to ask researchers about their training needs. Every effort was made to ensure the survey was quick and easy. It was available online and also given out at in-house research events, such as research governance training and a symposium for young researchers. The results of the survey are helping to plan a programme of training.

www.invo.org.uk/training-case-study-11-2

When is the best time to carry out a needs assessment?

Although it is helpful to provide some kind of training and support before people take on a new role, for example via an introduction/induction event, until they have spent some time on the job, they may not know what further training or support would be useful. In addition, people's involvement roles may develop over time extending into new areas of responsibility. Therefore carrying out a needs assessment is not a one-off event. It is best carried out after people have had time to learn about their role, and then repeated regularly in parallel with the individual's (or group's) personal development.

It is important to be realistic about training and support opportunities and not to raise expectations too high. If you ask about people's needs, then you need to be prepared to respond relatively quickly. For example, if people are asked about training and then don't receive any, they can get disenchanted. Think about the availability of funding and possible sources of suitable training and support when carrying out an assessment – you may need to limit what you ask about/offer.

Find out more

about needs assessments:

Case study nine: Informal approach to assessing training needs www.invo.org.uk/training-case-study-nine-2

Case study ten: Assessing training needs for patient advocates involved with the Diabetes Research Network www.invo.org.uk/training-case-study-ten-2

Case study 11: Training needs assessment of researchers at the National Institute for Health Research (NIHR) University College London Hospitals Biomedical Research Centre www.invo.org.uk/training-case-study-11-2

Mental health researchers' Toolkit for involving service users in the research process: sample training needs analysis form www.mhrn.info/pages/mental-health-researchers-toolkit-for-involving-service-users-in-the-research-process.html



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