

INVOLVE

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

Training for Public Involvement in Research: Seminar Report 22nd April 2004

89, Albert Embankment, London



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1. Introduction

The Seminar

The seminar, held on 22nd April 2004 in London, was organised by INVOLVE. INVOLVE have an interest in training as a method of promoting good practice in public involvement in research.

What are
INVOLVE?
See Appendix 6,
page 39

In 2001, INVOLVE commissioned a research project to look into training for involvement in research. This became known as the TRUE project, a research collaboration of people from academic, service user, and NHS backgrounds. The findings were presented as part of this seminar.

What is the
TRUE Project?
See Appendix 1,
page 23

The seminar involved a high level of delegate participation, and this document reports on the discussions and recommendations made. It also analyses some of the issues in order to help condense and clarify the key messages.

This Report

For ease of use, we have used the following format for the report:

- The report starts with a summary of the key points from the seminar.
- It goes on to give some background about why the seminar was organised and who organised it, then reports on the seminar itself.
- It concludes with a discussion about the issues raised to help place them in a context of actual practice.
- In Appendices 1 to 5 you will find a good deal of useful background information, as well as references to further reading material.

We have started the report with a brief summary so that the key issues can be picked up quickly. However, we recommend in-depth reading of the report in order to develop a thorough understanding of the context in which the issues have arisen, and the further development needed to address them.

2. Summary of points from the seminar report

The following key issues have been extracted from the discussions that were held at the seminar:

The training and learning process

1. 'Training' is probably too limiting a word to use to describe all the situations in which learning takes place for involvement in research. The word 'training' tends to imply a formal one-way flow of information with an associated one-way power relationship.
2. Training for public involvement in research should not just be for people who use services. It is equally applicable to professional staff, commissioners, funders, and researchers.
3. Two-way learning, shared learning and co-learning elements should be included in training and learning packages wherever possible. This can be used to promote power and expertise sharing in public/professional involvement partnerships.
4. People in training and facilitation roles need to have skills in delivering training and facilitation, as well as knowledge and experience of the subject area being learned.
5. The guidelines produced by the TRUE project are a good starting point for the development of training quality standards.

Building training capacity for involvement in research

6. There is a need to explore how training in partnership with service users can be developed and resourced. It may be possible to collaborate with a range of organisations concerned with public involvement to pool resources for some aspects of training.
7. Further research-specific elements of training could be commissioned and delivered more locally.
8. A sort of 'dating agency' linking those wanting training with providers of training and learning packages is likely to help encourage more training activity for involvement in research.

Continued....

Specific issues for INVOLVE

9. There is a potential role for INVOLVE in further encouraging the development of quality training for public involvement in research. A training network database is likely to be a useful way to help catalyse this.¹
10. There is also a role for INVOLVE in encouraging researchers applying for funding to include training within their project budgets, and to encourage funders and commissioners to recognise this as added value.
11. INVOLVE could also network with other organisations concerned with public involvement in health and social care in general, to explore resource pooling for training.
12. Whereas INVOLVE can be a catalyst, advisor, networker and supporter for quality training, it is not a training provider.

Once again we recommend that this report is read in full for a complete understanding of these points.

¹ At the time of writing INVOLVE have started work on developing a web based database, and it is hoped that this will be fully operational by the end of 2004.

3. Why is INVOLVE interested in training?

In 2000, the Empowerment sub-group of Consumers in NHS Research (now INVOLVE) identified that training was likely to be a key element in enabling patients, service users, and lay people to become actively involved in research. Whereas in the earlier days researchers would often draw on 'lay' people who already had some knowledge of research, this was not a sustainable situation if public involvement in research was to become a wider, and meaningful concern. Capacity building was a key issue.

The Group was aware of some training taking place, such as part of the Alzheimer's Society 'Quality Research in Dementia' programme, and the significance of the Critical Appraisal Skills Programme (CASP) to non researchers was already realised. However, a request placed in the Consumers in NHS Research newsletter asking people involved in training to let us know what they were doing brought just a few responses. The picture seemed to be that training in this area was:

- very patchy
- often associated with a specific project or programme
- short term, and
- locally based.

INVOLVE were clear that their remit was not to provide training since the Group was set up principally as an advisory body. However, a systematic approach to the issue of training for capacity building needed to be developed. INVOLVE needed to find out what training was taking place nationally, and what kind of training was most effective for involvement in research.

In 2002, after a call for proposals, INVOLVE commissioned a collaboration from Worthing and Southlands Hospitals NHS Trust, the University of Brighton, and CAPITAL Training (a user led organisation). This collaboration was to become known as the 'TRUE Project' (see Appendix 1) and was asked to:

- undertake a scoping study of the training for involvement in research already taking place
- identify what in training was effective, and
- produce some good practice guidelines for this sort of training.

In the two years it took to reach this point, the field of public involvement in research had developed and expanded, partly due to dissemination of knowledge of involvement practice, and partly due to the implementation of the Research Governance Framework for Health 2001, which included public involvement in research.

What is the Research Governance Framework?

This document published by the Department of Health in 2001 sets out a regulatory framework for research practice in the NHS and social care.

With more compulsion to involve the public in research, there was the increased danger that researchers who did not understand or agree with the principles behind involvement would only do the absolute minimum in order to comply. This in turn would lead to the disillusionment and cynicism of members of the public who were keen to be involved but felt disempowered. The importance of relevant, empowering training was therefore more important than ever.

The TRUE Project, which completed its work in Autumn 2003, has picked up on these very issues and much more in its report. The project has provided:

- a 'snapshot' at one point in time of training being undertaken nationally
- a study of six 'case sites' in order to help identify what approaches to training are effective, and
- a set of good practice guidelines for training to be used by training providers, training commissioners, and people seeking training.

How do I get hold of the TRUE Report?
See Appendix 1, page 23.

It is recognised, however, that public involvement in research - and the associated training issues - are part of a constantly evolving field of dialogue, awareness, and practice. As part of taking the training theme forward, INVOLVE organised the seminar on Training for Involvement in Research on 22nd April 2004.

4. What was the purpose of the seminar?

The seminar had three main aims:

- to act as a launch event for the TRUE report, encompassing a presentation by members of the TRUE team.
- to provide an opportunity for some 60 delegates from a wide range of backgrounds from across the country to discuss some of the key issues raised by the TRUE report, and make recommendations for action.
- to encourage networking and the exchange of ideas between delegates.

Who came to the seminar?
See Appendix 5, page 37.

5. Who organised the seminar?

The seminar was funded, organised and facilitated by INVOLVE and held at 89, Albert Embankment, London.

The seminar was chaired by Derek Stewart, a member of INVOLVE, the National Cancer Research Institute Consumer Liaison Group, and a freelance trainer.

The discussion group facilitators were Sarah Buckland and Helen Hayes of the INVOLVE Support Unit, and Mary Nettle, Kate Sainsbury and Deborah Tallis who are INVOLVE Group members and were part of the planning team.

From the Support Unit, Barbara Dawkins organised the practical aspects of the day and provided administration support on site. Achara Western assisted with administration leading up to the event. The planning and the event itself was co-ordinated by Roger Steel from the INVOLVE Support Unit.

What is INVOLVE? See Appendix 6 on page 39.

6. The 'TRUE Project' Presentation

Derek Stewart welcomed delegates and introduced the seminar. He then introduced Rachael Lockey (University of Brighton) and Sherée Parfoot (CAPITAL Training) who were part of the TRUE project team.

They began with a short role play, based on Laurel and Hardy, to illustrate issues and attitudes to do with the involvement of service users in services and research, and how these have a bearing on the training agenda.

Rachel and Sherée went on to describe what the TRUE project aimed to achieve, and who was involved in the research collaboration and project team. They then reported the conclusions from six 'case sites' – training events/programmes which were studied in detail. They also talked through the guidelines that the TRUE project produced as part of its brief.

For a summary of the findings of the TRUE project, see Appendix 1, page 23.

For the TRUE guidelines, see Appendix 2, page 28.

Following the TRUE presentation there was a short time available for questions and discussion. Comments and questions raised included the following:

- One of the collaborating organisations was CAPITAL Training, a mental health service user organisation involved in training. Members who had been involved in the TRUE Project had made tremendous steps forward in their ability to make contributions elsewhere because they had become more confident and assertive. It should be recognised that personal development can be a major benefit of involvement in research projects.
- There was a question about funding for training. The TRUE Project was not specifically asked to identify funding sources but has described in almost all cases how different training initiatives were funded. In the discussion it was suggested that the NHSU was a potential funder of training, amongst others.
- One participant said that the research training in which he had been involved had had no difficulty attracting funding because it had a clear purpose relating to the research project. He said that training was important to develop the initial confidence to be involved.
- The TRUE team were congratulated on an impressive, detailed piece of work. Were there any plans for a long-term evaluation of training? The TRUE Project is more of a 'snapshot' of a point in time giving information about the quality and quantity of training available at the moment. There were no plans to evaluate training in general in the longer term.

What is the NHSU?
 The NHSU is the new National Health Service 'University'
www.nhsu.nhs.uk

Following the TRUE presentation and discussion, seminar delegates broke into smaller and more specific discussion groups.

7. The small group discussions

There were four different parallel discussion groups in the morning and these were repeated in the afternoon so that individuals could attend two different discussions in the day. The following areas were discussed:

1. Good practice guidelines for training: A standard to sign up to?
2. Bridging the training need/provision gap nationally: How to match those requiring training with good training provision?
3. Who is training whom? Power, equity and quality issues in training and involvement practice.
4. What sort of training for involvement in research is needed?

Each group was facilitated by a member of INVOLVE or the Support Unit staff, and following the discussion, participants were asked to write key points and ideas on 'post its' and put them on flip-chart paper provided as a record and for reflection. Towards the end of the discussion time, each group was asked to come up with some key recommendations.

The quotations in this report were all taken from the small group discussions.

The discussions were wide ranging and there was a good deal of overlap in the areas explored by different groups. The points raised addressed not just the immediate issue of training, but the whole context in which training might be used, and the involvement of people who use services in research. It was as if discussing the issue of training was a 'catalyst' giving rise to valuable deliberations as to the nature of the relationship between the research world and that of people who used services. An issue that came up repeatedly in the discussions was that of the power implications in the training process.

The following sections report on the discussions for each of the four seminar questions, and lists the recommendations arising from each group in a text box like the one below.

During the final session, seminar participants had the opportunity to see all the recommendations displayed on flip chart paper, and to indicate their views of each. This was done by 'voting' using three different coloured sticky dots applied directly to the written recommendation from each discussion group. In this report, the following symbols are used to represent the votes on each recommendation:

- 😊 means 'definitely like it',
- 😐 means 'maybe',
- 😞 means 'don't like it'.

In some cases recommendations were not voted on at all. This may have been because their meaning was not clear.

7.1 Good Practice guidelines for training: A standard to sign up to?

There were a variety of responses to the guidelines produced by the TRUE Project, but it was generally agreed that, overall, they were very useful. The discussion was mostly concerned with how they might be applied. Some thought that they should be signed up to as an absolute minimum, others that they needed to be developed further. Somewhere in between these views was the idea that they should be used for guidance and not used as a quality

What are the TRUE 'good practice' guidelines? See Appendix 2, page 28.

7.2 Bridging the training need/provision gap nationally: How to match those requiring training with good training provision?

This was a very useful discussion which produced clear recommendations. There was just one session on this discussion topic due to low delegate take up, but the recommendations were well supported by the seminar as a whole.

The group identified that capacity building was not just about having the right information about who needs and who provides training, but was also about attitudes and resourcing training.

Comments included the following:

'Please can we have a 'dating agency' - matching people who want to access training with (currently limited) training provision?'

'Register of training and people who have been trained.'

'Funding streams that fund training and after training activities is a good thing.'

'How to get professionals on board? How to get them supportive or even to believe in consumer involvement? Training for them?'

'Tendering systems can result in rigid concepts of 'training.'"

'The training envisaged takes time and money; from a research commissioner's position, the pressure is to process proposals quickly and at a low cost. The two do not sit comfortably together.'

'Collaboration of INVOLVE, NHSU, Patient Safety Agency and the Commission for Patient and Public Involvement.'

'Topic diversity for our organisation makes it difficult to build up a 'reusable' pool of trained service user peer reviewers.'

'NHSU is a potential national scheme for co-ordinated training and funding.'

'Performance management will encourage uptake of training.'

What is the NHSU? –
NHSU is the new
National Health Service
'University'
www.nhsu.nhs.uk

Recommendations:

- Explore with NHS University and other organisations, e.g. Commission for Patient and Public Involvement in Health, how training at different levels can be developed and resourced in partnership with service users and trainers.



- 'Dating agency' for health and social care to provide information on where training and funding is available. Needs to be in accessible formats and easy to find the information, with potential to develop into further networking.



7.3 Who is training whom? Power, equity and quality issues in training and involvement practice.

These discussions tended to emphasise that learning for involvement in research needs to be a two way process in order to:

- Help bridge the 'culture' gap between the research community and people who use services and the public.
- Enable involvement in research to happen in ways which are effective and meaningful for all concerned.
- Help moderate power imbalances by recognising that everyone has knowledge and experience that is useful to others, and everyone has something to learn.
- Provide a foundation for better, more relevant research, more likely to lead to improvements which are helpful to people who use services.

Comments included the following:

'Whatever the question we ask re training - the conversation always returns to the issue of the power balance and the need for culture change!'

'Learning is two way. A professional said 'I have learnt so much from the service users I was training. We have learnt from each other.' Service users are influencing the Trust. Our Trust got 3 three stars!'

'Definitions of training - danger of it being too limited.'

'Can we think about less formal ideas of what is training?'

'Stop seeing training as a one-off - see it as part of development.'

'Training (could be) seen as wider than 'one-off' sessions. i.e. there is a need for ongoing support, training and development throughout a project.'

'Training may enable public representatives to be more effective - not just tokens.'

'Recognise 'training' as 'learning.' Service users, professionals and researchers are all learning and should learn together.'

Everyone needs training for involvement in research:

'Health professionals need training to involve service users.'

'Training is needed for service users and it is also needed for practitioners and researchers to enable them to work effectively with service users - i.e. in a collaborative partnership. Perhaps a way of thinking about training is as a method of enabling stakeholders to be active participants in research.'

'Training is not just needed for service users - training is also needed for researchers. Training for an attitudinal shift is needed.'

'Train researchers in writing for a lay audience.'

'Need training for commissioners in how to find people and support them.'

Choice seems to be an important issue:

'Training is exceptionally beneficial to both academics and service users, but should not be enforced.'

'Are the models of service user involvement in research important? E.g. can panels be useful, where members help each other, allow

people to support each other, drop in and opt out of the panel if they want to...'

Flexibility was also identified as important:

'Safe space - workshops without health professionals present as an introduction. Then more specialist workshops including professionals.'

'Different levels of training for public involvement in research to ensure people are not intimidated by the need for qualifications.'

'Multi layered training - e.g.

- Information
- Roles of volunteers
- Specific research process - different stages
- NVQ'

'More 'on the job' practical experience would be more beneficial and easier to get to grips with than all classroom tuition.'

'Break down barriers - mixed training for different service users.'

'Shadowing researchers.'

'Different levels of training - some people want certificates, others not.'

'Training depends on which kind of research you're involved in...'

- **Technical knowledge and skills** e.g. peer reviewing, questionnaire design, data presentation and analysis, planning, writing lay summaries, etc.
- **Knowledge of research systems** e.g. applying for funding, research methodology, ethical review, routes for dissemination, etc.
- **Interpersonal and collaborative working skills** e.g. communicating and listening with respect, interviewing, disability awareness, inclusive meetings, involving people equitably, etc.
- **Knowledge and awareness of working context** e.g. voluntary and statutory sectors, organisational structures, identifying service users, resources, etc.

These skills and knowledge areas become increasingly critical the more closely the public are involved in research. For example, in very technical areas of research, such as statistical methods of analysing data, there are quite specialised skills to be learnt if the public are to participate fully at that stage (assuming they do not already have a mathematical background).

However, people may choose to be involved in a more generic way. For example, commenting on the causes or implications of research data from the point of view of someone who uses the technologies or services concerned, having had the data interpreted.

8.2 Choice

All this has implications for choices about how involved members of the public and people who use services want to be, and what research professionals and the public expect from one another in terms of involvement. These choices need to be articulated and negotiated from all sides.

Choice about how involved the public want to be, or can be in research, depends in part on the training resources being available. Likewise, the extent to which research professionals intend to involve the public has implications for training and support budgets, as well as their own and their organisations' training/learning needs.

8.3 Types of learning

A wide range of learning approaches were cited in the seminar, and some people thought that 'training' was too limited a concept to cover all types of learning that applied to involvement in research. This was also an issue highlighted by the TRUE project.

Each method and area of learning has different implications in respect of the skills, experience and knowledge of those who are facilitating learning, whether they call themselves trainers or not. One seminar participant said:

'Provision is not just about courses, facts. It's also raising awareness, supporting individuals/interpersonal development through a range of means: mentoring, learning sets, etc.'

It might be helpful to list different types of learning situation mentioned during the seminar:

- Informal
- Formal
- 'On the job'
- Mentoring
- Shared learning or co-learning
- Learning from experts
- Distance learning
- Traditional classroom learning

These types of learning situation are explained in Appendix 3, page 34.

There are some shared aspects across the learning situations in this list. For example, mentoring can be formal or informal, 'on' or 'off' the job. However, the list still serves to illustrate the range of different learning situations.

8.4 Learning and support 'packages'

One type of learning does not suit all situations and all learners, nor on its own is it likely to span the range of skills, knowledge, experience and support needed for realistic involvement in research. A training or learning 'package' approach is likely to be better than opting for a single training method because it allows for continuity and choice. The importance of 'training needs assessment' was cited during one discussion - a precursor, perhaps to package design. However, negotiation amongst all stakeholders as to what training was needed by whom, and how it would be delivered, was also an important message from both the seminar and the TRUE project findings.

Comments included the following:

'Representative organisations should be involved in specification and content (development).'

'We do need different formats of training.'

'Training depends on which part of research you are involved in.'

'There has to be a "step-on/step off", "pic 'n mix" nature to training.'

'Look at the Public Health Networks model - action learning sets and networks/webgroups.'

'Computer based access to training. Gateway to research. Would service users really want that?'

'The assumption seems to be that training must be face to face - should it? All the time and in all circumstances?'

'On the job - best training. But need foundation course in basics as well.'

8.5 Power and ethics

Some participants linked the term 'training' with assumptions about the power relationship between trainer and trained. There was a strong message that learning can take place in several directions, with people with different experience and expertise learning from each other. We should not assume that it was just service users who needed training.

Ethics in training and learning was clearly important to most participants at the seminar. It was thought that the TRUE guidelines should be promoted as a good practice baseline guide, although they should not be used too rigidly. Participants thought that training and learning should be part of a continuum of involvement and not just a single event at a point in time. Having the right support at the right time to enable learning to take place was also thought to be very important. Learning on the job can be stressful, for example, so support systems need to be in place.

The guidelines produced by the TRUE project are reproduced in Appendix 2, page 28.

From the discussions at the seminar, it seems that good training and learning for involvement in research might be described as an interaction where knowledge is exchanged and generated between people of differing backgrounds, experience and/or expertise, in a way that is safe, supportive and neutral.

9. Where to next?

It was recognised that many aspects of involvement in research were also true of more general involvement. Whereas public involvement organisations could be doing collaborative work to establish generic training and learning as a core resource, specific aspects of learning for involvement unique to

research need to be developed separately. Some people thought that training programmes should be allowed to develop independently, but with some national co-ordination. Comments included the following:

'Generic training should be provided by the NHSU, then more detailed training provided later.'

'INVOLVE need to push the agenda for collaboration with other (public involvement) agencies.'

'National training with access for all service users for all levels of training? Answer: National Patient Safety Agency - 'User training and facilitation for involvement' - training that will go national.'

In terms of resources, it was definitely thought that organisations such as INVOLVE, NHSU, the Commission for Patient and Public Involvement (CPPI) and the Social Care Institute for Excellence (SCIE) might work together on establishing networks and resources for user involvement training.

A strongly supported recommendation was that a 'dating agency' to match those requiring training with training providers as well as funders was needed. Some of the feedback from the seminar was that more opportunities for face to face networking would be helpful. These are ideas that INVOLVE may be able to take forward.

One participant said:

'I tried to access training for 2 years. I was learning 'on the job' but wanted some formal training too!'

It seems that INVOLVE could have a role continuing to encourage more needs and value based training/learning for involvement in research. A training network database would be a helpful way forward to this end. As part of this, INVOLVE could also identify a value baseline for training by offering guidance on good practice, and the TRUE Project guidelines will be a good starting point for this.

Funding for training and support is an important area to look at. INVOLVE could have a role to encourage researchers to budget for training when applying for funding for their projects. INVOLVE could also help identify other sources of funding for training.

Whereas INVOLVE can be a catalyst, advisor, networker and supporter for quality training, it is not a provider, or training resource. A training network has to be alive and active and that depends on the activity and contribution of the network components.

There is much that training providers might do in being pro-active and imaginative about identifying gaps in the 'market' to which they might be responsive. Trainers may need to be imaginative about how they deliver training whilst training commissioners need to think in terms of learning and support packages as an integrated part of project activity.

Often individuals and organisations do not exactly know what they need until the options are presented to them. However, there should also be opportunities to negotiate package delivery and content. We hope this seminar report gives some useful pointers to such needs in terms of skills, knowledge and values for involvement in research.

- Roger Steel
INVOLVE
October 2004

Thanks to all those who attended the seminar (listed in Appendix 5) for contributing to the 'pool of information' that forms the basis of this report.

Special thanks to Sarah Buckland and Helen Hayes from the INVOLVE Support Unit for their editorial assistance.



This is the end of the main part of the report. What follows are some appendices where you will find useful supporting information.

Appendix 1:

Summary of TRUE project presentation and findings

Service user researchers on the project:

- Saleh Ahmed
- Clive Bennett
- Tina Gillingham
- Sheree Parfoot
- Jan Millyard
- Julie Sigrist
- Geoff Sigrist

Project coordinator: Rachael Lockey

Project supervisors:

- John Sitzia – Worthing Hospital Research Department
- Anne Beales – CAPITAL Project
- Carolyn Miller – University of Brighton

The team

- carried out 35 telephone interviews; of these 26 were 'active' training providers in 2003 and contributed to the results.
- visited 6 training examples – interviewing participants, trainers, commissioners and observing training taking place.

Main points from findings:

- ❖ Training for service user involvement in research was not readily available. Only a handful of organisations provided open access training on a regular basis. Training was diverse in style and content, and often was developed for a particular service user group or project.
- ❖ Training was perceived as being most useful when it had a clear aim and purpose, and was centred around specific research tasks and real research problems that drew upon the participants' experiences.
- ❖ Participants wanted to be involved in creating and developing ideas in which they could become absorbed and take some ownership. Service users wanted their input to be creative and not just reacting to others'

ideas, and wanted to be involved in both training and research from the start.

- ❖ A key aspect of successful training was exchange and sharing between people, both trainers and participants. This was mutually supportive, sometimes using ice-breaking exercises, small group work and role-play.
- ❖ Training helped affirm the strength and value of service users' experiences and understanding of health conditions and services.
- ❖ Confidence to contribute developed in a 'safe' environment. This is one where others show that they value what a participant is saying and that if they wish to challenge it, then that is done in a constructive and helpful way.
- ❖ Considerable time and space was needed to allow all participants to make a full contribution. Project timescales and funding should reflect this.
- ❖ Training had enormous value to participants' personal development and confidence. Almost without exception, training led to actual involvement in research and a desire to do more.
- ❖ Language was a significant challenge for those providing training. Effective training 'demystifies' research, providing a base from which stakeholders can understand one another's language and purpose.
- ❖ Payment was a sensitive issue. Although training commonly was seen as a mutual 'exchange' of skills and knowledge, typically participants were not paid for attending training, whilst trainers and employed researchers were paid.

The TRUE Project identified 6 training events/programmes to study in detail, these were known as 'case sites'.

The case sites:

Multiple Sclerosis Society

- Participants particularly enjoyed small group work. Having the small groups re-arranged after a break was well evaluated as it provided the opportunity to meet lots of people.
- Time was given to 'setting the scene' where participants expressed their views, wishes and concerns for the day.
- It was emphasised that people should feel free to ask questions, with the ethos that 'no question is a silly question.'

- Participants we interviewed all stated that the training boosted their confidence.

Norah Fry Research Centre

- Facilitation and support were an ongoing process during and beyond the life of a research project.
- Informal on the job training and collaboration worked best.
- Getting people with the label of learning difficulties involved from the beginning can help to ensure correct language, style and pace is set.
- The research process can raise awareness amongst researchers/service users about labels and discrimination they may experience.

Listening for Change - A youth project

- All participants we spoke with clearly stated that they had benefited from the training, developing research skills as well as useful life skills.
- The young people liked a flexible, informal training approach and to be involved in deciding the structure and content of the day.
- Fun, social activities were included in the training timetable and the young researchers highly recommended this.

Consumers as Researchers

- The commissioners and trainers adopted a non-directive approach, giving a broad theme for the research, which participants could develop.
- The style of the trainers was to get things going and then take a bit of a 'back seat' – participants liked this.
- The group was very diverse and people felt this was a benefit as they learnt about other people's disabilities and it informed the research.

The Leeds Survivor-Led crisis service

- Support is an important element that can lead to motivation and successful involvement, and in turn promotes good research outcomes.
- Treating everyone in a project as equal is important and preferable to a 'top down' approach to training.
- An informal and relaxed training style worked well.
- A good trainer will train you without you even knowing it!

Older People Researching Social Issues (OPRSI)

- Exposure to a variety of researchers/trainers was seen to be beneficial, as people could see different approaches to research.
- Everyone is a on a learning curve - trainers and participants.
- The impact of involvement for individuals – both service users, researchers and trainers – can be great and sometimes life changing.
- Training activities should be directly related to research activities to be undertaken.
- Service user researchers should be involved in developing research tools – questionnaires, interview schedules, etc. – as this makes them easier to use in practice.
- Researchers/trainers should allocate some time after the course/research has ended to assist with continuity and further research developments.

The TRUE Project was itself an example of service user involvement in research. Training was provided throughout the project – both in research and mental health, in the form of both designated study days and ‘on the job’.

There are two reports relating to the TRUE project and a 4 page project summary:

1. The TRUE research report (and summary):

Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. (2004) **‘Training for service user involvement in health and social care research: a study of training provision and participants’ experiences. (The TRUE Project)**, Worthing and Southlands Hospitals NHS Trust

2. A further report looks at the collaborative process and experiences of members of the TRUE team:

Faulkner, A. (2004) **Capturing the experiences of those involved in the TRUE Project: a story of colliding worlds.** INVOLVE

Both reports and summary can be downloaded from the INVOLVE website www.invo.org.uk or are available in hard copy from INVOLVE, Wessex House, Upper Market Street, Eastleigh, SO50 9FD.
Telephone: 023 8065 1088. Email: admin@invo.org.uk

Appendix 2

The TRUE Guidelines

These guidelines have been developed from the research findings of the TRUE project, in particular from interviews and focus groups with a diverse range of service user researchers.

The main guidelines are intended primarily for people who plan to provide training to service user researchers and we use the word 'you' to mean 'the trainer'. However the guidelines will also be of use to:

- Commissioners of training/research
- Researchers
- Service users involved in planning of training
- Participants in training

The following is a brief summary of key points for commissioners and service users followed by the full guidelines.

Key points for Commissioners of Training

Commissioners of training may also be commissioning the research project to which the training is related. They may also be service users themselves. Key points that need to be at the forefront of any commissioning of training for research involvement are:

- Are the trainers able to demonstrate knowledge and understanding of service user involvement?
- If you are commissioning external trainers, have you ensured that they are able to provide suitable training? This may include considerable dialogue and working together during planning stages, along with service users.
- Are you confident that the trainers and yourselves will be able to provide adequate support both during and after training? This may include practical, emotional and research support.
- Training for service user participants can have considerable costs involved. Is the training budget realistic, including possible transport, accommodation and payment of service users costs?
- Make sure that the training is closely related and applicable to research roles/activities that participants will be involved in.
- If you are paying participants directly have you made sure you will be able to make prompt and adequate payments?

Key points for Participants

Participants or representatives of participants should be involved in planning of any training. At case sites where this was the case participants needs were well catered for. The following are some key issues for service users involved in planning training:

- What experience do the trainers have of service user involvement? Are they willing to access training for themselves on involvement issues if necessary?
- Are the trainers able to demonstrate a sound knowledge of the issues and practicalities of undertaking training for service user participants?
- Do the trainers want to work with participants or representatives of participants in order to ensure training is planned to suit participants' needs?
- Have arrangements regarding payment, transport and any other costs been made clear?
- Do the trainers, if external, fully understand the purpose of the training and what roles/activities it will be applied to?
- Make sure everyone is clear about what follow up support/training the trainers will be able to offer – or not.

The Main Guidelines

The guidelines are divided into three parts:

- Part A – BEFORE training
- Part B – DURING training
- Part C – AFTER training

They are presented in the form of a checklist that is intended to be immediately useful in practice. The checklist presents specific points for consideration, however they should be seen in the context of building a responsive and enjoyable training experience. Give to and gain from the process and make sure that participants do too! Experience shows that 'successful' involvement in research means not only achieving the research outcomes and the development of research skills but also the opportunity to develop confidence, social inclusion and life skills. Your training should aim not only to prepare people for research but also to provide a positive contribution towards these broader personal gains.

Part A : Before training

This part is by far the largest in these guidelines. This reflects the need to give very thorough consideration, time and planning prior to providing training (and involving people in research). In particular, by drawing on the experience of others, the training can be enhanced for all participants and possible problems and barriers may be avoided.

Preparation of trainers

- Are you able to demonstrate competence, knowledge and understanding of service user involvement generally?
- Do you have sufficient knowledge of the service user group your training is aimed at?
- Do you have knowledge and understanding of the service user movement?

Preparation for training

- Have you worked with relevant service users and/or service user groups to plan the content, style and delivery of the training?
- Have you budgeted for extra costs that may be involved including transport, overnight accommodation, and payment that service users might require?
- Have you considered which learning environment will be most suitable, e.g. classroom, workplace, home based or combination?
- Have you considered what the most appropriate training methods are, e.g. role play, practice examples, factual information, learning on the job or a combination?
- Have you planned to include informal learning opportunities, where people can share experiences, build confidence, learn from each other and have fun?
- Does the training relate to a planned role/activity that will be accessible to participants following training?
- Have you ensured that the language to be used is clear and free of jargon?
- If using external trainers have you ensured they are able to provide suitable training?
- Have you made information available to participants in advance about:
 - Aims and objectives of the research?

- Aims and objectives of the training, including learning outcomes?
- Personal time commitment required to participate in the training and research?

Time

- Does the proposed time and place of training suit the participants?
- Does your proposed timetable allow enough time for a flexible and responsive training approach?
- Does your timetable allow participants to have time and space to input into the structure and content of the training?

Venue

- Have you ensured the venue is accessible to all participants? (A site visit is advisable)
- Have you provided participants with a map and directions for getting to and around the venue?
- Have you arranged transport and overnight accommodation if needed?
- Does the venue allow for an informal and relaxed learning environment including:
 - Comfortable seating
 - Good lighting
 - Suitable room temperature
 - Adequate space

Participants' needs

- Have you ensured that people's personal needs will be met including:
 - Refreshments
 - Dietary needs
 - Parking arrangements and proximity to public transport
 - Adequate washroom facilities
 - Comfort breaks
- Have you ensured that communication will be possible for all participants, including interpreters if required?
- Have you ensured there will be adequate support during training? (Extra people might be required to give practical assistance and for small group work facilitation).

- Have you made plans for prompt and adequate payments to participants, including expenses?
- If project-based training, have you planned for providing support, facilitation and further training during the research involvement period, e.g. mentoring?
- Does your timetable take into consideration participants' commitments, such as schooling, religion and health?
- How will you acknowledge participants' involvement and learning? In some cases accreditation might be appropriate or a certificate of their attendance.

Evaluation

- How will you obtain participants' feedback immediately following training?
- How will you evaluate the longer-term benefits of the training, both in terms of participants' involvement in research and personal benefits such as increased confidence?

Part B : During training

- How will you ensure that people feel welcome?
- Have you communicated clear aims and objectives so that the participants know what they have come for and what the goals are?
- How will you ensure that service users participating in the training will be treated as equal partners and their expertise valued and used?
- How will you involve participants in 'setting the scene' for the training so that people can express views, wishes and concerns including establishing group agreements?
- How will you find out at the beginning how people view themselves and how they like to be referred to?
- How will you make sure everyone's contribution is recognised and acknowledged?
- How will you identify and address individual learning needs, e.g. literacy, numeracy or use of computers?
- Have you made it clear to participants that they should ask if clarification is needed and that no question is a silly question?

Part C: After Training

Evaluation

- Have you ensured you have collected feedback from participants both immediately following training and at a later date?

Continuity, support and further training

- Have you thanked people for their willingness to take part in the training and their contribution to it?
- Have you celebrated the success of participants' learning achievement, through, for example, the presentation of certificates or a social event?
- Have you allowed time after the training/research has ended to assist with further research developments?
- Have you considered how you will provide some continuity for people, so that the contact does not end abruptly when the training or project ends?
- Have you explored with participants their further training needs and wishes?
- If you are planning more training, have you used participants' feedback to inform it?
- Have you reflected on your own role in providing training? What have you learnt? And what you would do differently next time?

Appendix 3

Types of learning situation

- **Informal:** Learning in an unstructured way, by doing, listening, asking questions, and possibly informal reading, for example. Tends to automatically occur when learner is actively engaged with people who already have experience knowledge and/or skills in the area in question. Could be done by anybody as an interaction where information and knowledge is given and received or experience gained.
- **Formal:** Planned and structured learning through one or several learning media. Could be classroom, textbook and 'on the job' learning. Could be done by someone who explicitly has knowledge and communicates this in a planned, organised way. This person will need the skills of effective communication as well as knowledge.
- **'On the job':** Learning by doing the task in hand, and finding out as the learner goes along. Learning by doing can be self-directed. It may also be supported by an instructor or mentor who already has experience and/or knowledge in that area.
- **Mentoring:** The learner has someone to whom they can go to talk through the challenges of the task, receiving support, encouragement, knowledge and guidance according to the learner's need at the time. Mentoring can be formal or informal, and 'on', or 'off the job' A mentor needs the awareness to appreciate and work with the learning path, style, and pace of the person mentored rather than imposing this. They also need experience/knowledge/skills in the area of learning.
- **Shared learning or co-learning:** People with different backgrounds, knowledge, experience and skills learn from each other on an agreed area of learning in an equitable environment. This could be a workshop or seminar. There is usually an independent facilitator who helps the process along in a semi-structured way. A facilitator needs well-developed group facilitation skills in order to provide a comfortable, 'safe' and equitable learning environment. The facilitator does not necessarily need specific knowledge and experience except in facilitating itself, although some experience in the general learning area may be helpful.
- **Learning from experts:** Specific knowledge is sought by the learner through enquiry. This can be part of structured or unstructured learning. Usually one-way learning, it can be done in all the other learning situations described. Someone with specific experience and/or knowledge is able to communicate their area of expertise to others who need it. This can happen in a variety of contexts, including through text books and papers.

- **Distance learning:** Typically, learning through a variety of media such as video, audio tape, text, illustration, internet. Learning media designed by people who understand both the issues and how to communicate ideas clearly and accessibly.
- **Traditional classroom learning:** Traditionally, knowledge provided by someone flows in one direction and is formalised for general consumption by a wide range of people. Collective rather than individualised learning.

Appendix 4

Seminar Programme

10.00 Registration, Tea/Coffee

10.30 Introduction and housekeeping by Derek Stewart, Chair

10.40 TRUE findings and guidelines presentation
Followed by questions and discussion

11.40 Tea/Coffee

11.50 Morning parallel discussion groups

1. Good practice guidelines for training: A standard to sign up to?
2. Bridging the training need/provision gap nationally: How to match those requiring training with good training provision?
3. Who is training whom? Power, equity and quality issues in training and involvement practice.
4. What sort of training for involvement in research is needed?

12.50 BUFFET LUNCH

Informal networking and 'Market place' – display tables for trainers, funding organisations etc.

2.10 Afternoon parallel discussion groups

1. Good practice guidelines for training: A standard to sign up to?
2. Bridging the training need/provision gap nationally: How to match those requiring training with good training provision?
3. Who is training whom? Power, equity and quality issues in training and involvement practice.
4. What sort of training for involvement in research is needed?

3.10 Tea/Coffee

3.20 Plenary session

4.00 Seminar ends.

Appendix 5

List of seminar delegates

Delegate	Organisation
Alice Hicks	RCN Institute
Angela Barnard	Peninsula Medical School
Angie Hart	University Of Brighton
Anne-Laure Donskoy	Service Users Research Forum, Avon and Wiltshire
Barbara Crosland	NZMHE West Midlands
Barbara Dawkins	INVOLVE Support Unit
Bec Hanley	Co-Director, TwoCan Associates
Brian Little	Norwich PCT
Brigid Morris	Independent Research and Development Worker
Carey Ostrer	SURE
Chris Hunt	Southampton Centre for Independent Living
Claire Lanyon	National Children's Bureau
Colin Jackson	Mental Health Services
David Blastock	Training participant
David Britt	Training participant
David Howes	Training participant
Deborah Tallis (Facilitator)	Member of INVOLVE
Denise Blissett	Sure Start
Derek Stewart (Chair)	Member of INVOLVE
Elizabeth Clough	Department of Health
Gill Gyte	Cochrane Consumer Network and National Childbirth Trust Antenatal Teacher
Graham Duffy	Young Person Advisor
Helen Hayes (Facilitator)	INVOLVE Support Unit
Howard Taylor	Young Person Advisor
Hugh McLaughlin	University of Salford
Jane Stewart	Nottingham Primary Care Research Partnership
Jean Harding	Alzheimer's Society
Jennie Fleming	Centre of Social Action/ De Montfort University
Jinny Briant	National Children's Bureau
John Sitzia	TRUE Project
Jose King	Healthcare Commission (CHAI)
Joy Stokes	NCCHTA
Kate Sainsbury (Facilitator)	Member of INVOLVE
Kathleen Banks	Ethica
Kris Bentley	University of Leeds
Kristina Staley	Trainer
Linsey Hovard	Public Health Resource Unit
Mandy Williams	Birmingham Heartlands and Solihul NHS Trust
Marcia Kelson	NICE
Martin Williams	Trent Focus for R&D in Primary Care

Mary Carter	Researcher
Mary Nettle (Facilitator)	Member of INVOLVE
Maryrose Tarpey	INVOLVE Support Unit
Mohammad Abuel-Ealeh	Anglia Polytechnic University
Pamela Baker	NCCSDO
Rachael Lockey	TRUE Project
Rachel Purtell	FOLK us
Roger Steel	INVOLVE Support Unit
Rosemary Telford	Sheffield Care Trust
Ruth Cohen	Health First
Sandy Heron- Marx	University of Birmingham
Sara Morris	Institute for Health Research
Sarah Buckland (Facilitator)	INVOLVE Support Unit
Sarah Wright	Strategies for Living
Sheree Parfoot	TRUE Project
Steve Leverett	University College Worcester
Sue Spiers	National Forensic Mental Health R&D Programme
Suzanne Candy	Community Fund
Torsten Shaw	Making Waves
Tracey Bignall	REU
Tris Benedict Taylor	Patient, Public and Community Involvement Unit
Vinod Kumar	Member of INVOLVE

Appendix 6

Background to INVOLVE

INVOLVE is an advisory group on public involvement in research and development (R&D) in the Department of Health. We met for the first time in 1996, as 'Consumers in NHS Research.' For the next five years we offered advice to the Director of R&D for the NHS on involving members of the public in NHS Research.

In 2001 we also began to cover R&D commissioned in other areas of the Department of Health through its 'Policy Research Programme'. This includes R&D in the areas of public health and social care. In 2003 we changed our name to INVOLVE to reflect this wider remit.

The group meets four times a year. We have about 20 members, a broad mix of people including: users of health and social care services, carers, representatives of voluntary organisations, health and social services managers, and researchers. They are appointed by the Director of R&D at the Department of Health. We believe that involving members of the public leads to research that is:

- more relevant to people's needs and concerns
- more reliable
- more likely to be used.

What do we mean by 'the public'?

When talking about the public we mean people who are:

- patients and potential patients
- informal (unpaid) carers
- people who use health and social services

As well as:

- members of the public who may be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services
- groups asking for research because they believe they have been exposed to potentially harmful substances or products e.g. asbestos or pesticides.

What do we mean by 'involvement'?

By public involvement in research we mean active involvement, where people are not the 'subjects' of research but are active participants e.g. on a research steering committee.

Active involvement is where research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

What are our aims?

We aim to ensure that public involvement improves the way that:

- decisions are made about what should be a priority for research
- research is commissioned (chosen and funded)
- research is carried out
- research findings are communicated.

What are our objectives?

- To develop key alliances and partnerships which can promote greater public involvement in research
- To support members of the public to play an active role in research
- To monitor and assess the effects of public involvement in NHS, public health and social care research.

The INVOLVE Support Unit

INVOLVE has a Support Unit to carry out its work. The Support Unit is based in Eastleigh, Hampshire. There are nine members of staff (six of whom work part-time) to carry out and support the work of INVOLVE. The Support Unit:

- builds links with and provides information, advice and support to members of the public and researchers
- gives talks and workshops and organises conferences on public involvement in research
- has its own website, and keeps a database of research projects that have actively involved the public.

INVOLVE publications

We have produced a range of publications, including:

- Involving the Public in NHS, public health and social care research: Briefing notes for researchers (2003)
- Getting Involved in Research: A Guide for Consumers (2001)
- A Guide to Paying Members of the Public Actively Involved in Research (2003)
- Various conference and workshop reports

We also produce a free quarterly newsletter. If you would like to receive this, please contact us by telephone or e-mail and we will add your details to our mailing list.

All our publications can be downloaded from our website www.invo.org.uk or you can order a free copy from us at:

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