Training for service user involvement in health and social care research: a study of training provision and participants' experiences
(The TRUE Project)

Final Report

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We are indebted to the project Steering Group. The Steering Group provided invaluable enthusiasm and ideas, and helped us work through some difficult decisions. The group met formally three times. Special thanks are due to Robert Johnstone, the Chairman, for facilitating these productive and inclusive days. A list of Steering Group members can be found on page 131 of this report.

Rachael would like to thank Jac Mathews, who provided her with external support of an exceedingly high quality, which basically 'got her through'!

Thank you to all the people who shared their experiences and insights via the User Led Research Forum, an e-mail discussion group facilitated by the Mental Health Foundation, and to the many others - some working in the field of research involvement, and some not – who gave encouragement, support and reassurance along the way.

The evidence for the report has been gathered from many service users, trainers and researchers. Without their considerable help, research such as this would be impossible to undertake. We are very appreciative of their contribution and thank them for sharing their knowledge and experiences so readily.

Contents

Finding your way around this report

What is in this report?

This report presents the findings from the TRUE project, a research study commissioned by INVOLVE (a Department of Health funded group that aims to promote public involvement in NHS, public health and social care research). The purpose of the project was to explore the provision of training to support the active involvement in research of the public and users of NHS, public health and social care services. The project was carried out over fifteen months in 2002/2003 by a collaborative team including seven people who use mental health services.

This report does not describe in any detail the processes undertaken within the TRUE team that were required for the work, for example the training undertaken by the service user research team. Those who are interested in these 'internal' aspects of the project might like to know that INVOLVE also commissioned a 'reflective evaluation' of the project, the report of which is available from INVOLVE.

Definition of 'service user' and of 'training initiative'

We use the term **service user** throughout this report to mean people who use health and social care services, or potential users. INVOLVE provide the following list of groups of service users: NHS patients and potential patients; informal (unpaid) carers; people who use health and social services; 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, such as asbestos or pesticides.

We use the term **training initiative** throughout this report as a broad term to include a course, or practical session(s) or event at which training takes place.

To save space, the training initiatives are sometimes referred to in this report by identifying letters: A, B, C, etc. A list matching the initiative with its identifying letter is provided in Section 5.3 starting on page 153.

The parts of this report

This report has five parts, some of which are divided into sections:

Part 1 **Summary**	This part presents the key findings of the report, plus a short summary of the background to the project. The important messages from the project are provided in brief, and this part is suitable for reading as a separate document.

Part 2 **The findings in detail**	This part presents the findings of the project in detail and also presents a discussion of the findings. This part of the report is divided into three sections:
Section 2.1 Scoping exercise	This section presents the information we collected through 31 telephone interviews with 26 training providers across England. It gives 'facts and figures' about the initiatives, such as who the training was for and what the content of the training was.
Section 2.2 In-depth examples	This section presents the information we collected by visiting and talking to people involved in six of the 26 training initiatives. It discusses each initiative 'in depth', looking at topics such as the structure of the training, trainer-'trainee' dynamics, equality and empowerment.
Section 2.3 Why are these results important?	This section draws together the key themes that emerged from the findings and discusses them.

Part 3 **Background to this project**	This part (which is formed of three sections) is likely to interest people who want to know more about why INVOLVE commissioned this project, and about who did this work and exactly how we collected the information.

Part 4 **Guidelines for training**	This part of the report provides guidance for people who will be involved in training, both those who commission or deliver training, and those who participate in training. The 'guidance' is in the form of bullet points intended as a 'checklist' of important issues.

Part 5 **Further information on the project and the initiatives**	This part has seven sections that provide further information for reference. These include contact details for training initiatives, and a list of books and articles for those interested in further reading.

Finding your way around this report

There are three aids to assist the reader in navigating this report.

- First, you will find the **page number** at the top of each page.

- Second, at the bottom of each page, below a single line across the page, you will find some lines of text. These lines of text show the **location** of this page in the report. So, for example, at the bottom of page 45 you will see this text:

  Part 2 : The findings in detail
  Section 2.2 : In-depth examples
  Example 1 : Multiple Sclerosis (MS) Society

  This tells you that you are Part 2 of the report, and in Section 2.2 within that part, and that you are reading about Example 1 within Section 2.2.

This is a help box.	Third, occasionally throughout the report a **'help box'** will appear. A help box will either direct you to other pages or sections of the report that provide further information on a particular topic, or tell you other information about the section you are reading. An example of a help box is shown at the left of this paragraph.

Part 1 : Summary

Users of health and social care services bring unique and invaluable experience, knowledge and perspectives to research. However, sometimes people need to gain new and specific skills and knowledge to be actively involved in research, and so research training for service users is a key principle of successful involvement. The TRUE project, commissioned by INVOLVE and carried out by a collaborative service user / university / NHS team, aimed to explore the provision of this training. Through interviews and visits to training initiatives, the project found that:

❖ 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 'demystified' 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.

Introduction

Service user involvement in health and social care research has in recent years become rapidly and formally recognised as a right, not a privilege, and as an activity that has positive outcomes for both the individuals and the research activity concerned. Training is a key principle of service user involvement, as it is recognised that people who are 'novice' researchers may need to gain some specific skills and knowledge in order to work effectively. The TRUE project aimed to describe training for service users in this context, to identify factors that constitute 'good' training, and to explore the impacts of training for the individuals involved.

Map of training for service user involvement in research

Training for service user involvement in research involvement is not so readily available. We found only a relatively small number of initiatives that actively provided training and most of these had been recently established. Many more people and projects we spoke to were developing plans for training, and commonly people asked us where they could get training. The training examples that we found were diverse, ranging from involvement in one aspect of a research process to user-led research. The majority of initiatives existed within a collaborative working environment.

Universities were the most common training provider. Nine initiatives provided training in preparation for a specific research role or activity (such as for critical reviewing of research proposals). The other 17 initiatives provided training for several research roles, often for roles throughout a whole research project. Eight of the 26 initiatives (31%) provided training for all types of service users, a further eight (31%) were for mental health service users, and the remaining 10 for other specific groups. A variety of training styles were used. The most highly valued were those that were informal and relaxed, and supportive to participants. 'On the job' training was particularly important in project-based initiatives. All 26 initiatives had funding to provide the training. Trainers were almost always paid. In 21 initiatives, participants' expenses were reimbursed.

Clear aim and purpose

Service users identified two key questions that they ask of training: Why do this? Why me? Training was most valued when it had a clear purpose, when it was centred around specific research tasks and real research problems, and above all when it was linked to a defined and real research project or role. Of key importance in highly-rated initiatives, service users' contributions/roles in the training and research clearly and explicitly drew upon their experiences as service users. These contributions ranged across a large part of the research process, but in all cases there was a clear purpose to the contribution. For example, the research topic in some cases was prompted by participants' experiences; or recruitment or interview methods were informed by these experiences. The clear identification of this 'added

value' helped ensure that involvement was constructive and relevant, rather than vague, confused and ultimately despairing.

Involvement in the research process

Service users did not want to have knowledge 'handed down' by trainers but wanted to be involved in creating and developing ideas in which they could become absorbed and take some ownership. Trainers were praised for getting the ball rolling and then taking more of a back seat, only giving a steer if the work was going off at a tangent. Participants welcomed this approach because it put them at the centre, allowing them to be proactive, driving the ideas forward as well as determining the route. To achieve this, trainers did not simply cease to do anything, but rather they set up ways in which participants could be enabled to take things forward with others that facilitated interaction and exchange of ideas.

Exchange and sharing between people

Strategies for enabling people to work together, such as small group work and role-play, appeared to be particularly significant in these training initiatives. These strategies allowed participants to share their experiences, enabling them to feel that they were not alone, and then placed these into a broader research context, so that participants were 'thinking bigger than ourselves'. During the sharing of experiences, the skills of listening to others and being heard oneself enhanced feelings of self worth. Participants were able to bring out what was described as 'a wealth of knowledge, experience and expertise' that may have lain dormant.

This sharing was not only mutually supportive. It enabled people to feel that, together, they could make a difference in the area of the service they had experienced. The participants described being more assertive and less reserved. Significantly, this could go with being more challenging of themselves, so it was not simply a confirmation of what they were already doing. Participants felt more powerful and in some instances could illustrate that they had indeed been empowered to make changes happen.

Strength of the service user's experience being recognised

The process of listening to and valuing individuals' experiences reinforced – and sometimes redefined – for the individual that their experience and understanding gained as a service user was a strength that they brought to research. Non-service users could not and did not have this body of knowledge and insight.

Safe environment

Confidence to contribute develops 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.

Time and space for contribution

It takes time for service users to make a full contribution to research and successful involvement cannot be done under pressure. The time needed to involve people meaningfully and provide good quality training was frequently underestimated. Time for planning is particularly important: service users need to be involved from the start, for example to identify facilities and support needed, to identify training needs and to ensure that the training style and language is appropriate, and to plan for continuity.

This message should be noted in particular by research commissioners. Commissioners need to agree realistic time scales to allow adequate training for effective involvement. Project proposals should clearly indicate training and support needs of both service users and researchers. Most importantly, some flexibility in the project plan and timetable needs to be allowed for.

Outcomes of training

A key message is that, without exception, the training had enormous value for the participants' personal development, confidence, motivation and skills, and generally had a positive impact in their lives. Service users from at least 21 of the 26 initiatives went on to be active in research and utilised the training in practice.

The language of research

Language is a real consideration for those providing training. Several trainers said that one of their aims was to 'demystify research', demonstrating that research is an activity that we all undertake in our daily lives – and therefore have skills in. It is not the 'concepts' of research that cause difficulty for new researchers, but the 'language'. Research language appeared more of a problem issue in 'scientific' quantitative research as opposed to qualitative research, research about peoples' lives and experiences. Training is vital to identify strategies to bridge the 'language gap' between scientists and the public, as can the requirement by commissioners that researchers write in as accessible a language as possible.

Payment

For the majority of training initiatives we identified, participants were not paid for attending training, thus raising the question of inequality with trainers and with employed researchers attending training. The participants were however usually paid for resulting research activities undertaken. In most cases all participants' expenses were paid; there was a strong sense that if people were participating on a voluntary basis then good refreshments and other forms of 'hospitality' – such as social events – should be provided. It must be recognised that unless *all* expenses are paid, then the activity will exclude some service users.

Beyond reimbursement of expenses, payments was an issue that arose repeatedly in the study. For some people payment was not an issue, and indeed some service users were adamant that they wished to give their time freely, seeing it as 'giving something back'. Other people felt payment was not a high priority, as they were financially secure enough to give time freely. However, some respondents believed firmly that as service users bring unique knowledge and expertise, this should be financially acknowledged, as it is for other 'experts' in the team.

The issue of payment needs to be fully considered in training and research, discussed and agreed by all parties concerned right at the beginning of a project or initiative, and these costs must be considered in the initial budgeting. Payments should be made promptly. INVOLVE have published guidelines on paying consumers and can offer further advice.

Conclusion

In conclusion, without exception the participants in this study felt the training was hugely valuable, worthwhile and empowering. Training increased people's knowledge and skills, and boosted participants' confidence in their ability to understand and undertake research. We recommend that training should be an integral, vital part of any research activity if service user involvement is to be effective and meaningful.

Thinking of involving service users in research?

Through discussion and sharing of ideas with all stakeholders, reach agreement and clarity about what the service users' contribution will be, what means will be set up to safeguard real involvement, what activities will take place to facilitate service users' commitment and draw out their knowledge, and how a relaxed and friendly setting can be provided to encourage participation and make the most of the strengths the individuals have to offer. This requires time, discussion and planning. Individuals cannot, for example, be parachuted into existing, formal Research & Development Committees and be expected to make a full contribution from day one. Our findings indicate that training will help provide a good and confident start to this collaboration; but that the relationship needs attention and care if this confidence is not to be eroded.

About the project

The project was funded by a grant from INVOLVE and conducted from July 2002 to October 2003 by a collaborative team of 11 researchers from service user, NHS and academic backgrounds. We collected the information through 31 telephone interviews with 26 training providers, and through follow-up visits to and interviews with six examples of training.

Part 2 : The findings in detail

Section 2.1 : Scoping exercise

This section of the report presents the information we collected through 31 telephone interviews with 26 training providers across England. It gives 'facts and figures' about the initiatives, such as who the training was for and what the content of the training was. The section is divided into seven parts:

A : Introduction to the training initiatives

B : The service users attending training

C : The content and delivery of the training

D : The practicalities of the training

E : Financial arrangements in the training

F : Evaluation of the training

G : What now? Using the training in practice

A : Introduction to the training initiatives

How many initiatives did we find?

Look at Section 3.3 (starting on page 131) for more details on the identification of initiatives.

We identified and were able to collect data via interview from 26 initiatives providing training for service user involvement in research.

Where were the initiatives located?

The initiatives were spread across the country with no discernible pattern; eight, however, were located in London. Seven of the initiatives operated only within their own local geographical area, whereas eight worked within a wider regional area, and eleven initiatives were 'national', in that they either provided training across England or training was intended for people from across the country.

Who provided the training?

The pie chart below shows the relative proportions of different types of initiatives in the sample based upon 'organisation type'.

Pie chart of initiatives by organisation type

- Service user group
- not known
- Independent training provider
- University
- Voluntary sector
- DH / NHS

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Section 2.1 : Scoping exercise
A : Introduction to the training initiatives
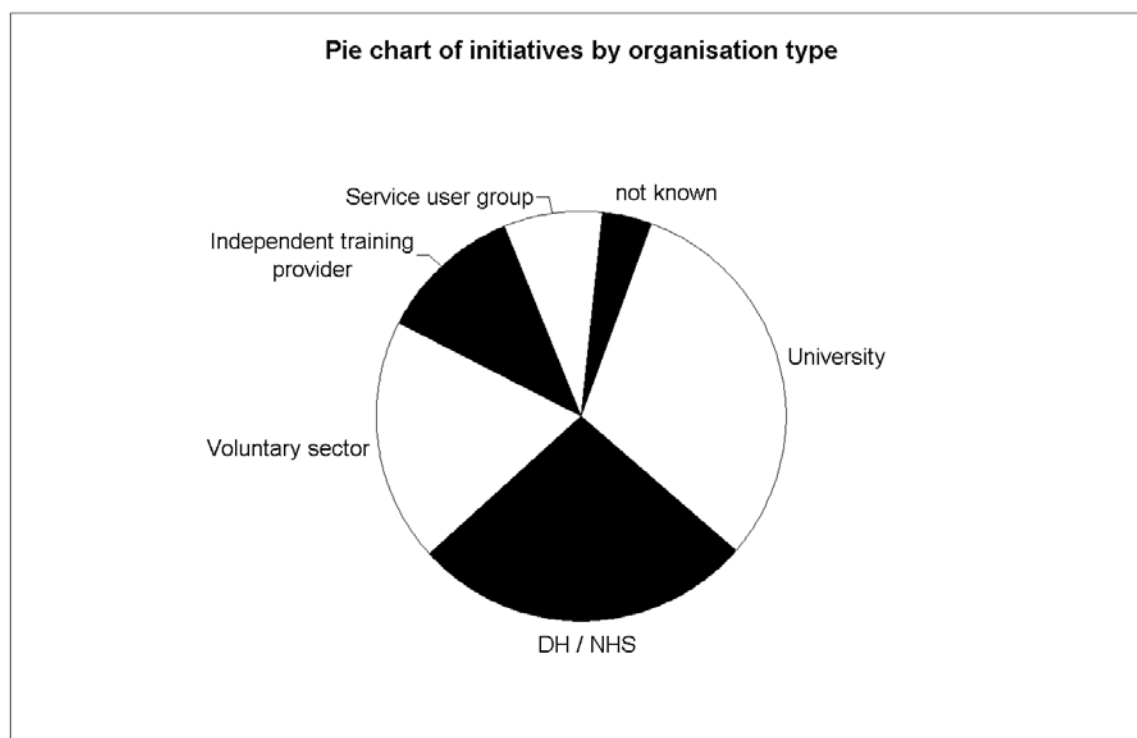
Universities were the main providers of training within the sample, with eight examples (31% of the sample). However, the provision from these units was often in combination with user groups, local social services, or voluntary organisations. In one example (Health R&D NoW: Initiative V), three universities in north-west England worked together to provide training in collaboration with the local NHS R& D Support Unit. In many cases the universities were approached by other organisations such as user groups and voluntary sector organisations to work together.

Department of Health / NHS were the second most frequent provider under the auspices of, for example, the Patient Involvement Unit at the National Institute for Clinical Excellence (NICE) (Initiative N).

The sample included three **independent trainers**, who provided training and research support to groups on a commissioned basis.

Who was interviewed?

We interviewed 31 individuals from the 26 initiatives. For all initiatives, we interviewed a member of the training team. The additional interviews were:

- For the OPRSI initiative (Initiative S), our first contact was with a service user who was also interviewed.
- For the Bristol MIND initiative (Initiative U), we interviewed a further service user/trainer.
- For the University of Stafford initiative (Initiative R), we interviewed one further informant who was key in setting up the initiative.
- For the Health R&D NoW initiative (Initiative V), we interviewed two further informants who were key in setting up the initiative.

When were the initiatives set up?

Of the 26 training initiatives, 21 had been set up since 2000. Many of these 21 initiatives were very recent developments, getting started in the year prior to data collection. Of the remaining five, two had been set up in 1999 and three in 1997.

Four of the trainers we interviewed had however been involved in research training for service users for a lot longer. These were Diana Rose (Initiative Z), Alison Faulkner (Initiative I), Mohammad Abuel-Ealeh (Initiative P) and Brigid Morris (Initiative Q). Three of these trainers were themselves service users.

What was the training for?

All 26 training initiatives were designed to give service users the knowledge and skills to be involved in some aspect of research. The initiatives fell into two groups: those

Part 2 : The findings in detail
Section 2.1 : Scoping exercise
A : Introduction to the training initiatives

that prepared people for a **specific role or research activity**; and those that prepared people for **involvement in several aspects** of research, often within a particular project.

Preparation for a specific role or research activity

Nine initiatives were currently providing training to prepare people for a specific research role or activity, as opposed to involvement in several aspects of research. These were:

- Critically reviewing research proposals: the MS Society (Initiative A) and CASP (Initiative D).
- Peer review of research protocols and guidelines: National Institute for Clinical Excellence (Initiative N) and Cochrane Collaboration Consumer Network (Initiative W).
- Research and involvement 'awareness' training: Health R&D NoW (Initiative V), Trent Focus (Initiative E) and Folk.Us (Initiative G).
- Training to be a member of a consumer research group: North Trent Consumer Network (Initiative H) and the National Cancer Research Institute Consumer Liaison Group (Initiative M).

Preparation for involvement in several aspects of research

The remaining seventeen training initiatives were developed to support service users to be involved in several aspects of a particular research project or initiative. Several of these initiatives were identifiably user-led:

- CityZEN (Initiative B)
- Leeds Survivor-Led Crisis Service (trainer Alison Faulkner, Initiative I)
- Southampton Centre for Independent Living (Initiative K)
- Strategies for Living (Initiative O)
- MATRIX Project (trainer Brigid Morris, Initiative Q)
- Bristol MIND (Initiative U)
- Making Waves (Initiative Y)
- SURE (Initiative Z)

Part 2 : The findings in detail
Section 2.1 : Scoping exercise
A : Introduction to the training initiatives

Examples of descriptions of aims:

> "To use the knowledge, skills and experience that the user researchers have and combine this with the skills needed for research. The end product being a credible piece of research that will meet the requirements."

> "To give people research skills, to enable them to undertake research during the period of time that we are funding them, and give peer support."

> "To introduce research, demystify research, give them the chance to see that other people are doing things, give them some kind of information about, and insight into the structures involved around research in the NHS, and just give them the chance to meet others and discuss things, really."

> "The training is developed to ensure that people have a basic standard for carrying out interviews and a level of consistency can be achieved. It is developed to get people to think about the questions and develop skills in eliciting information."

Who were the trainers?

A diverse range of people provided training at the 26 initiatives. Two initiatives had been set up specifically to provide training on a consultancy basis to other organisations: EQUIP and CASP (Initiatives C and D). However, in most initiatives the training was provided by people for whom training was only one aspect of a broader role. These wider roles included research, lecturing and project leadership. These individuals also had diverse backgrounds in other subject areas, including social work, clinical psychology and community development. It is important to note that they all shared a common interest in service user involvement in research and had developed projects and training as a result of this interest. Indeed in eight initiatives, the trainers were themselves service users.

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Section 2.1 : Scoping exercise
A : Introduction to the training initiatives

B : The service users attending training

The table and pie chart below show the number of initiatives providing training for different types of service users.

Service user group	Number of initiatives
All types of service users and carers	8
Mental health	8
Medical condition (cancer, multiple sclerosis)	3
Young people and children	3
Disability across all impairments	2
Learning difficulties	1
Older people	1

Pie chart of initiatives by participant group
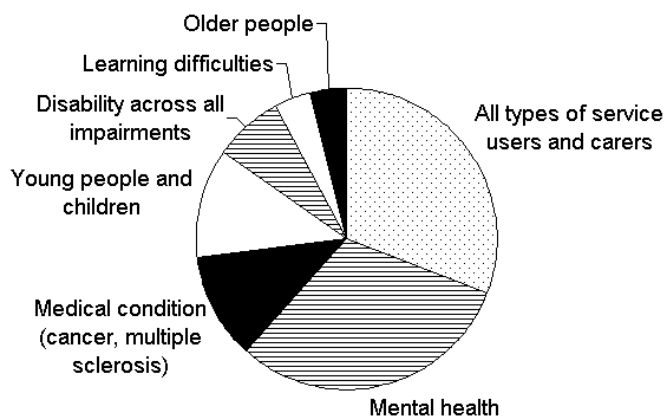
Eight initiatives provided training for all types of service users, but within this group training could be tailored for one specific group. For example, the CASP initiative (Initiative D) has provided tailored training for many different service user groups.

We also identified eight initiatives designed for mental health service users.

Part 2 : The findings in detail
Section 2.1 : Scoping exercise
A : Introduction to the training initiatives

C : The content and delivery of the training

What was in the training?

Training in skills and knowledge specific to research

Aspects of research covered in the training were categorised by the stages of the research cycle (see Royle and others (2001) for further details of the research cycle). The results are presented in the bar chart below.
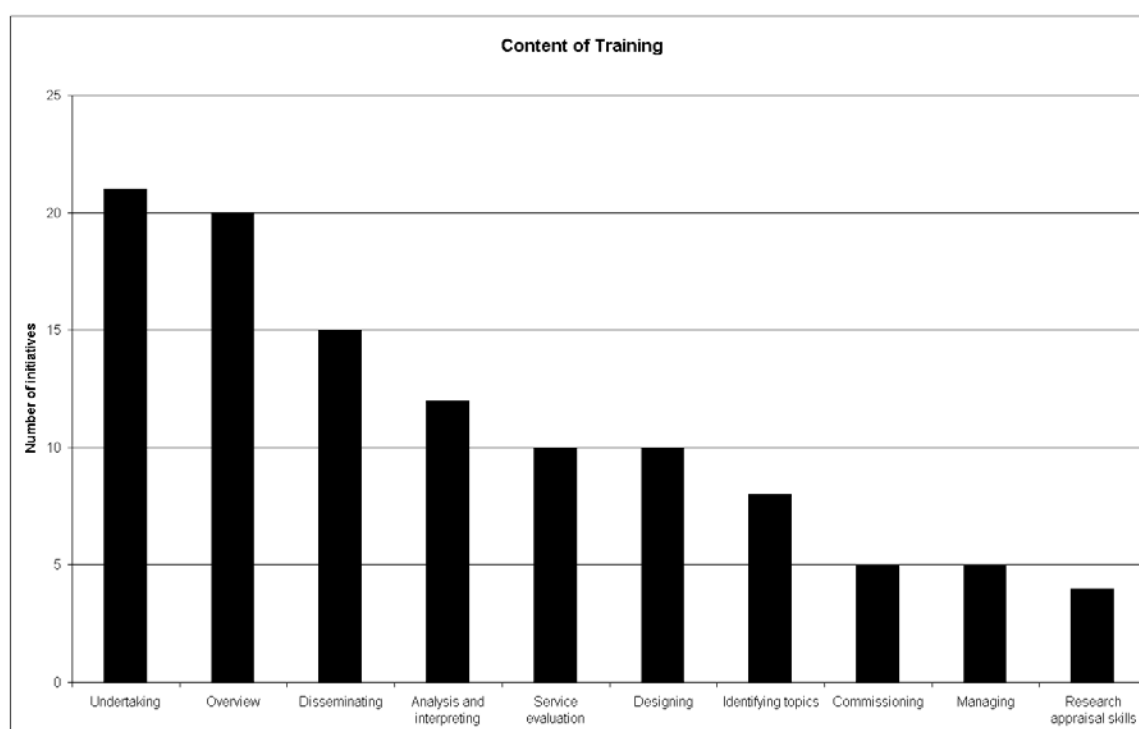
Training for **undertaking research** was the most common activity, with 21 initiatives stating that this formed part of the training content. Training was mostly around conducting interviews and devising questionnaires. CityZEN (Initiative B), for example, listed the following: skills to be a researcher, communication skills, 'first contact' skills, introductions, introducing the research, approaching people in the street, code of conduct, risk assessment, health and safety, developing questionnaires, trying out questionnaire.

An overview of research was provided by twenty initiatives as part of the training. The overview included subjects such as:
- What is research?
- Different research methods

Part 2 : The findings in detail
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C : The content and delivery of the training

- Research cycle
- Why do research?
- Ethics
- Structures for research in health and social care

An example of the range of topics included in an overview of research training was provided by the University of Salford (Initiative X):

- Identifying questions and conducting interviews
- The philosophical underpinnings of research – what is research? – different traditions
- Qualitative and quantitative approaches
- Ethics and politics

Fifteen of the 26 initiatives included aspects of **dissemination of research findings**. This included preparation of findings for conference presentation, and 'writing up' the research.

Analysing and interpreting training was provided by twelve initiatives. Two examples are below:

> "We had to do an assignment at the end of the interviews and we were given a transcript of two interviews and then we could choose one and do a piece of analysis, because one of the things we had looked at was analysis; picking out concepts and developing them, I found that really interesting actually."

> "What we have done is get them to read transcripts, got them to highlight things, got them to agree everything, got them to choose the quotes they think are the best …so we've had to work with them."

Ten initiatives provided training on the range of methods and skills for the **evaluation of services.**

Designing research tools was identified by ten initiatives as part of the training, such as designing data collection tools and designing questionnaires. For example, the trainer from Making Waves said:

> "The focus of the course is User Focussed Monitoring. There is an overview of UFM. Then lots of time spent on questions, developing questionnaires, asking the right question, and practising interviewing each other."

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Section 2.1 : Scoping exercise
C : The content and delivery of the training

Commissioning and **managing research** were the least taught aspects of research; for each of these only five initiatives provided training.

Research appraisal skills (or 'critical appraisal' skills) were specifically noted as being included in the training by only four initiatives. One trainer said:

> "In the afternoon ... they did a case study that was looking at whether allowing people who were ringing up with colds to have a telephone consultation with the doctor, whether that cut down on visits to the surgery. That was a randomised controlled trial. It gave it more of a quantitative emphasis rather than a qualitative one... Going through the case study I was amazed at how canny they are actually. They really can pick holes in things. Ordinary people can see right through [research]. And not just on the research case study but also on the research system and things like that, how politically determined it might be and things like this, it was quite amazing."

Training in skills and knowledge not specific to research

Sixteen respondents stated that the initiatives provided training with broader application than research. Topics included the following:

- Why consumers are being involved in research
- Health and social care services and voluntary sector services
- Communication and listening skills – body language – asking questions
- Safe working – team working
- Raising awareness about jobs
- How to involve people
- Equal opportunities in research
- Ethics
- Icebreakers
- Presentation skills
- Mental health issues, problems and legislation
- Committee skills
- Group dynamics and development

Part 2 : The findings in detail
Section 2.1 : Scoping exercise
C : The content and delivery of the training

CityZEN provided an example of communication skills about contacting people:

> "We usually spend quite a lot of time practising what I call first contacts –
> so all of the research that we do pretty much is a detached style where
> they would be approaching young people on the street, on the estate – so
> first contact [is] about before you actually start conducting an interview,
> how you introduce yourself, how you say what the research is for, how
> maybe you get across that it's for their benefit to take part in the interview,
> and maybe looking at things to avoid. Sometimes it's appropriate that you
> do need to be asking people's permission. Later on we look at a code of
> conduct, respecting the interviewee's rights and so on."

How was the training done?

The format of training varied enormously. Different formats included a single day of training, a set of days spread out over a number of weeks/months, training that stood alone from research activities, training that was interwoven with research activities and 'hands on' training. Training might take place separate from other activities or might be a part of a wider meeting (e.g. Initiative M: National Cancer Research Institute (NCRI) Consumer Liaison Group).

On a few occasions people mentioned that distance learning packs would be a useful approach; however, we did not find an example where this had yet been developed.

Initiatives employed a wide variety of training 'styles' and methods, including: discussions, presentations, tutorials, workshops, exercises, handouts, interactive activities, sharing knowledge, role-plays and case studies. Rather than try to quantify the use of these, or to describe their content in detail, we asked interviewees to highlight issues of 'style' that might be useful to other trainers.

Informal and relaxed style

Eleven respondents from the twenty-six interviewed identified their style of training as informal and relaxed:

> "The training that we do is very informal. We don't give handouts or lots of
> input, we like to do it by posing questions to the group and getting them to
> think about things and make decisions on what's most appropriate for
> them. So we wouldn't give them a list of the ways you can collect
> information, we would ask them what ways they know about collecting
> information. Obviously if they miss something that we think is appropriate
> we would contribute that too, but our experience is that people actually

Part 2 : The findings in detail
Section 2.1 : Scoping exercise
C : The content and delivery of the training

learn much better by thinking through things for themselves rather than being told what to do."

"It's very relaxed. We don't set ourselves up to be experts, so it's based around hopefully sharing and knowledge of everyone who's there, because even if people haven't had research experience they will have had some experiences in their lives, which will help towards being a researcher. It's very facilitative, so that I'm facilitating the sharing of information. I do have a planned agenda and there are certain things I aim to get through on each session. We do as much practical exercises as possible and there's lots of opportunity for people to talk and discuss aspects of the day."

"What's worked the most effectively for us has been breaking the training down into quite small steps. We present information, then practise straight away, trying things out. We role play. Use humour, because that always helps – we try to make it light and fun. After practising on each other, we give each other feedback about how it worked, what worked well and what didn't."

Role play

Role play was a commonly used training method and benefited from participants being well prepared. For example:

"We had a role play of a big meeting … It was a really productive session that one actually, it was really good. How that was able to work so well – and we got a lot of feedback on it, around what people liked about it was the inclusiveness of it, the fact that we'd had such a mixed group and managed to make it work, certainly the inclusiveness was something people really liked – but why that was able to work so well I think, was that this group from [name of hospital] had actually done some preparation: we spent quite a lot of time liasing with them in advance of the work shop, talking about what the content was going to be, what types of activities we'd do, what the expectations would be on the day, so that some of the people who might have found that difficult came along with some degree of preparation as to what to expect."

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C : The content and delivery of the training

Training as part of 'doing' research

In cases where training was attached to a specific research project or role, training was frequently part of ongoing research activities:

> "We will be training in the sense that we will be reflecting on our first experience of doing an interview but after that … will be support meetings and/or analysis and so forth, we'll still do a bit of training and analysis I guess. It's very much an organic process, it's not really clear-cut."

> "It's really hard to teach analysis unless you're actually doing it."

Being responsive to participants' needs

Many of the training initiatives contained essential contents while the structure and style of the training depended on participants' needs and wishes:

> "Much of the training comes from what the group needs, you know they might say 'I'm a bit worried about this' and 'Okay, let's think about that next week'. I have a loose training plan of things to cover."

Supportive style

Support was commonly referred to as an important part of training:

> "One huge thing of mine is about actually supporting a group. To think about how it would feel for them (doing the research) and actually getting away from what the books say and what an academic would say. It's about encouraging the group, I think, to find their own way."

> "But at the same time some of the workers on the project for whom it's a kind of stepping stone, who have some potential, to help them gain new skills and use them in different ways … I've been trying in the last few months to see what I can do to actually support that a bit more. What's been happening around that is I've been starting up more individual supervisions with workers on the project and looking at their involvement in the project together … so that means it's really different, it varies enormously between different workers on the project."

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Getting people together

Another approach was residential training. All three of the youth initiatives felt this was important:

> "I think the big advantage is you get everybody together, and get a chance for them to work together, you get a chance for them to learn together and play together, which I think has big plusses throughout, because when they come together they slip quite happily into knowing each other and being friends with each other … It's as much to do with as a group development exercise as it is to do with teaching research skills."

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C : The content and delivery of the training

D : The practicalities of the training

How long and how often was the training?

> Look at Section 5.3 (starting on page 152) for a list of initiatives and their features.

A majority of initiatives (17 of 26) provided training 'on demand', meaning that they did not follow a regular pattern of provision or were time-limited. Most such initiatives were 'project-specific', providing training solely for the purposes and duration of a particular research project. 12 of the 17 interviewees used phrases such as that training was provided 'as and when required' or in response to 'demand':

> "They're not a regular thing. It's something that we do when we're approached by an organisation and we agree that that's the right way forward, so it's not like they're run every six months or anything like that."

Nine initiatives that provided 'recurrent', as opposed to 'on demand' training. These nine organisations provided training between two and four times per year, that is once every three, four or six months.

For 14 of the 26 initiatives, the training consisted of a single episode of two days or less. The periods of training reported for the other 12 initiatives were as follows:

- Three days, plus ongoing 'on-the-job' training
- Six sessions, three hours each, over six weeks
- One half-day per fortnight for three months
- One half-day per fortnight for 'several months'
- One half-day per week for seven weeks
- Three and a half days
- Ten sessions, each of three hours, over a six-month period
- Ten sessions, one per fortnight, each of one half-day
- Five days
- One day per week for 12 weeks
- One day per week for 20 weeks (in two blocks, each of ten weeks)
- One half-day per week for seven months

A minority of projects provided substantial, regular training: for the MATRIX project (Initiative Q), for example, the service-user research team met every Monday for seven months for training and research work; similarly, the Centre for Research in Health and Social Care at Anglia Polytechnic University (Initiative P) provided one training session per week over a 12-week period.

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'On the job' training

It is very important to note that, for the project-based training at least, the 'ongoing' or 'on-the-job' element of training was generally regarded as being of equal or greater importance than the 'formal' training sessions. For example:

> "Some of the training is completely on-going. We've got work meetings here where we come together to get work done and during those meetings there is quite an exchange of skills, and people learn by doing. So although that's not specifically 'training' a lot of the time, not labelled as such, it is a quite important learning process."

> "Apart from this intensive training which prepares people to do User Focussed Monitoring there is on the job support and training when people are doing projects. We have also had a refresher day for people who have done the training, using interview examples to discuss further issues about asking the right question and getting useful information. This has particularly focussed on developing people's skills with open-ended and supplementary questions."

The Norah Fry Research Centre (Initiative J) in particular emphasised this point: "We did a six week course one day a week at the beginning. But I don't think it could work just like that with a six session course and then just get on with it. I don't think that's actually the best way to approach training with this sort of set up, because it's more an ongoing process. I felt that it really needed to be an on-the-job learning thing the whole way through, and that was how we did it in the end."

How many participants attended the training?

Where there was delivery of training to a group, the number of participants taking part in the initiatives ranged from four to 31, but most commonly (in 80% of cases) the number was between five and 15. A number of interviewees mentioned that attendance numbers dropped as the course or project progressed; the initial group would 'thin out' to a committed 'core'.

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D : The practicalities of the training

Where did the training take place?

A variety of venues were used for the training, as shown in the table below.

Venue	Number of initiatives
Hired rooms in hotels or conference facilities	6
Administrative base of a service user organisation (e.g. London offices of the National Children's Bureau)	6
University premises	6
Community resource buildings	3
Government buildings (e.g. Department of Health premises; Medical Research Council offices)	2
Non-NHS palliative care centre.	1
Combinations of the above	2

Some trainers preferred independent settings, for example:

> "I think there's a policy that we run them outside of a university or a hospital environment, just to make it more independent, I think, and perhaps less intimidating. A nice environment, certainly the one in Lancaster we ran in a four star hotel, which was very nice. So we've used a hotel, we've used a community conference centre, and another – they're just in the community, basically, where there's facilities for rooms, and they provide lunch and things like that."

Only one respondent mentioned 'accessibility' as a priority in selecting a venue, though others indicated that some thought had gone into access issues:

> "Another thing we didn't get right or that we've learned from it is the directions to the building! When we have someone with communication difficulties, each time we did our best with that in that we set up a man on reception to expect people to come and to guide them. But because of funding issues most of the workshops have been held in the Department of Health building which has got loads and loads of different rooms and loads of things going on, so it wasn't a straight forward thing for the chap on reception. I think we did it reasonably well but I'm sure there is more we could have done about that. There's something about the detail or the way

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you give people information about access to the venue and what system you set up … We did do things like check up for a hearing loop in the place, because there was an older person in one of the groups who did say he'd got a hearing loss … We asked in advance of any special needs every time; special needs, dietary requirements, car parking was a big one, all of that. At one of the buildings there was quite an elaborate system we had to get into to get people in wheelchairs, in fact nobody turned up in a wheel chair but we had it anticipated that some might and we had to go through some elaborate system, you know 'the security man second in command will meet you wearing a red carnation in the back of the car park' … that kind of system!"

What helped and what didn't in setting up training?

Interviewees were asked to identify factors that helped or hindered the setting-up of the training, or particular challenges in setting up the training.

Resources

The first set of factors – 'barriers' and 'facilitators' – identified were resources: funding, time, staff. However, these were reported relatively infrequently as barriers: only four of the 26 initiatives noted that funding had been a problem, for example, whereas 12 noted it as an important facilitator (and ten did not mention it). One trainer's view of resources was that:

> "It's easy to find resources to train health professionals but not easy to find resources to train users. I think things will be very different once the Commission for Patient and Public Involvement is set up."

In some cases the problem was not funding for the training but for funding to meet the participants' costs:

> "It was easy to get funding for our training. What was more difficult was that we also pay the patient reps on the guideline groups and that was a bit more difficult, to get people to agree to that. But they do now get paid."

Clarifying Expectations

The expectations of trainers, service users and project researchers or organisation staff were not always clear and agreed at the start of the initiative. However, the dialogue required to resolve this was also seen as fruitful and enabled service users to be more involved in planning and directing the training and research, for example:

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"We've had a lot of that, people asking 'What is our role?' Everyone wanted a clear idea of what was expected of them, but at the same time we were also saying, 'Yes, but we want you to tell us how to develop this role as well.' So I think that still needs working [on]."

"Actually talking to the people themselves [was helpful], the people we'd funded to do the research, and getting their ideas and how they expected things to be, so that we would try and meet their needs as much as possible."

Organisational change

One Department of Health funded initiative found it difficult to work as structures at the department shifted:

"The major thing really was the change organisationally at the very top [in the Department of Health] and this sort of shift in the way research was being managed and organised. It's been devolved down more to Strategic Health Authority and PCT level and therefore our input changed to have this focus on eleven individual projects that we were having to try to bring together more rather than something that started off as a cohesive network."

Recruiting service users

A number of initiatives – of all types – reported a challenge in 'finding' and recruiting service users. Other initiatives reported no problem, sometimes attributing to this to having an available existing 'pool' or previous contacts. For example:

"Every year we have a consumer conference to feed out to members of the general public just what's going on in research here. So at those conferences [we invite] people to get involved in research … people can comment on particular projects that are in the pipeline and give their feedback on things. That's one way we've got hold of people. Another source of recruitment is, people who were directly involved in research (locally) and wanted to be more involved in [it] now. Then we've got another group, SPORG, the Supportive Care and Psycho-oncology Research Group where consumers have always sat on there anyway, that was another source of recruitment for us."

"Just having a ready-made group really in terms of setting it up and getting young people who were already motivated and very willing to listen and learn was a great help."

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Motivation / Interest in research

Getting people attracted to research in the first place could be a challenge, for example:

> "Partly the problem was trying to promote it to people and get people interested. It was originally going to be seven training sessions and it ended up being four because we just didn't get the take up … partly it's just people's response to the idea of research and training in research, it's not particularly an area people sign up to."

> "Working with young people can be very exciting, but it can also be quite difficult at times, because their interests are different, and that's why we want to use them, because obviously they're in a much better position to find out what other young people think than adults can, because they share similar types of views and issues."

This trainer went on to describe how to get this group wanting to join in and keep coming:

> "You've got to build fun into the process, and you've got to build in some rewards for the young people, in doing the process. We've not been able to pay them money directly, but we've been able to take them away, and pay for them to have quite nice accommodation, decent meals, and having some fun in terms of leisure activities, plus we've also been able to get them some publicity, in terms of papers, some of them have got someone who wants to interview the young people."

The tricky bits in the subject matter

> "There were barriers about, for example, to get over some of the more complex issues to do with research, like quantitative methodologies and statistics, looking at the issues of qualitative analysis and making sure things are valid and reliable and how you can make generalisations."

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Differing levels of knowledge and abilities

Trainers commented on the need to consider the challenges of how to provide for different kinds of impairments and different levels of experience and understanding amongst participants. For example:

> "We had to really look at the way that people's different impairments were going to affect their training, how we had to accommodate them within the training, how we had to make sure that people had the right support they needed to get through the training. We had to make sure that the training was delivered in small pieces so that people could digest it, so we had to spread the training out over a long period."

> "People were at different levels. So some people had had no research experience whatsoever, whereas some people had actually had quite a lot of experience, which isn't necessarily the people that we were aiming for. So that was a bit of a problem."

Information needed to be accessible:

> "[Another barrier was] information, making the information easy to understand for people with learning disabilities, because these were all people with the label of 'learning difficulty'. So the information had to be put in a way that people could understand and take in. That is always a problem, if you like, but it's something that we tackle all the time."

Confidence of the trainer

In one case, a trainer who was also a service user, identified her own confidence as a 'challenge':

> "One thing was my own confidence, because I hadn't actually delivered training as such before in the same way."

Attitudes of the User Organisation

One other factor was mentioned as a facilitating factor (but not as a barrier): the attitude of staff in stakeholder user organisations or funders. For example:

> "There was a lot of help from the Sainsbury Centre [for Mental Health] and I think that was really good. The development worker at that point had a lot of experience of service user involvement but wasn't really trained in

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research. [The worker] got himself trained up quite a lot, read up a lot of things and developed his own skills, but he really did need that support from outside. The Sainsbury Centre were good at supporting."

"The attitude of the staff at the crisis service, the manager of the crisis service has been entirely facilitative, entirely helpful. That's the way they want it to be, like this, and they've been very helpful and supportive to me to do it in that way. I've got a lot of good things to say about the people in the crisis service."

Government policy

One respondent noted that the shift in government policy towards greater user involvement was an important supporting factor:

"What was helpful was that there was a lot of NHS policy around saying that users should be involved at a strategic level, so there was the NHS Plan and the Kennedy Report, so we tried to use that to justify getting the resources to get the training."

Gate keepers' approval

Finally, one respondent from an initiative where training was project-based mentioned the barrier of getting 'permission' from gatekeepers to involve service users:

"But we also had to apply to the local Ethics Committee for permission for the research, and they stipulated that those who wanted to be user researchers had to go through their GPs to get permission, which we thought was quite irrelevant, but we didn't feel we could change that. I can't see the relation, and neither could [the service users], the relationship between the GPs and people wishing to get training or work as user researchers. This was really stigmatising, I thought."

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E : Financial arrangements in the training

Where did the money for the training come from?

Each of the 26 initiatives reported that some funding was available to support the training. Funding sources are presented in the table below. As some initiatives received funding from more than one source, the number of initiatives does not total 26.

Funding source	Number of initiatives
[1]Department of Health / NHS	12
Charity	5
Local council / social services	3
Other research project commissioners	5
University	1
User organisation (with National Lottery funding)	2

[1] Funding from Department of Health / NHS sources supported 12 initiatives. The specific sources were varied: Department of Health R&D Programme (both project/programme grants and NHS R&D Support Units), NICE, local health authorities, NHS trusts and PCTs, the NCRI and an NHS cancer network.

Were the trainers paid?

In almost all cases, those people who provided training were paid to do so. In some cases the training formed part of a broader salaried role; in others, external trainers were hired. In one user-led initiative, the trainer, who was also key to setting up the group, gave his time on a voluntary basis.

Were participants paid?

Payment for participants was provided in nine initiatives and not provided in 15. Two respondents were unsure about payments to participants, as they would not be routed through the respondent.

Of the nine who provided payment, five were able to state the payment rate; the daily rate ranged from £10 to £50.

However, it is important to note two points regarding payments to service users. First, the three NHS RDSUs do not generally pay participants but they are providing a 'public service' rather than 'training for work'. These units stressed that no charge is

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made for this training (and on some occasions participants' expenses were reimbursed).

Second, a number of the 'training for work' initiatives noted that while participants were not paid specifically for attending training, they were often paid for the research work they did (and attendance at training may be part of that paid role).

Were participants' expenses reimbursed?

Twenty-one of the 26 initiatives confirmed that participants' out-of-pocket expenses were reimbursed. Of the remaining five, in the interviews with two initiatives it was unclear if expenses were reimbursed or not. The remaining three initiatives confirmed that they did not reimburse participants' expenses. However, in two cases participants received payment for attendance, and it had been agreed that this would also count for expenses. In the third initiative, OPRSI (Initiative S), service users paid the University of Lancaster to provide the training, although at a reduced rate. Service users were then paid for the research work undertaken.

Travel was the minimum expense reimbursed (though at least eight respondents noted that a free lunch was also provided). The other expenses reimbursed in a minority of initiatives were carer costs and overnight hotel accommodation. In addition, in some initiatives social activities (such as evening meals) were also provided: CityZEN (Initiative B), University of Salford (Initiative X), and Listening to Change (Initiative T).

How much did training cost?

Interviewees were asked to estimate the overall cost of training. Some were able to do this, as a specific training budget had been set or could be easily estimated. For the MATRIX project (Initiative Q), for example, 20% of the project budget had been spent on training (approximately £5,000). The Department of Health provided £40,000 per year for three years for the training of service users in the 11 projects in the London Primary Care Studies Programme (Initiative C: EQUIP).

Fifteen respondents provided an estimated cost for one day's training (though the length of this day varied). The costs ranged from £200 to £4,000 for one day: eight estimated less than £1,000; four estimated £1,000 to under £3,000; and three estimated £3,000 and over.

Ten respondents did not know and were unable to estimate the cost of training. Several noted that training was paid for from a broader budget, e.g. project, or user involvement budget.

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F: Evaluation of the training

Feedback / evaluation by participants

Without exception, all of the 26 initiatives provided a route for participants to feed back their opinions of the training, for example through completion of an evaluation form.

> "Yes, we always do an evaluation. We've done an end of year report for the Alzheimer's Society, and we always have an evaluation as part of that. Usually a bit of both verbal and filling in forms, an evaluation form, which says what went well, what went less well, what would you do differently, things like that … For the Alzheimer's we constantly adapted the course we ran."

All initiatives received generally positive feedback, but often with suggestions for changes to the training. Many respondents stated that they did act on the suggestions and introduced changes the next time the training took place.

These suggestions fell into two groups – 'content' (e.g. more of one topic, less of another) and 'format and style' (e.g. more group work, shorter breaks) – illustrated by some example quotes below:

> "They had a warm-up exercise one morning [in which] they worked in a small group, then they'd shift to tables and started quite a heavy exercise straight after. Some people fed back saying it was quite hard because they didn't know the people in their new group to then start on this exercise. So in the next one we added an extra warm-up in the afternoon with the new group …The main difficulties were some of the practicalities and some of the locations, how accessible or inaccessible they were, and the timing. We had some scientists come in and give talks, and even though I thought they ran on over time and droned on terribly some people said that was the most fantastic bit of the day."

In the following example, the trainer had particularly noted from the evaluations the importance of preparing and reassuring participants:

> "Yes, we would always evaluate the course, both at the end of the course and at the end of the whole project. People like the participative nature of the training and they like the fact that they then have a say in what the project looks like and how it develops … I think we have learnt that people

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do need a lot more preparation and reassurance than we might have thought that they did, and now would increasingly look to build that in."

This example shows feedback having an effect on course content:

"People need more training around quantitative research as the course was largely qualitative … next course will include quantitative research."

Independent evaluation

Only two initiatives stated that an independent evaluation of the training had taken place (though in some other cases there had been independent evaluation of the project for which training was being provided). These two were North Trent Consumer Network (Initiative H), which had been evaluated by the School of Health and Related Research (ScHaRR), University of Sheffield; and the Southampton Centre for Independent Living (Initiative K), which had been evaluated by both the Department of Health and Hampshire Quality & Performance Management. An independent evaluation of the training for the London Primary Care Studies Programme (Initiative C: EQUIP) is being commissioned at the time of writing.

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G: What now? Using the training in practice

The key 'outcome' question asked if those who had undertaken the training were actually using it in research practice.

Service users from at least 21 of the 26 initiatives had gone on to be active in research. Two initiatives did not know if this had happened or not. Service users in the other three initiatives were not known to have gone on to do research activities, but respondents identified many other positive outcomes of the training.

However, without exception, trainers reported that the training had increased motivation and skills, which had encouraged a number of participants to take up new activities, such as voluntary work for example, or to pursue education courses. In some initiatives, a large proportion of participants had either begun new activities or expected to do so, although it was difficult to give exact figures. An increase in participants' confidence was frequently mentioned. This was thought to have helped some to be successful in applying for work.

Some examples of the applications of the training are given below:

Research

- Young people have run focus groups with other young people in universities
- Two participants became lay members of NHS research committees
- People went on to Do interviews for the Housing Decisions Project
- A core group have successfully been part of a newly funded project (Joseph Rowntree Foundation), which includes them as elderly researchers
- The participants play an active part in CRAG (Consumer Research Advisory Group), some are also currently planning to do some User Led Research, and a longer term aim is to do collaborative research with researchers at the Institute of Psychiatry
- People have been using some of the skills that they've picked up here in other research projects that they have since got involved in
- People have been doing other community-based research
- At least one participant contributed to another research project on personality disorder

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G : What now? Using the training in practice

Other activities

- A group has been invited to talk at a conference on pensioners
- Eleven [of 14] participants have started new activities … three participants have plans to do voluntary work
- Two people have gone on to do courses in research with the Trent Institute, and one person is doing a certificate in Community Mental Health
- Several people are considering going on to do education courses to develop themselves as educators
- People have become active members of NEST, the local service organisation for mental health service users … meaning chairman or accountant or committee member of this or that within the service user organisation
- One service user is now on our Management Committee, and people who were involved in the training have been part of our courses planning group

Confidence

- The training has given the participants confidence to do things that they didn't think they would do
- People report having increased confidence to question and discuss their own care with their psychiatrists; doing the interviews has given them a breadth of knowledge in the area and they know it's 'not just them' that feel this or think that

Employment

- At least in part doing the project helped this participant to regain some of her confidence to seek and to successfully obtain a job working in mental health settings as a mental health service worker rather than user
- A few researchers have got work since they've been doing work with us, and I'm not saying it's all about us but I do think definitely confidence has improved for people as well with these new skills
- People have moved from not being in work to going into part-time work, and using the skills that they learned through the course in other areas of their life.
- At least one person went to work as a worker in a mental health setting and at least two to three became proactive members within the local services organisation

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Section 2.2 : In-depth examples

This section presents the information we collected by visiting and talking to people involved in six of the 26 training initiatives. It discusses each initiative 'in depth', looking at topics such as the structure of the training, trainer-'trainee' dynamics, equality and empowerment.

The section begins with an Introduction, which gives an explanation for some of the terms we use in this section and also regarding our policy on anonymity.

Each of the six training examples is then discussed in turn. Generally, within each example, the text follows these headings:
- Background to the training
- Observation of the training
- Participants' views of the training
- Trainers' views of the training
- Outcomes and future plans
- Key learning points from this example

Note that KEY POINTS come at the end of each example; also, that as the characteristics of the site visits and the examples themselves varied so much, not every example has all of these sections.

Introduction

You can find the Guidelines in Part 4 of this report, starting page 139. Details of selection of Training Examples and data collection begin on page 134. Contact details for the examples begin on page 155.

As a means of getting more in depth information about training for involvement in research our methodology included six visits to training examples. Our aim was to capture the views and experiences of trainers and participants in order to inform our Guidelines. The processes we undertook for selection of the examples, and for data collection and analysis, are described in Section 3.3 of this report.

Please note two points regarding 'names' and 'labels'.

First, originally we had intended that the training examples would be named in the report but that individual participants and trainers would remain anonymous (as this is the convention in research reports). However, in some cases people stated that they preferred to be named and therefore we asked all informants if they would prefer to have their real name disclosed or to remain anonymous. Some people responded that they would like to be named, and others that they preferred to remain anonymous. Therefore, in some examples people are named and in others they are not. Traditionally in research the convention is that people remain anonymous. A move away from this within this report, as a direct response to some of the research participants' requests, reflects a transparent and open approach to research that can be seen to be evolving out of service user involvement in research.

As a consequence of the request to keep real names within the text we decided to undertake a participant validation process. This meant that once we had written up the training example we sent a copy to each of the people who had contributed asking them to give us feedback. At this point people were asked to decide whether they wished to be named or not. This process took considerable extra time but could be seen to be making our own research process more open and inclusive, where research informants were able to have some control over the data.

The second point concerns 'labels'. The informants in these examples included both those providing training and those undertaking training. In order to maintain clarity and some consistency across the six examples, we have labelled the respondents into two broad generic categories of 'participants' and 'trainers'. However, we would like to emphasise in the strongest terms that this categorisation in fact over-simplifies the complex, two-way learning relationships that we found in these examples. The labels 'trainer' and 'participants' suggest an inequality in knowledge and expertise that is contrary to the ethos and actual experiences of the examples we visited.

Part 2 : The findings in detail
Section 2.2 : In-depth examples
Introduction

Example 1 : Multiple Sclerosis (MS) Society

Background to the training

The participants in this training example were either people living with MS or carers of people living with MS. The training we observed was a day-long workshop preparing people to critically review research proposals, with the aim that they could then play an active part in the selection of projects seeking funding from the MS Society.

The MS Society is a large national charity committed to serving the needs of people affected by MS. The MS Society Research Department has a key role in overseeing the allocation of money for MS research nationally.

The MS Society began developing the involvement of its members in research in 2001, including setting up the Members Research Network. MS Society members were recruited for this network via 'MS Matters' (the organisation's newsletter) and the Society website. There was an enthusiastic response to this recruitment drive, with approximately 160 members showing an interest in getting involved.

The next stage took place in 2002 when three workshops were held in different locations within Scotland and England. The aim of these workshops was to get people together to find out what kind of involvement they wanted and what they needed in order to help their involvement. The workshop format was the same in all three venues. In the morning, information was given by staff from the MS Society research department and there was discussion of the expectations, needs and possible barriers of getting involved. In the afternoon participants worked in small groups and looked at two previous applications for MS Society research grants. The participants were encouraged to explore what further information they would need to make decisions about the project proposals, just as would be required when they became involved in the real review process. The workshops included a discussion of the next step in developing the research network. The MS Society produced a written report of these three initial workshops (MS Society 2002).

During the workshops research network members were asked also to contribute their thoughts regarding a mission statement for the research network. The two most popular statements were:

> "To actively participate in the evaluation of current and proposed MS research to ensure the most benefits for people affected by MS."

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"To be actively involved in all aspects of the MS Society research programme in order to make a difference to the direction and quality of MS research."

So, the next stage of development following these workshops was to provide some training to enable research network members to begin to take an active role in reviewing research grant applications. That is, the members would evaluate the applications for research funding submitted to the MS Society by external researchers. These training workshops took place in Autumn 2002 and it was one of these training days that we observed for the purposes of the TRUE project.

Participants were not paid to attend the training workshop but all expenses were covered, including overnight accommodation if required. The reason for this is that, historically, people affected by MS get involved in many different types of activity with the MS Society, and all these activities are performed on a voluntary basis. The role of reviewing research proposals for the MS Society was therefore also to be a voluntary role for Society members.

Four of the TRUE research team observed a day of training (Julie, Geoff, Tina and Rachael). This was the second of a set of three identical training days provided by the MS Society to research network members in different locations across England and Scotland. Some of the participants had taken part in the Autumn 2002 workshops discussed earlier.

Observation of the training

The title of the training day we observed was **"Training in Evaluating Research Proposals"**. The training day was held in a hotel on the outskirts of Birmingham. Participants came from a large geographical area and included some people who lived in rural locations. Whilst this meant some considerable travel for a proportion of participants, much of the future role for which they were being trained could be done at home, using e-mail and post for communication.

The day started at 10.00 am and finished at 4.00 pm. There were eighteen participants, all of whom were affected by MS: sixteen were people living with MS and two were carers for people with MS. Many participants had physical disabilities and used wheelchairs and walking aids. The trainers were Kristina Staley, a researcher working at the MS Society, and Gillian Fletcher, a commissioned 'external' trainer. Gillian has a background in providing training for service user involvement generally and more specifically in providing training for the appraisal of research bids and papers. Two members of staff from the MS Society were also

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present, to provide practical support with moving around, getting tea and coffee, lunch, and so on.

The room was laid out so that people were sitting in groups around tables. There were four tables with four or five people around each. The places were allocated by trainers prior to participants' arrival and then re-allocated following lunch so that participants got to work with a mix of people.

The schedule for the day was:
1. Welcome and introductions
2. Expectations and ground rules for the day
3. Setting the scene – an overview of the MS Society Research Grant funding process
4. Understanding research terminology
5. Review of an MS clinical trial (small group work)
6. Introduction to research methods
7. Review of lay summaries of previous grant applications (small group work)
8. Next steps for the Research Network

The content of the day focused on evaluating research proposals, as this was the core role for which training was being provided. This 'evaluation' work would require people to be critical and questioning of research applications. As reviewers they would need to ask questions such as:
- Have they thought about this?
- How will they do that?

And, in particular, providing the expertise of someone affected by MS:
- What will the benefits be for people with MS?
- Is it important and relevant to people like me?
- Will there be any harm to people with MS?

The practical exercise looking at the process of reviewing proposals took place in the afternoon (session 7). This core session complemented others that aimed to provide information necessary to the effective undertaking of this role. These sessions included 'research terminology' (session 4) and 'setting the scene' of MS Society grants (session 3).

In session 7, three proposals were used to practice critical review skills. These were real, previous applications for MS Society research funding that had been unsuccessful (i.e. had not received funding).

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Prior to the main review exercise in session 7, a spoof research article from a spoof newspaper was used to warm up participant's skills in critically reading and questioning research. The subject of the article was a miracle cure for alcohol-induced 'hangovers'. Participants were asked to consider:

- If they themselves needed a hangover remedy, does the article provide enough information to inform their decision on whether or not to take this remedy? What more information would they need?
- How the research was carried out?
- Who funded the research?
- Who was presenting the results?

This exercise caused much laughter and provided a very good warm up to the three much more serious, lengthy and complex grant applications to follow.

Gillian, the external trainer, drew on her extensive experience in the field of training for service user involvement, in particular the CASP style of small group work for learning appraisal skills. Kristina brought her knowledge of the MS society and her background as a researcher.

Of the two trainers, one member of the TRUE team, Tina, said:

> "They seemed to share their roles as trainers very well, they seemed well organised and knew which part of the training they were teaching… they paced the day well, made it fun as well as educational and interactive."

All the participants appeared to be engaged and interacted with each other and the trainers. There was a willingness to learn.

Overall Geoff, Julie and Tina described it as a 'good day'. They thought that the participant audience had reacted well to the trainers and to the content, and that there had been a good atmosphere. Geoff said that the training was much better than his experience of training in the army and the fire service. Julie said it was better than experience of her university courses. Things that stood out were:

- Everyone was involved and brought into the discussion, and things they said were written on a flipchart, signalling that all individual contributions mattered.
- Clear language was used about research methods.
- There was a good introduction to explain the day and its purpose.

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- The research articles that the trainers gave out to read were to help people understand the research terminology and Julie described them as "a good teaching tool for laymen".
- Participants were encouraged to say if they had any difficulty in hearing what was said or were experiencing any pain or discomfort during the day. This was discussed during 'ground rules' at the start of the day.
- The day was full of humour.
- At the end of the training day, keeping in touch in the future was discussed.

The hotel venue was visited by a member of staff from the MS society when planning the day to ensure that it could cater for wheelchair users. However, despite these efforts, there were still difficulties on the day. There were insufficient disabled parking spaces, and sadly one participant left as he was unable to find a disabled parking space. Also there was some distance to move for lunch, which was a disadvantage for people with a physical disability.

Participants' views of the training

We interviewed five participants who had attended the training day we observed. All five had heard about the MS Research Network and training through the MS Society, of which they were already members. The interviewees stated a variety of reasons for getting involved:

"My daughter has MS. The Society was very good to us when she was first diagnosed at age thirteen. They helped a lot. I became involved because I wanted to repay them but also at the same time to be of some use to other sufferers."

"Because I wanted to know more about the complaint I have."

"Because I have the condition, and there is no better person to become involved than a user. You can't complain when things go wrong unless you are involved. I also have a modicum of medical background. Use the experience you have got."

"Now I am retired I've got spare time, plus the fact that I felt I wanted to do something to help the MS Society as well as occupy myself and I can't do … sort of things on a regular basis, you know, I can't work for local committees and turn up every Friday because I might not be well enough, but something like this where … alright, you might have a month to go

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through some proposals, it's not time critical from day to day, so it seemed a useful thing to get involved in."

For this last respondent, then, it was the nature of the involvement on offer, i.e. the fact that the activity could be managed around his own health, which made it possible to get involved. People with MS told us that this is a common problem and there is early discussion within the MS Society research department of developing a long distance training pack to increase accessibility to members.

One of the participants had been involved in the early stages of the development of the Research Network, as a member of a planning reference group:

"I was involved from the very early stage, which is about eighteen months ago, when the MS society decided that it wanted to involve more people that actually have MS in their decisions in what they were going to fund, what they were going to put money into … and I got involved then and it's grown since really. There was six people to begin with …"

Some early barriers to being involved in the Research Network were also identified:

"Originally, at the second meeting I had been to … it wasn't very thought out and well planned and because I have this condition … the very nature of it tires you out. So I thought, 'How am I going to get from A to B?' It was about 100 miles there and 100 miles back, I don't drive any more. My husband kindly offered to take me and bring me back but obviously it's too much for me to do in one day so I asked the Society, they said they would pay expenses and I asked them if I booked accommodation would they do that, they said Yes … they said to me next time they would book it for me through the Society."

By involving people with MS in the planning and development of the Research Network these teething problems were being addressed:

"Like I say I've been involved for a number of months now … I've seen it from the first sessions we had up until the last one that we had … there has been a dramatic improvement … I think the main one – not the content as much as the actual day, with understanding the participants' requirements."

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Overall, participants thought the training day we observed had gone well. Some participants were already actively reviewing bids and they were able to say that the training related very well to this task.

Regarding the style of training, people particularly liked working in small groups:

> "Yes, I must admit the mixing and matching – so you were with one group in the morning and then the change in the afternoon – I thought was good because you got to meet – not being a sufferer but more a carer, I got to speak to people who are far more advanced than my daughter, sadly, and understand a lot more about the barriers they come into contact with on a daily basis."

We asked people what they thought had worked particularly well on the day:

> "The balance was about right between sort of … listening to people, presenting topics and actually doing work in small groups."

And most importantly:

> "I think in general the people attending were prepared to be involved. I think that was the major thing."

When asked how the day might have been improved, suggestions included:

> "Well, not going with any real preconceptions, I can say that everything I wanted I got from the training."

> "Can't think of anything, but it's difficult not knowing much about it. If something's not there then you don't know it's not!"

At this early stage, then, people were very positive of the training. Perhaps most importantly, participants felt the training day had prepared them for the research role intended:

> "I think it has helped by hopefully cutting through some of the jargon, which is what it's all about. That's the most difficult thing I think from the layman's point of view."

> "… to get an overall picture of the process and the way that research is done and the proposals for research that are put thought the MS Society."

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People expressed other benefits to attending the training including increased confidence:

> "Slightly more confident … training and things makes me a bit nervous – 'Will I understand it?' and, you know, those sort of things. 'Will I look stupid?' and that sort of thing. So I suppose I have got boosted my confidence."

There were also the benefits of meeting other people affected by MS:

> "It's made me aware of signs and symptoms to look out for in my own daughter. The whole day was a positive experience from start to finish."

> "It was quite useful. I talked to a few other people, in the small groups particularly but one or two others at lunchtime. I mean that's nothing to do with the training but for myself that was quite useful, it's always informative talking to other people with MS."

Lastly, we asked people to think about future training: would they want any and did they have suggestions?

> "I think you probably could go a bit deeper into certain subjects. That's not a criticism of the training we have had so far but I think maybe there should be a follow on which would go a bit deeper."

> "I'd like to see something that builds on the basic building blocks that have been put in now. I've spoken to people on the MS sufferers day who had already been given research projects to comment upon and they certainly felt more positive to comment now and I felt I've got that ability now but I would like to think it's an ongoing process rather than one-off day here and you're left to get on with it. I would like to see it every twelve months or as frequently as possible."

> "If you've been asked to comment on a particular research project, [it would be interesting to know] whether that project was successful or unsuccessful, because it would give you a boost to think, 'Yes, I've done something positive', or if you didn't think the project was worthwhile or cost effective, then you'd like to feel as though your point of view has been taken into consideration by the professionals when they make their decisions."

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Overall, then, people felt more training at a later date would be beneficial, as would feedback on the review process to which they were contributing. The formal training then is seen as only part of an ongoing process of feedback and learning.

Trainers' views of the training

We interviewed both Gillian and Kristina. Firstly we asked them how they thought the training had gone. Gillian thought that the participants:

> "… seemed to be fairly satisfied, that they were taking away some of the skills and tips and hints that would help them look at the current proposal."

Kristina also thought it had gone well and felt that what they had learnt from running previous sessions had enabled them to achieve what they set out to do. She was particularly pleased that one of the needs identified by participants – a list of questions for people to use when they are reviewing proposals – had resulted in the generation of this research tool from the three workshops.

Gillian clarified the trainers' aims:

> "I hope to instil confidence in people that … actually they already have a lot of the skills to help them do the job, they just don't always recognise it or they call things by different names."

Gillian went to discuss how she thought participants learnt from one another and that the trainer's role was often more of a facilitative one:

> "By sharing in small groups with each other, they learn because there's a mix of people. Some already have research experience and others don't, but by putting that rich mix of people together you're much more likely to get cross fertilisation going."

We asked Gillian to think about how she ensured that people felt comfortable and able to ask questions:

> "Setting the scene very carefully at the beginning, giving people the opportunity to say what they want out of the day … not to make assumptions that everybody's clear about what they want."

As well as allowing time for this on the day, Gillian told us that careful preparation before the training had taken place, getting people involved right at the beginning:

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> "Having a small reference group of people with MS to advise. They were there right at the very beginning to design the training and think about some of the practical issues that we would face in terms of working with people who perhaps weren't as mobile as some other groups that we worked with. We knew that we wouldn't be able to move people frequently throughout the day from one small group to another, so we thought very carefully about how we would have the rooms set up with the round tables and how we would move people at lunchtime rather than on frequent occasions during the day."

Gillian went on to explain that the actual training materials had been tried and tested in previous training with other groups and then adapted to make them more MS specific. The materials were based on the work that Gillian and others had done with the Alzheimer's Society 'Quality Research in Dementia' programme. Some of those materials were developed with the Public Health Resource Unit (PHRU) at Oxford and the permission of PHRU was gained to adapt and use them.

Kristina, who complemented Gillian by bringing knowledge about research specifically in the field of MS, explained why the research proposal examples were chosen:

> "One looked at specific microbiology and would have very complicated language in it. We wanted to look at one that was more socially based, so that was the one about people's concern and anxieties when they've not yet had a definite diagnosis in that interim period. Then the [third was] about nystagmus, which was in between the other two."

Kristina considered that the inclusion of a broader range of proposals would be a positive development for the training, not least because this would help to reflect the diversity of proposals people would be reviewing in their research roles for the Research Network.

Kristina went on to talk about 'pure science' proposals and the language used in these, which she thought might be a potential problem area:

> "The thing that's bothering me is the 'pure science' applications and how we handle those because I think they are very difficult to review in the way that we reviewed those ones at the workshops. What has happened in the latest round is some researchers have put in their line at the beginning saying, 'We are going to study this immunology thing and this is going to

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lead to a cure,' and then they go off on their immunology thing which may lead to a cure, but may not, but reviewers pick up on that and say we've got to fund it. How to counteract that or cater for that, I don't know."

Kristina also highlighted the communication problems that might occur between scientific reviewers and reviewers affected by MS:

"Some of the expert (scientific) reviewers have come back and said, 'You can't ask lay reviewers to evaluate these kind of proposals because they can't assess the technical side of things.' But I'm not too worried in some ways because that's the sort of conversation that needs to happen."

This issue of 'lay' review of 'scientific' research is one that will need much thought and consideration as the process of involvement further develops, and a challenge that is shared by many other people in other fields.

Outcomes and future plans

Following training, the participants commenced their role as reviewers and found that the training supported this role, assisting them to give critical feedback. Other benefits to the training were increased feelings of confidence and meeting other people affected by MS.

During the process of participant validation of this training example, participants told us that they were still involved in reviewing real grant applications, one year later. Two participants were involved in a 'buddy' scheme, one as a team leader and one as a buddy. The buddy scheme is a pilot study aimed at developing closer links between people affected by MS and researchers funded by the MS Society. The team leader had also accessed some further training in monitoring research and meetings with researchers.

The MS Society has recently changed its research strategy to include not only an 'open grant' round but also a 'themed grant' round. The themes were identified through a prioritising process in which researchers and people affected by MS worked together to agree themes. The result has been a greatly increased interest from applicants and there may be a shortage of both 'lay' and 'scientific' reviewers to cope with the greater numbers of applications. In response to this development, the training day was repeated in May 2003, to train another (approximately) twenty Research Network members for the role of reviewing research proposals.

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Key learning points from this example

❖ A lot of time and careful planning was needed to establish the MS Society Research Network. This included working closely with a reference group of people affected by MS.

❖ People affected by MS were involved in planning the training right from the beginning.

❖ Training was provided to enable people to critically review research proposals, providing the perspective of a person affected by MS.

❖ People's willingness to be involved made the training day a success.

❖ The level and style of involvement aimed for meant that many people could be involved, including people who needed to work from home at a time that suited them.

❖ People wanted to be involved because of their own experience of MS and to ensure research benefited people affected by MS.

❖ Support with travel and overnight accommodation was required by some participants.

❖ An accessible venue was essential and prior inspection is highly recommended.

❖ This training provides a good example that, with a group for whom mobility can be difficult, trainers need to think through carefully how they plan the day.

❖ 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.

❖ Language was clear and jargon 'cut through'.

❖ Extra people other than trainers were available to provide practical assistance to participants.

❖ 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 felt the training boosted their confidence.

❖ Some of the research proposal and language was very scientific. This is an area that needs further development to ensure people affected by MS and scientists understand one another.

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Example 2 : Listening to Change / Young Researchers Training Programme

Background to the training

This Training Example was for young people involved in a research project called Listening to Change. This was a national research project being carried out by a collaborative team. The team was managed by Perpetua Kirby of PK Research Consultancy Ltd, an independent researcher specialising in youth participation. Other team members included researchers at the National Children's Bureau (NCB) and youth researchers. The project began in early 2003 and was still ongoing at the time of writing. The project had a total budget of £110,000 and was funded by the Children and Young People's Unit. Of this £10,000 was allocated for the involvement of young people including a residential training weekend.

The aims of the Listening to Change project were to identify good practice in involving young people in projects/services for young people. The role of young people on the Listening to Change project was twofold: they were both **youth advisors** and **young researchers**.

The role of **youth advisor** was to advise the research from a youth perspective, including agreeing questions, designing materials to use in discussion groups/interviews with young people and children, advise on aspects of the research findings and on how the final report will be presented to young people and children who took part in the research.

The role of **young researcher** was to take an active part in doing the research by leading discussion groups at training examples, along with an adult researcher.

Ten young people were recruited to be youth advisors and all ten chose also to undertake the second, optional, role of young researcher. The young people were required to attend a weekend training and introduction course. This took place in February 2003. This was a one-off training event devised specifically for the Listening to Change research project. This training was also accompanied by on the job training and support, as well as a closing weekend towards the end of the project.

The young people were recruited nationally through the NCB or associated youth activities such as Youth Councils. They were young people who were already actively involved in youth participation issues. The training was held in London at the NCB.

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Tina and Rachael observed the second day of training, which we discuss in some detail. Tina was a good choice for our team; as Tina was 24 years of age at the time, the youngest of the TRUE team, we were particularly interested in her perceptions of the youth training.

Observation of the training

> "This training seemed to me to be informal but structured. The atmosphere felt very calm, relaxed and very friendly both coming from participants and trainer." (Tina, TRUE Researcher)

There were ten young people present at the training we observed: six young women and four young men aged 14 to 21, including people from Black and Minority Ethnic groups. Also attending were two researchers from the Listening to Change team, both working for the NCB, and one trainer from NCB.

The venue for training was NCB premises in North London. These premises are near a London Underground station. The Listening to Change research team co-ordinated the train travel of young people including meeting them off and escorting them to trains. This was important, as members of the group were as young as14 years old. Also it was important to make sure the young people left London promptly on the second day as some of them had considerable journeys to make. All were currently in education, either attending school or college.

The young people were not paid for their attendance at the training; however, all expenses were covered including hotel, meals and leisure activities. They were paid for subsequent research activities.

The training took place over two days. Each day started at 10 am and concluded at 3 pm, with breaks and lunch. The first day, which we did not observe, covered these topics:

- General introductions
- Icebreakers
- Understanding research
- Equal opportunities
- Respecting other people's views
- Confidentiality
- Choosing your research questions

This first day was followed by an evening out bowling and having pizzas. The young people were accommodated overnight in a hotel. The trainers/researchers

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considered the social events and the residential aspect of the training to be very important because they provided time for fun and relaxation as well as allowing space for the group to form and get to know each other. Other people we interviewed about youth involvement in research also clearly stated these were important factors.

The sessions in the second training day followed this order:

1. Welcome
2. Working with groups
3. Listening and communication skills
4. Discussion groups
5. Information on advisor and research roles
6. Evaluation of the day
7. Closing summary

The training was led by Rachel, who works for the NCB and has a lot of experience in working with and training young people, facilitating their involvement. Kathleen and Clare, both researchers on the project, supported Rachel in doing the training.

The focus of the day was working with groups and running discussion groups. First of all the trainers led an exercise where participants went into small groups to talk about what was helpful and what hindered working with groups. The results of this were fed back to the whole group and used to put together a set of guidelines for working with groups.

Each activity was done in an informal and interactive manner. Role-play was drawn on to bring subjects alive. An example of this was the discussion group training. As part of their young researcher role, the young people would be co-leading discussion groups at training examples. In order that they might experience what it felt like to lead or take part in a discussion group, the young people were given roles to play. These were written on a piece of card and included characteristics such as 'quiet and hard to involve' or 'very talkative and hard to shut up!' The young people acted out their given roles. By doing this the young person allocated the role of group facilitator experienced the task of trying to involve everyone equally in the discussion and to keep them on the relevant subject area. This exercise was accompanied by a lot of laughter.

After the role-play, people fed back their experiences to the group and an informal session on trouble shooting in relation to discussion groups followed, this included sensitive issues like if a member of the group makes insulting comments to another, or someone reveals racist attitudes etc.

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Issues relating to confidentiality were also addressed further on this day. This was done again by a practical exercise: people were asked to write a secret on a piece of paper and then fold it and it give it to another member of the group to hold. They were then asked to reflect on how it felt to have this secret held by someone else, whether they could trust the other person not to open it or share it with anyone else.

Tina, TRUE researcher, summarised the day observed:

> "The whole day was based on working together. There was very good communication skill both from participants, trainer and the researchers. Role-play seemed a big part of this training in understanding both about themselves and training. In all, this day seemed to have worked VERY well and was both a learning tool and a fun day."

Participants' views of the training

We held a focus group with the young researchers in July 2003, at the closing weekend of their involvement in the project. This was at the same venue as the training weekend, the NCB premises in North London.

Tina led the focus group, supported by John. There were five members of the original ten young researchers present. Some of the other participants were unable to attend due to school examination commitments. Those present were Jack, Hannah, Robin, Graham and Mattie. It was agreed between the young researchers that adult researchers from the project would leave the room for the focus group.

When asked why they had wanted to get involved in research, the participants answers included: wanting to learn new skills, to meet new people, because it was interesting, because they wanted to be involved and because they felt it was worthwhile. Jack stated that he wanted to see:

> "How other organisations are run and how they involve kids in their decision making."

The young people had become involved through various routes including letters and e-mails from NCB and contact through organisations in which they already played an active role, such as Youth Councils.

We asked them to tell us what they had thought of the training and what stood out for them as good examples of training. The confidentiality exercise from the second day was identified as a good example:

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"I enjoyed when they were teaching us about confidentiality and I though it was really clever how we all had to write down a secret on a piece of paper and pass it round, and it was like, Oh God! Yes, that was really effective for me." (Hannah)

The exercise in equal opportunities from the first training day was also cited s a good example:

"I thought it was quite fun when they gave us a page of pictures of random people and asked us to be really judgmental about them … who would be most interesting to talk to, who would you be friendly with, not so friendly with?" (Robin)

The training in leading a discussion group was also discussed. People had found role-play a good method by which to learn. They also valued the discussion of how to deal with problem situations when leading a discussion group.

When asked, the group could not think of any examples of training that they thought had not worked so well. Overall the training was very positively evaluated. The participants said that they had both enjoyed and learnt from the training weekend, and that the training had helped them to be effective in their roles on the Listening to Change research project.

We asked them to think more about how the training had prepared them for their role, what kind of skills they had learnt. Robin, who visited three case sites for the research project said:

"Those kind of skills about interviewing people, making people feel comfortable, just those kind of skills really." (Robin)

And Hannah gave a reflective example of how she considered the training had prepared her:

"In one of the projects I went to, it was really useful that I learnt how to be objective, because there was a guy there that we were interviewing and I didn't agree with what he was saying, so I sat there and I was thinking, 'You can't say anything, you're interviewing.' So the training really helped me there because …. well you know what I'm like (laughs), normally I'm quite outspoken. So it helped me there to not say, 'Actually, I disagree.' So that was good." (Hannah)

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The training weekend, was at the start of their involvement and was designed to prepare the young researchers for their research roles. The weekend could be described as the 'formal' part of their training. However, as Graham explains, this is only one aspect of training and support for their involvement:

> "I went to three projects. The first one I went to, Cathy and Claire were really, really supportive and they just gave me extra on-the-spot training, and then by the time I went to the second project I felt really equipped to do interviews and I did one just myself, without Cathy and Claire, and the training was really, really helpful."

What Graham describes is a 3-step process:

1. receive training
2. undertake research activity supported by researchers
3. take a lead role in research activity

This then can be seen as an ongoing learning process with the formal training being only one component of the overall training, learning and support.

We asked the young researchers to identify those qualities that they thought were important in the trainers for the training to be successful. Responses included those qualities that would not be good:

> "Ordering us about with out asking us what we feel is not going to work."

> "Some people have got their rules and they're not going to budge."

A good trainer was described as someone who met the following criteria:

- Friendly
- Being part of a group – not 'us and them'
- Being able to reach their objectives by the end of the session
- Getting things done whilst spending time with us
- It is important that the trainers can relate to us as young people
- Flexible but has to know how they are going to run group
- Meeting us half way
- Good listening skills

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There seemed to be a balance required between having a structure and also being flexible as well as balance between having fun and reaching the session's objectives:

> "I think that the structure used is really important. It has to be a sort of free structure but not necessarily fun – well fun, but not like all games – it has to be quick and interesting and not drag on." (Hannah)

Tina, our TRUE 'young researcher', shared lots of these views and also agreed that it was important that participants had input into how the day was run. This involvement of people in their own training can even take place on the day if time is given to establishing people's needs and wishes.

We moved on to ask the young researchers to think about how the training might have benefited them in other ways, beyond the research activity:

> "I got experience in how to deal with certain situations, met new people and just had a generally good time." (Jack)

> "It gave me more confidence to go somewhere really different and meet new people. I'd never been to London on my own before, that was a whole new thing. Experience, new skills, general things like that. Some of us are working on another NHS project so that's going to help us as well." (Hannah)

> "I've learnt really good life skills, just generally, use them all the time." (Robin)

These responses, which included broad benefits such as general life skills, prompted a discussion of whether the training could stand-alone i.e. be done not in relation to a specific research project. Whilst Robin thought the training wasn't that specific and could stand alone and be of use, Graham felt that it was important that the training was accompanied by specific research purposes/activities.

Trainers' and researchers' views of the training

We interviewed Rachel, the training organiser and Perpetua, one of the research team, about their views of the training and generally about involving young people in research.

Perpetua's role was as research manager of the Listening to Change project. We asked her why they had chosen this involvement within their own project:

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"The project is looking at user involvement, so we're looking nationally at
how children and young people are involved within services, to make
decisions to influence those services. So obviously when you're doing a
project like that, or even if you're not, user involvement has to be integral
to it. We wanted it to be informed by young people and to give them the
opportunity to get involved."

For this involvement to take place, the research team felt that it was necessary for
training, particularly for the role of young researcher. For the role of youth advisor,
information and an opportunity for the group to get to know each other were
considered necessary. Therefore the weekend was planned to meet these needs.

Rachel was the lead trainer and took responsibility for putting together the weekend
training course; other than this she was not involved in the Listening to Change
project. The aims and purposes of the training were pre-determined by the research
project and Rachel saw her role as:

"I think all we were trying to do was just really give them a very basic
understanding, not to say that they can go off and be a researcher but just
a little bit of a taster of some of the things that they might have to come up
against."

During the weekend she had hoped to give them some preparation for both the role
of advisor and researcher, on the project:

"Yes, so, for the advisory thing we would give them basic information on
the first day about different types of research methods so that when they
come along to work in an advisory capacity at least they know what people
are talking about. So it's just basic information-giving and then also just a
little bit of experiential stuff so that they can see what might happen if they
were taking part in a discussion group or something like that."

The main problem she identified with providing the training was short notice, which
meant lack of preparation time for the young people. This was also the case in
Training Example 6 and whilst both respondents felt that this had been overcome this
may need to be considered, particularly by commissioners, in cases where training is
attached to a research project, notice to start the project may be short.

Rachel, the trainer, stated that having participants:

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" … who were already motivated and very willing to listen and learn was a great help."

When asked about her approach to training with young people, Rachel replied:

"I think it's just about being flexible in your approach. I think the key thing is just trying to get the start of the session off and running well and getting the young people to feel comfortable with one another. So maybe being flexible and having a bit longer for ice breaker session and generally getting people to know each other so they feel comfortable in the group. With some of the more reluctant young people that I've dealt with in the past, we've tried to sort of change activities and split groups up so they can do something slightly different if they're not comfortable with the role play or something like that."

From the above quote it is easy to see why Rachel was evaluated well as a training provider as she identifies many of the same issues the young people cited as important in a trainer.

Overall, the participants' feedback at the end of this, their second day of training, was positive. However Rachel made the following point:

"A lot of the feedback was just, 'Yes, I had a really great weekend, enjoyed meeting all the people,' which is really good, it's nice for them and everything but it doesn't really tell you that much about how you would improve the course."

During our focus group, which was held several months after the training weekend, the young people were able to say whether the training had prepared them for their research roles and how they had used the training in other ways. Therefore, it appears that evaluation of training may be needed at more than one stage:
- in the short term, directly after training
- during research activities
- in the long term, whether people stay involved, research outcomes, impact on individuals.

Outcomes and future plans

The young researchers had all taken an active part in the training and the research, as well as having fun. Many of them were already getting involved in other research related to youth involvement.

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The young people in the focus group clearly stated that the benefits of doing the training and being involved in the research had been greater than just doing the research; they felt that they had developed useful life skills.

Key learning points from this example

We asked the young researchers to make recommendations for anyone considering planning training for or research with young people:

❖   Go into it with a positive attitude – trainers, researchers and participants alike.

❖   The environment is very important: if you are in an environment where it's uncomfortable or formal for young people, then it's not the right place for learning new skills.

❖   Both the researchers and young people have got to want to do the project for the right reasons.

❖   Try to get everyone involved during the training.

❖   Build up people's confidence by developing a good relationship.

❖   Trainers have got to be 'in touch' so you feel you can talk to them.

❖   Be very clear as to what you are saying, don't use jargon.

❖   Have aims and objectives so people know what they've come for and what the goal is at the end.

❖   A flexible, informal training approach works well with young people.

❖   Involve young people in deciding the structure and content of the day.

❖   Fun, social activities should be included in the training timetable.

❖   Be mindful of school/education commitments when planning training and research involvement for young people.

❖   The formal training is only the beginning – support/training on the job are equally important.

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Example 3 : Norah Fry Research Centre

Background to the training

This is an example of training for researchers who are people 'with the label of learning difficulties'. We use the term 'with the label of learning difficulties' as this was the preferred term of the people involved in this initiative.

The Norah Fry Research Centre, University of Bristol, was set up in 1988. The centre undertakes both national and local research in the field of learning difficulties. The aim of the centre to is to undertake research which will improve the lives of people with learning difficulties. This is done by producing research which can influence policy and service provision and/or by empowering service users and carers so that they can influence services.

We interviewed the research supporter from Norah Fry, Val Williams, early on in our research project. This interview raised lots of interesting questions about what 'training' was. The interview schedule we used proved to be too rigid and assumed the notion of training being delivered in a course type structure, which people could then go on to use for involvement in research.

The researcher we interviewed told us about a set of training sessions that she had provided for researchers with learning difficulties, as part of a total package of support to one particular research project. She explained that the training sessions themselves consisted, in total, of only 18 hours over a two and a half years long research project. Val explained that researchers at Norah Fry had learnt, partly through feedback from participants, that this style of training was not always the most suitable. A more formal, 'course' type approach was not the best way to ensure that information was made accessible and easy to understand for people with learning difficulties. In fact 'training' was not a word Val used to describe her role, which she described as 'facilitation' and 'support'. Val called herself a 'research supporter'. This research support was ongoing throughout the life of the research project and beyond.

This interview then, done very early on in the life of our own research project, broadened our concept of what 'training' for research might be. The nature of the researcher group, those who experienced learning difficulties, presented an opportunity to think differently about how people learned to be researchers, as well as challenging more traditional beliefs around who does research and what 'research' actually is.

We arranged a visit to Norah Fry to conduct a group interview with two researchers who experienced learning difficulties and one research supporter, Val. On the day

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only one of the researchers, Mouse, was able to attend. We were also joined by Robert, who also has the label of learning difficulties and was doing some work experience at the centre.

Interview with researcher and research supporter

> "We received a very warm welcome. I felt comfortable about the group interview, having prepared with Rachael. We divided the questions between us and I took notes when I wasn't asking. The questions were set up with the researchers in this group in mind. I was very inspired by Mouse and Robert." (Sherée, TRUE researcher)

Mouse had become involved in the work at the Norah Fry Research Centre a few years previously, initially working on the 'Finding Out' project, a piece of research about self advocacy. She herself experienced some learning difficulties and was researching into this area. She was currently not working on a specific project but meeting regularly with other researchers and also developing her own role as a trainer. We asked Mouse to tell us how and why she got involved in research:

> "I'm interested in what people do … I wanted to get involved so I can learn from them and they can learn from me. The more research I do the more interesting it gets."

We asked both Val, the research supporter, and Mouse to tell us about how they worked together. In the following dialogue between Mouse and Val they discuss some work they did together on a project called 'Having a Voice':

Mouse: The Government wanted somebody to do a project about helping the kids to speak up for themselves. So what we did is, Val and I went along to a hostel were the kids were staying, we introduced ourselves, played with them, we showed them photos and pictures and asked them what they would like to do when they grow up.

Val: We did interviews and as you rightly said we showed them photos and we had a kind of booklet, didn't we?

Mouse: Yes.

Val: But the local council, who paid for this project, they didn't tell us to do these things; the booklet came from something you wanted to do because you had a chat with …

Mouse: That's right, we did a booklet. If we were going to write down a couple of things I could imagine the kids would say, 'Well, what are they on

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about? It's all right writing but we don't have an understanding.' So I thought because the kids are about seven to nine years old and they don't have an understanding, so if we do a bit of writing and do a bit of pictures, perhaps they could look at the pictures and writing and think, 'Ah, I know what their getting at,' because there are so many things they don't understand, I thought it's easier – I've seen people do this and it gives me ideas on how I can put it. So that's one way of doing it.

Val: That was really good because you came up with those ideas about how you wanted the booklet. We did take time – we had as much time here at Norah Fry doing preparation and thinking about what we were going to do – and feedbacks as well, it was one day with the children, next day on preparation and feedback and so on.

Mouse: Yes.

Val: I think it worked because of your skills. Actually because no matter how much support I'd done it would have only worked if you had those skills.

The above dialogue is an example of the researcher and research supporter working together. Mouse brings innovative and creative ideas to the research process drawing on her knowledge, skills and own personal experience. Val is there to help put this into action.

We asked Mouse to think about what her skills were:

"Understanding kids. I have worked with kids before and the more I get to work with them the more I understand them ..."

During the group interview it was apparent that Val and Mouse worked together closely in every aspect of research, including the process of being interviewed. Val's supportive and facilitative role was observed and Mouse was comfortable to challenge and did so on many occasions. This also included Mouse asking us to say things in a clearer or different way so that she could understand us. We asked both Val and Mouse to tell us about this working relationship:

Val: Personally, things do work when you know someone very well, we work together, hopefully quite well, because we know each other.

Mouse: Val and I just say what we've done, how we've done it, why we've done it. Everyone who wants to know about it, we just tell them.

Mouse made several references to this 'What? How? Why?' approach, breaking the process down into clear, manageable chunks.

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We asked Mouse to think about what kind of support she needs in order to help her learn skills for research:

> "It's Val being there for you really, supporting me all the way. She knows when I'm stuck … she's always there, if I can't explain anything, she's there to explain for me, like she did earlier, she had to help me to explain it in a different way. I feel comfortable with having Val around. If I had a new person then it wouldn't work because, as Val says, we've known each other for years."

Again Mouse's comments reinforce the importance of working together with people who know you well. In order to be involved in research, 'training' in this case is an on-going facilitation and support process, and research activities are done together.

In the following extract Mouse described the working relationship between herself and Val when presenting at a conference:

> "Going to a conference, Val will give me a few ideas of what to remember, how do it, when to say it, why I should say it. Once I've gone through it all with Val, it's up there (points to head). I can remember, that's not a problem but when you've got to go through the whole record that's when it's tough."

More recently Mouse has started taking more of a training role herself at open days and introductory days for other people with learning difficulties getting involved in research. She said:

> "I find it interesting when you've got all the skills, when you are actually working with that person and training that person, you're going back to square one and teaching other people what you've done before."

This process of training seemed to help Mouse to remember and consolidate her own learning. Val went on to explain the benefits of people like Mouse training other people with learning difficulties. She makes the point that getting people from the 'target audience' involved right at the beginning of research and training is likely to help set the right tone and style and thereby make the training more effective:

> "When people with learning difficulties do training and so on themselves, it's very different to if I'm just going in and doing it. I'm not saying there can't be team work and you can do things together but having, if you like,

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'real' people there at beginning is really important because it sets the right way of talking about it."

We asked Mouse to think about what things she does now that she didn't do before she got involved in research. Referring to a presentation she did at an international conference, Mouse replied:

"Face two thousand people."

Mouse clearly stated the personal benefits that she has experienced though being involved in research:

"To be taken seriously, it makes me sort of professional. I now know what I'm talking about, at one time I thought I was a laughing joke."

During the interview an important discussion developed on the subject of labelling and labels, which has implications for both those involving and those getting involved in research and training. The following is an extract from Mouse talking about herself:

"I don't see myself as a service user, I see myself as normal. Everybody says, 'What's normal?' To be honest I don't feel disabled at all, I might be but I don't feel it. At one time when I was about 13 I really played hell because they told me I was disabled. I wouldn't go out the house because I was frightened. I just feel like a normal person who has not got any disabilities at all."

Val made it clear that through getting people involved in research it is not intended to 'normalise' people but rather to make their experience of having a learning difficulty their strength. As part of this she considers it important to work towards having a pride in your own identify and supporting others to do so. She went on to say how labels and self-awareness of labels had emerged as one of the central themes of an earlier research project. Mouse had the following to say about labels:

"Someone said to me, 'What does a label mean?' I said a label means people see you as a disability but not only a disability; they're putting barriers up saying, 'You can't have this place or that place because you have a disability.' They're saying, 'You can't do this, can't do that because you are too slow. You can't read, you can't write, can't count.' That really bugs me."

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Mouse went on to talk about how she has often felt 'shut off' by people and workplaces. She described her involvement in research as different because:

> "When I'm here (Norah Fry) it's different, yes I am normal and yes I feel professional, yes I feel open."

And Val made the following comment:

> "I think the whole area of identity is something that's really important to this research. They're doing it because they're a person with a 'learning difficulty', so it becomes their strength. But it's not something that you can sit and teach people or impose on them; it's got to come from them because it's about people defining themselves."

This is a complex area and further exploration of it would be beyond the remit of this research report, but an area that does need further discussion and development. However for those wishing to involve people in research it may be appropriate to give some thought and time to the issue of labels. It is clear that the process of being involved in research in an area similar to the researcher's own experience may raise self-awareness about their own situation, including the possible prejudice and discrimination experienced by people like themselves.

Outcomes and future plans

We asked Mouse and Val about their future plans. Mouse wanted to 'carry on researching' and Val was keen to involve more people in research and work alongside them.

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Key learning points from this example

❖ The researcher without the label learning difficulties called herself the 'Research Supporter' and described facilitation and support as her main roles.

❖ The researcher with the label of learning difficulties and the research supporter work together through stages. This facilitated successful research involvement.

❖ 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.

❖ Research supporter must not take over.

❖ Getting people with the label of learning difficulties involved from the beginning can ensure correct language, style and pace is set.

❖ The research process can raise self-awareness in both researchers and research informants about labels and associated possible prejudice and discrimination they may experience. Time may be needed to discuss and explore this. Find out at the beginning how people view themselves and how they like to be referred to.

❖ The experience of having learning difficulties becomes the researcher's strength.

❖ Good, clear information should be made readily available.

❖ Encouragement and support from people who believe in you – such as carer, supporter, social worker and family – are crucial.

❖ People should be welcoming and friendly.

❖ Open the barriers up – give people a chance.

❖ People should learn more about disability and focus positively on people's potential.

❖ Involve people in the planning and delivery of training and research – preferably right at the beginning.

❖ Provide some continuity for people – it doesn't just end when a research project ends.

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Example 4 : Consumers as Researchers

Background to the training

In early 2001 the steering group of Staffordshire's Welfare to Work Joint Investment Plan (JIP)[1] formed a partnership with the Centre for Health Policy and Practice, Staffordshire University to develop a research training course titled 'Consumers as Researchers'.

The first course started at Staffordshire University in 2001 with the aim of teaching research skills to disabled people living in the Staffordshire area. The course was made up of ten sessions that included: an overview of research, questionnaire design, interviewing skills, doing focus groups and writing up findings. Students worked in small groups pursuing a shared research interest. The outcome of this course was a conference where participants presented their research. A written report was also produced.

The funding for the first course was £17,000, which came from South Staffordshire Heath Authority and Staffordshire County Council. Staffordshire County Council also contributed £7,000 as part-funding for the second course; this was match-funded by the University. Findings from both courses are being disseminated by the Welfare to Work initiative to raise disability awareness amongst service providers and employers.

Participants were paid £5 per hour to attend the course and all their travel costs were met. Other costs, such as those of a signing interpreter for people with a hearing impairment, were also met.

The course leaders from Staffordshire University were Liz Boath (Head of Centre for Health Policy and Practice), Eleanor Bradley (Senior Research Fellow), and Paul Jenkinson (Research Psychologist). Participants on the first course were a mixed group of older people and disabled people; the second course was for disabled people only. Liz had previously run a similar course for young people.

The second course started in November 2002. We observed a session from this course and later met with participants for a focus group.

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[1] JIPs were set up in response to national guidance from the Department of Health in 2000, the aim of which was to develop plans to improve job opportunities for disabled people.

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The course was made up of ten sessions each lasting three hours, spread out over a period of a few months. The course aimed to provide training and support so that consumer participants can undertake some research. Liz also stated that one of the aims of the course was to help participants find employment through gaining useful experience in research.

The sessions were held from 3 pm to 6.30 pm, at the university premises. The room had good access and was large enough for people to sit comfortably and have space to move about. All participants had joined the course after seeing a flyer advertising the course, which had been distributed to voluntary sector agencies and the local social services. The course was also advertised on local radio, in local newspapers and newsletters.

The Consumers as Researchers course training is not attached to a specific research project: students decide what it is they wish to research within the theme of disability and employment.

Observation of the training

We met six of the seven participants on this course. The disability experienced within the group included physical disability and sensory impairments. Of the seven participants one was a woman and six were men. There were two Black and Ethnic Minority group members and five White. Also present were a carer, a signing interpreter and the three course facilitators.

On first meeting the group, most striking were both the diversity of people and the measures in place to accommodate everyone: much attention had been given to ensuring that people were included.

Early on in the course, participants had agreed a research question, research approach and devised research tools together. This group decided that they wanted to find out about the 'barriers and levers to disabled people getting paid employment' and their chosen approach was a postal questionnaire to disabled people.

We observed the final session, in which results from the questionnaire they had devised were being discussed. The session was 'work in progress' as well as training and support on how to achieve the group's goals, rather than a delivered form of training. This model then is that of informal training coming out of a group's research process, needs and wishes. The style observed was a discussion with everyone sitting around a table. A summary of the session follows.

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At the beginning of the session, after practical things had been sorted out, such as signing expenses forms and waiting for the interpreter to arrive, participants took it in turns to report how they were generally and to speak about what had changed for them since starting the research. One participant, Wayne, had just got a job as a mental health support worker in an out-of-hours voluntary service. Another participant, Don, had received some money to provide a counselling service and a third participant, David, was in the early stages of applying for a job as a Disability Access Officer.

This was an up beat start to their final 'training' session. There was a lot of acknowledgment from people that they had found the group supportive and enjoyable and that they had learnt a lot from each other, including knowledge about each other's disabilities. This was summed up by Wayne, who said he'd gained "A hell of a lot!"

In conclusion, the group expressed a wish that their research should reach and hopefully influence the employees; as this was a piece of collaborative work with the local council's Welfare to Work group, there was a commitment to disseminate the findings.

Following this the group moved on to talk about the questionnaire responses. The history of this questionnaire is that a small group of people on the first course had developed a questionnaire to find out about disabled people's experiences of work and access to work. The research project was delayed both by the process of gaining approval from a university ethics committee and by the negotiations for access to the research site, and the course had finished before the work could commence. The participants on the second course learnt of this and decided that they wanted to take this work further.

After some extensive re-working of the questionnaire, the second group sent out by post 190 questionnaires to people with a disability in their locality. The options were also offered of responding by e-mail, being contacted by telephone or a face-to-face visit to complete the questionnaire; however, nobody took these up. These people were located through a snowballing exercise including participants' own networks and organisations they knew. At the time of our observation, 43 responses had been received. The group discussed possible reasons for this low response rate – including recognition that questionnaire response rates are often low! Further hindrances may have been the length of the questionnaire (18 pages with large spaces for responses) and for some people with a disability the questionnaire may have been inaccessible.

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Brian, one of the participants, had previous experience as a researcher where he undertook many face-to-face interviews with people hearing impairments, and suggested that the response rate in their current project would have been much better if they had done face-to-face interviews.

Eleanor, one of the course facilitators, fed back some preliminary findings from the responses:

- The 43 respondents categorised their disabilities as follows: 34 physical: 11 hearing impaired; 9 mental health; 6 learning disability; 4 other. (Respondents could fall in more than one category).
- 12 were doing voluntary work – up to 25 hours a week.
- A high proportion of these respondents reported feeling uncomfortable about their disability in the workplace.
- 31 of the 43 respondents had never received any support to gain employment.

These findings stimulated discussion about how the respondents' experiences of disability and work reflected the group's own experiences.

It was agreed that Eleanor would further collate the results of the 43 responses and that she would e-mail these to the group members for further comment and thought in identifying those issues which were important.

So, already during this session recommendations based on the findings of the questionnaire and verified by participants' own experiences were beginning to emerge. Recommendations such as:

- Both employers and employees need to be given more information about disability and work.
- Potential disabled employees need to know where to go to find information.

Liz, the course facilitator, stated that they needed to produce a report including recommendations agreed by the group. As this was the last session of the course the process of reaching agreement about what was important to include in this report was to be done via e-mail and post, and a date was set for final comments and feedback.

After a break, there was an open discussion about who the report should be disseminated to. The group's extensive knowledge of disability services locally was

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used to draw up a dissemination list. The list included local employees, employment agencies and Members of Parliament.

At times the focus of the session strayed, as people were very enthusiastic and had a lot to say. Liz was able to bring the focus back in a humorous and good-natured way.

Participants then went on to discuss the layout of the report. Suggestions like 'as simple as possible, easy to read' were made. It was felt that the report should be made as accessible as possible to a diverse audience.

In the TRUE research team, this was Jan's first experience of undertaking research field work:

> "Initially, I was very nervous and told the group this when I introduced myself. However, during the session I was aware of a very relaxed atmosphere and did not sense any friction between anyone engaged in the training. So I in turn relaxed and began to enjoy the session. The participants were enthusiastic and interested in the subject of the research project."

It was clear to us after observing the session that people were very enthusiastic about the course and that the group provided a very supportive environment.

Participants' views of the training

> "Lots of individual ideas went in which were quite small and irrelevant but when they came together they created an idea." (Wayne, participant)

One week after the observation visit, we returned to hold a focus group with course participants. Five participants were able to attend: Lee, Wayne, Brian, Don and David. Also present was a carer with Lee and a signing interpreter for Brian. We used the same room as that in which the course had been held.

During the discussion a wealth of knowledge was demonstrated regarding disability, work, discrimination, policy, health services, and similar issues. It is not possible to draw fully on this within this report; however, it is worth reflecting on this as the participants certainly demonstrated an expertise in these fields and brought this expertise to their research work.

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First, we asked the participants why they had got involved in the research course. Everyone was driven by an interest in disability issues and trying to bring about change in employment for disabled people. Wayne said he did it to get 'experience':

> "I'm always interested in anything to do with disability, especially from the aspect of working. I've had quite a lot of experience in that area, good and bad. I can pass on that experience and hopefully help build a more cohesive and a better foundation for disabled people in the future."

> "I decided to do this course because my last job was as a research associate at Manchester University looking at deaf people's health service provision. So in doing this course I wanted to learn more about other ways of researching about what disabled people need." (Brian)

The belief was very strong that as a disabled person you have expertise in the field and this will enhance the research. Brian commented:

> "The main reason for getting involved with research is to look at it from a disabled person's point of view. All of us have disability and we have suffered different types of disadvantages in life; in employment, service provision or whatever. So by getting involved in research we are trying to find out whether other people have got the same types of problems we have faced ourselves, if so how can we all work together to improve the quality of services, facilities and employment for disabled people."

People's motives then were for empowerment, both personal and that of disabled people in general. What was clear was that everybody in the group felt passionately about improving services for disabled people and that they as disabled people had experienced prejudice and discrimination.

David went on to tell us that he sees this course as just the beginning in his research life:

> "When you go back home most of us during the course of the day are researching things; for instance if you are going to buy something you actually check out a lot of things out before you commit yourself. Sometimes your research wasn't so good so hopefully next time you do better. We've done all this research over the last six months and last week when we only got back 30 to 40 questionnaires, not mincing words, we've failed in some part of our research. This is now when it starts getting involved. The downside of this research is, I think, if we then call it a day,

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and our contribution is now finished 'cause I think we should now find out why we've only got a small return and how better to get the results we were looking for."

David was aware that unfortunately funding may restrict further research activities.

We then asked the group to think back over the last six months of the training. David gave an impression of how they got started:

"Do you remember when we first started and Liz gave us a broad plan of how we should approach things and then she asked us individually what we found? She gave us a questionnaire that was mind boggling as far as I can remember. What is it that made us change the way the questionnaire was to the final questionnaire that was sent out?"

"We were given a document and told, 'Here you are, you do what you want!' I think we all put our own point of view in." (Wayne)

Don continued:

"At the time I could see that most people would probably find it difficult. My view was that it has some questions that some people probably wouldn't accept."

Don went on to give the example of asking people about their disability, explaining that disability is not something easily fitted into a 'tick box'. Furthermore, he explained that as a group they needed to customise it; to make it belong to them:

"The personal part of the questionnaire was something that I think we really discussed and take out and added and so forth so that it makes it makes if feel less intrusive. Confidentiality was part of that as well, like taking out where people live."

Wayne remembered his first impressions of the original questionnaire:

"When we looked at the document first of all it was very – very university wrote, it wasn't easy to understand, it was full of jargon, questions that were completely inappropriate … the wording wasn't right, it was English, but not everyday English. We had a lot of discussion, arguments, point of views. We did it over several weeks. I think we ended up with a good document but I think we could improve that document even further."

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What came out of the discussion again and again was the large extent to which the participants' own experiences of disability informed the work. Brian stated:

> "The great advantage of having this team together is that everyone has a different type of disability so when we had to design the questionnaire everyone had to input their own personal experience. For instance, when I did my research work I realised that deaf people find it difficult to read the English language so my input was to try and make the English language as simple as possible."

There was a lot of discussion of how the research might have been improved. There were many suggestions, for example putting the questionnaire in other formats such as tape, Braille and email. Resources and time were clearly identified as the limiting factors.

This discussion demonstrated that the participants had developed their analytical skills as researchers over this ten-week session. They were able to be critical of their own work including plenty of recommendations to improve the research.

We moved on to discuss what people felt they had learnt and how they had benefited from doing the training. 'Increased confidence' was frequently mentioned in relation to the benefits of doing the course. Lee described the course as having given him an 'educational opportunity' and one in which he was, "included, had a voice and was taken notice of." The course provided an opportunity to be listened to as well as to improve skills in listening to others.

David described how the group had helped him focus in the right direction with regard to gaining employment. He described how he felt he must be doing something 'wrong' as he was having no success with employment agencies and so on. However, on hearing the similar experiences of other group members, he realised that it was not himself that was at fault but the fact the agencies were very poor at assisting disabled people to gain employment. Dave has since re-focussed on 'how' and 'where' he is looking for work. He described this as:

> "Amazing in a short space of time what I have learnt."

Other identified benefits included:
- Learning about involving people and meeting their needs.
- Diversity of group a big plus.
- More confidence in looking for jobs.

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- A sense of being more assertive, less reserved.
- More challenging of self.
- Being more proactive to get what I want.

As a very diverse group we asked the participants to identify those things that facilitated their involvement in the training. Brian noted:

"We had a problem at the beginning because of lack of interpreters. It was difficult for me to access what everyone was saying when there was no interpreter; it meant I was always behind the discussion. With an interpreter everything was okay. Sometimes the interpreter can't come and no-one turns up."

The signing interpreter added:

"I know that happens, that sometimes the interpreter can't come and they're not always able to get a replacement."

In cases when the interpreter had not turned up lip reading was the only possible alternative. Brain went on to describe what it was like trying to lip read a whole room of people having a discussion. He described it as very tiring and that after a while he would withdraw from the conversation so that people could just 'get on with it'.

This moved on to a discussion of how the group had managed to 'include' everyone. Reflecting on the focus group so far and how Lee, who has a speech impediment, had said less than most of the others, we asked people what kind of things would increase the inclusivity of a group like theirs:

"My daughter has a speech impediment and of late it seems to have got worse. What I have found is that when I was speaking to her she stammered speaking back to me … then after a bit I found she stopped talking. I realised it was easier for her sit back than carry on, because when she comes to speak everything stops. Now I think when we first joined up and with Lee – we didn't as often on the first or the second visit, but thereafter we spoke directly to Lee, we give him the time and the space. If I'm going to ask him a question, I know to wait a bit longer. Likewise when you speak to me, people tend to wave so I know you're speaking to me. I'm quite happy for that. I think with disabled people it's giving a bit of space and time. With my daughter she actually speaks to me more because I shut up and give her the time to speak …" (David)

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Lee related to this:

> "It's a lot more difficult for me … a lot harder."

We asked the group to tell us about the trainers. In this training example, it came across strongly that the strength of the trainers was their ability to hand over some control:

> "Thinking back, Liz and Eleanor have been a driving force from a back seat. In the beginning they were the driving force, but now we are. They have been super to work with." (Wayne)

> "They started you off and then the rest of us talked and talked and talked. And then what they did was guide us if we were going off track a bit so it was all being focussed." (David)

From this discussion, there was a sense of the group taking responsibility for itself. It would seem that a priority for the trainers in their approach was the development of the individuals involved by providing an empowering opportunity.

The issues raised by course participants in this focus group were reflected within our own research, particularly those issues relating to the 'making' of time and space so that everyone can be included. Using interpreters takes longer, listening to someone with a speech impediment can take longer and more time is required to check that all participants are understanding what is going on. This focus group took longer to conduct than the others. Furthermore, we did not have the audiotape of this focus group transcribed by an external transcriber, as it was easier for people who had been in the group to transcribe it, so this took longer. We highlight this because of the importance it has for those who wish to undertake inclusive research and training.

We felt that having met the group prior to conducting the focus group greatly enhanced the experience and the information that we were able to obtain. For example, we knew that we needed to book a signing interpreter and that there would be extra people in the room. We knew to allow more time. Possibly we may have needed to undertake some individual interviews to have been fully inclusive of all group members.

Previous participants' views of the training

Unusually, in this training example we were also able to look at previous participants' views of the training. The session we observed was the final session of the second

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course that had been run: the first course, which ended in October 2002, had provided training for a mixed group of both older and disabled people.

It was decided not to attempt to contact previous participants directly as they had recently been asked by the course facilitators to evaluate the course. Instead we were given permission to use information from this same set of evaluations.

Seventeen people had attended this course. Seventeen evaluation questionnaires had been sent out and 14 responses received. Some key results:

- 13 participants felt that they had learnt new research and communication skills.
- Three had plans to extend ongoing voluntary work.
- Two had plans to develop voluntary work.
- Two wanted to develop further their research project work from the course.
- Four found the course had increased their confidence.
- Two had been approached by voluntary agencies to discuss future potential involvement (following presentation of their research).

When asked what changes people would recommend, three participants thought it would be beneficial to have a more structured course.

The following quotes from the questionnaires demonstrate some of the benefits people experienced:

On research skills:

> "Understanding how to use open questions to encourage people to talk about what is important to them and closed questions to obtain specific information."

And more personally:

> "At a time when my eyesight was deteriorating, taking part in the course was quite therapeutic. It improved my confidence to feel that tutors were willing to be so supportive and helped me to find ways of getting round my visual impairment."

> "I cannot express enough the benefits I gained by attending this course. By far the greatest personal benefit was to restore my confidence and feeling of self worth."

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> "It showed me that it was useful to use a support worker. I now use a support worker in my main employment. It taught me to adopt a positive attitude towards receiving appropriate assistance."

The benefits of belonging to a group of people with diverse experiences were also highlighted:

> "As the group included people with varying disabilities it gave me an insight into the problems some have and how they overcome them."

> "I really enjoyed meeting new people with differing disabilities and age range. I like finding out about other disabilities and how they affect others, rather than staying with visual impairment."

In summary, the benefits experienced by the members of the first course strongly reflect the themes highlighted by the participants we met from the second course.

Trainer's and commissioner's views of the training

> "Our motives in this were not just about research findings, but also trying to make a difference to the people who attended the course. We hoped, but didn't know, it would work and we hoped it would, for some of them, lead to employment, or other things. We didn't want it to be a case of, for our group of people, we use them, then off they go back to whatever they were doing before, and the aim was to help them progress in whatever way they wanted to, if they wanted to." (Mike, Planning and Partnerships Officer)

We interviewed Liz Boath, the course leader and Mike Wood, Planning and Partnerships Officer, who co-ordinated the Welfare to Work Joint Investment Plan at South Staffordshire Social Services, and whose role included commissioning the research.

The approach of being 'hands off' came from both Mike and Liz; both emphasised that they did not want to be too directive, preferring to enable the participants to come up with ideas about how and what to research. Here Mike is talking about the first course:

> "When they started, we didn't necessarily have terribly high expectations. We didn't know of any other models of research quite like this, where so

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much of the control is being given to the students themselves, and from the outset we didn't really want it to be us saying, 'This is what you now research'. The only guidelines we really set were that we wanted to look into barriers to employment, and solutions, and we were interested in the students' own priorities, their own experience and perception. Also we thought there were probably going to be quite a few mistakes and difficulties along the way in doing this, and we thought that was okay as long as we learnt from it."

Mike then saw his role as:

"In some ways, I've had a greater role in trying to either spread their findings, their challenges that they're going to present us with, and also raising the profile of what we're doing, because the funding has been vulnerable."

Liz reflected on the students' reactions to this non-directive approach:

"They tend to be quite surprised when they arrive. I think they felt that initially they come along and think they are going to be told what to do by the university and that they are coming along to take part and do a project that's already planned. I think ultimately because the ideas were their own, it was their baby, it was something they were really interested in, I think that's why people were so keen to be involved and carry it out. Whatever they come up with came from the heart."

Liz went on to explain:

"Yes, we have a plan in our head which will be something like a ten or twelve week course, it will cover various different aspects of research methods like ethics, sampling, focus groups, interviewing, anything that's a practical thing about research as well as some top tips on how to actually do it. So we will cover things that they would need to know and would need help to maybe do some research ultimately but the course will probably vary based on what people actually want to do."

Among factors that helped the course to run was the partnership between the Social Services and the University. Liz talks about some of the individual barriers both for her as a tutor and for participants:

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"… how we would teach someone who had a hearing impairment as opposed to someone with visual impairment, whose needs are the complete opposite of each other. So our barriers came from things like that, how we could overcome that."

She reflected upon the fact that it had been a learning process for them as tutors, and told us about changes that were made as a result of participant feedback:

"The way the room was set out was we were standing in front of a window so it made it much more difficult for people with visual impairments to actually be able to see our faces or to read properly what was up on the board, so those kinds of things. It seems pretty obvious to us now we think about them but at the time they certainly were not."

Also, Liz told us, tools for getting information disseminated had to be thought through more carefully:

"Before we would have probably used something like PowerPoint … but because that wasn't the ideal method for everyone, what we've done is … a lot more talking, rather than writing things down and flip charts which we would probably have done quite a lot before. We haven't done that, we've just got someone in the group to take notes individually or maybe to type them up as we go along, that way they can be e-mailed out to anyone who has a visual impairment so that they can use whatever systems they have to help them read it."

Furthermore, Liz continued, some of the usual 'top tips' for researchers were turned upside down:

"The people who were doing one-to-one interviews with visual impairments interviewed other people with visual impairments, so one thing we did learn was that when the room she was in, she had the blinds shut and the lights off and of course for us to come in it looked really unwelcoming, because it looked so dingy, but she was saying it was better because she could see the screen and the person who's visually impaired will understand why I have got it like this … So it was those kinds of things that we would learn, more by chance really than anything else."

Lastly, Mike described his reaction to the conference put on by the participants on the first course:

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> "For me it was very powerful, because you weren't hearing 'academics' or 'professionals', in inverted commas, delivering from the standpoint of being experts – you're actually listening to real people, who've not just read about this but experienced some of the issues, and in their own words … and personally I found it very powerful."

Outcomes and future plans

The participants we met were very clear that they wanted more courses and more research. Funding was the main barrier to this at present. Two of the six participants we met were embarking on new work and one was in the process of applying for work. All felt they had benefited from the course both personally and in their role as researchers.

One of the students from the first course is now a member of the Welfare to Work Joint Investment Plan steering group. Other members of the first group have developed their involvement in voluntary work activities.

Mike is currently trying to secure funding for a third course for disabled people. For this third group the topic may be employers' views on disability and employment to provide another viewpoint to the previous research done on the two courses.

Liz has been approached to run a course for parents at a local SureStart project (a government health initiative with the principle of participation), and has also been funded to provide training for mental health service users. This is an indication that involvement in research, and the training to facilitate this involvement, continue to be growing areas.

The final report from this group's research study can be accessed via the Welfare to Work website: http://www.w2w.org.uk/

Key learning points from this example

❖   The partnership between South Staffordshire social services, Staffordshire University and local disabled people made for successful involvement on the research course.

❖   The commissioners and trainers adopted a non-directive approach, giving a broad theme for the research.

❖   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.

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❖   Course participants wanted to do more research.

❖   Allow plenty of space and time so everyone can contribute and understand.

❖   Trainers may benefit from having disability equality training before leading a course.

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Example 5 : Older People Researching Social Issues (OPRSI)

Background to the training

In 2001 a team at Lancaster University led by Roger Clough (Professor of Social Research) received a grant for a three-year research project looking at Housing Decisions in Old Age. As part of this project, they planned to recruit older people (aged over 60) and provide training for them to undertake research interviews with other older people. This proposal was based on the principle that if interviewed by someone of 'similar' experience and background (in this case older age), then the interviewee might feel more relaxed and therefore disclose a different quality of information.

In order to recruit older people for this role, the Department of Continuing Education at Lancaster University worked together with the research team to devise a course called 'Social Research Methods for Older People'. This course was advertised in the local press and in the Department of Continuing Education newsletter, which has a mailing list of 30,000. Subsidised places were offered. This was to be a two term course, starting in February 2001. The course was closely linked to the Housing Decisions research project with the main purpose of training people for the 'interviewer' roles. The students who enrolled were supervised to carry out research interviews during the second term of the research course, having completed the first term. As part of the Housing Decisions research project, the course was repeated in London and is now in its third year.

Some members of the first cohort of this course, that is the February 2001 cohort in Lancaster, having completed the course and gone on to conduct research interviews for the Housing Decisions study, then went on to form a group of 'older researchers'. This group was initially called 'The Interviewers', and later renamed 'Older People Researching Social Issues' (OPRSI). The members of OPRSI decided that they wanted to further develop their research skills and experience beyond interviewing. After doing interviews for the Housing Decisions project, they felt some frustration at not being fully involved in the analysis and writing up of the project. They experienced a sense of lack of control over the data they had collected.

After a meeting with researchers and lecturers at Lancaster University, a short course (of five two-hour sessions) was held in the summer of 2002, entitled 'An Older People's Research Network?' This brief course included the following sessions:

- The current research agenda concerning later life.
- Are key decisions on policy made on the basis of research?

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- Research skills and the experience of people who had acquired them.
- Current relevant research in the North West of England.
- Review and next steps.

Following on from this, and in response to the older researchers' desire to be further involved, the decision was taken to seek funding for further collaborative research projects between the Lancaster University researchers and OPRSI. In time, Roger Clough and OPRSI were successful in securing funding from the Joseph Rowntree Foundation (JRF) for a project titled 'Older People as Researchers: Potential, Practicalities and Pitfalls'.

Within the project outline for this new work OPRSI members would have an active research role through all stages of the research process. Further training for OPRSI researchers was built in to the project and budgeted for. The resultant course was called 'Developing a Research Proposal' and it took place within the Department of Continuing Education, Lancaster University, during Spring 2003. The course was free to OPRSI members who were working on the JRF research project, and also open to other older people who were required to pay a fee. The course consisted of ten modules, each of 90 minutes duration. The ten modules were spread out over five sessions, with two modules per session (so that each session was three hours in duration), over a ten-week period.

Observation of the training

"The feeling of the afternoon was of keenness, enthusiasm – humour as well." (Geoff, TRUE Researcher)

Three members of the TRUE team – Geoff, Julie and Rachael – observed two of the ten sessions of the 'Developing a Research Proposal' course. As Geoff and Julie are in the same age range as OPRSI researchers we thought it would be particularly interesting to see how Julie and Geoff found the session. It provided a good opportunity for the TRUE project to take a 'peer research' approach.

We observed Session 4, consisting of modules 7 and 8 of the course. The session was held on a Monday afternoon between 2 and 5 pm at Lancaster University, in a classroom setting. There were 15 participants in the room – six men and nine women – all of whom were White. All participants were aged 60 and over, as this was a requirement of the training.

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The afternoon was facilitated by Roger Clough, Emeritus Professor of Social Research and a co-applicant for the 'Older People as Researchers' project grant, and Les Bright, a freelance Consultant/Trainer (from 'Bright Solutions' Consultancy and Training, Peterborough). Both of these people had worked with OPRSI on the first research project and had met them in follow-up meetings after the OPRSI team had completed the interviews.

The three-hour session was divided equally into the two modules. First, Les led a module called 'Setting Out Your Stall'. Then, after a break, Roger led a module on 'Developing a Research Proposal.'

Setting Out Your Stall

This module consisted of a presentation by Les, using overheads, giving a step-by-step overview about how a researcher or research team can promote themselves in the research world. For example, the first overhead was:

Setting Out Your Stall

- What have you got for sale?
- What's special about it?
- How do you know?

The presentation was designed to raise lots of issues and food for thought, including practical issues such as getting in the 'know' with research language, journals and websites, publicity, insurance and fees, as well as ethical issues such as equal opportunities, involvement, empowerment and 'establishing your value base and key principles'. The presentation was aimed at people who were looking to set themselves up in independent research, which was one of OPRSI's aims.

Geoff and Julie found this an interesting and informative session and were able to make sense of it. Geoff reflected:

> "[The session] was deep, straight to the point, and well researched including illustrative anecdotes and examples. Questions afterwards were searching and well answered."

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Developing a Research Proposal

After the break, Roger facilitated the second half of the afternoon. This was an informal module. The participants were asked to write any queries or problems they had about 'developing a research proposal'. Roger then used these to facilitate an open 'question and answer' style discussion. Questions included issues of funding, searching the literature, getting started, best practice, defining what it is you want to look at, and constructing a proposal.

Whilst Roger steered this discussion it was very interactive. Roger was able to draw on his own research experience in response to the questions asked.

Geoff and Julie found both modules easy to follow and clearly presented. They enjoyed being present and got quite a lot out of it for their own research endeavours!

Participants' views of the training

> "I think our group is quite amazing really. We all complement each other in some way." (OPRSI Researcher)

We had invited OPRSI members to take part in a focus group to be held on the day following the session we had observed. Four participants attended this focus group. Rachael, Geoff and Julie facilitated the discussions.

During the focus group participants discussed their experiences regarding both the first training course 'Social Research for Older People' and the current course 'Developing a Research Proposal'.

Members of OPRSI were asked to introduce themselves and say a bit about why they had become involved in research. Their responses varied but there was a common theme of wanting to be engaged in stimulating activity in their retirement years:

> "I retired early and unfortunately I had a stroke some six months after I retired. I didn't see it as the end of my working life but I was then thinking 'What am I going to do?' Fortunately my health wasn't too bad. So I saw an advert in the local press, that's when I first saw the course. And I thought it seemed interesting and that I could do that."

> "I'm always doing courses in various things! Either in the arts or whatever presents itself. This presented itself because it was subsidised. I'm

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involved in health aspects, I'm on the Community Health Council and I thought it might tie in, so that is why I did the course."

"I think essentially I wanted to do it as a get away from earning. I like being with people, I like talking to people and trying to understand what makes them tick."

We then asked them to think more specifically about the training:

"I think the training and the whole group activity has cemented our belief, if you like, that we can change things."

In many ways this Training Example, and hence training, is an example of a success story – the participants formed a strong group identity as a result of the first course and have gone on to receive funding for a second project with accompanying training. Not all the participants of the first course went on to be members of OPRSI, so our data is from this well-established sub-group.

When asked to discuss the content of the training, the OPRSI researchers focused mainly on the first course, 'Social Research for Older People'. It is important to note that it was during this first course that the group developed the interview schedule, the research tool, that they then went on to use in practising interviewing. The course also covered broader social science research issues including ethics, as well as information about the research area 'Housing Decisions'.

Some quotes from group members illustrate the importance of this course in that they felt they had changed and developed through doing this course, particularly in relation to interviewing and listening:

"I've been in personnel for quite a number of years now so I thought I could interview. Of course the (research) interviewing was totally different and I had to learn the skills of interviewing and so that was a learning curve for myself."

"This is the story, let it develop, let's find out what this person actually wants to say. It's not that they're saying it to make an impression – they are actually saying it because it's their experience."

"You're thinking of the next question you'd like to ask, and the whole learning to listen and also on top of that this infectious dream thing … finding out their journey, their contributions are important – 'We want your

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story, tell us your story!' – and listen to your story rather than what I'm thinking."

'Good' training examples

We asked OPRSI members to tell us about a module or session or training approach that particularly stood out for them.

The questionnaire design and development was highlighted, particularly for its relevance to the research activities:

> "The questionnaire, writing the questionnaire, because it's such a very difficult thing to write, questionnaires. I enjoyed it when we had it, I thought it was a good session because we were given a rough out of the ideas of what they wanted us to ask people when we went to do the interviews, but in fact we altered it quite considerably, this is where there was an awful lot of feedback."

Also a presentation on ethics by a visiting lecturer was well thought of:

> "There was a young chap that came and talked about ethics, that was very well presented. It was like half an hour and he did take you through the topics and you had to consider what you were doing in the interviews, getting people to talk to you and the responsibilities that went with that."

One member of the group then made a direct reference to how he had applied this ethics session in his research practice:

> "I think the confidence, if you've gone down the road of getting someone's confidence with your interviewing technique and they have opened up and responded to your questioning, you owe them respect for doing that. You realise how easy it is to bend the truth if you want. How you present those findings is very important, rather than just what was actually said. It's how you interpreted it."

And another member of the group compares this developing awareness of research ethics to a previous world where ethics was not, perhaps, so much at the forefront:

> "I think I have probably been too blasé with my ethics in a commercial world. As I say when you've finished work you can look back in that respect and say, 'I was telling people what to do and what right did I have to do that?' Well this was the opposite, where a layperson from the other

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side was telling you, 'Look, I'm a consumer, this is what I want, rather than what you think I need'."

As some of the above quotes illustrate, the training draws on existing skills and life experience, complementing these with new ways of looking at things and doing things beneficial to the research process.

Participants' views of trainers

We invited the participants to talk about the 'trainers' that they had experienced on both courses. On the first course these were mainly two younger researchers, Mary and Vince, who were working on the Housing Decisions project. The training team also included visiting lecturers with specialist knowledge areas, such as the ethics session discussed above. The second course was largely led by Professor Roger Clough.

During the discussion about trainers, the group made many comments about the differences between Mary and Vince in terms of their research approach:

> "Yes, here I had two academics saying two different things. They're not presenting themselves as just one, they are prepared to interact."

These differences were found to be helpful, in that they introduced the budding researchers to different styles and attitudes in research, as did the visiting trainers/lecturers.

The group then went on discuss their perceptions of teaching a group of people like themselves:

> "But imagine them (the researchers) they're in their early twenties, and seeing us, half a dozen, all over sixty with life long skills. A bit daunting I guess."

> "I don't think the tutors were always in control of the flow of the discussion."

> "We didn't sort of end up by talking about what we were going to buy each other for Christmas, it was all concentrated on the subject. But there wasn't sufficient time in fact, because a point would come up – there wasn't opportunity to develop the point and I think the tutors thought they were going to get a group of people as undergraduate students would be, who would sit there and be told, 'Do these various things'. But we weren't

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like that, we said, 'Ah yes, but wait a minute, you can't do this, and what about that …' I think they were taken by surprise."

Apart from identifying that more time is needed, these comments highlight the newness and experimental nature that is typical of many of the courses we have looked at within this report. A constantly repeated theme is: It's a learning experience for all, not just for the participants:

"We were most aware, I think, throughout the course that it was a learning curve for the tutors."

Benefits/Learning

Throughout the focus group the OPRSI researchers gave many examples of how they had put learning into action, as demonstrated by one member in her understanding of a conventional research principle:

"It's putting away your own beliefs and feelings about it as well. You've got to stand back from it and not bias it."

We then asked them tell us about how they felt when they went off to do their first research face-to-face interview, upon completion of the first training course:

"I enjoyed it, I enjoyed every one."

"I was fascinated."

"I was frightened; you didn't know what you were getting into. They were all very nice people but again in a sense they were all self selected to a certain extent."

"I think we all found it rewarding, all in our different ways, either before the interview or after the interview."

As stated by members at the beginning of the focus group, they had all had various life and working experiences, which often included 'interviewing'. However, a sense of learning to listen differently comes across from the group, described by one member as 'this learning curve of learning to listen'. This new way of listening, of wanting to hear the person's story and put aside yourself in order to elicit the views and experiences of others is described in other Training Examples (see Training Examples 2 and 4).

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Trainers' views of the training

This Training Example was based at the Department of Continuing Education at Lancaster University. We interviewed the Director of this department as part of the Scoping Exercise in this project. In this next section we draw on interviews with Roger Clough and Les Bright, those trainers whose sessions we observed.

Both Roger and Les were team members of both of the research projects we introduced above ('Housing Decisions in Old Age' and 'Older People as Researchers: Potential, Practicalities and Pitfalls'). The two trainers brought different perspectives: Roger was a recently retired Professor of Social Research, in the field of older age; and Les had worked in the voluntary sector, again in the area of older age, before going freelance. Both showed a commitment to public involvement in research and a desire to facilitate those who are more commonly research 'subjects' to be actively involved, here voiced by Roger:

> "It's part of a wider philosophy, but specific to the research was a very strongly held view that the more we could involve older people in the whole life of the project, the richer the project."

This view was shared by Les:

> "There was a certain amount of policy rhetoric about involvement or inclusion or enabling or empowering, that wasn't matched by the amount of real involvement that people had, which gave them power or control or a more formidable stake in work."

And as Roger quite openly stated:

> "I was also aware that this was likely to be something that would enhance the bid, because I knew that this was something that was likely to be at the forefront of fashionable …"

In thinking more specifically about the involvement, Roger describes a kind of co-dependency that existed between the 'students' and the trainers:

> "We were dependent on the quality of the interviews, we needed them to have skills in interviewing, and to do that I thought we needed to be training the interviewers … I wanted them to be the core interviewers so the research depended on the quality of the research of the older people."

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In this first project and course the goals were quite clear and focused largely on interviewing. However, neither Roger nor Les had expected the OPRSI members to become so enthusiastic and hungry for more involvement. There were unforeseen implications for all involved – both lay researchers and researchers – as well as impact on time and resources of the research. Roger was able to sum up how he perceived the students felt at the end of the first course, and this matches what the group told us:

> "They did feel very let down, and were saying, 'You can't just do this, you've done all these things with us and we want more and you don't seem to be responding.' It wasn't exactly like that but that's sort of my summary of what it felt like to have people saying, 'What's going on?', and making demands back at us, and the bit that they'd rightly picked up – we'd moved on to another stage of the research, we were analysing the results and we wanted to get on with that."

The interviews with Les and Roger and the statements of the OPRSI members themselves made it clear that the impact on individuals who get involved in research can be great. Again, a theme that runs through this TRUE project report is that taking part in the training and the research can actually change people's lives in profound ways. Roger talks here of one of the other participants in the first, not an OPRSI member:

> "He'd left school at sixteen, and he couldn't believe that he was on – first a university course, and that on the university course he was talking to people with university degrees, and that they were helping him at times, but at times they were also listening to him. And he said that his whole view of himself changed in terms of who he was and his capacity."

Furthermore, the relationship between the lay researchers and the 'academic' researchers can encompass more than doing research training and activities. Roger talked about Mary and Vince, the two researcher-trainers on the Housing Decisions project:

> "[Mary and Vince] got far more engrossed in the course than they expected. It took much more of their time and energy, they were far more available to students than was typical in a continuing education adult course. Phone numbers, e-mails available, a lot of contact, and the students were very demanding, and I'm not meaning that's necessarily improper, but they were making a lot of demands on the staff, of a very

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different order than when I go to watercolour classes – I just go to a class, and I don't have a tutor available outside of the class."

The effect then on trainer-researchers also can be great and far beyond what their expectations might have been. This is important for people to think through, both researchers and commissioners, in terms of time, resources and support. Roger stated:

"It's important for teachers to realise the significance of what they're doing for people. It's three hours a week, and it would be very easy to move on from one thing to another for a teacher, and not recognise the significance of the event for the people participating."

We asked Roger if there was anything that he might do differently and his response was in respect to planning and lack of time:

"I would have wanted to be planning better and further ahead, so that the administration and everything was sorted. That bit I would have liked. But the fact that there was a bit of muddle and confusion that we had to sort, I didn't mind that. It was a responsive course, we were building on what was happening … I think you often do your best work when you're struggling to sort things and develop new ideas."

And there is certainly a message here to be prepared for a bit of 'muddle', to try things out, and that some things will not works so well as others. As with so much of the work described within this report, and the field of research involvement generally, this work is often new and there are many lessons to be shared.

Both Les and Roger commented on how important and sometimes consuming the process had been:

"There are some very powerful personal stories, and part of the danger for us has always been that we get much more involved in the process of the activity. A lot of what people want to talk to us about is, 'What was it like working with older people?', rather than 'What information have you got about housing decisions?' So we're very caught up in the significance of the activity of doing the interviewing and helping the students. I'm very comfortable with the philosophy behind it and the reality of doing it – it just is and has been immensely time consuming, so it did affect the timetable of the course." (Roger)

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"And there's no doubt about it, a lot of people showed a lot of interest in us having recruited lay people, one key criterion of whose 'layness' was also their age, which demonstrated that you can learn new things in later life that are very different than you would have been doing in your former life, that can make a large amount of difference to people's life. It does feel very positive in that sense." (Les)

This emphasis on the process as well as the research outcomes is echoed throughout the TRUE project, and the process was more strongly emphasised in the projects/training where levels of involvement were the greatest.

We asked Les to think about the training we had observed and he stated that he had felt uncomfortable with the formal layout of the room, which obstructed more informal interaction. Also he had this to say about training 'versus' education:

"I suppose the first thing I'd say is that in a way, I didn't see what I was doing two weeks ago as being training, and I hope that's not heresy, but … I think that I don't use the term training and education interchangeably, and I thought that the session in Lancaster was closer to being education, in the sense of conveying information and ideas. Whereas training, I think, is actually about developing people's knowledge and understanding alongside of skills that they can then actually hone and deploy to make a difference somewhere. [Though] I think that's probably too stark a contrast."

The sessions that focused on developing a questionnaire or practising interviews would then fit more with Les's definition of training.

Lastly, Les considers the central point of the group's characteristics:

"[The older researchers] are a group of people that are not drawn from service users, they're a group of people who came forward in response to an advertisement seeking people to go through a course of training and education that would give them a university certificate in research methods. In a way it was a stark reminder of just how different the group was, to see you and the two people (Geoff and Julie) who came with you, one of whom has been a long term user of mental health services, the other of whom was a carer supporting that person … they've got a very definite interest in influencing what's available to them, and minimising the worst effects of what's available to them, and maximising the benefits of what's available to them."

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Outcomes and future plans

Overall the OPRSI researchers found the training of good quality and an enjoyable experience. They were able to use their training to undertake the required research activities and develop an interest in further research activities. Being a part of a group was also seen to be beneficial to members. One OPRSI researcher stated:

> "The group activity also enlarges this picture again. It's involving us …
> thinking bigger than ourselves if you like. So I think that must be good."

In this Training Example we see a model of training being closely linked to research role and projects. Furthermore, a considerable amount of time was dedicated to training in preparation for research involvement, more than in the other five Training Examples. This could be described as frequent and intensive training, taking place in a classroom environment.

For OPRSI researchers this training was seen as essential, and they felt it crucial to their successful later research involvement.

The feelings of being 'abandoned' and not having enough control over data they collected for the Housing Decisions project have made way for, and maybe provided, the momentum for the forming of OPRSI.

At the time of writing, October 2003, OPRSI continue to meet as a group on a regular basis. They have completed the second training course and will being doing interviews for the related research project. The Housing Decisions Project has now been completed and everyone involved was invited to the House of Lords for a launch!

The course 'Social Research for Older People' has run for the third time within the department of Adult Continuing Education, Lancaster University. For this third course, the course was not attached to a specific research project but as a stand-alone course on research and research methods.

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Key learning points from this example

❖ The training in this example drew on and further developed existing life experience and skills.

❖ Exposure to a variety of researchers/trainers can be beneficial, as people can see different approaches to research.

❖ Everyone is a on a learning curve - trainers and participants.

❖ A flexible approach to training enables responsive and innovative work.

❖ The impact of involvement for individuals – both service users, researchers and trainers – can be great and sometimes life changing.

❖ Make sure everyone knows what is happening with research project/data if they are not involved in all stages.

❖ Allow plenty of time during training for discussion.

The OPRSI members offered the following recommendations to anyone planning training for research:

❖ Ensure the course has a 'good' status – OPRSI felt it was good to have the course located within a University and to have it accredited.

❖ It is advisable that training is tied into an actual research project. Training activities should directly relate to research activities to be undertaken.

❖ Be involved in developing your own 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.

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Example 6 : The Leeds Survivor-Led Crisis Service

Background to the training

This is an example of a user led research project in the field of mental health. This research project was commissioned by the management committee of a mental health crisis service in order to evaluate the service from the perspective of both people using the service as well as people providing the service (the employees and the management committee). Alison Faulkner, a user of mental health services herself, was the commissioned co-ordinator of the evaluation project. Alison wrote the original outline for how the research would be carried out; this involved interviews with people who had used the crisis service and interviews with staff and management committee members.

Alison had responsibility for overall project management and also provided the necessary training and support for the service user researchers working on the project. At the beginning of the project, in January 2003, Alison recruited four mental health user-researchers to work on the project. All four had used mental health services locally and two were previous users of the crisis service.

The project had no rigid timescale. In one way this was positive, as it reduced the pressure upon the research team and allowed for adequate support and training to take place as and when needed. However, this also posed some issues for the research supporter who had budgetary responsibility, and indeed for the whole team as it was not clear when the project would end.

The 'model' used in this Training Example was one of ongoing training provided according to the task or skills needed for the research project. The training was an integral part of the research project and took place during regular research team meetings. This differs to other Training Examples, such as 1, 2 and 5 where the training was provided separately from other research activities. This example has similarities with Examples 3 and 4, in which training and research activities were developed hand in hand.

Two members of the TRUE research team met with the research supporter, Alison Faulkner, and two of the service user researchers, Linda and Judy, for a group interview. Following this we carried out individual telephone interviews with the other two service user researchers, Carol and John.

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Participants' and trainer's views of the training

The involvement of the four service user-researchers was motivated by wanting to bring about service change, as well as being occupied and possibly working towards employment:

> "I felt that at the end of the day I want help make the service better and also get knowledge that I can carry through to actually working." (Linda)

> "I really did feel that I was on the scrap heap. The fact that there were people around who were interested in what I had to say or what I brought to a project … gave me the motivation to become involved." (John)

Carol, a long-term user of mental health services and also a carer, felt that involvement itself was very powerful and empowering:

"I started getting involved and noticed how much power – how empowered you were, if you had a service user involvement group, how you'd get better access to managers and listened to in that group than the staff who'd been trying to do things for yonks, things that we were able to do in a matter of a few weeks as a group."

The fact that the work was user-led was also important to people, as emphasised by Judy:

> "I value greatly that this is survivor-made research and service users talking to people who have used the services."

This was a view also shared by Alison, the project co-ordinator:

> "One of the things that attracted me to working on this was the fact that it could be a user, survivor project. This is one [project] that interested me hugely because right from the start it was made clear that as a group we would be in charge of how we did it."

That they were all users of mental health services was seen as crucially important to all members of the team. This was seen to have provided a safe working environment as well as encouraging a certain kind of openness that might not be present in other working environments.

All of the four service user-researchers had become involved in the project through existing networks in the mental health services. One had experience of working in research on a previous project.

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As explained earlier, the style of training in this example was mostly that of informal training done alongside the research process, with some more formal training at the beginning, as Linda explained:

> "It was very interesting training because it was very much 'hands on', from the way we see it. We were very involved, from the way we see it, and involved in putting forward what we thought should be in there. I thought that was very good. We were involved in doing the questions and establishing the format of how things should be going. But obviously there were certain things we had to do, we had to practice doing interviews and things of that nature. The training itself has been quite fluid really, we've put as much in I think as Alison and it's worked as a team rather than one person leading the way."

John describes how the process of the team designing questions themselves helped when doing interviews:

> "You knew where the questions were going. When you were asking a question and if a certain answer came up you would be able to ask a question that was maybe down the line a little bit rather than just following the list of questions, and then adapt and go back to the question that was missed … It gave you a general feel for where the questioning was going."

We asked the service user-researchers to give an example of some aspect of the training that they thought had worked particularly well:

> "There's two things. One was, we all wrote a piece about what we thought was a 'crisis' for us as individuals and that was really useful in terms of gelling the group together and also getting the sense of how different a crisis could be for different people. The other thing, I think, was a really good training method … was just doing the role-play of interviews, that was really useful to do." (Judy)

The first example Judy provides above relates to the research topic and an exploration of its meaning. This gave the team time to understand each other's experiences as well as think about the possible responses that research informants might give. The second, practice interviews, is an example of a very practical training tool.

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All four service user-researchers highlighted the importance of the informal approach to training, along with time for group development:

> "I found that even though we'd gone through this training, we're being trained without actually knowing that we had been trained. It's all just flowed quite naturally, it's been a gradual build up of relationships within the group." (Linda)

Whilst they had training interviews and developed questions at the beginning of the project, when we visited the team they were more focussed on work in progress where training would take place less formally. For example, after doing interviews, bringing the issues raised back to the team for discussion and analysis. Here, Judy describes the process of analysis of interview data:

> "We actually split up the subject areas to listen back to tapes with a particular issue in mind so you could perhaps focus your attention on an element of the interviews. Because sometimes certain things seem more prominent but actually the person's speaking about other things which you don't necessarily hear unless you're focussing on that."

We asked the service user-researchers to think about the training style. All of them stressed how important it had been to have a relaxed and informal approach:

> "One of the things I think has been very good is that sense of team work. Somebody who's not needing to exert a kind of controlling influence over the rest of the group. That's been very valuable and it's had a positive impact, I think on the whole group." (Judy)

And time for everybody's input was also very important, as Linda noted:

> "It doesn't matter how small the point is, it's always taken on board and debated or acted upon. It does make you feel good and valued."

Again, in this Training Example, as with Example 3, time was built in for exploration of issues in the research topic area, in this case mental health, including issues of labelling and possible resulting prejudice and discrimination:

> "We did have some really in-depth discussions, loads of other issues came up … like the way people judge you instantly if you've got a mental health problem … like a taxi driver can pick you up at the day centre and he'll talk to you all the way home and say, 'How long have you worked

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there?' And as soon as you say, 'I don't work there, I'm a member,' they shut up!" (Carol)

Providing this opportunity for discussion and exploration was important, as it directly drew upon the participants' expertise as service users to inform the research.

Support and motivation were strongly emphasised within this Training Example. Support was repeatedly cited as a good motivator leading to successful involvement and getting the research done. Linda said:

"Because of the support that's there it just naturally follows through, the support kind of gives you the motivation to keep doing it."

Interestingly, this was also a view shared by Alison:

"I get a lot of support out of it as well, so it's very much a mutual thing."

Motivation not only benefits the project in terms of research outcomes and successful involvement but also brings with it a satisfaction in having achieved something:

"The other thing that's been really good and positive is being able to stay with it. I think if you've had periods where you've been ill in hospital or whatever, you quite often have this sense that everything's just going to go from you and you won't be able to stay with something. Because there's a feeling of being supported and an understanding within the group, it's meant that actually all of us have stayed in there. So I think that has been valuable to be able to say that you've been able to stay with something." (Judy)

Confidence was a factor stated by all the service user-researchers as one of the benefits of getting involved and doing the research project and training. John, who had not been in employment for some time due to mental ill health, started a new job before the research project finished:

"I think it's to do with providing me with confidence. It's an important stage in getting well, starting to work again – you had to be there at a certain time … it was like work … I was paid for it. It was an important stage in bringing me to the next part, which was actual regular occupation, an all-important stage in becoming that little bit better …"

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And for another member of the team, Judy, involvement in the project had improved her confidence in other aspects of her life:

> "For me I know there's been a positive effect from coming to this group. I go on to an evening class on Monday evening. The difference in me since January from coming here on a Monday and then going there, I've actually been more confident in this other group and I think its from having been in what feels like a really safe group working on something together."

Conclusions and future plans

With the exception of John all the researchers are currently analysing and writing up the report together. John recently started paid work as a service user involvement worker on an acute mental health ward.

Key learning points from this example

❖ 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!

❖ People felt that because all team members were service users this helped to create a safe and open space.

❖ Value placed on the service user perspective meant people felt valued and acknowledged at all times. This helped create confidence and empowerment.

❖ The learning and support is a two way process between trainer and participants – both learning from one another.

❖ Support was important for group development, teamwork and enhanced self-worth.

❖ "I would encourage any service user to become involved in this type of work because they bring an insight into the difficulties that people are facing."

❖ Involvement in research can be a positive step in the road to recovery.

❖ Be clear about payment for service user researchers during training.

❖ Don't use jargon.

❖ Establish people's roles from the start.

❖ Make sure that people's experiences are valued in every way.

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❖ Ensure that involvement is not tokenistic.

❖ Do not assume that because someone is a survivor that they are necessarily extremely vulnerable – recognise the resilience of people who've been through the mental health system, it takes quite a lot to survive that experience – find out from them what they are able to do.

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Section 2.3 : Why are these results important?

This section draws together and discusses the key themes that emerged from the findings from both the Scoping Exercise and the In-Depth Examples.

Map of training for service user involvement in research

The study presented in this report, the TRUE project, found that training for public involvement in research involvement is not so readily available. We identified only a relatively small number of initiatives that 'currently' provided training, and most of these had been established within the last year or two. Many more people and projects we spoke to were developing plans for training, and commonly people asked us where they could get training. There are some useful resources available from previous research and projects, including 'Knowing How: A guide to getting involved in research' (Thorne and others 2001), and 'The DIY Guide to Survivor Research' (Mental Health Foundation 1999).

All the initiatives we spoke with and visited included training as an element of participants' research involvement. Training took the form of being either 'formally' delivered (i.e. a discrete training day or course) or 'informally' provided (i.e. part of ongoing learning, facilitation and support). In both approaches, a certain 'informality' in style, including time for open discussion, socialising and having fun, was deemed important.

It is not always the case that training is provided and we were told about projects where training had not been fully considered. Our six in-depth examples then could be seen as examples of good practice in terms of research involvement and certainly in all six cases service users evaluated the training well in terms of enabling them to be effectively involved in research.

The training examples that we found were diverse, ranging from involvement in one aspect of a research process to user led research, where service users are in control and often undertake all aspects of the research process. Most of these initiatives existed within a collaborative working environment. For example Training Example 4 was a union between people with experience of a disability, Staffordshire Social Services and Staffordshire University.

We found 'generic' research training – meaning training that had been or was designed to be useful across research contexts or groups – to be relatively rare.

Some generic training is available through CASP (Critical Appraisal Skills Programme, Initiative D), a well-established provider supported by NHS funding. CASP provide training on (1) Finding Evidence, (2) Appraising Evidence, and (3) Acting on Evidence. The second of these, which focuses on critical appraisal skills for reviewing research articles and research proposals, is most relevant to active involvement in research and most widely used among research organisations. CASP have been used by the Alzheimer's Society Quality Research in Dementia Programme and the National Childbirth Trust, as well as the MS Society (Initiative A and Example 1 in this study). The participants we talked to found this CASP model of training to be effective, inclusive and enjoyable.

A clear finding from the research was the value of linking training closely to a research project or role. Furthermore, the nature of many research tasks means that whilst training is an important part of facilitating involvement in research, people equally learnt by putting skills into practice by actually doing research. It was also strongly advised by both participants and trainers that everybody should be involved in developing their own research tools, such as questionnaires and interview questions which participants then found much easier to use.

What has come through strongly throughout the project's findings is the enormous value of the training initiatives to participants' personal development and confidence. This has spurred them on to continue with their interest in research and to want to contribute further; indeed participants in one case study were described as 'hungry to do more'.

There are several key elements about the training that have made this possible. The lessons learnt from the research suggest that these elements are important, not only to future trainers, but to people who are now thinking of including service users in ongoing and new research activities and wish to avoid 'tokenism'.

The key elements, which are illustrated through the Training Examples, are that service user participation needs to have:

- Clear aim and purpose
- Involvement in the research process
- Exchange and sharing between people
- Strength of the service user's experience being recognised
- Time and space for contribution
- Safe environment

All these combine to contribute to confidence and enthusiasm to participate in the research endeavour and are discussed further below. In addition, we highlight two further issues that we found were often significant 'challenges' in training: the language of research, and issues around payment for participants.

Clear aim and purpose

An assumption about service users being trained in research might be that they would be being trained to understand different 'research methods' which would be 'taught' to them and then, in the future perhaps, they would be able to use this knowledge to contribute to research in some (unspecified) way. What we found was that the training was centred much more around specific research tasks and real research problems. In many cases, participants had a topic that they developed into a piece of research that drew on their experiences as service users. They aimed to find out about something and they contributed with this purpose in mind. Even in those training initiatives that did not involve designing and taking part in a project, there was a clear goal: for example, the aim of reviewing research proposals which fell within the person's field of experience. Thus the participants' experience was identified with a purpose. This in itself is not enough to ensure that service users can contribute without the other elements of participation discussed below. But it makes the point that user representation in research needs to address the question of 'What am I here for?' as a constructive and relevant question to avoid it becoming a despairing one. Although it might appear self evident that the service user is there 'to contribute' this is not a clear enough goal in itself without more thoughtful clarification. This leads on to the next, related element, that of involvement.

Involvement in the research process

The training initiatives illustrated that participants did not want to have 'something handed down' but wanted to be involved in creating and developing ideas in which they could become absorbed and take some ownership. This adds to arguments that service users need to be involved in research from the start, but not only to make an impact on the research from its beginning but also that they can feel that their input is creative and not just reacting to others' ideas.

Trainers were praised for starting the ball rolling and then taking more of a back seat, only giving a steer if the work was going off at a tangent. Participants welcomed this approach because it put them at the centre, allowing them to be proactive, driving the ideas forward as well as determining the route. To achieve this, trainers did not simply cease to do anything, but rather they set up ways in which participants could be enabled to take things forward with others that facilitated interaction and exchange of ideas.

Exchange and sharing between people

Ice-breaking exercises, small group work and role-play are well-known strategies for enabling people to work together. They appeared to be particularly significant when used in the training described in the research. This was because the sharing of experiences between participants enabled them to feel that they were not alone and then broadened their views so that they were 'thinking bigger than ourselves'. For example, in listening to others' experiences of being unable to get employment, a service user realised that it was not because he was doing something 'wrong' and this enabled him to re-focus on how and where he was looking for work.

During the sharing of experiences, the skills of listening to others and being heard oneself enhanced feelings of self worth. This was because they were able to bring out what was described as 'a wealth of knowledge, experience and expertise' that may have lain dormant. The attention to and recognition of that by others as reflecting their experiences too made the participants feel valued as individuals.

This sharing was not only mutually supportive. It enabled people to feel that, together, they could make a difference in the area of the service they had experienced. The participants described being more assertive and less reserved. Significantly, this could go with being more challenging of themselves so it was not simply a confirmation of what they were already doing. They felt more powerful and in some instances they could illustrate that they had indeed been empowered to make changes happen.

However, the power differentials inherent in the research process itself are not always easy to deal with. Although they did not emerge as an issue in the case studies, they are discussed in the literature and for many, remain problematic (e.g. Carrick and others 2001).

Strength of the service user's experience being recognised

There was some evidence from the case studies that the process of listening to and valuing individuals' experiences could redefine for the individual that their experience and understanding of the impairment, difficulty or health problem that made them a service user was a strength that they brought to research. Their 'condition' had given them knowledge of services and insights which others without that condition did not have. This may seem obvious to some, but those service users who have suffered debilitating problems and negative labelling in society have frequently not had much chance to conceive of this as a strength.

Time and space for contribution

The findings have illustrated that enabling service users to make a full contribution to research is likely to take time and that it cannot be done under pressure. The time needed to involve people meaningfully and provide good quality training it seems was never overestimated, but frequently underestimated. Participants in training needed to be able to say what facilities they needed and for these to be adequately catered for. This might be support for hearing or visual impairment or for restricted speech or movement or need for translation.

Time to prepare properly for training included allowing enough time for joint planning with team members, including service users. Working with service users as early as possible can help to ensure that the training style and language is appropriate. Examples of this kind of planning were demonstrated in Training Example 1 where people with experience of Multiple Sclerosis helped to plan training and in Training Example 3 where people with experience of learning difficulties were involved in providing training. It was clear that training should not be seen as a discrete activity. Some time and consideration needs to be given to how to provide support, facilitation, continuity and further training possibilities for the duration of the research involvement.

For commissioners of research then time is also an important issue to consider. In the current climate of a competitive research market, commissioners need to agree realistic time scales and start dates to allow for effective involvement supported by adequate training. Project proposals that state they will involve service users should clearly indicate training and support needs of both service users and researchers. Commissioners should be asking 'Is there adequate time and skill to provide a good standard of training and support?'

Furthermore, where significant involvement is planned, some flexibility in the project's outline need to be allowed for, as once commissioned the involvement process can begin more fully including the recruit of service user researchers and further development of the project plan with their input. Always allow for more time than expected in every aspect of the training – planning, delivering and afterwards is relevant advice.

Safe environment

Confidence to contribute develops 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. Safety was enhanced in the training sessions where it became apparent that there were others there with similar experiences to share.

The language of research

Language is a real consideration for those providing training. Several of the people we interviewed described part of what they hope to do as 'demystifying research', and in fact demonstrating that research is an activity that we all undertake regularly in our daily lives. Some trainers started off their training by asking people to think about what they already did, and how these life experiences might relate to research and thereby demonstrating how we all bring skills with us to the field of research.

Most of the training we came across was preparing people for qualitative research, research about peoples' lives and experiences. In some examples, people spoke of the issue of language in relation to scientific quantitative research. This is an area that presents a challenge to both service users and scientists in understanding one another's language and purpose. We heard plenty of anecdotal evidence whilst undertaking this work about scientific researchers finding it difficult to include service users and to understand what they bring to the research process. Discussion of these kinds of potential problems can be undertaken during training. Attempts to overcome resistance and break down these barriers include requirement of a 'lay summary' of research project when applying for funding.

Payment

For the majority of training initiatives we identified, participants were not paid for attending training, thus raising the question of inequality with trainers and with employed researchers attending training. The participants were however usually paid for resulting research activities undertaken. In most cases all participants' expenses were paid, typically including lunch, travel and in some cases overnight accommodation. There was a strong sense that if people were participating on a voluntary basis then adequate refreshments and in some cases social events, particularly in the youth examples, should be provided.

The issue of payments for service users getting involved is a topical area. For some people payment was not an issue, and indeed some wished to give their time freely, seeing it as giving something back, such as those we interviewed from the Multiple Sclerosis Society research network. For others the issue of payment for training was not a high priority as people felt they were financially secure enough to give time freely, such as the Older People Researching Social Issues initiative.

However, for many people, the option to get involved in research and training will be dependent on all expenses being paid. Some people we spoke to had firm beliefs that if service users bring their own expertise, then this expertise should be financially acknowledged, as it is for other 'experts' in the team.

The issue of payment remains controversial. Some people expressed concerns that if service user researchers were paid more for being involved in research, including payment for attending training, then this would be prohibitive to undertaking involvement in research. What we can say is that the issue of payment needs to be thought out, discussed and agreed by all parties concerned right at the beginning of a project or initiative, and that these costs must be considered in the initial budgeting. Payments should be made promptly. INVOLVE have published guidelines on paying consumers and can offer further advice (Steel 2003).

Recommendations for further research

This study raised far more questions than it answered. Many dimensions of training for service user involvement in research merit further exploration, such as the potential for distance learning, and the concept of 'communities of practice' in this context. A prime message from this study is that the relative merit of 'formal' training and 'informal' (on-the-job) 'training' as modes for learning and sharing knowledge and skills requires careful consideration, and provide a most useful avenue for further research. In the same way – though not with specific reference to training – an important sub-text in this study was the question of differences between 'user-led' initiatives and 'collaborative' initiatives. There is growing recognition within the research community that these differences are often marked, and some systematic comparative analysis of these modes is long overdue.

Thinking of involving service users in research?

The last few years have seen a growing recognition of the value of public involvement in research by the Department of Health, research funders, universities and the other historical holders of power, influence and funding for health and social care research. Many people in these institutions support the concept of public involvement and are working hard to reform their conventions and institutions. While a few individuals and groups in the conventional research establishment are embracing the principles of user-led research, a large majority are working to a less radical but nevertheless genuine agenda to develop collaborative research and research structures. These last comments are directed at those hoping to establish such collaborative initiatives.

Through discussion and sharing of ideas with all stakeholders, reach agreement and clarity about what the service users' contribution will be, what means will be set up to safeguard real involvement, what activities will take place to facilitate their commitment and draw out their knowledge, and how a relaxed and friendly setting can be provided to encourage participation and make the most of the strengths the individuals have to offer. This requires time, discussion and planning. Individuals cannot, for example, be parachuted into existing, formal R&D Committees and be

expected to make a full contribution from day one. The findings from our study indicate that training will help provide a good and confident start to this collaboration; but that the relationship needs attention and care if this confidence is not to be eroded.

Part 3 : Background to this project

This part of the report is likely to interest people who want to know more about:

Section 3.1: the evidence base for training for service user involvement in research, and why INVOLVE commissioned this project

Section 3.2: who carried out the TRUE project

Section 3.3: exactly how we collected the information in the project.

Section 3.1 : Why carry out this project?

Service user involvement in NHS and social care research

Over the past 30 years there has been growing, widespread recognition that the active involvement of National Health Service (NHS) and social care service users is vital to the ongoing organisation and delivery of these services. Service users have been the driving force for this advance. At the forefront of the movement have been service user groups including disabled people and mental health service users, users of maternity services and people living with HIV/AIDS. These groups have demanded inclusion and active participation as a right, not a privilege, stressing the principles that those who actually use the services, who have first hand experience of the issues and problems concerned, are actually the people whose knowledge is most valuable in making decisions and whose interests should be paramount (Beresford 1999, Beresford 2001, Finkelstein 2001, Oliver 1983, Oliver 1996, Wilson & Beresford 2002).

Successive governments have attempted to rise to this challenge to transform the values of these services, from services that require users simply to be passive recipients to services that embrace the active participation of service users. In the NHS alone, since the launch of the government strategy *Working for Patients* (Secretary of State for Health 1989) a number of national-level reforms and initiatives have appeared addressing issues of choice, information, involvement and patients' rights (Department of Health 1991, NHS Executive 1996), with the most concerted and sustained change initiated in 1997 with *The New NHS* and developed through to the *Shifting the Balance of Power* programme of reforms (Cabinet Office 1998, Department of Health 1998, Department of Health 2001a, Secretary of State for Health 1997).

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Service user involvement in NHS and social care research

As service users over recent decades have demanded greater involvement in the policy-setting, planning and delivery of services, a parallel movement has grown which demands that users of health and social care services also be involved in *research* that affects them. Several arguments have been put forward as to why this involvement is important. One is that active involvement in research helps protect the service users who provide data, a concern which has grown in recent years with scandals such as the Alder Hey Children's Hospital, where children's body parts were used for research without the parents' consent (Redfern and others 2001). Another argument is that active involvement produces better research: research that is more relevant to people's needs, is more reliable, and collects more useful information, as well as being more ethical (Hanley 1999).

The importance of active involvement in research has been recognised by the government. In 1995, the Department of Health set up an advisory group now known as INVOLVE, but known for many years as 'Consumers in NHS Research'. This group has been a catalyst for the advancement of active involvement particularly in health research, to the extent that the government, through the 'Research Governance Framework', requires all NHS organisations to ensure that service users are actively involved in research projects and research management wherever possible (Department of Health 2001).

This work in the health care sector however undoubtedly has its roots in – and owes a large debt to – the earlier pioneering work of service users in the fields of social and community care. Perhaps most prominent is the work of disabled people and of mental health service users, who have developed radical new models for research, in which disabled people and mental health service users, and their organisations, rather than professional academics and researchers, control the research agenda, funding and process. This new model of 'user-led' research in the disability field is called 'emancipatory disability research', and in the mental health field 'survivor research' (Barnes 2001, Beresford 2001, Beresford 2003, Gibbs 1999, Oliver 1996).

However, whilst service users and their organisations have on the whole welcomed the shift towards active involvement in health and social care research, many feel the shift is not moving far enough or quickly enough. Some research funders and research groups have tried to work with the movement, but it is acknowledged that others have not. Anecdotally, one of the reasons given by people who are reluctant to work with service users is that there is no proof that this involvement makes a positive difference to the research; others are that active involvement is too costly, or time-consuming, or simply too difficult.

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Service user involvement in NHS and social care research

Training, learning, and 'communities of practice'

Both those who support service user involvement in research and those who are more resistant recognise that important questions remain unanswered about this activity. Training for involvement is one of these key issues. While service users bring their experience, knowledge and perspectives to research, it is also recognised that those who have not done research before may need some specific skills and knowledge in order to work effectively with researchers, commissioners, and health or social care staff. Training has been identified as one of 12 key principles of successful public involvement in NHS research (Telford and others 2003). Some training 'initiatives' have appeared in response to this need and the purpose of the work presented in this report was to illuminate the prevalence and nature of these initiatives.

While training facilitates effective involvement, it is also about empowerment in a broader sense. In practice, service user involvement can be closer to tokenism than partnership and this can be entirely disempowering. Members of CAPITAL have personal experience of this. For example, having been invited to meetings and forums as mental health service user 'representatives', the professionals at the table made many assumptions about lack of intellectual capacity, of the ability to solve problems, and to make informed decisions. On the basis of these assumptions, representatives were provided with inadequate or oversimplified information, or excluded from certain discussions. This made it impossible to make an adequate contribution, which then of course substantiated prior assumptions about low capabilities.

But what kind of 'training' would be the most effective to help service users to make an effective contribution in these kinds of situations? This question has also been asked during the education of health and social care professionals: how much do they need to know about research in their work as practitioners? 'Research awareness' is often considered to be the most fundamental need. This translates as becoming familiar with the language of research and its presentation by reading examples of published research papers and then asking questions about what they are saying and showing. Some of these questions may relate to the methods used to collect the data reported in the papers. Thus the next stage of education about research can move on to finding out about different methods that can be used and how they can answer different types of research question. Some of this may be quite technical and involve statistics. However, many research questions are not best dealt with through statistical measurement and require, for example, face-to-face interviewing in order to try to understand experiences and emotions. The skills underlying good interviewing and analysing its results are also complex. This means that training in such skills, whether statistical or interpersonal, may not really be

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effective until the skills have been tried out in a practical situation, with a realistic research problem or question. Therefore education in research may move to the next stage of carrying out a project of some kind to learn the skills, to appreciate the difficulties of dealing with data and of drawing it together into 'findings'. But the whole process is not yet complete. Findings need to be placed in the context of what is already known through previous research and its publication. This comes back again to reading the research literature.

Service users, like students of health care professions, may want to go through all these stages or feel that 'research awareness' is sufficient. However, there is another aspect of involving service users in research that is not just about skills and about knowledge from the research literature. It is about users becoming part of the 'community of practice' in which researchers work together. Some interesting concepts about learning in society (Lave & Wenger 1991, and elaborated by Wenger 2000) attribute a great deal of learning to taking part in the activities of different communities. We all belong to a number of 'communities of practice': home, work, school, for example. Communities of practice are everywhere. A community of practice is both an obvious and a novel way of looking at things. Learning is a social phenomenon, with its primary focus as social participation – people are active participants in the practices of social communities.

In spite of the different forms communities can take they have in common a particular area of knowledge or understanding, a community of people who care about this area and the shared practice they are developing to operate within it. This creates common ground and a sense of common identity. Whole organisations may refer to themselves as communities and they also refer to the surrounding population as 'the community'. While community care is outside hospitals, community colleges and schools offer education within their walls.

A political definition defines communities as interest groups who have to be wooed in the local and national political arenas. These can be occupational groups, such as the farming community, or religious, ethnic or cultural groups. They are all interested in acquiring resources for their members. In terms of resources for learning, often public funding is given to learning for qualifications or learning that takes place in formal situations where learning can be monitored. This prioritises the needs of some learners over others who are not comfortable learning in formal situations.

An ideological definition of communities of practice advocates the development of 'ideal type' learning communities that maximise participation in a culture of inclusive, interdependent views of human relationships and democratic values. This view constructs learning as a part of the interchange of human interaction, constrained

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and facilitated by skills, structures, networks and cultural factors. This can apply to whole organisations or smaller groups within organisations. Within this construct of a community there would be opportunities for mutual learning across professions and between professionals and their clients. This would have been thought unrealistic twenty years ago, but today's organisations for health and social care are increasingly committed to relations of mutual respect between professionals and clients (at least in terms of the ideology). Wenger (1998) defines three key aspects of a community of practice:

1) Mutual engagement of participants, acting together, alongside each other, making complementary contributions, from those with different types of competence to those engaging with peers who have largely overlapping forms of competence. In a research community of practice, service users' competencies would be recognised as different in several respects from those of researchers but equally valuable.

2) Joint enterprise involves not only a shared goal but mutual accountability and struggling to define the enterprise and reconciling conflicting interpretations of what the enterprise is about. The 'enterprise' could be the research problem and how that is defined.

3) Building up a shared repertoire of talk and action and producing or adopting tools, artefacts, representations; recording and recalling events, inventing new terms and redefining or abandoning old ones; telling and retelling stories; creating and breaking routines. These would be the shared language of research amongst the community.

Some communities of practice grow spontaneously while others need careful seeding, feeding and watering (the Alan Titchmarsh theory of communities of practice). Cultivation is an art (the Rolf Harris theory of communities of practice) and has to be negotiated and not developed like traditional organisational structures. However organisations can: 'value the learning they do, make time and other resources available for their work, encourage participation and remove barriers' (Wenger 1998, p13). Once the idea of service users as equal participants in communities of research practice has been accepted, there are still problems of different power relationships in reality as opposed to the ideal version of equality. The idea of a 'community' itself may, to some people, mean that individuality could be lost. If service users are essentially being trained to enter the 'research community of practice', will they be allowed in when they have been trained? This remains to be seen.

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Why was this project needed?

So, the knowledge and skills needed for research, like anything else, can be passed on from one person to another, sometimes through 'formal' teaching and learning, at other times through a more democratic process of mutual learning.

Prior to the TRUE project, it was known by 'anecdotal evidence' – word of mouth, discussions at meetings, and so on – that NHS and social care service users sometimes were indeed gaining the knowledge and skills needed for involvement in research through 'training'. However, no precise details were known about this training, and a number of important issues needed to be addressed:

- While examples of individual initiatives could be found, no centralised, easily-accessible list of training initiatives and contacts existed.

- We did not know how much training is taking place (is it very often provided for service users – or very rarely?); and we did not know where the training is taking place (is it all over the country, or just in a couple of places?); and we did not know who is doing the training, and what sort of training methods they use.

- Also, we had no idea if the training is 'good' or 'bad': Does the training actually prepare service users to do research? Do the service users get anything else out of the training? What constitutes 'good' or 'successful' training for consumer involvement in research? What 'works' and what does not, both from providers' and recipients' perspectives? Are they able to use the training afterwards?

- Finally, we wanted to collect information to help guide the provision of future training.

The specific research questions / objectives for this project were:

1.   What is the prevalence of training initiatives that enable NHS and social care service user involvement in research?

2.   What are the characteristics of these initiatives? For example, type of involvement in research, type of training/audience, nature of training institution and its aims in providing the training, teaching style, mode of delivery and cost.

3.   What are the factors that stakeholders use to identify successful training, 'successful' both in terms of preparation for involvement in research and in terms of personal empowerment? For example, type of training, delivery method, the role or task for which training is being provided, and the service users' role in instigation and content of the training.

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4.　　What impact does training have upon participants? For example: skills or knowledge relevant to the role or task for which training is being provided; participants' confidence, enthusiasm and assertiveness in relation to involvement; subsequent involvement in research; additional training needs.

5.　　Which criteria are most appropriate and useful for guiding future training initiatives?

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Section 3.2 : Who carried out this project?

The project team

The TRUE project was a collaboration between three organisations:

- Research Department, Worthing and Southlands Hospitals NHS Trust.
- Centre for Nursing and Midwifery Research, University of Brighton.
- CAPITAL (Clients And Professionals In Training And Learning).

The TRUE team was comprised of 11 people: a Project Co-ordinator; seven service user researchers; three project supervisors. The individuals had not worked together before, and the first three months were taken up with recruitment, some training, and team building. This period was crucial to the later effectiveness of the project, and we are grateful to INVOLVE for building this 'start up' period into the funding.

The service users working on the project were recruited from CAPITAL. CAPITAL is a charity that is run for and by mental health service users, with the goal of improving services for people with mental illnesses. CAPITAL provides training to mental health service users to enable them to influence health professionals; also there are sessions on treatments available and attitudes towards mental illness. CAPITAL members are involved in a diverse range of activities. These include: the training of social workers at university; sitting on a variety of committees; giving presentations to health professionals; undertaking research; working in hospitals; sitting on interview panels.

At the beginning of the project, each member of the team wrote a short biography by way of introduction. These biographies are reproduced below. In some cases, the biography also includes an 'update' written towards the end of the project.

Saleh Ahmed (Service User Researcher)
I have worked in aviation security nearly thirty years. My job included a wide range of activities. About eighteen months ago I started feeling depressed, without any particular reason. I did have some domestic problems, which is normal, and still it is there. My management asked me to see the company doctor and later referred me to my family doctor. I was then asked by my family doctor to go to hospital, which I did and got an appointment with psychiatrist for the first time.

It was the first time I came to know about CAPITAL, while I was having hospital treatment. I attended a number of CAPITAL meetings and it felt great to be a member of their service user group. During the meetings/sessions with CAPITAL I

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became very aware of the causes why people suffer mental depression. And I strongly believe that mental depression can be cured either by medication or talking therapy or both. A few months ago I was asked by CAPITAL if I was interested to join in a research project. My reply was Yes, because I took early retirement from my company due to my adverse mental health. Now being a member of the research team I enjoy every minute of it. Because I could learn many things through our project and can also contribute something from my past experience.

I am a member of an ethnic minority and also National Registered Public Service Interpreter. In my past experience as a language interpreter I came across many cases that were strongly linked with mental depression among the members of ethnic minorities. Being a member of the research team I could help the members of ethnic minorities whose first language is not English. Today we all live in a multicultural society, therefore we all can contribute our experience to solve the problems of mental health today and for the future.

Anne Beales (Project Supervisor)
I have worked within the social care sector for 26 years. I have seen my work practice change from providing all embracing care to enabling and supporting. It could be said the education system did not provide well for me as I left school with only three 'O' levels and five CSEs. However, I went on to study and pass my certificate of qualification as a Social Worker in 1989.

Always keen to support people's rights and bring an awareness of the effects of discrimination and poverty, I became the chair of London's Labour Party youth section from 1980 to 1982.

I have a thirst to understand new ideas and take on challenges. To this end, I have worked within the voluntary and statutory sector supporting people who have learning disabilities/difficulties and others who have mental health problems. This I have done within residential community and day service settings. As a training officer for the London borough of Havering, I once again found myself out on a limb in that I felt the need to train the clients was as important as the need to train staff. To act upon my belief I became a freelance trainer from 1995 onwards, taking work which involved co-training with people with learning disabilities or mental health problems. This training was primarily with other people who use services and on occasions with staff. During this period of self employment I was retained by various organisations including local authorities to conduct investigations into service standards, and standards of work practice. On occasions I have worked with the Metropolitan Police Force. On one occasion this led to the publication of a document about a local authority service.

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Throughout my life, I have experienced a depressive illness leading to breakdowns on occasions – which I prefer to call breakthroughs. It is my belief, because I have been out on the edge and faced fear, that my insight, empathy and problem solving skills are quirky and unique. Indeed, I believe this has made me far more effective in my work with others who use services.

At present, whilst still running a small business, I am currently the co-ordinator of the CAPITAL project and responsible for the day to day management of every aspect involved with a small charity. The ethos of CAPITAL is to fulfil two functions. Firstly, to support members, all of whom access/ed mental health services in West Sussex. This support takes the form of valuing every member's contribution and every members inclusion in the activities of CAPITAL. Secondly, the CAPITAL project provides training, research and consultation to the statutory and voluntary sectors. The project has been running for five years and the work of the members has gained tremendous respect, leading to invites that evidence this appreciation. For example, presentations at international conferences about the work of CAPITAL, articles written in specialist journals also about the work of CAPITAL, and invites onto interviewing panels to appoint people to positions such as Chief Executive of the West Sussex Health and Social Care Trust.

I am 45, and enjoy riding pillion on motorbikes and will be taking my test to gain my licence in the near future. I am also taking belly-dancing classes. I am the keen owner of two cats.

Clive Bennett (Service User Researcher)
I have a pure science background with emphasis on mathematics and computing skills. In the early eighties I attended Imperial College, London University, reading for a Computing Science degree. After graduation I joined Logica PLC in central London. We were part of a team working on development of multi-language teletext systems. Following Logica I spent a year cataloguing Roman artefacts at Fishbourne Roman Palace. Then I started a contract at IBM in Havant, Hants, where we maintained the disk drive manufacturing process software and entered the 'clean room' regularly. Moving to Ampthill in Bedfordshire in the late eighties I joined Hunting Engineering as a Systems Analyst responsible for simulation systems and their associated software as applied to defence procurement.

I am currently very settled in my own little studio flat in the heart of Chichester. I live with the 'label' of a schizoaffective diagnosis and survive despite the obvious drawbacks! After a number of breakdowns and periods as an inpatient, for the past decade I have been living mostly in the community residing mainly in Group Homes. I

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desperately want to do something useful to help others (and myself). This research project will, I hope, help to go some way to usefully occupy the otherwise endless acres of spare time on my hands!

Tina Gillingham (Service User Researcher)
As a young person I lived in care and adolescent hospitals. I then came out of care and went into nursing assistant jobs and lived in the community. After two years, at the age of eighteen, I became unwell and have since been a service user of mental health services, living in Jupiter House, a low secure unit for the past five years. My interests are looking after people, art, finding out information and meeting people. I am the editor of 'Well Being' a magazine for patients and staff where I live. The groups and projects that I'm involved in are helping me to feel more confident and secure and not so scared about moving back out into the community.

Since starting the 'TRUE' project, I still don't have any formal 'qualifications' but I feel I have the experiences now to look at a future in research. Also since the project started I am now out of hospital and have settled down with my partner Dougie and am now five months pregnant. Thanks TRUE project!!!!!!!!!!!!!

Rachael Lockey (Project Co-ordinator)
I have a particular interest in research and practice in the area of health inequalities. As part of this I have developed an interest in and gained experience in undertaking participatory research. In my practice role I am a midwife and I most recently I have worked with families who experience substance misuse. The TRUE Project has given me the opportunity to put into practice some of my beliefs and interests around service user involvement in research. More personally I have the experience of having been a teenage mum and of single parenting. This has given me skills in living life 'creatively' particularly in the areas of finance, studying and housing!

Carolyn Miller (Project Supervisor)
I am Professor of Health Studies and Head of the Centre for Nursing and Midwifery Research at the University of Brighton. I gained my research experience in psychology at Cambridge University and at Edinburgh University, where I worked on student and staff experiences of learning and assessment. I taught research methodologies to mid-career professionals and carried out research and evaluation in education for a number of years at the University of Sussex, before moving to Brighton University.

My research interests are in the investigation of issues in multi-professional work and training in health care. I am currently directing a team evaluating the new nursing curriculum and, in another project that complements this, I am researching nurses'

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learning and support needs in their first post after they qualify. I am beginning a research project to evaluate modernisation of education for the allied health professions. This project also studies shared learning between health and social care students in programmes which train nurses, physiotherapists, occupational therapists, radiographers and doctors. The majority of this work is about people's experiences as 'consumers' of education and developing evaluation methods that will capture their experiences. The TRUE project is the first evaluation that has offered the opportunity to work directly with service users as research assistants and I have enjoyed and benefited from this very much.

Jan Millyard (Service User Researcher)
I am an enthusiastic fifty-year-old woman. In 2001, despite my illness, I was awarded a BSc (Honours) degree in Social Sciences with Psychology. I am a volunteer for the Adur Learning Exchange, which provides courses, educational outings and a monthly book club, for people who are past retirement age and housebound. Since working on the TRUE project, I enrolled to study for the European Computer Driving Licence (ECDL), and am currently halfway through the course, and enjoying it. My interests are: food (cooking and eating), our dog, country walks, wildlife, personal development, reading and socialising.

Sherée Parfoot (Service User Researcher)
I am in my early 40s and live in Chichester, which is a beautiful city. My interests – apart from my passion about mental health issues – are many and varied. I love sport of any kind, particularly football, and support Pompey and Leeds United. I used to play for a women's team and it is the thing I miss most after getting old and unfit! I enjoy all kinds of music and have studied Jazz at college. I read a lot, like films and the theatre and live concerts. I love spending time with my friends and enjoy voluntary work.

I have a Management, Care, Admin and Finance background. I am just finishing a two-year full-time post working for MACA (The Mental After Care Association). This has been my first full-time job in the last twelve years due to health problems. It was to co-ordinate a project in West Sussex to involve Service Users (I hate that phrase!) and Carers in Mental Health Issues in the county.

I have experienced mental health problems for most of my life following a traumatic childhood. My psychiatric 'career' began at age 14 years when I was frog-marched to the psychiatrist! I have survived a difficult life and a lot of 'labels' to come to this point. I want to put something back and turn bad experiences into useful ones. Being a member of CAPITAL and being involved in this research project is part of that goal. (Back to football again, which gave me 'sane' moments in my life).

Part 3 : Background to this project
Section 3.2 : Who carried out this project?
The project team

Geoff Sigrist (Service User Researcher)

I am over 70 years of age, a retired fire officer, who has also had a wide experience of other occupations. One of these was of a dental nurse working with Julie the dentist, who is now my wife. My background is obviously well suited to working with a team; with people who are distressed and upset; with report writing; with talking and lecturing. My work has always been of a non-sedentary nature. My wife's illness has brought me into contact with the Mental Health Services, and how they need to be improved and funded. This is my motivation for this work, however small a cog!

Julie Sigrist (Service User Researcher)

I am 70 years old. I am the mother of five and the grandmother of twelve. When I was twenty-five years old, following midwife abuse on the occasion of my first baby's first feed, I had depression. I reported my distress to my GP. He shouted at me, said I was looking for trouble, he said it was my own fault and nothing was the matter with me. I used to sit on the stairs and cry most of the time. After three years, I asked again, got referred and received a diagnosis of depression. I got tablets; I wanted an acknowledgement of the abuse but didn't get it. I got worse and after my fifth child I entered hospital but not before I had a few suicide attempts which were not taken seriously. I was sectioned. The treatment was tablets and group therapy. I got a little better. I continued with the outpatient treatment at which my husband was present. I then felt well enough to leave my husband. I left him and met my present husband.

I started my own dental practice, did well, finished treatment and was well for nine years when I had a disabling stroke, which stopped my working. My depression descended. I entered treatment, which was kindly and effective. I then turned sixty-five, entered another level of treatment, the only good psychiatrist. I was referred to psychology where I had the diagnosis of post-traumatic stress disorder from my childhood. I had an apology, my doctor said he believed me about the midwife, and then I proceeded to get better.

John Sitzia (Project Supervisor)

I am one of the three project supervisors along with Anne and Carolyn. I work as the Head of Research at Worthing Hospital in West Sussex, which involves looking after the research staff and managing the hospital's research activity. I am also the Director of the Sussex NHS Research Consortium, a collaboration of 14 NHS organisations working together to develop high-quality research.

I began working in the NHS as a researcher in 1993, and I am able to continue doing some research alongside my research management role. Most of my research work has been in cancer services, for example looking at people's experiences of

Part 3 : Background to this project
Section 3.2 : Who carried out this project?
The project team

chemotherapy. I have been interested in patient and public involvement in health research for some years. I sit on the INVOLVE committee and also I am doing another two research projects around patient and public involvement. I am not a health professional. Before working in health research I worked as an archaeologist in London.

I am very excited by this project and I feel privileged to be working with the CAPITAL members. It is interesting to be part of a project in which the people involved are contributing so many different experiences and skills – this is very unusual in health research! My strong feeling is that this project is also a positive learning experience – for me certainly, and I think also for others involved – and it is important to be open to that experience and to enjoy it!

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Section 3.2 : Who carried out this project?
The project team

The project Steering Group

Robert Johnstone Service User, and Trustee of Long Term Medical Conditions Alliance

Liz Catchpole Public Involvement Co-ordinator, West Sussex Primary Care Trusts

Andrea Cornwall Research Fellow, Institute of Development Studies, University of Sussex

Jill Fardell Director, Disability and Rehabilitation Education Foundation (DARE)

Angie Hart Principal Lecturer, Centre for Nursing and Midwifery Research, University of Brighton

Mary Nettle Service User Researcher, INVOLVE Empowerment Sub-group

Clair Ockwell Service User, and Co-ordinator CAPITAL Project

Keji Okeowo Chair, CityZEN / Youth Peer Education Project, London

Roger Steel Development Worker, INVOLVE

Deborah Tallis Service User Researcher, INVOLVE Empowerment Sub-group)

Howard Taylor Youth Service User and Researcher

Part 3 : Background to this project
Section 3.2 : Who carried out this project?
The project Steering Group

Section 3.3 : How was this project done?

This section of the report describes the work that was done to collect and analyse the information from the study participants. This work consisted of two separate activities:

A : A national 'scoping exercise', which used telephone interviews to collect background information from as many training initiatives as we could find.

B : An 'in-depth' study of six examples of training, with data collected through site visits in which researchers observed training and interviewed trainers and participants in order to explore the training and its outcomes.

Other methodological aspects, such as NHS Ethics Committee approval, are described in Part C of this section.

A : Scoping exercise

Stage One : Identification of training initiatives

The first stage in the scoping exercise was to try to identify as many training initiatives for service user involvement in health and social care research as possible. This sample of initiatives was restricted in two ways.

- First, the study was restricted to England (as this is the geographical area covered by INVOLVE, the project commissioners).
- Second, the study was concerned only with training initiatives that had done some training recently. We defined 'recently' as any time in the 12 months up to the time of data collection, ending May 2003.

As no pre-existing database of training initiatives was available, we identified initiatives through a number of sources:

- INVOLVE members, Support Unit staff and various contacts provided by INVOLVE.
- Department of Health R&D Division regional offices.
- NHS R&D Support Units.
- 'Consumer Liaison' type officers for health and social care research programmes, including the Medical Research Council, the NHS R&D Health Technology Assessment and Service Delivery and Organisation programmes, the UK Cochrane Centre, and research charities.

Part 3 : Background to this project
Section 3.3 : How was this project done?
A : Scoping exercise

- Relevant user-led and voluntary organisations, groups and projects, such as the Toronto Group, the Consumers Advisory Group for Clinical Trials, Shaping Our Lives, and Help the Aged.
- Relevant university-based groups and centres, such as the Centre for Citizen Participation (Brunel University), the School of Community Health and Social Studies (Anglia Polytechnic University), and the Folk.us Programme (University of Exeter).
- Hand searching of published training reports and conference abstracts.

These sources typically were contacted by telephone by a member of the TRUE team. Following a verbal explanation of the research project, these sources were asked if they could provide any of the following information:

- providers of training in research for consumers
- past, current and planned training initiatives of which they are aware
- contact details of the co-ordinator for each initiative (unless the disclosure of this information would be considered a breach of the Data Protection Act).

In total, this process identified 33 initiatives that appeared to meet the criteria for inclusion stated above. Of these:

- six were unavailable for interview despite repeated approaches
- one other was found to have the same training provider as another initiative that we had already interviewed.

A number of other initiatives were proposed from different sources but, on further investigation, we found that they did not currently offer relevant training. So, we identified and were able to collect data via interview from 26 initiatives providing training for service user involvement in research. A list of these is provided at the end of the report in Annex 7.

Stage Two : Data collection

The process described above produced a database of initiatives and contacts. The lead contact for each initiative was then contacted by telephone by a researcher from the TRUE team. At this 'first contact', the researcher explained the purpose and method of the TRUE project, answered any questions regarding the project and the proposed telephone interview, and finally asked whether or not the contact was willing to be interviewed by telephone to provide details of the initiative.

All the lead contacts were willing to be interviewed. A date and time for the interview was arranged at the end of this 'first contact' discussion. A Participant Information

Part 3 : Background to this project
Section 3.3 : How was this project done?
A : Scoping exercise

Sheet was then sent by post or e-mail to the contact. It was emphasised that the contact was still free to change her / his mind and to cancel the interview.

The telephone interviews were tape-recorded. Permission was explicitly sought from respondents for tape recording and an assurance given to all respondents as to the confidentiality of the data. The interview schedule used for data collection is presented in Annex 5. Training providers were also asked to send any documentation they had about the initiatives.

In all, 31 interviews were conducted for the scoping exercise. For four of the 26 initiatives, more than one person was interviewed: two respondents each for initiatives R, S and U; and three respondents for initiative V. The reason for these multiple interviews is that there was more than one lead contact for these initiatives.

Stage Three : Data analysis and interpretation

The tapes of these 31 interviews were transcribed. Each transcript was read by two, and sometimes three, members of the TRUE team. Each reader extracted the interviewee's responses to each question and these were recorded separately in summary form in a Microsoft Excel spreadsheet. Useful quotes were highlighted in the transcript and a record of these made. When this process was completed, the 'agreement' between the two readers for each response was determined. If the 'readings' differed, this disagreement was fed back to the two readers for resolution, or a third member of the team would look at the transcript to compare the source data with the 'extracted' summary. The final 'agreed' version was stored in the Excel database.

This information was analysed by three different members of the research team. The analysis was essentially 'quantitative', in that we were trying to 'quantify' the initiatives in terms of a number of factors. For example, how many were 'user-led'? We referred back to the transcripts to provide quotes to illustrate some of these 'quantitative' results. These results are presented in Section 2.1 of this report, starting on page 14.

Part 3 : Background to this project
Section 3.3 : How was this project done?
A : Scoping exercise

B : In-depth examples

Stage One : Selection of the examples

As a means of getting more in depth information about training for involvement in research our methodology included six visits to training initiatives. Our aim was to capture the views and experiences of trainers and participants in order to inform our Guidelines (see Part 4, starting on page 140). It was important, therefore, to include a diverse range of examples that were designed for different service users and different kinds of involvement. The scoping exercise found that training was being provided for many, diverse involvement activities. The six examples were also chosen to reflect this variety, ranging from reviewing research proposals for funding (Example 1) to undertaking all aspects of a user-led research project (Example 6). Other examples aimed to involve people in certain aspects of a research project, such as collecting data through interviews or focus groups (Examples 2 and 5).

However, our choice of examples was also restricted by the practical consideration that the example had to be 'active' during the six-month period of the project available for this phase activity. Eight possible training examples were identified that we might visit. The two we did not visit:

- In one of these the trainers decided that there were too many external pressures already on the course to accommodate our project.
- The other possible example we did not visit was an NHS Research & Development Support Unit that provided training. This was a relatively uncommon example of an NHS RDSU that provided training for service users to get involved in NHS research. Unfortunately we were unable to attend for a visit in the available period.

Stage Two : Data collection

The list below provides details of the six training examples we selected, and of the team for the data collection visit to each.

Example 1: Multiple Sclerosis Society (Initiative A)

People affected by a long-term medical condition

Location:	Birmingham
Observed:	One day of training
Interviewed:	Five participants (members of the MS Research Network) and two trainers
TRUE researchers:	Tina, Geoff, Julie, Rachael

Part 3 : Background to this project
Section 3.3 : How was this project done?
B : In-depth examples

Example 2: Listening to Change / Young Researchers' Training Programme (Initiative T)

Young people

Location: London
Observed: One day of training
Focus Group: Five young researchers
Interviewed: One participant, one trainer
TRUE researchers: Tina, Rachael, John

Example 3: Norah Fry Research Centre (Initiative J)

People with the label of 'learning difficulties'

Location: Bristol
Observed: not applicable
Interviewed: One service user researcher, one research supporter
TRUE researchers: Sherée, Rachael

Example 4: Consumers as Researchers (Initiative R)

People with a physical or sensory impairment
Location: Stafford
Observed: One session of the training course
Focus Group: Five participants
Interviewed: One trainer, one link person from local Social Services department
TRUE researchers: Jan, Rachael

Example 5: Older People Researching Social Issues (OPRSI) (Initiative S)

Older people

Location: Lancaster
Observed: One session of the training course
Interviewed: Four participants, two trainers
TRUE researchers: Geoff, Julie, Rachael

Example 6: Leeds Survivor-Led Crisis Service

(the trainer for this example was Alison Faulkner, **Initiative I**)
People who have used mental health services
Location: Leeds
Observed: not applicable
Interviewed: Four service user researchers, one trainer
TRUE researchers: Sherée, Rachael

Part 3 : Background to this project
Section 3.3 : How was this project done?
B : In-depth examples

For each training example we observed training taking place when possible. This ranged from observation of a training workshop for a specific task or project (Examples 1 and 2) to observation of just one session that was part of a longer course (Examples 4 and 5). In examples 3 and 6 we did not observe training, as training was provided as an integral part of the research project through informal, 'on the job' training, ongoing support and facilitation.

For all six examples we gathered the views of the participants (sometimes referred to as service user researchers) using a focus group, face to face interview or telephone interview, depending on the most suitable method for each example. In recognition of the time we asked of people, we were able to offer each participant £20 as a one-off payment.

We used 'topic lists' to guide our discussions with participants and trainers (Annex 6). The participants' topic list was used as a template, as we varied the questions we asked to suit the example being studied. For example, the language and style of questioning used in the Norah Fry Research Centre (Example 3) was different to other examples. Similarly, the questions relevant to a single day, one-off training workshop were different to those relevant to a year-long course.

Questionnaire survey of previous participants

At the beginning of the project our intention had been to survey previous participants in the six training examples. The purpose of this was to supplement the views of the current training participants (i.e. the views we had accessed through our visit to the initiative) with those of participants on previous courses to see if the views and experiences had changed. For example, we wanted to see if the content of training had changed over time.

However, with the exception of one example (Example 4), there were no previous participants from whom to collect views. The initiatives were either specific to a current research project (Examples 2, 3, 5 and 6) or the first of a planned training programme (Example 1). A previous course of Example 4 had run. Participants from this course had recently completed an evaluation questionnaire sent to them by the course facilitators. Due to this, it was decided not to ask them to complete a further questionnaire sent by ourselves as this would be, in large part, simply repeating the internal evaluation. It was agreed that we could access the responses from the internal evaluation.

Part 3 : Background to this project
Section 3.3 : How was this project done?
B : In-depth examples

Stage Three : Data analysis and interpretation

The tapes of the interviews and focus groups from training examples were transcribed. Each transcript was read by several members of the TRUE team. Each reader generated core themes, which were brought together with the other readers' interpretations to arrive at a shared interpretation. Quotes to illustrate the themes were highlighted in the transcript and later selected for inclusion in this report. This process took place in facilitated small groups, with sessions often lasting one or more whole days.

We also undertook a process of participant validation. This is described more fully in the introduction to the findings from the In-depth Examples, starting on page 41 of this report.

Part 3 : Background to this project
Section 3.3 : How was this project done?
B : In-depth examples

C : Other aspects of the research process

To ensure compliance with the Department of Health Research Governance Framework, the project proposal and documentation (e.g. Participant Information Leaflet) were approved by:

- The Worthing Local Research Ethics Committee (for NHS research ethics approval). The study did not recruit participants by virtue of their being NHS patients or staff, nor did it use NHS premises (other than at Worthing Hospital), nor did it involve NHS patients' data or other material. Therefore, approval was not sought from a NHS Multi-Centre Research Ethics Committee (MREC).
- The Research Approval and Monitoring Committee of the Sussex NHS Research Consortium. The study did not involve NHS organisations other than the host organisation and so organisational approval was not sought elsewhere.

All questionnaires, documentary evidence, tapes and anonymised transcripts will be stored in a locked archive cabinet in the Research Department, Worthing Hospital. Electronic data will be stored on a secure server at Worthing Hospital. Data will be archived for ten years.

Part 4 : Guidelines for training

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 form 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?

Part 5 : Further information on the project and the initiatives

This part of the report has seven sections that provide further information for reference. These include a list of books and articles for those interested in further reading, and contact details for training initiatives.

Section 5.1 : References and further reading

This is a list of the articles, books and reports that we have mentioned in this report. The list also includes other documents not mentioned in the report but that we, the TRUE team, read and felt were important and informed our work.

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Section 5.2 : Explanation of some terms used

DH	Department of Health
MS Society	Multiple Sclerosis Society
NCRI	National Cancer Research Institute (www.ncri.org.uk)
NHS	(UK) National Health Service
NICE	National Institute for Clinical Excellence (www.nice.org.uk)
OPRSI	Older People Researching Social Issues
PCT	(NHS) Primary Care Trust
R&D	Research and Development
RDSU	NHS Research & Development Support Unit. A unit, typically based in a university, funded by the DH to provide research support to local NHS staff.
SCIE	Social Care Institute of Excellence (www.scie.org.uk)

Section 5.3 : Selected details of the 26 initiatives

ID	Organisation / Project	Base / Location	Organisation Type	National / Regional / Local	Service User Group	Recurrent / on demand	Training for specific work?
A	MS Society	London	Voluntary sector	National	Medical condition	Recurrent	Yes
B	CityZEN	London	Voluntary sector	Local	Young people	On demand	Yes
C	EQUIP[1]	Oxford	Independent training provider	Local	All service users	On demand	Yes
D	Critical Appraisal Skills Programme (CASP)	Oxford	NHS RDSU	National	All service users	On demand	Yes
E	Trent FOCUS	Nottingham	NHS RDSU	Local	All service users	Recurrent	No
F	Centre for Social Action	Leicester	University unit	Local	All service users	On demand	Yes
G	Folk.us	Exeter	NHS RDSU	Regional	All service users	On demand	No
H	North Trent Consumer Network	Sheffield	NHS Cancer Network	Regional	Medical condition	On demand	Yes
I	Alison Faulkner[2]	London	Independent training provider	National	Mental health	On demand	Yes

[1] Training provider for the London Primary Care Studies Programme
[2] Training provider for the Leeds Survivor-Led Crisis Service Study

ID	Organisation / Project	Base / Location	Organisation Type	National / Regional / Local	Service User Group	Recurrent / on demand	Training for specific work?
J	Norah Fry Research Centre	Bristol	University unit	National	Learning difficulties	On demand	Yes
K	Southampton Centre for Independent Living	Southampton	Voluntary sector	Regional	Disability	Recurrent	Yes
L	Anglia Polytechnic University (Social Work)	Cambridge	University unit	Regional	Mental health	Ad-hoc	Yes
M	Consumer Liaison Group, National Cancer Research Institute	Leeds	Dept Health	National	Medical condition	On demand	Yes
N	Patient Involvement Unit, National Institute for Clinical Excellence	London	Dept Health	National	All service users	On demand	Yes
O	Strategies for Living (Mental Health Foundation)	London	Service User Group	National	Mental health	On demand	Yes
P	Anglia Polytechnic University (Centre for Research in Health and Social Care)	Chelmsford	University unit	Regional	Mental health	Ad-hoc	Yes
Q	Brigid Morris[3]	London	Independent training provider	National	Mental health	Ad-hoc	Yes

[3] Training provider for the MATRIX Project

ID	Organisation / Project	Base / Location	Organisation Type	National / Regional / Local	Service User Group	Recurrent / on demand	Training for specific work?
R	Consumers as Researchers (Centre for Health Policy and Practice, Staffordshire University)	Stafford	University unit	Regional	Disability	Ad-hoc	Yes
S	OPRSI, Lancaster University (Adult Continuing Education Department)	Lancaster	University unit	Regional	Older people	On demand	Yes
T	Listening to Change (National Children's Bureau)	London	Voluntary sector	National	Young people	On demand	Yes
U	Bristol MIND	Bristol	Voluntary sector	Local	Mental health	On demand	Yes
V	Health R&D NoW	North-West England	NHS RDSU	Regional	All service users	Recurrent	No
W	Cochrane Collaboration Consumer Network	Liverpool	Independent	National	All service users	Recurrent	Yes
X	University of Salford (Social Work)	Salford	University unit	National	Young people	On demand	Yes
Y	Making Waves	Nottingham	Service User Group	Local	Mental health	On demand	Yes
Z	Service User Research Enterprise (SURE) (Institute of Psychiatry)	London	University unit	Local	Mental health	Recurrent	Yes

Section 5.4 : Contact details for the 26 initiatives[‡]

ID	Organisation / Project	Contact name	E-mail	Phone	Website
A	MS Society	-	researchadmin@mssociety.org.uk	020 8438 0770	www.mssociety.org.uk
B	CityZEN	Steve Curtis	cityzen@peerpressure.org.uk	020 7241 2365	-
C	EQUIP[1]	Linsey Hovard	linsey.hovard@phru.nhs.uk	01865 226707	www.phru.nhs.uk/~casp/contacts.htm
D	Critical Appraisal Skills Programme (CASP)	Jon West	jonathan.west@prhu.nhs.uk	01865 226986	www.phru.nhs.uk/~casp/casp.htm
E	Trent FOCUS	Beverley Hancock	beverley.hancock@nottingham.ac.uk	0115 846 6912	www.trentfocus.org.uk
F	Centre for Social Action	Jennie Fleming	dmucsa@dmu.ac.uk	0116 257 7777	www.dmu.ac.uk
G	Folk.us	Rachael Purtell	folk.us@ex.ac.uk	01392 403049	latis.ex.ac.uk/folk.us/findex.htm
H	North Trent Consumer Network	Tony Stevens	t.stevens@sheffield.ac.uk	0114 271 1707	-
I	Alison Faulkner[2]	Alison Faulkner	AlisFl@aol.com	-	-
J	Norah Fry Research Centre	Val Williams	val.williams@bristol.ac.uk	0117 923 8137	www.bris.ac.uk/Depts/NorahFry/

[‡] All initiatives gave permission for these details to be reproduced.
[1] Training provider for the London Primary Care Studies Programme
[2] Training provider for the Leeds Survivor-Led Crisis Service Study

ID	Organisation / Project	Contact name	E-mail	Phone	Website
K	Southampton Centre for Independent Living	Chris Hunt	audit@southamptoncil.co.uk	023 8033 0982	www.southamptoncil.co.uk
L	Anglia Polytechnic University (Social Work)	Shula Ramon	s.ramon@apu.ac.uk	01223 363271	www.apu.ac.uk/chss/social/work/index.html
M	Consumer Liaison Group, National Cancer Research Institute	Derek Stewart	info@ncri.org.uk	020 7061 8460	www.ncri.org.uk
N	Patient Involvement Unit, National Institute for Clinical Excellence	Marcia Kelson	piuinfo@collegeofhealth.org.uk	020 8983 1225	www.collegeofhealth.org.uk/main.html
O	Strategies for Living (Mental Health Foundation)	Sarah Wright	strategy@mhf.org.uk	020 7802 0335	www.mhf.org.uk
P	Anglia Polytechnic University (Centre for Research in Health and Social Care)	Mohammad Abuel-Ealeh	crhsc@apu.ac.uk	01223 323271	www.apu.ac.uk/crhsc
Q	Brigid Morris[3]	Brigid Morris	brigidm@morrisb.fslife.co.uk	-	-
R	Consumers as Researchers (Centre for Health Policy and Practice, Staffordshire University)	Liz Boath	e.boath@staffs.ac.uk	01782 294000	www.staffs.ac.uk/schools/health/centre1/whole.htm

[3] Training provider for the MATRIX Project

ID	Organisation / Project	Contact name	E-mail	Phone	Website
S	OPRSI, Lancaster University (Adult Continuing Education Department)	Bert Green	bertgoal@aol.com	01695 423763	cgi.eskrigge.force9.co.uk/research/people.php#older
T	Listening to Change (National Children's Bureau)	Ruth Sinclair	rsinclair@ncb.org.uk	020 7843 6072	www.ncb.org.uk/projects/projectdetail.asp?ProjectNo=260
U	Bristol MIND	Jon Fowler	ufm@bristolmind.org.uk	0117 373 0336	www.bristolmind.org.uk
V	Health R&D NoW	Sarah Morris	hrdn@lancaster.ac.uk	01524 593209	www.lancs.ac.uk/users/ihr/hrdn/
W	Cochrane Collaboration Consumer Network	Gill Gyte	ggyte@cochrane.co.uk	-	www.cochrane.no/consumers/
X	University of Salford (Social Work)	Hugh McLaughlin	H.McLaughlin@salford.ac.uk	0161 295 0727	www.chssc.salford.ac.uk/scswr/
Y	Making Waves	Torsten Shaw	torsten@makingwavesonline.org	-	-
Z	Service User Research Enterprise (SURE) (Institute of Psychiatry)	Diana Rose	d.rose@iop.kcl.ac.uk	0207 848 5066	www.iop.kcl.ac.uk/IoP/Departments.HSR/sure/index.shtml

Section 5.5 : Training initiatives not included in the report

Organisation / Project	Reason for exclusion
Afiya Trust	Does not provide research training for service users
Alzheimer's Society	Training provided by CASP (Initiative D)
ARVAC (Association for Research in the Voluntary and Community Sector)	Unavailable for interview
British Heart Foundation	Does not provide research training for service users
College of Health	Does not provide research training for service users
East Berkshire MIND	Unavailable for interview
FRIEND	No training since January 2002
Groundswell	No training to
National Childbirth Trust	Unavailable for interview
The Point	No training since January 2002
Sainsbury Centre for Mental Health	Unavailable for interview
SURESearch (Service Users in Research and Education)	Unavailable for interview
SCIE (Social Care Institute of Excellence)	No training to date

Section 5.6 : Scoping Exercise interview schedule

Telephone Interview for training initiatives

Part A: Opening

- Introduce yourself
- Check that the information about the project has been received in post.
- Does the informant have any further questions?
- Seek permission to tape record interview – only project team will have access to this
- Permission to stop interview at any time

Part B: I want to ask you a few background questions about the training you provide

1. Can you tell me when your training was set up?
2. Can you tell me the reasons why the training was set up?
3. Were there any problems or barriers that you had to overcome in order to get set up?
4. Or anything that was helpful in getting set up?
5. What would you say are the main aims and purpose of the training?

Part C: The next few questions are about people attending the training

6. Who are the service users your training is aimed at?
7. Can you tell me about the age, gender and ethnic mix of people attending training?
8. Can you tell how you recruit those service users who attend training?
9. Are any service users involved in the planning, recruiting and/or delivery of the training?

Part D: The following questions are more specifically about the training

10. How often are courses run?
11. How long is each course?
12. How many people on each course?
13. Where do you run the courses?
14. Which aspects of research does the training cover?
15. Does it include any information or skills not specific to research? (such as communication?)

16. Can you tell me about the format and style of training you use?
17. Who are your trainers? (Are they external/internal?)
18. What time commitment is required of people who receive training?
19. Do they get paid to attend training? (Check if expenses are paid)
20. Do the trainers get paid to provide training?
21. Do you know the approximate overall cost of providing a training course?
22. How are the costs met?

Part E: Finally I'd like to know a bit about outcomes of training

23. Do you collect feedback from course participants?
24. Is there anything in the feedback that stands out?
25. Have you changed anything as a result of participant feedback?
26. Has there been any independent evaluation? If so by whom: contact name
27. Do you know how people who have done the training are using it?

Part F: Closing

28. Is there anything we haven't covered that you'd like to tell me about?
29. Do you have any information/literature about your organisation/training? If YES, would it be possible to have a copy? (Read our address)
30. Lastly, do you know of any other training/projects in research for service users that would be of interest to this research project?

Section 5.7 : In-depth examples topic lists

A : Topic list for training participants

Part A: Before the training

1. What made the participant decide to become involved in research?
2. How did the participant hear about the training?
3. What were the participant's expectations of the training?
4. Were there any problems or barriers that the participant had to overcome to get access to the training?
5. Was the participant involved in any of the following:
   - planning of the training?
   - recruitment of participants who attended the training?
   - facilitation of the training?

Part B: About the training

6. Apart from attending the training did the training require any other time commitments? (reading, homework, preparation)
7. Have there been any financial costs for the participant?
8. What were the participant's overall impressions of the structure and content of the day?
9. Was there anything the participant thought worked particularly well?
10. And anything that didn't work so well?
11. Was there anything not included in the training that should have been?
12. Did the participant find opportunities to ask questions?
13. What was the participant's experience in terms of engagement and interaction with the group?

Part C: After the training

14. Does the participant feel that the training has developed your understanding of research, and if so, in what ways?
15. Was the training relevant to your involvement in (project / activity)?
16. How will the participant be able to use the training?
17. Has the training had any other benefits?
18. Have there been any disadvantages to doing this training?
19. Does the participant have any suggestions for how the training might be done differently?
20. What opportunities would the participant like to have in future for using the training?
21. If there was more training, what would the participant like to see?

Part 5 : Further information on the project and the initiatives
Section 5.7 : In-depth examples topic lists
A : Topic list for training participants

B : Topic list for trainers

1. How did the trainer come to be involved in the training? (brief background)

Thinking about the training we observed:

2. How does the trainer feel the training went?
3. Was there anything the trainer thought worked particularly well?
4. And anything that didn't work so well?
5. Is there anything the trainer would change next time?
6. Ask about the training materials used. How were they developed?
7. Did the trainer get feedback from participants about the training?

If the trainer is a commissioned trainer:

8. How is training tailored to groups' needs?
9. Is the trainer involved in ongoing planning and delivery?

Part 5 : Further information on the project and the initiatives
Section 5.7 : In-depth examples topic lists
B : Topic list for trainers