

**Capturing the experiences of
those involved
in the TRUE Project:**

A story of colliding worlds

A Report to INVOLVE by

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Capturing the experiences of those involved in the
TRUE Project: *A story of colliding worlds*

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The TRUE Project

The TRUE (Training in Research for service Users: Evaluation) Project was commissioned by INVOLVE to carry out research to scope training provision in the UK relevant to consumer involvement in research: to identify what elements are effective, and to develop a good practice guide. The project was a three-way collaboration between Worthing & Southlands Hospitals NHS Trust, CAPITAL (Clients and Professionals in Training and Learning, a mental health service user organisation), and the University of Brighton. The work was completed in October 2003 and a report submitted to INVOLVE.

The TRUE Project consisted of a team of 7 service users (members of CAPITAL), three project supervisors and a project co-ordinator. The three supervisors represented the three organisations involved in the collaboration: one researcher from Worthing & Southlands Hospitals NHS Trust, one researcher from the University of Brighton, and the third being the Director of CAPITAL. The aim of the collaboration was to train and facilitate the service users to take an active role in the research, co-ordinated and supervised by the researchers.

Capturing the experiences of those involved

The people who were actively involved in the TRUE project requested the opportunity to reflect on their experiences of being involved as part of the project. This opportunity was provided by INVOLVE at the end of the project, through making some money available for the work reported here.

As stated in the brief for this work: “the experience of doing this work has had both positive and negative aspects for individuals, and the issues which have arisen are not only important to those involved, but are also very relevant to public involvement in research in general”.

The aims of this piece of work, as given in the briefing document, were as follows:

- To provide an opportunity for those involved in the TRUE project to reflect on their personal experience of being part of the project, with the opportunity for self and peer evaluation. This may also serve as a helpful completion process for some of those involved.
- To capture in writing and on a short video these experiences, extracting key themes which will hopefully inform others who plan to do similar collaborative research work involving both people who use services and professionals who may have no experience of working in this way.

Reflecting with some honesty on the experiences of being involved in this kind of research gives us the opportunity to learn from any difficulties encountered,

and to maximise the lessons learned for the benefit of others. The TRUE project provides an excellent opportunity for researchers and service users to learn from the experience of a team who have conducted collaborative research: a three-way collaboration between academic and NHS researchers and mental health service users.

Methods used

1. One-day event: a day was organised to take place at the end of the project, to bring everyone together in order to reflect upon the project and effect an ending. Five service users and three researchers attended (one supervisor was absent, one service user declined to take part and another was unwell at the time).
The day was organised into three main strands:
 - a. Small group work exploring Benefits & Difficulties, Successes & Barriers
 - b. Creative work exploring the visual or creative images of the project held by each person
 - c. Video box providing the opportunity for each person to speak directly to camera about their experiences of the project and lessons learnt

2. Reflective writing exercise: a second half-day was organised for those people who wished to take part in a further opportunity to share their views in more depth. Four people (one researcher and three service users) attended and one further service user submitted a response in writing. One researcher declined to take part in this exercise.

Analysis

Analysis relied upon examining through qualitative methods (based on the framework method) the following data:

1. Results of the small group work
2. Transcripts of responses made by all participants to camera in the video box
3. Results of the reflective writing exercise

The intention was to identify themes and issues arising from people's experiences of being involved in the project. A qualitative approach was particularly appropriate in this case due to the small sample size and the methods of data collection. Whilst every effort has been made to avoid identifying individuals, this has not always been possible given the small number of people involved and the roles they had within the project.

It is a testament to the hard work of the TRUE Project team members that their draft final report¹ was delivered (almost) on time and found by the funders, the INVOLVE Empowerment sub-group, to be more than satisfactory. The report is due for completion in January and should be available shortly thereafter.

Exploring the research process

Many service user and survivor researchers have recognised that the process of carrying out research is almost as important as the outcomes where user involvement is concerned (see, for example, Nicholls et al, 2003). And yet, why should this be? Academic and social researchers have long realised that research can be tedious at times, and that the outcomes or the search for knowledge in itself (hopefully) make up for the long hours of data collection and data entry, lost interviews and low response rates. However, professional researchers are also seeking career progression through research, publication in peer-reviewed journals and recognition through further grant awards.

These long term goals tend not to be the motives for service users and survivors, who more often are seeking to have an impact on the services they are using (or have used), or on the lives of others with similar problems. One of the implications of this is that service users may invest more of themselves in the research, hoping for something to change and giving of their personal experiences in the process. The fact that service users do not share the longer-term goals achievable through research, places a greater emphasis on their experience of the process. Furthermore, it is the meaningful occupation and the potential for skills development offered by the research process that may be offering them the greatest benefits.

Understanding these differences in perspective is central to understanding user involvement in research. We have different agendas in approaching the research enterprise, and the value of acknowledging these from the outset lies in the potential for a greater understanding of where each of us is coming from.

An initial course of action might be to ask all potential 'involvers' and 'involvees' *why* they want to embark on a project. Finding out the motives behind each stakeholder is vital to a frank exploration of why and how to start the project. Ideally, for a project to succeed, there should be some overlap in the motives across stakeholders; but, failing that, achieving some honesty about where each is coming from and an understanding about their different perspectives is vital.

¹ Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J (2004): *Training for service user involvement in health and social care research – a study of training provision and participants' experiences (The TRUE Project)*. Worthing: Worthing & Southlands Hospitals NHS Trust

A personal note

'User involvement' is – to my mind – essentially a personal enterprise: it is about the effect that some people's *personal experiences* of using (in this case, mental health) services may have on a research project. This does not always fit well with the project or enterprise concerned, whether it be service planning and delivery, or research. Those whose job it is to plan and run services or to conduct research may not be familiar with the entirety of experience that service users often bring with them into an involvement enterprise. The former may be relating to others from within their work or professional roles, whereas the latter may be bringing their whole life experiences to bear. This means that a willingness to listen, to learn and to change and compromise – from everyone – is essential to the success of user involvement.

As a survivor researcher myself, I welcomed this opportunity for enabling service users and researchers to reflect upon the process of being involved in a project. Over the years that I have been involved in similar work, I have become aware of the core significance to service users of the *process* of involvement: the quality of the experience of working with researchers, gaining skills, meeting and working with others can be key to the success of a project. Similarly, it is important that professional researchers be given the opportunity to reflect upon the experience of involving and working with service users in order that we can all learn from this for future projects.

My approach was to give people several different ways of contributing their experiences, including creative methods, in order to maximise the value of this part of the project, which is also intended as an ending for the team.

From the start of this venture, it was clear that – notwithstanding the successful completion of the project – there had been some substantial difficulties, the implications of which remained in the form of tensions between certain team members. For some time, this seemed to form the prevalent tone of the project and I found this disheartening. However, listening to and watching the video box contributions and reading the reflective writing exercise helped to counter this initial impression and some very positive outcomes and experiences shone through. I hope that this report reflects all of these views and reaches a balance between some quite polarised feelings and opinions; as one team member described it: 'I both loved and hated this project'.

For further reading on some of these issues, please see Trivedi & Wykes (2002), Faulkner (2003), Beresford & Wallcraft (1997), Nicholls et al (2003), Ramon (2000).

Emerging Themes and Experiences

1. PROJECT STRUCTURE

a) Management

As stated earlier, the TRUE Project was the result of a three-way collaboration between Worthing & Southlands NHS Trust, the University of Brighton and CAPITAL. The structure of the project was intended to involve supervision or management from all three 'host' organisations. In reality, this did not work as planned, with the CAPITAL supervision and support to members withdrawing early on. Furthermore, the Project Co-ordinator and team members were based in the Trust in Worthing but the former was officially managed by the University supervisor based in Brighton. This led to some difficulties in communication between the three researchers, and to a lack of clarity about individual as well as corporate roles. In addition, the University supervisor was absent for three months early in the project due to ill health.

These all led to additional pressure being placed on the Project Co-ordinator and on the Trust-based researcher, to whom most problems were taken. A few months into the project, the Co-ordinator was afforded external supervision by the commissioners, which she found to be helpful.

Nevertheless, it was agreed by the researchers that the management arrangements of the project turned out to be far from ideal, and had subsequent implications for the management and supervision of the project.

"I wanted CAPITAL to fulfil their own responsibilities to us as members. [X] has apologised for not being around enough but that doesn't help with the enormity of the struggles we had to face let alone the crisis issues like Occupational Health which was a disaster."

b) Accountability

A further level of difficulty in this regard concerned the number of organisations involved in the TRUE Project from a distance. The project was accountable to the funders, INVOLVE, and through them to their Empowerment sub-group. A steering group was also involved to which the project reported on a regular basis. Finally, the NCCHTA (National Co-ordinating Centre for Health Technology Assessment) were managing the project from a financial perspective and consequently also made demands upon the project team. Some of this complexity only became clear to some team members on the day of the Event, and served to explain some of the confusions encountered and the demands made upon them.

Recommendations:

- 1) That arrangements for the management and supervision of a project are made clear to all from the start, particularly in the case of a collaborative project and with particular reference to the support needed for service users and project co-ordinator(s) (see below).
- 2) That alternative arrangements are put in place immediately if difficulties are encountered.
- 3) That the funders endeavour to simplify the commissioning process for any future projects; e.g. simple lines of accountability with a limited number of organisations or groups communicating with or making demands upon the project.
- 4) That funders endeavour to check the viability of proposed collaborations in advance of funding a project.

2. RESOURCES

The initial project proposal planned and budgeted for the involvement of two service users in the project, and it was decided to involve four people in order to manage possible absences or withdrawals from the project. When nine people applied to become involved, a decision was made to accept all of them, partly because it felt hard to say 'no' to people who wished to be involved. This was later recognised to be a mistake in organisational terms, not least because there were neither the human nor the physical resources to support this number of people. However, it was difficult for some people to voice this as they did not wish to appear to regret involving anyone! Undoubtedly this early decision had implications that were felt throughout the project.

"So I think in retrospect we'd have to say we've only got resources for four people... we would have to go through some kind of selection process, and I personally feel quite uncomfortable with that..."

"Seven was simply too much, it was too much for (the co-ordinator) to manage, it was too big a team for her to manage with the resources that she had"

There was little office space and only one computer to be shared between the service user team, which led to the need to co-ordinate the days that individuals could come in to work. This was disappointing to those team members who wanted to work more, and stressful for the project co-ordinator to manage.

Another resource issue concerned travel and transport. Several team members mentioned how difficult it had been for them to travel within the county to the project base and beyond. Many were using public transport and travelling from e.g. Crawley, Horsham or Chichester to Worthing and Brighton. Again, this was an issue that affected the co-ordinator as well as the service user team members themselves, in that travel arrangements needed to be organised and expenses available to pay people either prior to travel or on arrival.

The lack of resources had clearly influenced several team members; in the reflective writing exercise, three people wrote about resources in the form of computer & office equipment and communications when asked to imagine spending extra funds on user involvement. (See also, section 8).

3. OCCUPATIONAL HEALTH REQUIREMENTS

The project hit problems early on, when prospective team members were referred to the Trust Occupational Health Department for interviews prior to appointment. This raised enormous difficulties for some individuals who were subject to what turned out to be unnecessarily intrusive and stressful interviews; they found the process to be personally damaging.

Not only did this result in a substantial delay to the project, it also laid down some difficult feelings about the Trust and its bureaucracy which lasted throughout the project. It was felt by some that more could have been done to address this issue on behalf of team members: that an early resolution would have improved team relations.

"Some of the questions were quite disturbing, quite upsetting"

"Only speaking for myself... I had a particularly traumatic occupational health interview that I was very dissatisfied with and I didn't feel it had been sorted, or has been sorted or ever will be sorted, and that was a great disappointment to me."

It was agreed subsequently that future volunteers not working directly with patients would not need to go through the full Occupational Health procedure. At the time of writing, it is not known to the author if the issue has been followed up and resolved to everyone's satisfaction.

Recommendations:

- 1. That all researchers planning to involve service users in any capacity should**
 - a. clarify whether or not service users will need to go through the Occupational Health procedures for involvement, and**

- b. If so, communicate with their Occupational Health department in advance to ensure that everyone knows and understands the basis on which people are being involved or employed. This is particularly important in the case of mental health service users who may experience discrimination at the hands of occupational health professionals.**
- 2. That INVOLVE explore ways of involving or communicating with Occupational Health professionals about these issues.**

4. RELATIONSHIPS AND ROLES

i) Interpersonal difficulties

It became clear from the outset of the work reported here that relationships between some of the team members had become fraught and tense. Two people were not speaking to each other at the time of the event in September 2003, and some others were expressing feelings of frustration and anger about the project. At the start of the day, a couple of people expressed concern about trust and confidentiality. In attempting to understand this, it was my intention to focus on the structural or project implications rather than on the personal aspects of these difficulties.

The main areas of difficulty appeared to involve project support, and a lack of honesty or transparency and trust that had developed over time. Some of these are dealt with under other headings, but it is worth reflecting here on the ways in which a few team members characterised these difficulties. One service user member said she felt that '*splitting*' had occurred within the team, and said that she would want to prevent what had happened in the TRUE Project from happening in other projects. One of the researchers reflected on his realisation that they were not working well as a team:

"I have never worked on a project quite so fraught with conflicts and divisions... there were so many instances of somebody or other having a 'problem' or 'issue' with somebody else, that at times this seemed the pervasive theme of the project..."

It would appear that when difficulties arose, the Project Co-ordinator was not always clear about where to take them or how to get them resolved. This situation was largely created by the structural and resource issues mentioned above, but was complicated by the lack of appropriate support (see below). As she was effectively the single person bridge between the service user team members and the management and supervisory members, much of the pressure landed on her. This pressure was transferred up the line of accountability to the Trust researcher, who often felt that he carried the

burden of blame for issues not resolved. It is perhaps inevitable that some 'splitting' of the team occurred as a result.

ii) Social bonding & fun

In contrast to the feelings expressed above, most of the TRUE Project team members reported that the development of social relationships within the team had been the most positive aspect of being involved in the project. People variously mentioned meeting people through case site visits, getting to know team members and having fun together, and going on trips to seminars or conferences.

"We got very fond of each other in spite of being extremely annoying at times... just like a typical team, in fact!"

"...we went out for dinner, had some laughs, we were a very jolly crowd going there..."

"People got a lot of fun out of it - fun was important."

Several of the service user team members identified the Project Co-ordinator in particular as having provided support and friendship.

"It was a delight working with (the co-ordinator)."

For some people, it went further than this in the sense that they felt themselves to be a part of something worthwhile, a project that involved giving something back to the community of service users and researchers.

"I loved being part of something bigger than myself."

5. SUPPORT

Support to the project and to team members was one of the areas of contention. Many team members felt that there had been insufficient support for service user team members and in particular for the Project Co-ordinator. This was not a view shared by all, however. There were differences of understanding about the nature as well as the amount of support needed for this project. Several quotations are given below in order to represent these different views:

"I'd make sure they looked at having an external supervisor, not just for service users but for the professionals involved as well; everyone should have someone they could go to to talk to that's going to be there from the start."

"We can manage, but there are certain things that need to be in place to make that a possibility"

"The support aspects took up a lot of time... I thought there was almost over the top support compared to the research... perhaps you need a support person as well as research co-ordinator."

"'Support' is a vague word but, generally, I think everyone in a collaborative project needs support. For me, the single most valuable form of support is 'good will' by which I mean wanting the best for others..."

The responses of service user members were more concrete in this respect, and specified such elements as flexibility (to accommodate people's good and bad phases), good information and communication, personal support around difficulties in doing the work, and group or team interaction and support. Some felt that they had received some of these in the project, but several felt that CAPITAL could have done more to support them and that most of the burden had fallen on the co-ordinator.

"I felt I could come if I felt ill. The support was knowing colleagues would understand, however I felt... I needed not to be pressured by quantity of work because I must not be stressed and I was correctly managed."

"More flexibility to capture the good and bad phases we can experience, more flexible working hours/attendance."

The issue of support is central, both to this project and to 'user involvement' in general. Consequently, it makes sense to explore it further here. In "Guidelines for the Ethical Conduct of Survivor Research" (Faulkner, A. *in progress*, funded by the Joseph Rowntree Foundation), 'support' is broken down into the following elements:

- Emotional support: often needed because people are involved in work that touches on their own experiences or is distressing in itself, or because people are unfamiliar with the world of work.
- Practical support: may be the glue that sticks a project together, e.g. money in cash form available for people's expenses, an adequate

administrative function, regular communications, travel arrangements or vouchers dealt with, payments available for childcare or other support needs.

- Research support: is important to ensure and maintain the standards of the research. This may be in the form of supervision; perhaps to the co-ordinator of the project or to a whole team on a regular basis, depending on the skills and experience of the co-ordinator.

It would seem that, for the most part, the TRUE Project Co-ordinator was expected to provide all of these forms of support – or perhaps, ended up doing so by default. In the recent report about the Mental Health Foundation's Strategies for Living programme, "Surviving user-led research" (Nicholls et al, 2003), these forms of support and their limits are explored in some detail. Aside from research support, the team found that they provided support 'in a variety of different ways including dealing with difficulties between research team members and between different organisations, emotional support and stress management, and in one instance liaison with care staff working with a researcher'.

A particularly insightful comment from this report concerns the nature of support as a balancing act along a continuum; in their case, they refer to Research Support Workers (RSW) in a team supporting several projects, whereas in the TRUE Project, we are looking at one co-ordinator with one large team. However, the issues are very similar.

"In the middle of the continuum is the 'ideal' relationship where the RSW is providing advice, guidance and some support, and the researcher and the RSW are both in agreement about how the research should be done. At one end of the scale is a 'confrontational' relationship, where the RSW is constantly having to assert various rules and requirements and there is disagreement between the RSW and the researcher as to how the research should be done. At the other end of the scale is a relationship where the emotional support element of the RSW role has become the main part, and there is difficulty in maintaining appropriate boundaries."

There are different views about where the balance lay in the TRUE Project, and it is difficult for me to judge. I have heard different views and I have come down on different sides of the continuum at different times. Overall, however, I would say that there was little experience within the *active* management team of user involvement in research or of working with mental health service users, and consequently a limited appreciation of the support needs of such a project. The absence of support from CAPITAL further complicated the situation. It was a learning experience, as several people suggested, but a learning experience with some personal costs.

6. LEARNING FROM TRUE

All of the service user team members who took part in this venture were appreciative of the opportunity the TRUE Project had given them to learn new skills, to meet new people and to attend specific training sessions.

"I loved the way you worked... the way that I knew that every week I was going into work ... the way that you worked as a team and you trained and you went out and had the opportunity to go to conferences..."

In terms of skills, computer working, project working, telephone interviews, précis and analysis were mentioned, as well as specific training sessions such as observation, focus groups, role play, and practice interviewing. One person had learnt what research was about.

Many people also mentioned the value of the case site visits: the opportunity to meet people in different parts of the country, with different disabilities or backgrounds, and to learn about their experiences. These visits had often been enjoyable as well, as mentioned in 4ii) above, and two people felt the project had had a positive impact on their mental health.

"Since I joined this project, I have felt much better than ever before."

For two people the experience had confirmed their choice of career for the future:

"I've gained knowing that it's what I want to do, this is the career I want to take... I've gained a hell of a lot from it."

For the researchers involved in TRUE, the benefits were perhaps more ambiguous in nature, in that the learning was not always framed positively. Two mentioned being very naïve before the project, primarily about the practical aspects of user involvement, about which they now felt much better informed. They also mentioned the value of working with mental health service users, and the knowledge and experience this had given them. Other issues mentioned were: a reluctant experience gained in project management skills, and IT and communication skills.

7. (IN)FLEXIBILITY

Many people, researchers and service users alike, reflected upon the need for greater flexibility in projects such as the TRUE Project. It had taken more time and resources than predicted, and the conventions of grant funding and

rigid timescales did not allow for this, despite a three-month lead in period supported by the funders.

Whilst some of this can be built into a proposal, it remains the case that commissioners may need to allow some additional flexibility where service users are required to be involved in research projects. One of the researchers referred to the incompatibility of this type of project with the conventional research grant, with 'its straight trajectory, and lack of flexibility'. Another referred to the commissioners as follows:

"Even though the commissioners were advocates of user involvement, there was very little flexibility displayed towards the TRUE Project. They expected us to deliver as though we were a conventional project, as if I was doing it myself... I think both commissioners and researchers need to realise that things don't go like clockwork."

In terms of time limitations, this meant that people could not be as fully involved in the later stages of the project, when the pressure was on to complete the report. But it also meant that some members of the team were caught in the middle with pressures coming at them from both sides. It may be that the project highlights a mismatch in understanding between the commissioners and the TRUE researchers about what is meant by flexibility.

Of course, flexibility is not just about timescales and deadlines; it is also about the way in which the research progresses, taking into account the needs and differences of individuals.

"[There should be] more flexibility to capture the good and bad phases we can experience, more flexible working hours/attendance."

Recommendations:

- 1. That commissioners of research to involve service users should allow for some flexibility in their requirements of such projects from the start; e.g. allowing the proposal itself to have flexibility built in (see below), and flexible timescales.**
- 2. That researchers and service users build in flexibility to their project proposals from the start, to allow for absences and the need for additional support arising.**

8. POWER & INEQUALITIES

Power, or the lack of it, and inequalities in access and opportunity are uncomfortable issues. Several people made reference to them during the course of this venture.

The project co-ordinator was particularly aware of these issues as a result of her background interest in health inequalities, as well as her current role which brought her into close contact with the inequalities that existed between team members. She found the financial inequalities particularly difficult to cope with:

"The people were not paid very much and over a period of time, I began to feel it was very little really"

Other people mentioned financial difficulties, too. During the course of the reflective writing exercise, participants were asked to write about what they would do with extra funding for user involvement in research. Three of the four people present wrote about physical resources, such as 'access to computers, printers, stationary library, photocopier, internet etc. etc'...

"People still have no idea what it costs to be properly involved without spending much needed benefit money on access to stuff"

Power – over the direction of the project – was something that one or two of the service user team members had concerns about. There was a sense in which they felt they had no control over it now that the proposal was written and agreed – no means of altering what seemed to be carved in stone.

"[if given the chance to do it again] I would want to be involved in the bid itself. I would want to be involved in the design of the project. I would want more information about the background of the people I would be working with and the organisations. I would (with my peers) want to hold more of the power."

This lack of power was highlighted during the occupational health interviews; some team members felt that they had been damaged by the experience and were powerless to do anything about it. It would need to be taken through the Trust Bureaucracy, which probably would need the support of the collaborating organisations.

However, there was also a sense in which the project had developed a life of its own, and the location of power was no longer clear. This was expressed by two people, one service user and one researcher, in writing during the event day, as follows:

Service user: 'Academics still holding the power inappropriately'
Researcher: 'I'm not sure who held the power in TRUE... perhaps no-one felt that they did (I didn't anyway!) but felt others did...? '

The extent to which any other power struggles may have been playing a part, between organisations involved at a higher level in the management of the project, was unknown to the author.

10. LESSONS FOR THE FUTURE

Almost everyone who took part in the video box was asked what lessons they would like to impart to others planning to undertake a similar project. The following are the answers they gave.

- Go for it but look after yourself, try to communicate with the people you're working with, check out what's been put in place for protection, to work well together.
- Go quite slowly, do it step by step, involve everyone from the start, attend to people's needs, pay attention to detail e.g. arrange transport etc.
- Everybody needs to have some education/training around involving people; researchers and professionals all need to get some training as well to help get it right.
- External supervision: everyone to have someone they can talk to outside the project.
- Be prepared; talk to service users as early as you can in the project – those who are actually going to be involved.
- Be clear about what is expected of people.
- Be realistic – about how long it will take, how many hours it will need per week, especially for people who haven't done research before; it's important to sit down and talk about those things at the beginning.
- Make sure the resources are adequate.
- The more people, more organisations and service users involved, the more complex it is ... things will go wrong. Patience is definitely needed.

ENDNOTES

Finally, a few quotations are presented here in order to encapsulate some people's views of the overall experience...

"It would be good for people to know that this kind of thing is very complex. You're bringing together worlds which up to now have collided... so you have the academic world, if you like, versus the patient or service user world where we've had everything done to us over the last few years and decades. And you've got the idea that some people are open to change and some people aren't... and that's still very significant - there's still a significant number of academics who don't want us to be involved still which isn't encouraging..."

So it's this idea that you've got all these different worlds colliding and none of us have the answers for how to facilitate that."

"The positives far outweigh the negatives. Overall we did a really good job, explored new ground, but the sheer hard work overshadowed it.

"It's a bit of a journey, you all need a willingness to learn and to change."

"People who suffer in mental health... if they join a project like this, they will definitely benefit because there are a lot of things to learn and they will pass their time very nicely"

"It was great to do, lovely to do, I hope the result's worth it, I think it is."

"I'd do it all over again."

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Appendix A
Flipchart notes from small group work

Benefits

Group 2

Individuals

- Feeling appreciated
- Great fun
- Mind stretching
- Occupation
- Company
- New skills – computer
- Increased knowledge of mental health
- Increased knowledge of research

Project

- A core of skills
- Experience brought to the project
- Lots of views, experiences and diversity
- Teamwork – increased outcomes
- Steering group useful, helpful

Organisations

- Learn about each other
- New experiences / new ways of working

Group 1

- Knowledge of research widened
- Skills attained (e.g. computer, précis, analysis, telephone interviews, observation, focus group, etc.)
- Working in a group
- Have consolidated ideas of wanting to be involved in audit and research
- Have been invited to other research for a
- Experience in case sites
- Getting to know other service users in research
- Met some wonderful people in the case sites
- Liked the group of service users and the way they took part and joined in

Group 3

- Mental education
- Meeting service user team (great experience)
- Working with experienced people
- Confidence and working with all team
- Find out if were able to work as part of team
- Learning about new ideas

Successes

Group 2

Individuals

- Stayed well! Through the benefit of occupation
- Getting to the end
- Doing the case sites
- Doing the work – analysis
- Working in a team
- External supervision
- Experience of working
- Friendships

Project

- Involvement
- People brought enthusiasm, time, willingness, motivated
- Development of new skills
- Earning for self or for Capital

Organisation

- Capital has developed its research capacity / researchers
- Reputation in the field

Group 1

- Produced a good report
- No-one dropped out
- Good working team, despite difficulties
- Personal empowerment
- Pre-information good
- On the job training excellent
- The co-ordinator survived
- We all survived
- Fun

Group 3

- We did the report and it reads well
- Project well done
- Stayed with the team for 15 months

Difficulties

Group 2

Individual

- Too much to do, need for admin support
- Too many people – only one facilitator
- Not being able to give people what they wanted, e.g. Julie wanted more office work

Project

- Incomplete team due to absences (illness) *we had a team but sometimes there were holes in it*
- Time pressures
- Providing people with adequate training/experience
- Geographically v. spread out – travel
- Cash flow workings – managing petty cash difficult
- Lack of support – what to do when someone comes to work unwell?

Organisation

- Time
- Lack of previous relevant experience

Group 1

- Working in a group
- Occupational health interview
- Inexperience of three organisations – lack of support, lack of supervision, lack of understanding, more training needed
- Whole project needed to be more flexible and responsive
- Fixed parameters of grant system meant the changing needs of the project difficult to meet
- People being away

Group 3

- Splitting – of individuals and organisations, between and across
- People's expectations of each other not clear
- Being very involved both professionally and mentally
- Can get lost within a project, can forget who you are with all the organisations involved

Barriers

Group 2

Individuals

- Lack of support – research; mental health
- Others taking over (one occasion)

Project

- Time limitations
- Occupational health process (really obstructed process)
 - Time
 - Upsetting
 - Not taken seriously
- Under-resourcing: desk space, computer equipment
- More feedback on our work/contributions
- More training before researching
- Squeezing new ways into old styles

Organisation

- Lack of communication
- Absence
- Lack of clarity re: roles

Group 1

- Occupational health process
- Relative inexperience of all three organisations in user involvement
- Office space inadequate
- Not enough space/planning to work the number of hours wanted
- Travelling on public transport
- Not enough supervision for the size of the group
- Once the grant has been accepted, the parameters are fixed

Group 3

- Long distance to travel from home to office
- Working environment not very good
- Too many organisations involved; and high expectations – must not be late! Didn't take into account the difficulties, illnesses, time needed
- Steering group – too many people to answer to, the HTA was also involved as well as INVOLVE where decisions could not be made without reference to the relevant sub-group.
- Mixed messages from INVOLVE – not understanding the process. It was implied that the project lead had badly managed the Occupational Health issues at the hospital

Appendix B
Presentations of creative designs

Capturing the Experiences of the TRUE Project
Event 10th November 2003
Presentations of creative designs

(yellow 3d mug)

Mug I made at the Christmas do over a year ago (pottery painting). Meanings: we had a good time, comfort, companionship, the office, variety, surprises, hard work, a good job done, friends...

(delicate drawing of flower)

Last year I missed the training in Chichester. Do something creative is always in my own mind. But I do not know where to start and where to finish. I did try to do a picture of a 'rose' but at the end it did not look like a rose. It is 'TRUE' I tried to picture a flower but not a cauliflower! 1938 – is the date of my birth.

(collage of mauve and blue)

Represents the spirit of the True project, shades of (co-ordinator's) skirt.

(pink spiral)

A labyrinth or spiral, start on your journey and follow it round, the struggles and challenges, never a dull moment, and sometimes it's mind blowing!

(3D hot rod car)

Uppermost in my mind was a journey of creativity, research is a creative process. So I wanted to represent a journey... With service users involved in research, there are no pilots and passengers, everyone is at the front, people are not sure who's driving the plane... In getting from A to B we had to create our own vehicle; it goes from 0 to 100 in 3 seconds(?). It has a huge extremely powerful engine, going so fast, we weren't able to know where we were going. And the pictures on the sides show everyone doing all sorts of other things than driving!

(box of things/words: hurt, no trust, eye opener)

"Some things may never be known". It speaks for itself really. Hidden things in the box, emotions. I did this for everyone to get something out of it.

(picture/collage in 2 halves)

Strong opposing emotions: tears, pain, trauma, anger, fun, loved people, inspiring, enlightening. Joined the two halves with something in the middle, a bridge. Some bad stuff is on the good side as well – mushrooms need shit to grow in. Sparkly paper is Julie, support. Joy, beauty. *Paid enough Money* along the bottom. A gruelling journey, blood, brain, tears, vomit, mess, crucifix. It is a balanced picture: I hope that this (positive) side will help me cope with that side of it.

(orange & yellow picture)

Orange is my favourite colour; it represents warmth, happiness, vibrancy, not as harsh as red, warm fire. There's a softness there as well. The lines – none are straight and they go off at tangents; it was not as you imagine a project would be. It doesn't end neatly – jagged shapes but warm orange.