

# 2

## ***Why Service Users Bother or Why Bother Involving Service Users in Research?***

### **Introduction**

In this chapter we will examine why it is seen as worthwhile to involve service users in research. But first we ask the question: What do service users hope to gain by becoming involved in research? Also, we ask whether these hopes are deliverable? We then go on to explore the differing levels of service user involvement and the mandate and philosophical underpinnings for service user involvement. This will be followed by an examination of the benefits and identified costs of involving service users in research including the costs and benefits to the service user, the lead researcher and the research.

### **Why do service users bother?**

---

---

#### **Reflexive Questions**

- \* Before reading any further, why do you think service users become involved in research? What do you think they hope to gain from the process?

In trying to put your list together you may have thought about such issues as:

- Frustration with research.
- Desire for change in services.
- It's my right.
- Fancy being a researcher.
- Status.
- Personal needs.
- Having a voice.
- Personal development.
- To earn some money.

### ||| Why Service Users Bother |||

Torvey (2006: 6) in a literature review examining the reasons why service users get involved in research concluded:

The studies we looked at suggest that those that are motivated to get involved do so for a combination of reasons related to their personal situation, their experiences of health and/or social care services (often negative) as well as possibly having a more general commitment to getting involved and bringing about change.

All of us have had the experience whereby we have become frustrated with being at the receiving end of a service, such as in a restaurant, shop or even research where we have thought we could have done a better job. This is particularly likely to be the case where our experience has been negative and frustrating. In such circumstances we may wish to be the waiter, shop assistant or researcher to be able to put things right or to tell the story as it 'really is' and to bring about the changes we want to see that will make a difference. A potential service user researcher may view their involvement as an opportunity to have their voice heard where in the normal flow of everyday life their voice and views would be drowned out by those of the experts or professionals. It is important to note that people often wish to get involved in research both as service user and as academic researchers because they believe a situation or a service could, and should, be improved. This issue of a commitment to change will be dealt with further when we address the philosophical underpinnings of research in Chapter 4.

The next suggestion was that some service users may view it as their right to be involved in research that is about them. It is they who are the 'experts' on their medical condition or service and that any research that does not involve them is in danger of being at best partial and at worst misleading. This is a central tenet for the involvement of service users in research and will be re-visited and explored in greater detail throughout the book.

Alternatively, from a different perspective we may have thought that being a researcher seemed like fun and we could do a job like that. However, it is clear that personal reasons can and do play a part in why people volunteer to become involved as service user researchers. Other personal reasons may include the idea that being a researcher is a preferred role and status in comparison to other available roles and statuses. Being a researcher provides a distraction from other life events or that being a researcher presents an opportunity to get involved in something worthwhile. There is also the possibility that some service users will view the opportunity of becoming involved in research as a potential for their own self-development and to learn new skills. Lastly, service users who volunteer to become involved as researchers may view their

## ||| Chapter 2 |||

involvement as an opportunity to gain some financial reward and supplement their income.

Obviously service user researchers may identify one, or more than one of the reasons identified above. It is worthwhile reflecting that it is not surprising that the reasons given for service users becoming involved in research are not very different from many of those that are likely to influence health and social care researchers.

Having identified why service users will become involved in research it is important to ask whether these aspirations are likely to be met or not. It is obviously possible, but by no means guaranteed, that we can do a better job at research than anyone else. There are a number of issues which we will discuss later as to how we can seek to ensure that research with service users has the best chances of success. However, the point is, there is no guarantee that in believing you can do something better than anyone else that you will in fact be able to do so. This may be a very legitimate motivation and may help someone put in the extra effort required, but it provides no certainty of a better product. Similarly, all researchers want their research to make a difference, but again there is no guarantee that this will be the case.

Service user researchers may view being involved in research as an opportunity to have their voices heard, but this is likely to be constrained by the research process which needs to be able to establish academic credibility and rigour for its results to be acceptable to academic, practice and policy communities. Also, once the research report is published and is in the public domain there is no guarantee of how it will be received or used. Whilst all researchers may wish their research to make an impact and to change policies or services for the better there is no assurance that this will necessarily be the case. Once the report is written and the dissemination process undertaken how individuals, agencies and organizations interpret and use the research is in their gift, not the gift of the research team.

From my experience it is quite clear that research can be fun, but it is also likely to be hard work. Whilst parts of the research process are likely to be experienced as exciting and stimulating, others are likely to be boring and hard work. As with most worthwhile tasks, it is not possible to have one without the other. Service user researchers should be able to be recompensed for their efforts in undertaking research, but there are limits to this and potential benefit issues to consider. This topic will be discussed further in Chapter 6.

It is clear from this section that those service users who volunteer to become service user researchers do so for a range of motives and there is a need to temper expectations, to ensure there is a balanced view of what can and cannot be achieved. Involvement as service user researchers is not a therapeutic intervention, a pleasure-seeking experience, alternative income strand or a

### III Why Service Users Bother III

mandate to change policies or services, although it may include elements of some or all of these. It is, however, very important not to oversell what can be achieved for service user researchers.

### **Levels of service user involvement in research**

---

Before discussing levels of service user involvement in research it is important to examine some of the assumptions behind involving service users in the research process. Building on the work of Christensen and Prout (2002) in relation to young people it is possible to identify a typology of service users as objects, as subjects, as social actors and as active participants. The first view represents service users as objects to be measured, collated and researched. The second viewpoint places service users in the foreground of the research able to tell their own story; however, this story is still tempered by researcher views on the validity, usefulness and competence of the service user. The third perspective sees service users as able to act, to change and be changed by their actions. In this perspective service users are seen as autonomous individuals and not merely as parts of another system or health or social care system. The last representation takes the third perspective to its logical conclusion in relation to research and sees service users as having an active part in the research process as creators and co-creators of knowledge and understanding. Within this book we attempt to examine the conditions, possibilities, strengths and weaknesses of this fourth position.

Up until now we have been discussing the involvement of service users in research as if we all agreed what that this was and as if we understood the same meaning when the term is used. This is an untenable position and we now need to become more specific about what we mean by involvement. Arnstein (1971) has probably developed the best-known model of citizen participation which suggests a ladder of eight rungs: manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control. The first two rungs of the ladder, manipulation and therapy, are described as non-participation, whilst the next three rungs are described as tokenism with only partnership, delegated power and citizen control viewed as meaningful participation. Arnstein's linear model can be criticized for its hierarchical approach, which suggests that each rung up the ladder is better than the rung before. This is not necessarily the case and neglects the possibility that in certain circumstances different rungs may be more appropriate depending on the nature of the activity. As Titter and McCallum (2006) note, Arnstein's ladder fails to capture the dynamic nature of user involvement, is interested only in outcomes at the expense of processes and conflates means with ends. It is unlikely that you will have the same level of

## ||| Chapter 2 |||

service user involvement in the research application stage as you might have in the data collection or writing-up stages. If this is the case, how would you describe the level of research involvement? There is a danger in such a model that you will either go for the highest or lowest rungs of involvement, neither of which accurately describes the degree of involvement. There is also the difficult question to answer that where you have more than one service user involved you may have differing levels of involvement. Within the model there is an assumption that you can only achieve one level, whilst in research you may in reality have a research involvement profile(s) depending on the stage of the process and the skills and abilities of the service user researcher(s).

A simpler model by Hanley et al. (2004) identified three points on a continuum: consultation, collaboration and service user controlled. Before exploring Hanley et al.'s (2004) continuum further the reader may have noted that in Hanley et al.'s model there is no room for either illusory or non-participative practices. This is a serious oversight in the model. To address this omission it is suggested that we need to add another point at the end of the continuum to capture those situations which we will call tokenistic. This term implies there is an attempt to involve service users, but this attempt, either through intent or lack of awareness, results in an illusion of involvement. For example, consider the position of a service user who volunteers to become involved in a research project only to find that the research team meetings are held at an inaccessible venue and at a time due to child care responsibilities they are unable to attend. In this case the researchers may well have set out to include service user researchers but that due to a lack of thought in their planning their actions have actually resulted in non-involvement. In such circumstances it is easy to see how service users can become cynical about a researcher's attempts to involve them. It is possible for such a situation to have been manipulated by a researcher, but such a devious approach represents unethical research and should be considered as such. It is also possible, with the increasing demand by research commissioners, to require service user involvement in bids, to include a service user's involvement as purely tokenistic. A service user researcher may be recruited to the research in order for the lead researcher to be able to tick the research commissioner's requirements but have no influence or impact on the research process at all. This would be the case when a service user is a member of a research reference group but no attempt is made to include them and the language and written material used in the reference group only serve to exclude rather than to include. It is therefore imperative that we extend Hanley et al.'s (2004) continuum. For the purposes of this book we will describe this as non-involvement to highlight the fact that although attempts have been made, through omission or commission, misguided or unintended intentions have resulted in service user non-involvement.

### ❖ *Consultation*

We are all familiar with consultation, whether this is about proposed government legislative changes, a reorganization of our work practices, a change in service, the concept for a new car or a new brand image for a well-known drink. We all experience consultation on a regular basis and will have differing views on differing occasions as to whether our opinions are either heard or acted on. Hanley et al. (2004: 8) describe consultation as:

When you consult people who use services about research, you ask for their views to inform your decision-making. For example, you might hold one-off meetings with people who use services to ask them for their views on a research proposal. You will not necessarily adopt those people's views, but you may be influenced by them.

Hanley et al. accurately capture the inherent ambiguity of a concept like consultation. This 'useful ambiguity' (McLaughlin et al., 2004) is one of consultation's greatest strengths and allows consultation to mean different things to different people. In consultation it is 'acceptable' for a manager to consult on a particular service reorganization and to gather opinions and views from all the staff and stakeholders but for the manager not to act on any critical views and still be able to say that they have consulted. Consultation does not guarantee that any ideas, changes or issues raised by those who are being consulted will have any impact or influence whatsoever on the outcome. This is not to imply that consultations may not radically change a project, but the 'useful ambiguity' of the term does not imply that they have any influence at all for them to be legitimately described as consultation. Hanley et al. (2004) describe consultation as a safe place to begin service user involvement as it is a simple process without any promises. The power in consultation firmly resides with those undertaking the consultation to decide who should be consulted and what they should be consulted about. It is thus unsurprising that Beresford and Croft (1993) claim that certain powerless groups are over-consulted with little evidence of their opinions creating any change. Butt and O'Neill (2004) found that black and minority older people complained that they had been over-researched, with researchers often asking the same questions and/or producing the same results that had been produced 15 years ago. Understandably they did not want more research; they wanted action and to be involved at local and national levels in decisions which affected their own lives.

Consultation may be the first point of involvement on Hanley et al.'s (2004) continuum but it is also a point that is equally open to those who do not

wish to share their power or to engage in meaningful involvement. It is for this reason you may be rather cynical about consultation as a means of involvement. Hanley's next point of the continuum is collaboration, which we now move onto.

### ❖ **Collaboration**

Collaboration, like consultation, is an unspecific concept occupying the ground between consultation, and service user controlled research. Collaboration, unlike consultation, implies that service users will be listened to and that you will be able to identify where their suggestions have impacted upon a research study. As such, collaboration offers a wide range of ongoing opportunities for meaningful service user researcher involvement. Service users may be involved in the writing of a research bid, membership of a steering or reference group, involved in identifying the research methods and questions to be asked, undertaking the data collection and analysis, writing-up of the research and disseminating the research findings. In other words, a collaborative approach promotes service user researchers' involvement in one, some or all aspects of the research process.

Collaboration requires the lead researcher to be more participative than is required for consultation as they are sharing their power to control the research as a means to ensure a more collaborative research process and a better quality product. Such a view moves away from a traditional 'zero sum' view of power where power is seen as a finite quantity, and for someone to give away power is to become less powerful. In participative research a zero sum view is eschewed as it is assumed that in working together the whole can be greater than the sum of the parts. Such situations are not necessarily 'win lose' but can be 'win win'.

Collaborative service user involvement in research is not without its difficulties. To undertake collaborative research is likely to be time consuming and to require extra resources, thus making the research more costly. Also, as already noted, collaborative research requires the research professionals to hand over some power and for some lead researchers this may be perceived as a disadvantage. For others, they may need to develop new skills in facilitation and negotiation. Whilst having done all this there is no guarantee that the extra time and resources will automatically secure a better result. Collaborative research provides an opportunity for the involvement of service users in research, but it is not an opportunity to be taken lightly or without due consideration to the nature of the research question, the skill set of the researchers or the resources available.

❖ **Service user controlled**

This is the opposite end point of the service user involvement in research continuum from that of tokenism. Whilst tokenism provides the service user researcher with no power, the locus of power at this point of the continuum remains very clearly within the ambit of the service user researchers. Service user controlled research presents a challenge to traditional ways of research production and ownership. Barnes and Mercer (1997) note that the traditional power of the researcher is enshrined in how researchers control the design, implementation, analysis and dissemination of research findings, often resulting in service users being treated as objects to be measured, categorized and quantified.

**Reflexive Questions**

- \* What is your initial response to the following scenario? How do you think the senior managers might feel about this?
- \* A group of mental health service users are granted funding to study directors of adult social services, chief executives of mental health trusts, Mind and similar large mental health charities. The service user researchers are collecting data on where such people lived, their lifestyles, how they achieved at school, the nature and length of their key relationships, their alcohol and drug use. On top of this they are also seeking to find out when they last conversed with someone with a mental health illness or last spoke to the partner of someone who had just been involuntarily admitted to a hospital. From this data the service user researchers want to be able to say something about the respondent's values and be in a position to comment on their suitability to run mental health services. (Based on Holman, 2001)

As the adaptation from Holman reminds us, researchers have power. Research is not a neutral activity; it can both empower and disempower. It is not an activity to be entered into lightly. Research and its focus can often represent a reflection of the inequalities of society whereby we find it easy to accept that the most vulnerable should be subject to research scrutiny whilst the most powerful remain aloof from such interventions in their lives.

So, what is entailed in user-led research? Essentially it is about service users determining the research focus, the research process, the interpretation of the findings, and the conclusions to be drawn for practice and policy. (Evans and Jones, 2001: 8)



## ||| Chapter 2 |||

Evans and Jones (2004: 8) go on to illustrate what they mean by user-controlled research by identifying 11 'who' questions:

- Who identifies and defines the issue or topic to be studied?
- Who identifies and defines the hypothesis to be tested and/or the questions to be asked?
- Who determines the methodologies to be used?
- Who undertakes the research?
- Who applies the methodologies/asks the questions?
- Who decides what, and how, to record the responses?
- Who collates and interprets the data?
- Who decides what conclusions should be drawn?
- Who decides how to present the conclusions?
- Who draws the lessons for policy and practice?
- Who follows through to see action results?

It is possible to suggest there should be a twelfth question: Who should write the research bid? For Evans and Jones' research, if it is to be service-user led research, the answer to most, if not all the questions, should be, 'service users'. There is, however, a difficulty of precision here, as what are we to make of the situation where we answer nine, eight, seven or six questions with 'service user researcher'. Or, to put it another way, how many 'who' questions do you need to answer with 'service user researcher' before research can be considered to be service user-led research? This also makes an assumption, which may well be untrue, that all aspects of the research process should be considered as of equal weight. The point to be noted is that service user-controlled research is not a simplistic notion and remains a dispute concept. Broadly, service user-controlled research implies that service users are responsible for the conduct of the research and any subsequent decision making, but this does not mean that service users have to undertake every aspect of the research process. Also, as Turner and Beresford (2005a) identified in their study, service users do not speak with a unitary voice on service user-controlled research. They found that service users disagreed about whether it should be service users who undertook the research or whether non-service user researchers could be employed as long as service users remained in control. Turner and Beresford (2005a: vi) also identify what their review identified as the aims of user-controlled research:

- The empowerment of service users and the improvement of their lives (both through the process and purpose of research).
- Being part of a broader process of making social and political change.

### III Why Service Users Bother III

- Changed more equal relations of research production (where the people who carry out the research and are the subject of the research relate to each other on much more equal terms).
- Being based on social models of understanding and interpretation (like the social model of disability).

For Turner and Beresford service user-controlled research is not merely a different epistemology but is a political statement.

In comparison to the consultative and collaborative approaches service user-controlled research locates the power to make decisions firmly within the control of service users. Thus, if non-service user researchers are employed to undertake aspects of the research they are doing so in response to the directions and remit supplied by service users. There is, though, a thin line to be drawn between employing consultants who are expected to make 'suggestions' as to how certain activities can be carried out effectively and to when such 'suggestions' become less like 'suggestions' and more like decisions. This is a perennial difficulty for anyone who employs a 'consultant' for their expertise to decide when they should agree with what is being suggested and when to go with their original design. This is not to suggest any devious intent on the consultant or non-service user researcher but to raise the question how far anyone can remain in control when they do not fully understand what is happening and why.

This raises another issue for further debate and consideration. Does service user-controlled research mean that it is only those service users who are receiving that, or a similar service, that can truly be called a service user researcher? Or conversely, can someone who is receiving a service for a physical impairment be a service user researcher in a mental health project when they have never been a recipient of mental health services? This is a tricky question, as at one level it could be argued that what unites service users is that they are recipients of a service. However, it is one of the key justifications for involving service users in research that it is their understandings of the services being investigated that justifies their involvement in the process. Otherwise, it could be argued that service users who are not recipients of those services do not add anything more to the process than would non-service user researchers.

User-controlled research is not without its difficulties; it demands that non-service user researchers hand over power, and for some non-service user researchers this will at best be uncomfortable if not impossible. Some research commissioners and sponsors will not agree to such an arrangement, wanting a known non-service user researcher to be responsible for the research. User-controlled research often costs more if it is to support service users properly (Turner and Beresford, 2005a). Any results derived from the research may be viewed as 'subjective', as those who

have the most to gain from the research have undertaken it. This problem of 'bias' is not something that is restricted solely to service user researchers and is also an issue for academic and other researchers.

As can be seen by this short exploration, service user-controlled research is contested and disputed and is still very much in its infancy with many questions yet to be answered. For our purposes, it represents one end of the service user involvement continuums whose individual points are not set in stone but represent a range of contested sitings often overlapping from one point into the next. We have identified a model of four points: tokenism, consultation, collaboration and service user-controlled research. All of these, except tokenism, may represent service user involvement in research. This book is located primarily within the collaborative area of the continuum although will on occasions include both consultative and service user-controlled research. In deciding which level is appropriate for which research project in which circumstance requires the consideration of a number of issues. These issues include: the skill levels of the service user researcher and non-service user researcher, the nature of the research topic, the resources available and the research methods being operationalized. It also needs to be noted that differing levels of involvement may be appropriate within the same research with possibly a greater involvement being experienced in the development of the research tools and undertaking interviews than might be the case in the analysis of the research if advanced quantitative or qualitative approaches are used.

Having discussed why service user researchers bother with research and seek to identify differing levels of service user researcher involvement, we now move on to ask what benefits are claimed for involving service users in research.

## Benefits of involving service user researchers

---

### Reflexive Questions

- \* If you were considering involving service users in research, what benefits would you be hoping to achieve for: (a) the research; (b) service user researchers; and (c) lead researcher or non-service user researcher?
- \* You may want to take a side of A4 and split it into three columns, one of for each of the three categories, which might make it easier to undertake the task.

There are many reasons identified in the literature why lead researchers should involve service user researchers and this section will identify these in

### III Why Service Users Bother III

relation to: (a) the research; (b) the service user researchers; and (c) the lead researcher. For ease of reading we will now refer to the lead researcher as opposed to non-service user researcher. This is meant to refer to a professional researcher for whom research is an expectation of their paid employment and who have undertaken an accredited research methods course. From this definition it is clear that some service user researchers will also come into this criterion and there are those who are able to wear both hats. This helps to remind us that we need to be continually sensitive and aware of the labels we use to describe others and the implications of those labels.

#### ❖ *Benefits to research and service development*

There are a number of claimed benefits that are worthy of further exploration including:

- Focusing the research. It is often claimed that involving service users as co-researchers can help to focus research to ensure that it not only remains relevant for those who deliver the service but also for those on the receiving end (Young et al., 2007). In particular service user researchers may help by being able to prioritize topic areas. This is recognition that service users and carers are experts by experience (see Chapter 1). No one else can claim to have had the exact same experience as they have had of health and social care services and it is they who know where it has worked well and where it needs to improve. This also serves to ensure that the research will address service users' concerns and not merely be an academic exercise.
- Service user researchers can ensure that any research tools developed for the research, including questionnaires, interview schedules, consent or information leaflets, are worded in such a way as to be accessible to the target population. Similarly they may also advise on wording including common expressions within the target group or the ordering of questions to best address the research question.
- Service users from hard-to-reach groups, like those who misuse drugs or who are living with stigmatizing conditions, are more likely to know where others in similar circumstances or conditions congregate, thus providing greater access to the target population. This can be further enhanced by service user researchers undertaking research interviews. Members of such groups may be sceptical or resistant towards traditional researchers and be more willing to participate if it is someone whom they feel is more likely to understand their position and views.
- The range and quality of the data can be enhanced.

- Having undertaken the data collection research, service user researchers can participate in the analysis of the results and help to ensure that crucial meanings are not misunderstood. They can also help to make connection between themes and ideas that would not be immediately relevant to a lead researcher.
- Service user researchers can help ensure that any recommendations include the unique perspective of service users which can help to develop services that are more likely to be used by other service recipients.
- Service user researchers can help with the dissemination of results. Service users speaking from their experiences of both being a service user and a researcher can have a much more profound effect than a professional researcher. The ability to be able to incorporate personal experience can be a major benefit.

### ❖ *Benefits to the service user researchers*

As identified in Chapter 1, we need to consider why anyone should wish to become involved in a research project, and in particular why service users bother and what is in it for them. This is not to claim that just by involving service users as co-researchers we will automatically ensure a better research product. It is, however, to suggest that there may be inherent benefits for service users being involved in research as co-researchers. In trying to identify what these benefits are you may have identified:

- The inclusion of service user researchers can enable service users to actively participate in addressing the issues that affect their, and those with similar conditions, impairments or service needs. As such, they can contribute to the improvement of the services they experience.
- Service user researchers, through training in research skills and involvement in the research project, can develop new skills, enhance self-esteem and improve their job prospects in becoming active participants in a research project (Lockey et al., 2004).
- The very act of being involved in a successful research project can improve confidence and an acknowledgement that service user experiences matter and are a legitimate expertise to bring to the research process.
- Involvement in research can empower service users.
- Remuneration is an issue we will return to in Chapter 5; however it is clear that service user researchers should be rewarded for their effort, skills and involvement.
- When the inclusion of service users' research is successful and mutual respect develops, a change of attitude is promoted that values the capabilities of service users and the roles they can play.

❖ **Benefits to academic researchers**

It should also be remembered that not only are there benefits for service user researchers, but there are also benefits for academic researchers. This form of research potentially benefits not only the research process and service user researchers, but also lead researchers.

- Increased awareness of the potential and needs of the target service user group.
- Increased understanding of the service user group issues, for example, it would be very unwise to open a five star day centre for D/deaf service users when what they want, and need, is employment.
- Direct contact with service users in a collaborative venture is likely to lead to a deeper understanding of the service users' issues and views.
- Helps to ensure that any end product doesn't merely reflect professional or academic considerations but is grounded in the reality of those who regularly navigate the health and social care system (Clark et al., 2005).
- Working with service users can be very energizing and great fun (McLaughlin, 2005). This can be very stimulating, creating new synergies and promoting new ways of looking at old problems. The GSSC and SCIE also note that this enthusiasm and commitment is contagious and potentially beneficial to everyone (GSSC and SCIE, 2004).

---

---

**Costs involving service users in research**

We have identified a number of possible benefits of user involvement in research and it is now important to consider some of the costs involving service users in research. Involving service users in research is not a cost neutral situation and those who both champion this approach, and those seeking to use it, need to first consider the implications of their choices both in terms of benefits and costs. It is only by analysing both costs and benefits that we can ascertain when such approaches are justified and under what circumstances.

❖ **Costs to research and service development**

Involving service users in research is often written about as if there were no costs and this is patently not the case. When trying to identify what you thought might be costs you may have identified: time, resources, training, support by others and competing pressures.

## ||| Chapter 2 |||

- In relation to time and resources Kirby accurately points out:

All participatory research projects (whether this is with older adults or young people) need the time and resources to support participation. This is easy to underestimate. (Kirby, 2004: 12)

Service user researchers may well be able to identify research questions or help to ensure the relevance of research, but this is not possible until the co-researchers are recruited. This is not a time resource or cost neutral activity. There are now a number of service user trained research groups who can be commissioned to undertake this work; for example SURF (Service Users Reaching Forward) and SUTRA (Service Users Training and Research Association), but depending on the project, the geographical location or the service user group, the lead researcher may need to recruit members individually – and this will require time and effort.

- Once recruited, the potential service user researchers will also need training to undertake the tasks required within the research project. Lockey et al. (2004) identified that training was not readily available but where it was available it was research project specific. This may create difficulties, because there are no short cuts in service user researcher training, as poor quality training is likely to lead to poor quality research.
- Service user researchers, like people with learning disabilities, physical disabilities or young people, will also need the support of others to be able to undertake the research (McClimens et al., 2007; McLaughlin, 2005; Williams and England, 2005). Again, this support can be resource intensive, as it may include ensuring that service user researchers are transported to research events, undertaking or supporting the completion of practical tasks, acting as a mentor or coach and has led Chappell to comment:

If people with learning difficulties need non-disabled allies in the research process in order to convey their experiences in a way which is acceptable to the research community and its gatekeepers, how can the integrity of their accounts be maintained? (Chappell, 2000: 41)

- Patience, things will not necessarily happen quickly; relationships take time to build and changes may not appear dramatic, a long-term perspective is required (Nolan et al., 2007b).
- Poor research experience for service user researchers can have a negative impact on future potential research projects within that service user community. If the experience is negative this is likely to have ramifications beyond the research project whereby service users will be less likely to become

### III Why Service Users Bother III

involved in research in the future, thereby contaminating the field for future research.

#### ❖ *Costs to service user researchers*

Having identified some of the costs to the research and service development involving service users in research we now move on to issues concerned with service user researchers. In particular, issues of lost opportunities, highlighting of inadequacies, and loss of self-esteem and confidence are highlighted. This is to reinforce that involving service users in research is not a cost neutral activity only in terms of resources but also in terms of its potential impact upon those who participate in the process. There is no rule to say that all participative processes will be experienced positively.

- This point relates to the last point but is seen from a service user researcher's perspective. If a service user researcher decides to use their time to become involved in research they cannot have this time over again to undertake some other activity. Whereas for some it may represent rescue from having to 'fill in time' (Leamy and Clough, 2006: 120) for many others it means curtailing their opportunities for meeting friends, working or searching for work. Deciding to be involved in a research activity is about balancing priorities and if the experience is less than positive service users will be less likely to become involved in research in the future and are likely to pass this message on to friends and colleagues.
- Again, this point relates to situations where academic researchers involve service users in research and do it in such a way that the service users experience a negative exclusionary process. A User Focus Monitoring Group (2005), a mental health project involving service users in research, describe a difficult research experience from the outset:

It appeared that the voluntary sector along with the university had decided how the project should be run. It soon became apparent that the non-service users there wanted to run the show. Many of us felt that we were just being used to rubber stamp the process and that we were not true partners in the project. We felt our input was not really wanted. It was a very demoralizing experience as we were regarded as ill and incapable. (A User Focus Monitoring Group, 2005: 41)

- Exclusion may be done wittingly or unwittingly. Unwittingly the language of the research or written materials acts as a means of segregating service



users from professionals and researchers. Research processes that emphasize inadequacies as opposed to abilities are likely to be experienced as prohibitive and as reinforcing negative stereotypes, resulting in a loss of self-esteem or confidence. Thus, volunteering to become a service user researcher can result in a negative outcome.

### ❖ *Costs to academic researchers*

- As already noted, involving service users in research is time and resource intensive and may require a trade-off between finishing the research promptly and delivering a quality product. Extra time and resources need to be built into a project involving service user researchers as these are often underestimated. McClimens et al. (2007: 119) also recommend keeping ‘a photograph of your loved ones nearby; it may be the only time you see them!’
- Similarly, this will have a knock-on impact to outputs. If outputs take longer and service user researchers are recognized appropriately within any publication (see Chapter 6) this could detract from an academic research assessment exercise which favours single authored publications in international peer reviewed journals.
- Just by bringing academics and service users into close proximity to work on a joint project does not ensure that both sides will necessarily develop an increased or deeper understanding of service user issues. This relies on both sides being open to these possibilities and requires extra facilitation skills of researchers that are not always apparent. A poor experience can result in an academic researcher believing that research of this type is not worth the investment and the development of a negative attitude towards participative research.
- Navigating ethical approval is likely to be more complex especially where the researcher wishes to involve vulnerable service users in the process.
- Potential limitation in research methods and data analysis. Service user researchers are unlikely to be proficient in advanced qualitative and quantitative research approaches. Thus if the researcher wishes to involve the service user researchers in all aspects of the research this will restrict the techniques and data analysis strategies that can be implemented.
- Whilst research like this can be fun it can also be very frustrating and challenging. This type of research does not suit everyone.

All these possibilities with their extra demands and resource constraints can result in research projects lasting longer and costing more, all of which may impact negatively on an academic researcher’s career.

## **Benefits and costs reconsidered**

---

---

It is neither possible nor desirable to merely add up the benefits and costs as if they were an arithmetic equation. This is not the case and some benefits and costs will be of greater impact than others, but it is important to try to identify the risks involved in any research approach before beginning. To believe that involving service users in research will of itself automatically result in better research is as misguided as believing that academically qualified researchers are the only ones who can undertake research. If such research is undertaken poorly or tokenistically it can result in more harm than good. In such circumstances it must be questioned whether the research should have been allowed to progress in the first place.

In considering the appropriateness of involving service users as co-researchers:

The decision is as much a political and ethical one as it is a practical and resource driven one. (McLaughlin, 2006: 1408)

### **Reflexive Questions**

- \* Thinking about what you have read so far and considering your own personal position, are you in favour of involving service users as co-researchers or not? Why have you come to this decision? What are the implications of your decision for involving service users as co-researchers?

The author has previously argued (McLaughlin, 2007a) that it is important for researchers to be clear and upfront about their views on research matters to allow those reading what they have written to be able to interpret how the author situates themselves and whether they agree with this or not. The author's own position is that he is committed to service users being meaningful involved in research. This goes back to my practice as a social worker where I sought (not always successfully) to work in partnership against a background of ambiguity and contradiction. My experience of involving service users in research is that they have offered me as much as I have offered them, both personally, and in terms of the research project and its outputs. This is both a political and a pragmatic statement in that I believe that involving service users as co-researchers is part of a participation agenda to involve those who are often excluded or treated as the objects of research. Pragmatically, failing to involve service users in research that affects them is to pass up an opportunity to learn about the knowledge that service users have of themselves. In other words failing to take up this

opportunity is to ensure an incomplete picture and to have ignored the possibility of improving the nature and quality of the research. However, this is mediated by the knowledge that involving service users in research must be done both with integrity and due diligence or it can, and does, cause as much harm as good to all involved.

## Summary

---

This chapter has covered the mandate for involving service users as co-researchers. In particular we have highlighted some of the reasons why service users may bother getting involved in research. It was important to identify the expectations service users may have of research and its outcomes. We then examined different levels of service user involvement: tokenism, consultation, collaboration and service user-controlled research. We noted that any research project may include different levels of involvement at different stages of the project and between different service users within the project. Having established what we meant by involvement, we identified benefits and costs for the research project, service user researchers and the non-service user researchers, clarifying a mandate for service user involvement based on positives and advantages that service users may bring to a research project but also sounding a warning note not to over expect and identifying the importance of proper preparation and support. Finally you were asked to identify where you stood in relation to involving service users in research and how that might impact on how you participated in the journey contained within this book.

## Suggested reading

---

- Hanley, B., Bradburn, J., Barnes, M., Evans, C., Goodare, H., Kelson, M., Oliver, S., Thomas, S., and Wallcraft, J. (2004) *Involving the Public in Health and Social Care Research: Briefing Notes for Researchers*, Eastleigh: Involve. This is a highly accessible document advocating service user involvement in research. This paper can also be accessed via the *INVOLVE* website ([www.invo.org.uk](http://www.invo.org.uk)) which contains many publications that can be read online or downloaded in relation to service user involvement in health and social care research.
- Lowes, L. and Hulat, I. (eds) (2005) *Involving Service Users in Health and Social Care Research*, London: Routledge. This collection of articles provides both theoretical and practical examples of service user research involvement in a range of service areas.

||| Why Service Users Bother |||

Nolan, M., Hanson, E., Grant, G. and Keady, J. (eds) (2007) *User Participation in Health and Social Care Research: Voices, Values and Evaluation*, Maidenhead, Open University Press. A collection of care case studies reflecting a diverse approach to involving service users highlighting both strengths and weaknesses.