

'No one knows like we do' – the narratives of mental health service users trained as researchers

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RESEARCH

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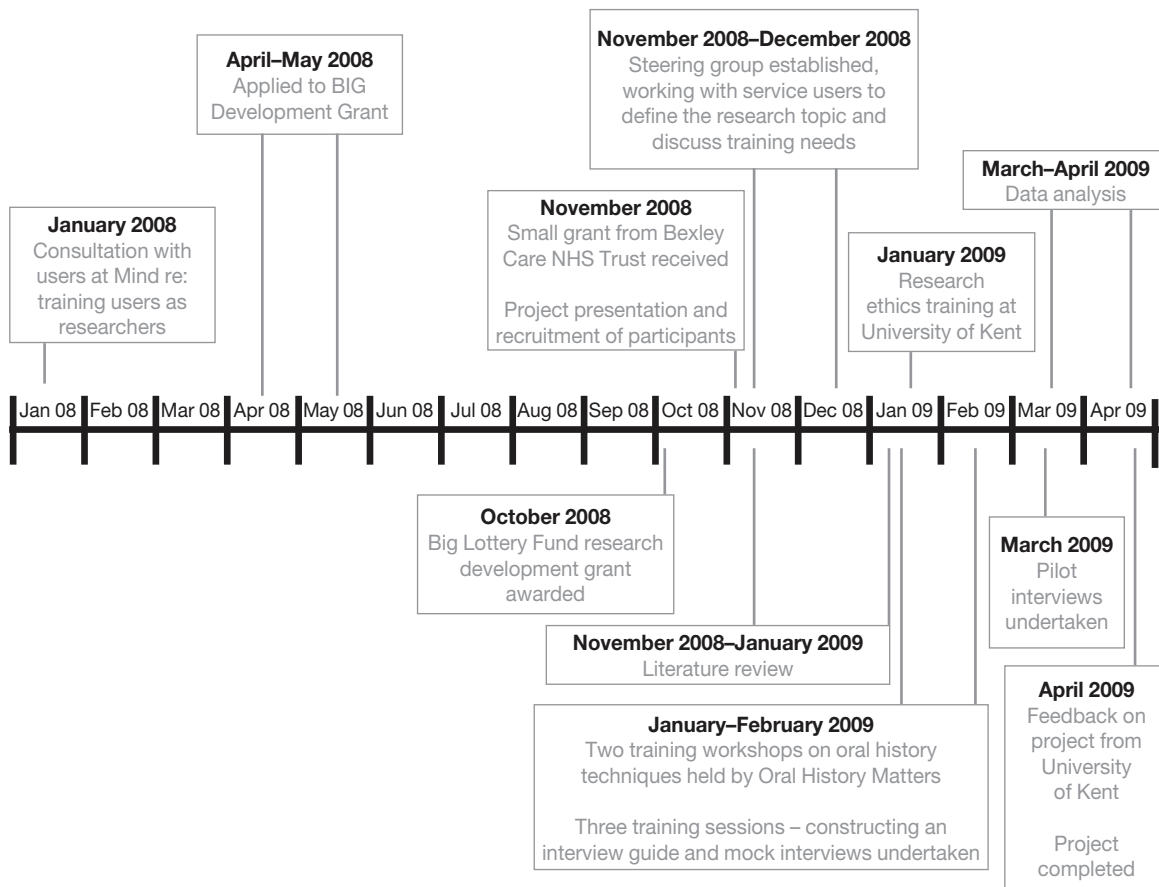
In 2008, Mind in Bexley received a research development grant from the Big Lottery Fund and a training grant from Bexley Care Trust to empower service users to participate and contribute to a pilot research project. The project aims were to work with, develop, train and support service users as researchers, in order to record the narratives of service users who have common experiences of mental health distress and treatment. The research development project set up an advisory group, created and developed a partnership with the University of Kent and provided workshops and training sessions to explore some of the principles of research and ethics. In addition, the group undertook a preliminary literature review, developed and refined a research questionnaire and piloted interviews with six service users. Many issues were raised and lessons learned during the planning and conduct of the project. This paper discusses the process and reflects on aspects of the project's design and delivery. In addition, this paper highlights some of the difficulties in undertaking service user research and suggests recommendations as to how to overcome some of these complex issues.

'At first being asked to be involved in the research project, my lack of confidence got in the way, did not know what to expect. ... I thought that I would be useless and could not cope with it. What I got in return for pushing myself ... and others having the confidence in me was awesome. I felt afterwards that I could do more than I give myself credit for. It made me realise that I had the potential to possibly commit to another project or work in general. What better project to have been involved in ... stigma ... can, and has, affected people's lives ... and I am glad to have been a part of this research project.'
(Researcher 3)

Mind in Bexley supports the recovery model of working with people who are suffering from mental distress and *'values a person's right to build a meaningful life for themselves, with or without*

the continuing presence of mental health symptoms' (Shepherd *et al*, 2008; p1). The organisation has a record of delivering health and social care services, including guided self-help cognitive behavioural therapy, peer support and mentoring projects, user-led gardening, art and writing groups to individuals, within the London Borough of Bexley for over 20 years, and works to promote good mental health and well-being for all. Mind in Bexley actively tackles stigma and discrimination relating to mental distress and works to promote the social inclusion of people with mental health problems. Connecting research and evidence to policy-making is a challenge, however this has been highlighted as a priority by staff, trustees and service users. Our position is a straightforward one: we believe that good research and reliable information and knowledge leads to better policy-making and service provision.

Figure 1 Project timeline



Since January 2008, we have consulted extensively with service users with a view to undertaking credible research into mental health service provision in the Borough of Bexley (see **Figure 1** for a timeline of the project). For the purposes of this paper, we are adopting the service user definition by Branfield and Beresford (2006), which is people who have or have had long-term experience of health and social care services or would qualify to receive such services. This study will identify factors in recovery that are particular to the London Borough of Bexley, while learning from the uniqueness of each individual's experience. Valuing individual experience as evidence is central to understanding the ways in which recovery can be realised for more people. To this end, we want to ensure that as many of our local community service users as possible are trained, empowered and supported to undertake an extensive programme of narrative research in the Borough.

Mind in Bexley submitted a funding application to the Big Lottery Fund Research Programme and

funding was awarded in October 2008. Match funding was received from Bexley Care NHS Trust. Work began in November 2008 and the project was completed in April 2009. The philosophy that underpins our research is the belief that it is necessary to engage with human stories, which tell us how people have felt about, made sense of, and coped with mental distress, if we are to fully understand how services can be improved for those experiencing mental distress. In this paper, we will briefly summarise the pilot project, how it was conducted, and highlight some of the learning outcomes from the process. The findings are qualitative and informative with individual 'voices' narrating and expressing opinion, and therefore contributing to the ongoing discourse within service user involvement in mental health.

The literature review

Following the first meeting, a short literature review was undertaken. Users helped to find relevant material on the internet and reviewed local sources

of information. However, the service user who had expressed a desire to work closely with Mind and the University of Kent on the literature review became unwell during the process and was unable to contribute as fully as she had hoped. The process of supporting and including users in the collection and analysis of literature has, therefore, not been without challenges. Some recommendations of how to improve the participation of users in this phase of the research will be included as part of the analysis of this pilot project.

The literature review that follows will first explore some of the available literature on the rationale for involving service users in research and of service user-led research. Second, it will focus on the issue of stigma, as this was a topic of considerable concern to the user participants of the research project.

Involving service users in research projects

Recognition of the contribution of service users is now well established; institutions including the Department of Health have officially advocated the involvement of service users in mental health services since the 1990s. The value of service user involvement rests on evidence that it not only improves the effectiveness of services, but that the process itself has benefits for service users. Simpson and House's (2002) systematic review of clinical trials involving service users argues that service users can be used safely and effectively in service delivery and evaluation. More recent research, such as that of Telford and Faulkner (2004), Linhorst (2005), and McAlister and Walsh (2004), has developed and refined thinking on how service user involvement can be best operationalised and taken beyond tokenism. Needham and Carr's (2009) work on 'co-production' develops knowledge further, but there is still some way to go before the role of service users is fully recognised and their involvement accepted as a routine part of service delivery, planning, evaluation and research.

This research project aimed for the 'transformative' involvement of service users described by Needham and Carr (2009), by which services reposition the service user 'as one of the experts and asks what assets they can contribute to collaborative relationships which will transform provision'. Lucock and colleagues' work (2007, p802) similarly affirms the value of service user-led research, arguing that user priorities for research are often different from those of practitioners; users emphasise the experiential knowledge and research that promotes emancipation and empowerment.

Peter Beresford's (2007) work on the role of service users in the research process notes that service user research is 'essentially value-based' (Beresford, 2007; p330). It does not set out to be neutral or to be universally applicable, but is always valuable as it reflects the views of those most affected by service provision. Beresford identifies three ways in which service users can become involved in the research process:

1. as an 'add-on' to more conventional research
2. as collaborators
3. as researchers fully in control of the research process (Beresford, 2007; pp333–334).

This research project to date has been closest to the second of these styles, as users have worked alongside conventional researchers but have yet to take the lead in the project. The ultimate aim of Mind in Bexley has been to support more truly user-led research, but it is recognised that support for this, in terms of adequate training and resources, is not yet in place. Future research with service users will draw on the work of Samele and colleagues (2007), who produced a comprehensive review of literature and methodology relating to research involving the users of mental health services.

Beresford (2007) draws on a review of user-controlled research carried out by Involve, which includes a statement of what users identified as being the advantages of user-controlled research. These were:

- the capacity to be useful – ie. to suggest relevant change in services
- the identification of new issues
- the ability to be more inclusive – which included the ability to encourage the involvement of diverse groups of users
- personal benefits for research participants, which included increased self-confidence and a sense of empowerment (Beresford, 2007; pp335–337).

These four points have underpinned the Mind in Bexley 'No one knows like we do' project, which sees its role as just a first step on the road towards truly service user-controlled research. In addition, this project has focused on the process of research as well as the outcomes – recognised as important by Thornicroft and colleagues, who report on a consultation with mental health service users who identified 'user involvement in all stages of the research process' as their top priority (Thornicroft *et al*, 2002; p2). The same consultation also identified 'discrimination and abuse' as their second most important priority for research – echoed by the users of Mind in Bexley.

Consultation with Mind in Bexley service users

As recommended by Alison Faulkner (2004), users were involved from the start of this project and the ethical guidelines proposed in Faulkner's work have been followed as far as practicable given the limited resources of this project. With greater time, financial and human resources, service user researchers could have been placed at the centre of the research but it was not practical to include users in all discussion of research protocol, design etc in this pilot project. The research training provided was of necessity, dictated by the direct needs of the project rather than to fully equip users to carry out research beyond the narrow remit of this project. The effect of resource limitation has been noted by the report commissioned by Involve (Turner & Beresford, 2005; p91) who argue that:

'Ensuring equal access, enabling diverse involvement and supporting service users to carry out their own research on equal terms, all have resources implications.'

Focusing on stigma

As noted above, the service users involved in this project unanimously identified stigma as the topic that they wished to take up with service providers as part of this project. For the purposes of this study, we have adopted the definition of stigma employed by Bruce Link and Jo Phelan (2001) who firmly connect the process of stigmatisation with access to social, economic, and political power. They state that

'we apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold'
(Link & Phelan, 2001; p367).

By this definition, mental health service users may experience stigma because of their association with certain services, because of certain stigmatised behaviours and because their illness reduces their life chances and opportunities. Involving service users in research on this important topic has the potential to keep the perspectives of those stigmatised to the fore. This is important to avoid the possibility of research further stigmatising or labelling groups by focusing on them as subjects of stigma, rather than on the processes and institutions that lead to their stigmatisation.

The existence of stigma is known to have a serious effect on the lives of mental health service

users (see Cass *et al*, 2009) and tackling stigma has been seen as a one of the most important areas for users involved in researching services (Faulkner, 2004; pviii; Wallcraft & Bryant, 2003). Service user involvement not only identifies and challenges the forces that can cause and maintain inequality, but their presence as agents of change confronting stigma can be effective in personally empowering service users and in demonstrating their capabilities. Stigma has also been identified by Mind as a major issue faced by mental health service users and Mind has launched a high profile campaign to tackle the issues (see <http://www.mind.org.uk/TimeToChange>).

Methods and developing a project theme

Repper (2000) argues that services need to build networks with education providers, employers and other agencies in order to promote social inclusion and to improve the lives of people with mental distress. Service providers need to facilitate opportunities for individuals to extend their social networks outside of mental health services. This philosophy has guided the development of this project. As part of this, individual lecturers and two PhD students from the University of Kent, the University of Kingston, an oral historian from the independent organisation Oral History Matters and staff from Mind in Bexley have provided intensive support, guidance and training to those involved in the scheme.

Non-probability sampling was undertaken to identify potential service users to be trained as researchers for this research project. This is an approach adopted where the sample does not reflect the whole population and can also, therefore, not claim representativeness (Jeffri, 2004; Denzin & Lincoln, 1994). The project was publicised widely throughout Mind in Bexley, our partnerships and through our strategic work. Key staff also gave presentations to various self-help Mind in Bexley groups. Interested individuals were then invited to a workshop about the research. A snowballing technique was also used to locate participants and some existing contacts at Mind services were approached as key initial informants. This technique, in which informants nominate others, has been noted for its suitability for dealing with small and 'difficult to find' groups or populations such as mental health service users (Bernard, 1994; p97).

Twelve individuals originally came forward to commit themselves as researchers to the project, however, only five became actively engaged in the scheme. Of the 12 who originally agreed to

participate in this study nine were female and three were male. The ages ranged from 18–67 years, with a mean age of 45.6 years. All participants lived in the London Borough of Bexley. Ten of the 12 participants had accessed or were accessing secondary mental health services, while two were receiving primary care mental health support. All respondents were unemployed or attending training, and two were also volunteering. All participants were in receipt of income support, incapacity benefit and/or disability living allowance in respect of their mental health. Those seven service users who decided not to engage listed health reasons and time constraints to explain why they did not want to continue with the project:

'I've decided not to continue. It's not for me... I don't think that I could cope with the stress. I also couldn't come to all the workshops.' (Service user who decided not to continue on the project)

Of those five who decided to join the research group and train as researchers, all were female and all had engaged with secondary mental services in respect of their mental health (see **Table 1**). Their diagnoses ranged from anxiety, moderate and severe depression, bipolar disorder and two individuals self-harmed. Two were receiving regular mental health support from secondary mental health services in Bexley.

During the consultation process, the group unanimously identified 'stigma' as a research topic that reflected their own particular interests, as well as the significance of this issue in the locality. Once the research group was confirmed and the theme identified, the next stage was to identify training needs and to set up a project delivery plan. The

group identified a need for training on various aspects of the research process, including undertaking a literature review, recording interviews, use of technology, ethics, narrative techniques, defining the research question, designing a semi-structured topic guide and piloting interviews. A steering group was also established that consisted of two Mind in Bexley staff members, a lecturer and a PhD student from the University of Kent, two service users who had accessed statutory secondary care services, two volunteers with experience of mental distress who used statutory services, a project worker from the Bexley Health Trainers scheme and a local clinician.

Findings on service users trained as researchers

Training in research ethics and oral history techniques

A one-day research ethics training course was conducted by a lecturer from St George's University of London and Kingston University. The training was held at the University of Kent in the Tizard Centre and included an overview of ethical principles and dilemmas in research, with a focus on conducting user-controlled research.

The trainer introduced the concept of ethics and discussed with the group the various meanings and uses of the term in everyday life, in science and in research. The group explored the value and importance of doing ethical research with human participants. In addition, issues of choice of topic and factors affecting decision-making in research were explored and debated in the group. These factors were examined in more detail in relation to the particular project the group was going to be involved in. It was acknowledged by participants that there were a number of restraints in conducting

Table 1

Researcher	Age range	Diagnosis	Area of Bexley
Service user researcher 1	26–35	Psychotic depression and obsessive compulsive personality disorder with self-harm Adjustment disorder	Erith
Service user researcher 2	26–35	Depression with self-harm	Welling
Service user researcher 3	26–35	Bipolar	Bexleyheath
Service user researcher 4	36–50	Depression with severe anxiety	Welling
Service user researcher 5	51–64	Moderate depression	Bexleyheath

this particular project, for example, researchers' expertise, the application of research methods, time and financial constraints.

The group also explored some of the potential risks when carrying out research and topics included: the violation of human rights; research that causes harm, fraud/deception; culturally unacceptable research; and paternalism. The training covered some ethical principles that should guide research according to the *Research Governance Framework for Health and Social Care* (Department of Health, 2005). These principles were discussed in relation to the project at hand; the trainees reflected on their particular significance in relation to both the form and delivery of the project. To do this, a number of case studies were used in a group exercise as a way for the trainees to consider the ethical challenges of particular research projects, and to reflect on their own research involvement in the project.

Issues relating to informed consent were also discussed and participants reflected on the current debate about capacity to consent for people with learning disabilities and mental health difficulties. It was acknowledged by participants that obtaining the consent of all participants in any project was important and they subsequently discussed ways that they would use to facilitate this process. To do this, the trainer discussed the significance of giving information about the research project in a clear, easy-to-access and jargon-free manner.

Legal matters related to conducting research and gathering personal information were also examined. More specifically, the trainer pointed to the relevance of various legislative documents such as the *Copyright Act 1988* (HM Government, 1988), the *Data Protection Act 1998* (HM Government, 1998a) the *Human Rights Act 1998* (HM Government, 1998b) and the *Freedom of Information Act 2000* (HM Government, 2000).

The trainer presented and discussed with the group the principles and applications of user-controlled (survivor) research. In particular, the group considered how the following principles could be promoted in the project:

- clarity and transparency
- empowerment
- identity
- commitment to change
- respect
- equal opportunities
- theoretical approach
- accountability to society
- accountability to service user movement/organisations.

Finally, the trainer and the group discussed the role of the research ethics committees (RECs) in the NHS and universities, and the necessity to apply for ethical approval before embarking on a research project in health and social care. It was noted that although RECs are active in health settings, there was no clear system of ethical review in social care settings.

Training materials for the session included:

- training session handout
- case studies
- the ethics of survivor research
- good practice in active public involvement in research.

Participant feedback

Without exception the training was well received. Although participants received ongoing group and individual support throughout the duration of the scheme, it was highlighted that this is an area that requires more time and further training.

'I found the trip to the University for an ethics workshop really helpful as I did not know a lot if anything really about ethics... I really enjoyed the group involvement, and learning about ethics because if you get it wrong and you don't understand it properly you could mess up the whole process including the interviews, and this project on stigma was important to me. However... there was much information and it's something I think that we as a group need further work on.' (Service user researcher 4)

'The minibus trip (to the University of Kent) was nerve-racking as we were late but when we got there it felt good, the tutor was a nice lady but I thought that we were given far too much information in such a short space of time. I thought that I would never remember it all. We had lunch and it was nice to be just me and the team spirit was good. I had the best night's sleep ever that night.' (Service user researcher 2)

Participants expressed concerns about working with academics. Concerns were raised about the hierarchical structure of academia, and all participants had reservations and fears that they would be intimidated and therefore not be able to contribute fully to the research process:

'When I heard about the university I thought no this is not me. I'd never been to the university. The Mind staff and other users helped me along. I did

feel you know like what it's called ... Educating Rita when she goes to the university for the first time.' (Service user researcher 5)

In order to create a more meaningful relationship between service users and academics, participants highlighted the need for further time to establish trust and the need for additional space outside of the education arena. This was somewhat achieved at the end of the project, when service users and academics involved in the project had a long informal lunch and the experience was viewed as a success by all parties.

'It was really a lovely day. We had a great lunch and the conversation flowed. We covered so many things. It really felt together and I learned much in the process.' (Lecturer, University of Kent)

Training workshops were also held by Oral History Matters, which provided an informal and practical introduction to oral history interviewing. It also provided an opportunity to become acquainted with digital recording equipment and to discuss some of the issues around oral history. These sessions were particularly successful as feedback demonstrated that, without exception, participants enjoyed the sessions and role-play interviews:

'At the workshop, learning how to use the digital recording equipment at Mind was at first quite daunting, I felt like I was the only one who could not use it, but everybody sounded like they were in the same boat, which made me feel better. As a group we had fun with them so I was not as anxious as I thought I would be. I am not good at all with gadgets but I felt good when we had finished, also I so impressed my son when I got home. It was something different and important to talk about other than my mental health.' (Service user researcher 4)

'I really enjoyed the workshop on digital recording equipment as that felt like a challenge for me, the tutor was very good and took her time which was nice as I can get anxious, I learned that even after feeling nervous at first, by pushing myself I could overcome those feelings and actually feel good about myself for once.' (Service user researcher 1)

Mind in Bexley will explore opportunities through health innovation and education clusters (HIECs) to develop partnerships that will enable service users to exchange ideas, participate in training, influence and strengthen local health

care agendas. HIECs are a new kind of partnership, formed between the NHS, higher education bodies, health care organisations and other public and private sector organisations. The purpose of a HIEC is to provide high quality care and services by getting the benefits of research and innovation as quickly as possible to patients, and by strengthening the co-ordination of education and training (Darzi, 2008). Importantly, HIECs acknowledge the existence and influence of service users, and how their experience can influence ideas and behaviours in terms of their preferred and accepted methods of dealing with mental illness.

Preparation for fieldwork: the first encounter

An oral history research method was selected by participants for this project because of the explorative nature of the topic and the need to better our understanding of issues pertaining to stigma. Qualitative social research has a rich and varied history, offering alternative methodologies in the investigation of human society. In particular, a biographical/narrative research perspective offers an excellent opportunity to explore social processes from the perspective of the subjects involved. The practice of oral history techniques is the collecting, recording, interpretation and preservation of historical information from observers and participants, and may be either individual or collective events, decisions or actions (Portelli, 1998; Thomson, 1998; Maynes *et al*, 2008). The most relevant distinctive contribution of oral history has been to include within the historical record the voice, experiences and perspectives of minorities and marginalised individuals, such as service users, who are 'hidden from history' (Rowbotham, 1973). This reconstruction of history from a 'bottom-up' perspective has redefined what it means to write history and 'creates a more inclusive, more fully human conception of social reality' (Personal Narratives Group, 1989; p3). An oral history approach ensures that the experiential knowledge of service users is given space, authenticity and validity. It is the perceived disjunction between individual service user experiences and the (few) representations offered in wider discourses, the media, and by traditional research disciplines that provides the motive for oral history research. In this way, oral history as a method can democratise the process of representations, actively incorporating and acknowledging the significance of individual everyday lives for both service users and more general historical research. As a result, in-depth

face-to-face oral history interviews were identified as the most appropriate data collection method.

'Collecting narratives is more than a method, it goes to the heart of what this project is about and we should use the narrative interviews as part of our efforts to inform and educate. It's powerful, very powerful to listen to someone. It's unique and deeply personal and we, including us as researchers can gain much from listening to others.' (Service user researcher 3)

Users had wanted the interviews to be conducted like stories; the interviewee would tell their story and the interviewer would listen and only interrupt if clarification of pertinent issues was necessary. It was established that two researchers would attend each interview; one to act as the interviewer, listening and asking questions and the other would provide support for both the interviewee and interviewer.

Three training sessions with a focus on constructing questionnaires were provided, where it was agreed to undertake a qualitative research method utilising unstructured explorative questions. To reduce possible anxieties about carrying out interviews, and especially unstructured oral history interviews, guideline prompt questions were prepared, taking into account possible themes that could be asked during the interviews. A summary table of some of these guideline questions and themes are illustrated below. Training was also provided on dealing with some of the possible challenges service users interviewing other service users may experience. Apart from considering how to deal with sensitive issues that may impact on their own recovery, the training included role-play, which was a useful way of illustrating how interviewers can be empathic, but at the same time maintain boundaries. Feedback from the interviews highlighted the need for further training on these issues.

Summary of guideline questions:

- What does stigma mean to you?
- Describe how this feels like for you.
- Where have you felt stigmatised?
- In what way?
- Has stigma affected your confidence? If so, in what ways?
- How does the stigma that you experience impact on activities such as:
 - looking for work
 - being involved in the wider community
 - relationships
 - your close family
 - looking for help relating to mental health distress?

'I found the experience [interviewing] rewarding but challenging. One interview brought back some uncomfortable issues... I felt very tearful and distressed afterwards. Although we talked about it I didn't think that it would happen and when it came up I wasn't ready for it. I talked to Mind staff after and felt better, however I think that it's something that needs further training.' (Service user researcher 5)

Mock interviews were undertaken as part of confidence building and mainly focused on the introduction stage of the interview to ensure that issues pertaining to background information about the research consent, confidentiality and dissemination were adhered to. This was useful because it also gave the researchers an opportunity to be creative in their approach to the interviews, develop trust, as well as ensuring that they provided sufficient information to the respondents.

During the workshops, users finalised the letter of consent, biographical information, questionnaire/topic guide and the covering letter.

'The questionnaire workshops with the trainer were very difficult for me due to the amount of supporting questions that we were discussing. I felt quite sick really and thought that I would not be able to do it or carry on ... but by the end of the day after lots of discussions and reasoning we all came up with what was more relevant to service users and felt better about that.' (Service user researcher 2)

The decision relating to the sample size was influenced by funding outcomes, time constraints surrounding the identification of respondents and the undertaking of the fieldwork. Factors such as gender, availability, ethnicity, age, mental health experience and the ability to participate in the project were to be taken into account in sample selection. Mind in Bexley and the service users were to identify the respondents from those that access Mind in Bexley's community service provision.

The pilot interviews and the learning process

The participants (n=5) identified suitable contributors and, as a result, six face-to-face interviews were arranged with other Mind in Bexley service users (one interviewer undertook two interviews). All interviewees lived in the Borough of Bexley, were unemployed, had a mental illness diagnosis and were accessing primary or secondary mental illness services in the Borough. The mean age of the interviewees was 41 years.

Although the plan was to interview individuals taking account of gender, ethnicity, and other variables in order to obtain a balance of participants, the final sample size only included female participants. Time constraints and difficulties in engaging other service users groups, such as the mainly male attendees at the Mind in Bexley writing group, and the Mind Vietnamese and Bangladeshi user groups, limited the sample selection to white female participants. If funding is available for further research, more time can be spent identifying the most effective channels to access other groups to ensure that the sample is more representative of the population in Bexley.

Issues and challenges identified

No insuperable difficulties were identified in terms of interview practice, however there was a range of 'common issues' identified from the feedback. One interviewer had failed to press the record switch on the recording device, and other interviews had distracting background noise, however the main issue was perhaps a tendency for some interview dialogue to be too conversational. Concerns were expressed about the difficulties experienced using recorders. In spite of this, the group was unanimous in their belief that the experience, despite the degree of challenge, had been overwhelmingly positive and there were evident gains in self-confidence for those participating in the project. Individuals reported that the confidence gained from being involved in the project had a positive impact on them psychologically and provided them with the motivation to participate in further research. In addition to increased self-confidence, the participants reported other crucial benefits such as increased self-belief, optimism and hope. These factors were found across all participants as highlighted below:

'Well to be honest I really enjoyed it. It gave me a feel for more. It was also fun and I learned lots and gained much confidence, even though I was very reluctant at first. It was hard but I'm so glad I did it and I really want to do more.' (Service user researcher 1)

'What I learned from being part of this project was that I can work as part of a team and feel valued, what I say and do matters, and that makes me feel good about myself. It also feels great to have a hand, however small, in making a change or a difference to people's lives, being stigmatised is nasty, lets help it stop. Also it has given me

confidence to maybe getting a job in the future.' (Service user researcher 2)

'The pilot interviews at first made me nervous, not sure if I was going to complete it, but got through it and surprised myself. It gave me a real confidence boost.' (Service user researcher 5)

It is evident that with each step in the process came the reassurance that they were learning something positive. One of the main challenges for the service user researchers was dealing with anxiety prior to conducting interviews. One of the researchers reported that due to anxiety she was unable to sleep and felt nauseous the night before the interviews, while another interviewer reported feeling tense. Despite this, they intended to undertake their share of interviews. After much reassurance and support and with relaxation techniques, they conducted their first interviews. Both participants subsequently expressed that they had actually enjoyed it and were able to interpret their experience as a success; both volunteered to conduct a second interview. These subsequent interviews were found to be a positive experience.

'I felt tense all morning. I was worried I would not be able to do it or I would mess up the whole thing but it turned out great in the end. In fact I wanted to do another one.' (Service user researcher 3)

The central lesson from the feedback relating to the individual experiences of the service user researchers was the importance of support, the need to ensure the involvement of service users in the preparation of the research and the need to reduce, or at least manage, the level of anxiety among the service user researchers.

At the same time, issues of anxiety and vulnerability were not just associated with the service user researchers, but also with the research participants, themselves users of mental health services. Although most of the research participants indicated that they found responding to this research therapeutic, there were some who found recounting some of their experiences of stigma distressing. These experiences confirm the need for time to be allocated for post-interview debriefings for both the service user researchers as well as research participants. The debriefing must be undertaken by the research team to allow time for those affected by the impact of the interview to recover.

Despite these observations, however, the process of data collection was successful. Once

the service user researchers went through the full process of planning and implementing the research, they appeared and indicated that they would like to develop the research further. It is likely that their participation in the next research project will be much more substantive because of the experience in this pilot.

A transcription from the digital recordings was undertaken by a participant with support from a staff member from Mind. Using a spreadsheet, a thematic control analysis approach based on *Grounded theory* (Strauss & Corbin, 1998) was used. Extracts were coded into units and each unit was used to develop categories leading to the development of a central thematic framework to describe the data. It is beyond the scope of this paper to discuss the findings in any detail; however, it may be of interest to note that the central theme generated from the research was that stigma faced by service users was reported to be widespread and impacted on recovery. Further research is clearly needed to explore this as the data was not collected to saturation point.

Participation

Twelve service users volunteered to participate on the research and had indicated that they would attend the training. However, out of the 12 service users expected to attend, only five attended regularly and in fact only one turned up to the first training session on designing the questionnaire. The main reason put forward for non-attendance was illness, which included stress and anxiety and generally 'feeling unwell'. Extreme weather conditions also contributed to the low turnout. The fact that absentee service users did not attend subsequent meetings confirms the observations that although most service users would like to participate in research, aspects such as anxiety or lack of confidence impacts on their commitment. It is important to note that due to anxiety levels a considerable amount of time was spent by project staff in encouraging and reassuring users about the process and it highlights the issue that 'recovery' is a process and a journey that is not always smooth or predictable:

'I received much support and encouragement. I feel stronger for the experience of this. I picked up things that can benefit me in the long term and although beneficial, I would not have attended without the constant support I received from the group.' (Service user researcher 5)

Conclusions

This research project has been both challenging and rewarding. It has allowed participants to develop both personally and as a functional, self-directing group. One of the most interesting and important aspects of this research has been the opportunity for learning and development, both on individual and group levels, but also importantly in terms of future research planning and administration. This project has highlighted the complex interaction between service user researchers and the research undertaken. It is evident that such research requires consistent support, training and monitoring both on individual and group levels. An important finding of this pilot research project is to ensure that potential participants are given adequate time, information, support and guidance during the initial stages in order to build confidence, knowledge and understanding if participation is to be maximised. The experience and lessons learned during this project have been invaluable, both in terms of positively impacting on the confidence and well-being of participants and providing insight and guidance on conducting such challenging research. This research and evaluation will undoubtedly contribute to the success of future research and add to the current knowledge and discourse on user involvement in research.

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