Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis

Irene Tuffrey-Wijne RN PhD* and Gary Butler†

*Research Fellow, Division of Mental Health, St George's University of London, London, UK and †Training and Research Advisor, St George's University of London, London, UK

Abstract

Background People with learning disabilities have been included in research as co-researchers since the 1990s. However, there is limited literature about the processes of involving people with learning disabilities in the more intellectual and analytical stages of the research process.

Aims To examine the potential contribution of people with learning disabilities to data analysis in qualitative research.

Methods This article is a reflection on one research experience. The two authors include one researcher with and one without learning disabilities. They each describe their experience and understanding of user involvement in analysing the data of an ethnographic study of people with learning disabilities who had cancer. The researcher with learning disabilities was given extensive vignettes and extracts from the research field notes, and was supported to extract themes, which were cross-compared with the analysis of other members of the research team.

Results The researcher with learning disabilities coped well with the emotive content of the data and with the additional support provided, he was able to extract themes that added validity to the overall analysis. His contribution complemented those of the other members of the research team. There were unexpected benefits, in particular, in terms of a more reciprocal and supportive relationship between the two researchers.

Conclusion It is possible and valuable to extend involvement to data analysis, but to avoid tokenism and maintain academic rigour, there must be a clear rationale for such involvement. Extra support, time and costs must be planned for.

Introduction

Involving people with learning disabilities in research is a relatively recent development. Until the 1960s and 1970, the voices of people with learning disabilities were not accessed or represented in a research context; people with learning disabilities were 'tested, counted, observed, analysed, described and frequently pathologized, but never asked for their views' (p. 188).[1] 'User views', if sought at all, were commonly solicited through parents and professionals.[2] The theory of normalization and the move from a medical model towards a social model of disability had a significant influence on the research environment.[1] It led to the development in the late 1980s and early 1990s of more inclusive styles of research, involving people with learning disabilities as interviewees[3] or in the evaluation of services.[4] It became increasingly accepted not only that people with learning disabilities could be reliable informants with valid opinions who had a right to express them, but that they were in fact the best authority on their own lives, experiences, feelings and views.[5]

During the late 1990s, self-advocacy organizations such as 'People First' began to demand inclusion not only as research participants but also as researchers who contribute to both the design and the execution of research. The terms 'participatory research' and 'emancipatory research' are sometimes used interchangeably,[5] but usually participatory research indicates a commitment of researchers to involve people with learning disabilities as allies, whereas in emancipatory research, people with disabilities control the research agenda.[6] By the beginning of this century, major grant-giving bodies (including the UK Department of Health) had made user-involvement a prerequisite for funding. National UK guidelines on good practice in active public involvement in research state that people with personal experience relevant to the research topic should be involved from the beginning and that this goes beyond simply taking part in the study.[7] Such involvement could mean helping the researcher to identify and ask the right questions in the right way; making sure that health and social care research is relevant to patients, people using services and the public; and getting involved in the research process itself, whether designing, managing, undertaking or disseminating research.[8,9] There is now a proliferation of studies in which people with learning disabilities are grant holders, advisors, researchers, authors and disseminators.[10] However, whilst there is a growing body of literature describing research projects involving people with learning disabilities as members of the research team, there is also some debate about the extent to which people with learning disabilities can be involved in high-quality research in a way that is meaningful and not just tokenistic. To go beyond tokenism, existing research practice must change to accommodate the new group member.[11]

This article takes a critical look at the potential research contribution of people with learning disabilities, the added value and the limitations. Whilst the importance of including people with learning disabilities in the research process is now widely accepted, there are limited examples in the literature of exactly how such involvement is achieved, particularly with regards to the more intellectual and analytical stages of the research process.

The article is mostly written by IT; this demonstrates, perhaps, how difficult it can be to involve people with learning disabilities in writing about abstract concepts. Others have also noted this methodological dilemma, where non-learning disabled researchers usually lead the way: 'In all co-authored accounts it is a professional/academic whose hands move across the keyboard'[12] (p.122). GB contributed through discussion of the issues. The section headed 'Reflection by Gary Butler' is taken from a verbatim transcription of GB's tape-recorded reflections on the analytical process. Box 1 is co-authored. GB read and approved the entire manuscript.

The potential of people with learning disabilities as researchers

Whilst some authors have questioned the integrity of research about people with learning

Box 1

The selected comments during reading Nick's story, at the end of this paper, are part of GB's comments during and after reading the story of Nick Ballard (not his real name). It was the fifth vignette GB had worked on. The following discussion of themes was not tape-recorded, but written down by IT whilst talking. It is almost (but not totally) verbatim.

Nick (age 56) had severe learning disabilities, with no hearing and no speech. He had cancer of the bladder. He deteriorated gradually and died 7 months after joining the study. Nick had lived in a long-stay hospital since child-hood and now lived in a staffed care home with seven other residents, managed by Mary. She was keen to support him at home and he died there. Nick had no family.

All other members of the research team had noted how institutionalized both the home and Nick's day centre were, with rigid structures that did not enable Nick to make his own choices. They saw that Mary loved Nick, but she was also rather patronizing and did not have the knowledge and skills to ensure adequate pain control. Overall, this was not a positive case in the team's analysis. GB, however, saw it differently. He emphasized the importance of Mary's love of Nick and felt that it made Nick's situation bearable. This caused debate within the team and influenced the overall analysis, putting an emphasis on the importance of 'genuine' carers. GB also noted, more than the other researchers, how the other residents in the home may have felt.

disabilities if they do not control the research agenda,[13] others have challenged this idea. Kiernan[14] argues that the strength of research to policy makers is the trained researchers' ability to be objective and that this objectivity is threatened by emancipatory research. He asserts that because the research process relies heavily on intellectual skills, people with learning disabilities are likely to need substantial support from trained researchers to participate fully or effectively. Others agree that the nature of learning disabilities means that there are particular problems if people with learning disabilities control the research agenda.[15] Walmsley[6] gives a vivid example of this difficulty, describing a project of women with learning disabilities telling their life stories.

'What we were unable to do, and what we non-disabled women refrained from doing, was to draw out the implications…. Our inability to share with

the coeditors the high level skill of abstraction of themes from a dense mass of anecdotal evidence meant that the stories had to be left to speak for themselves, if we were not to undermine the commitment to partnerships.' (p. 56–57).

There are descriptions in the literature of successful involvement of people with learning disabilities in shaping the research question, conducting interviews and disseminating findings.[2,12,16–18] Stalker admits that the generation of theory is a more challenging area and that more people with learning disabilities need to share their experiences in this area.[5] Reports of such involvement in data analysis remain limited. Williams[19] suggests that because of problems with memory, it is important to have frequent periods of concentrated time. She describes her experience of analysing data with a group of people with learning disabilities, who saw the process as recording the 'bits they find interesting' as well as their own reactions to these bits.

One of the clearest examples of people with learning disabilities working as full and effective partners in academic research comes from the Learning Disabilities Research Team.[20] It describes a study by 13 researchers, seven of whom had learning disabilities. Their study aim was to evaluate the involvement of people with learning disabilities in 12 other research projects across the UK that had been funded under the Learning Disability Research Initiative. Their findings indicated that very few people with learning disabilities worked as paid researchers. Researchers without learning disabilities were unsure how they could involve people with learning disabilities in the research process. Most research projects failed to prepare for proper involvement at the proposal stage by allowing for adequate funding, adaptation of methods and longer timescales. The standard of 'accessible information' was mostly poor. Maybe as important as the research findings themselves are the authors' descriptions of how they conducted their research:

'We did all the analysis together. First we got into the groups that did the interviewing at each research project to work out the answer to the

interview questions. Then, all together, we put all this information onto one big plan (this took lots of pieces of flipchart on the wall!). This process took a few sessions. A lot of us found this stage the hardest. It was quite difficult to understand at first but it became easier the more we practiced it. We started to see the findings, what the data was telling us and it became easier to see how analysis worked. We worked on the material a few times to test our findings.' (p. 35)

Identifying the skills of people with learning disabilities

Walmsley and Johnson[10] argue that in the name of inclusion, many have failed to identify what skills people with learning disabilities have and where the work is better performed by trained researchers. We should not expect people with learning disabilities just to be able to carry out work for which other researchers have had extensive training. Walmsley[6] asserts that asking people with learning disabilities to devise the methodology, manage the budget, analyse the data and write up the findings is likely to lead to so much time and effort expended in teaching and supporting that little will emerge from the project in terms of contributing to an evidence base, which can inform further work, or contribute to improved health outcomes.

At St George's University of London we have conducted research in a range of sensitive topic areas involving people with learning disabilities, including abuse, bereavement, cancer and dying. Two people with learning disabilities are employed by the university to be involved in research projects. We have found that their skills lie in advising on the suitability of research proposals, designing study information materials, wording ideas in an accessible way and disseminating research findings. They have helped to safeguard ethical standards by asking important and relevant questions about the participants. In some studies that involved groups of participants who had learning disabilities, they have also assisted with data collection.[21] However, we had not previously involved people with learning disabilities in

data analysis, except by sharing themes and theories as they emerged and gathering feedback – in other words, the analysis had been explained to them, but had not been done *with* them.

In the following section, Irene Tuffrey-Wijne (research fellow) and Gary Butler (training and research advisor, who has learning disabilities) each describe their own perspectives on GB's involvement in analysing qualitative data of a complex ethnographic study. It was the first time that they had worked together on analysing data in this way and they had no guidelines or blueprint. They both hold a salaried post at the university, where they have worked together on projects and research studies around end of life care for people with learning disabilities for eight years. Unlike IT, GB has no formal research training. The researchers without learning disabilities have taken time to train the researchers with learning disabilities 'on the job' and a member of administrative staff has supported GB in understanding and managing his workload. General research training, and indeed a paid one-to-one support worker, would probably enable GB to function more efficiently in his role, but there have been no resources for this.

'The Veronica Project': an example of involvement in data analysis

The process of inductive data analysis

'The Veronica Project' was a 3-year ethnographic study of the experiences of 13 people with learning disabilities who had cancer, ten of whom died.[22–24] IT was the principal researcher and visited the participants regularly during a mean period of seven months. Data were triangulated to increase validity. The main method of data collection was participant observation (over 250 h in total), but it also included interviews with participants, carers, families and health-care professionals; attendance at case review meetings; studying medical and social care files; and studying the literature. The data

consisted mostly of extensive field notes totalling over 1500 pages. IT read these repeatedly throughout the data collection period and identified common themes. These were fed back into the field, following the principles of Grounded Theory;[25] IT looked for similarities and differences and asked participants to comment on emerging findings. To increase reliability, she sent extracts of the field notes, which included observations as well as interpretations, to some of the participants, carers and relatives for further comment.

At the end of the data collection period, IT and a research colleague (who was a consultant psychiatrist in learning disabilities) each analysed all the data independently, reading the field notes several times to identify themes and categories. Following extensive discussions, they agreed on the categories. IT then read the data again, putting text segments within 40 categories with the help of Nvivo software.[26] These were gradually collapsed until eight main themes remained.

To assess the trustworthiness of the data analysis, IT condensed the data by writing extensive vignettes of each participant, amounting to 200 pages altogether, about half of which were extracts from the field notes covering all the initial 40 categories. These stories were read by three further members of the research team, including a social anthropologist, a professor of psychiatry of learning disability and GB. Their task was to extract main themes, which were then cross-compared with the themes extracted by IT. After discussions with the team and further re-reading of the data, the final themes were agreed upon. There was inevitable bias in selecting the data in the vignettes, but presenting the three additional researchers with the full set of field notes for independent analysis would simply be too time consuming.

GB's inclusion in the data analysis (and, indeed, that of the other two researchers who analysed the vignettes) can be described as 'consultation', rather than a full sharing of control and responsibility. IT's role in this part of the research process was to facilitate GB's meaningful contribution, which is an important aspect of including marginalized groups in research.[3]

Reflection by Irene Tuffrey-Wijne

The analysis of the vignettes by the three additional researchers was important in minimizing researcher bias, thus increasing credibility of the overall results. It was clear that our own personal and professional backgrounds impacted on the analysis. For example, with my background in palliative care nursing, I strongly noted situations where pain and symptom management were inadequate. One of the other researchers has an adult son with learning disabilities and picked out the theme of 'the importance of families' most strongly. Given the study aims, it seemed particularly important that the analysis included the perspective of a researcher with learning disabilities.

I was concerned that the topic would be too demanding for Gary. Even though he had been involved from the beginning as a member of the research steering group, the details of the participants' lives could be upsetting. This had been clear during one steering group meeting when my presentation of preliminary findings caused distress among the steering group members, particularly those with learning disabilities, who cried and asked to talk about their feelings. They wanted to know how we (myself and the palliative care and learning disability professionals in the group) could cope with these stories 'and keep a straight face'. However, Gary had offered to help with the analysis and I wanted to try and find a way to harness his views.

We set aside one morning each week to read through the stories. I was prepared (and fully anticipated) to stop the process as soon as Gary no longer wanted to carry on, but I was surprised at his enthusiasm for the work. We completed his analysis in three months. Each session involved him reading a vignette out loud, whilst I wrote down every comment he made, including expressions of surprise, upset, anger or joy. Often, I asked him to explain why something made him laugh or sigh and I wrote down his answers verbatim. At the end of each

vignette, I asked him to tell me what had struck him most in the story, what he thought the most important themes were and whether any data reminded him of anything else. Initially, I had to help him summarize his themes by referring back to the aspects in the story that he had commented on whilst reading it, but gradually he became clearer about the task of extracting themes. When we had completed analysing all the vignettes, we spent a long session remembering them all, looking at Gary's themes, and cross-comparing them. This led to a list of eight overall themes (see Box 1).

The process of analysis had unexpected benefits. There were moments when, maybe for the first time in our working relationship, I felt supported by Gary in my role as a qualitative researcher with ill and dying people, not only practically but also emotionally. Other colleagues who had listened to me in my need to debrief during the data collection period, and who had analysed my data, became an important source of professional support. However, maybe patronizingly, I had not expected such genuine support from Gary; I had anticipated a need to help and support *him* in his tasks, as I had always done. Reading extracts from my field notes, which contained vivid descriptions of the deep suffering of people with learning disabilities and of my relationships with them, Gary's compassion for the challenges I faced in my efforts to understand the participants' lives turned us into equal colleagues, not just on paper but in practice. This was, I believe, empowering for both of us, because it constituted a true partnership where I was supported as well as supporting. I was amazed and humbled by Gary's ability to consider each story in great depth; to be outraged, uplifted and moved in quick succession; to give his own perspective and his considered opinion; to comment on my influence on the data (which were not just supportive comments: in one instance, Gary was clearly angered at my failure to engage more deeply with one participant, confirming the presence of some difficult ethical issues in the study); and then to leave it all behind and move on.

Gary's analysis was invaluable. It confirmed the themes already identified by the rest of the research team, bringing some of them into sharper focus, and it helped validate the data analysis. We listened carefully to Gary's perceptions and interpretations, recognizing that he had a unique insight into the experiences of people with learning disabilities, for example, their dependence on social care staff. The whole experience has left me excited about future possibilities of involvement of people with learning disabilities in data analysis.

Reflection by Gary Butler

The study we did was about people with learning disabilities and cancer. We were trying to find out what it was like for them at the time and if they were told about the cancer. We had to get used to lots of difficult words, like qualitative research. I'm still not sure what half of them mean. It's to do with stories and experiences.

We had to do the information sheets. We actually design it using easy words and pictures, not long complicated words or jargon. Sometimes Irene gets the words a bit wrong and then it has to be made simpler, so there is a lot of to-ing and fro-ing. I think we got it right, because we had all those people in the study and they didn't drop out.

I was also on the advisory group. After a while, we decided that we needed more people with learning disabilities in the group, because in the beginning, I was the only one. That's when we asked Marion and Robert to join us. It makes a lot of difference, because I am not the odd one out. If it's only me I still say what I want to say, but it just makes it easier to have Marion and Robert there. I know that Marion really liked being in the group too. In the group we talked about how we are going to find people with learning disabilities for the study. And how to get all the research done in the time frame. There's also ethics, asking if we thought we were exploiting people, but I don't think we were. There was one time when everybody got really upset, when we read one of the stories. That was heart-wrenching. The agenda went clean out the

window! We broke for tea and had more of a personal discussion.

Then, in one of the advisory group meetings, Irene said 'I need someone to help me with these stories'. It was called 'analysis'. So me and Jane put our hands up. When I read the stories, Irene asked me to re-word it and make sense of it. She wanted to know what kind of things struck me on the page, because she needed another person's reaction, to see if it was the same as how she or Jane might have read it. To see what were the most important bits, because you couldn't just put all the stories in a book, it wouldn't look right, it would be too big.

Doing this was harrowing at times. It's the person's life laid bare, literally. Almost naked. You could pick over the bones of each person's life, find out what was going on, how they were coping, or weren't. The amount of negligence I've read really got to my gut, I much admit. It made me think, 'Is that what life's really like?'

I know Irene was worried how I would cope with the stories, but it was fine. I try to separate work from home life, so I just leave it all behind once I'm out that glass door. I would do it again, because it was hard but it was also enjoyable. The best thing about it was working with a good team. I enjoyed that. I also enjoyed getting a sense of people's lives. How they were before they had cancer. Like one of the people, I sensed there was a lot of pride. He didn't want the cancer to get the better of him. Even to the very last minute. So a lot of people were doing things and even when they got cancer, still trying to carry on their daily lives to the last minute. I really liked reading about people like myself and finding something positive. You don't usually get to find out so much about somebody's life.

If other people want to do what we did, it is important to make sure there's a team behind you that could help you read these stories. And make sure there's someone with you, that you can bounce ideas off and talk about your feelings. Don't read the stories on your own. I would say, 'Don't try this at home!' But however much of a team you got behind you, sometimes the stories just make you upset. I know I was fuming sometimes. Then you should stop, take a break, go and do something else. Then come back to it. You should have plenty of biscuits and chocolate for comfort! And it helps if you can have a laugh together, because even if it's really grim, you can still find something to laugh at. Otherwise it just gets too much.

The other thing you could do is read the stories out loud if people can't read so well. That would be good, because then you could bring a dozen people into the room and they could all think about the stories together.

Doing the analysis together was good and other people should try it. But it is important to take time and to make time. It isn't something you can do on the side.

Discussion and recommendations

Involving co-researchers with learning disabilities is essential when the research participants have learning disabilities and it is important they are involved throughout the research project.[27] This involvement could extend to data analysis, as our example has demonstrated. However, it is crucial that academic rigour is not compromised. In our study, the analytical contribution of the co-researcher with learning disabilities was to carry out content analysis with support, but the task of integrating these themes into theory rested with the non-learning disabled researchers. It may be possible for researchers with learning disabilities to make further analytical contributions, but it seems important that the question of 'added value' is given serious consideration. In other words, does it make good sense to spend time and resources (both likely to be considerable) on training and supporting people with learning disabilities to carry out complex analytical tasks?[6] It is, we believe, important to be realistic and upfront about the power imbalances within research teams. In our research, the power has remained with the non-learning-disabled researchers, but we have tried to involve researchers with learning disabilities as valuable, indeed crucial, members of the team, giving careful consideration to the tasks they could and should be asked to fulfil.

The analytical method described is not meant as a template to be followed blindly. We adopted this method because GB is skilled at immediate response to information, but needs a supporter to help him verbalize the thought processes that underpin his reactions. It is important to find ways of analysis that suit the individual research advisor. One size does not fit all. Another research advisor with learning disabilities currently working at St George's University of London prefers to read or take in information, have plenty of time to think about it, and give a considered opinion afterwards. Other researchers with learning disabilities (particularly those who lack written literacy skills) may need other methods, such as watching or listening to some of the raw data (in case of video or tape-recorded data), or having the data read out loud by a supporter. It may help some co-researchers to put emerging themes onto flipcharts, with pictures if necessary, to keep them in their memory. Other methods could be tried, such as listening to the data in a group of research advisors, where the possibility of discussion within the group may add value similar to that seen in focus groups.[28]

The supporter needs to be non-directive and non-judgemental, creating an atmosphere where the co-researchers can express their opinion freely and clearly. The supporter does not need to be the researcher who collected the data. The advantage of the presence of the data collector is that she can clarify the data and expand if needed; the disadvantage is the increased risk of bias.

It should be acknowledged that including people with learning disabilities in research and particularly in data analysis, requires a degree of verbal ability. Including those less able to communicate may well present insurmountable methodological difficulties and this exposes an ideological dilemma at the core of user involvement.[29]

There are significant cost implications in working with people with learning disabilities as advisors. Many will need a one-to-one supporter to contribute effectively and this too needs budgeting for. In planning research and defining researcher roles, we must be clear about the contribution we are asking people to make and be realistic about this. In our experience, there is much to be gained from involving people with learning disabilities in research, and our strong advice to other researchers is to give serious consideration to the possibility of employing research advisors with learning disabilities as members of the research team.

Selected comments during reading Nick's story

• *Reading bout Nick*'s home: 'They're serving dinner at 4.30. Blimey... From the way you describe his home, it sounds like a scaled down version of a long stay hospital… Mary sounds like the perfect person to run a group home. Because she likes to get to know the residents, and join them. Having a cup of tea with them. And she's really sensitive, according to this.

• *Reading about staff at the day centre stopping Nick doing what he wanted to do, like putting glitter on a picture:* 'He [support worker] sounds like a spoil sport. He sounds like a bit of a bully. They say they are 'managing' Nick. Ahem! What they called managing, I would call bullying… It sounds here as if staff ain't coping very well. If that person had a day off, who did one to one [support for Nick], the other staff were almost panicking: how are we going to cope, sort of thing.

• *Reading about Mary*'s sense that the other residents wouldn't miss him after he died: 'I am just wondering whether they really wouldn't miss him. Because he is like the centre of attention in the house. I wonder, when he died, whether they would be feeling relief or regret… *IT:* 'But they would have some kind of feeling about it?' 'Yes. Was it like 'I'm glad he's gone', or 'I miss him'?

Part of the discussion after reading Nick's story

GB: Some of that is hair raising.
IT: Which bit was hair raising?

GB: They kept tossing him back between the hospital and the home. Then he moved in with Mary. She took him on as a son almost. That's what stands out so clear in this story.

IT: Yes, it seems that the relationship with Mary is what you have picked up all through the story. What do you think of that?

GB: If you take out all the ethical stuff and all that, toss all that aside, whether it is ethical or not… If you can improve someone's life like that, it should be done. If your contact with that person is improving his quality of life, I can see no problem with it. Why not…?

IT: So one of the main themes is that the close bond with a staff member really helped Nick?

GB: Yes. Mary was an angel in disguise… You get staff for who it is just a job, but she really cared.

IT: What do you think of the home itself?

GB: If I'd been the management, I would have pushed for more staff. So they could have cared for Nick better and the other residents wouldn't feel resentful of all the attention Nick was getting. The home sounded really nice, but they should have kept on pushing for more staff and if they say no, don't let that stop you, just keep pushing.

IT: Any other things that really struck you?

GB: It was a bad, stressful situation.

IT: What was bad and stressful?

GB talks about the lack of staff again, the fact that the other residents didn't get enough attention and may have been resentful.

IT: Overall, do you think this was a positive or a negative story?

GB: That's a hard one to call. There was a lot of positives, but there was bitterness as well. The other clients might have been jealous of all the attention Nick was getting.

IT: How do you think it was from Nick's point of view?

GB: If he could tell you, he sounds like a bloke who really loved life. He liked to do things his own way, not be told what to do and when to do it…

IT: How do you think his dying was? I know it's never good, because dying is not what you want, but given that he was dying, how was it?

GB: I would say adequate. But they shouldn't have relied on Mary so much.

Themes from Nick's story

After this discussion, we pulled out the following themes:

- The importance of a close bond with the carer(s), transforming the experience of life/illness.
- Lack of resources in the home. Not enough staff. Poor support from social services.
- Day centre staff: lack of person-centred care; bullying attitude of some staff.
- The importance of relationships with other residents
- Hospital care: could have done better.
- Difficulty of making decisions. How do you take decisions for someone who can't decide for himself? (re. cancer treatment; pain killers).

GB's overall themes

These were the overall themes of all 13 stories:

- To tell or not to tell (too much pretence)
- Carers were ignorant and not properly supported
- Genuine carers are important (who really care and go the extra mile)
- Sad lives (being abandoned when they are most vulnerable)
- Being treated like a child (carers have too much power)
- Friendships are important
- Families are important (abandonment, importance of strong bonds)
- Keep going (don't let cancer or life get you)

IT's overall themes

- Difficult lives (including abandonment, bullying & abuse)
- Loneliness
- Dependence on others (protection, power & control)
- Lack of sexual & adult identity

- Importance of family relationships (but: lack of own partners/children/friends)
- Truth telling
- Carers: lack of knowledge & support; lack of appropriate facilities
- Resilience

Final analysis

These are the themes the team agreed on:

1. Deprived lives (abandonment, loneliness, bullying & abuse, 'keep smiling', lack of sexual & adult identity)
2. Dependent lives (lack of choice & control, dependent on others to support cancer journey)
3. Understanding (fear, protection from the truth, communication)
4. Importance of families
5. Inexperienced carers (brutality, importance of 'genuine' carers who listen and advocate)
6. Unprepared and inadequate services
7. Resilience

Funding

Conflicts of Interest

None declared.

Acknowledgements

References

1 Walmsley J. Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 2001; **16:** 187–205.
2 Ward L. Practising partnership: involving people with learning difficulties in research. *British Journal of Learning Disabilities*, 1998; **26:** 128–131.
3 Flynn M. Adults who are mentally handicapped as consumers: issues and guidelines for interviewing. *Journal of Mental Deficiency Research*, 1986; **30:** 369–377.
4 Stenfert Kroese B, Gillott A, Atkinson V. Consumers with learning disabilities as service evaluators. *Journal of Applied Research in Intellectual Disabilities*, 1999; **11:** 6–128.
5 Stalker K. Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, 1998; **13:** 5–19.
6 Walmsley J. Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry*, 2004; **11:** 54–64.
7 INVOLVE. *Good Practice in Active Public Involvement in NHS, Public Health and Social Care Research*. London: National Institute for Health Research, 2007.
8 Lowes L, Hulatt I. *Involving Service Users in Health and Social Care Research*. London: Routledge, 2005.
9 Nolan M, Hanson E, Grant G, Keady J. *User Participation in Health and Social Care Research*. Maidenhead: Open University Press, 2007.
10 Walmsley J, Johnson K. *Inclusive Research with People with Learning Disabilities: Past, Present and Future*. London: Jessica Kingsley Publishers, 2003.
11 Steel R. Actively involving marginalized and vulnerable people in research. In: Lowes L, Hulatt I (eds) *Involving Service Users in Health and Social Care Research*. London: Routledge, 2005: 18–29.
12 Abell S, Ashmore J, Beart S *et al*. Including everyone in research: the Burton Street Research Group. *British Journal of Learning Disabilities*, 2007; **35:** 121–124.
13 Chappell A. Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities*, 2000; **28:** 38–43.
14 Kiernan C. Participation in research by people with learning disability: origins and issues. *British Journal of Learning Disabilities*, 1999; **27:** 43–47.
15 Gilbert T. Involving people with learning disabilities in research: issues and possibilities. *Health & Social Care in the Community*, 2004; **12:** 298–308.
16 Rodgers J. Trying to get it right: undertaking research involving people with learning difficulties. *Disability & Society*, 1999; **14:** 421–433.
17 March J, Steingold B, Justice S, Mitchell P. Follow the yellow brick road! People with learning disabilities as co-researcher. *British Journal of Learning Disabilities*, 1997; **25:** 77–80.
18 Williams V, England M. Supporting people with learning difficulties to do their own research. In: Lowes L, Hulatt I (eds) *Involving Service Users in Health and Social Care Research*. London: Routledge, 2005: 30–40.

19 Williams V. Researching together. *British Journal of Learning Disabilities*, 1999; **27:** 48–51.

20 Department of Health. *Let Me In – I'm a Researcher!*. London: Department of Health, 2006.

21 Tuffrey-Wijne I, Bernal J, Butler G, Hollins S, Curfs L. Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *Journal of Advanced Nursing*, 2007; **58:** 80–89.

22 Tuffrey-Wijne I. *Living with Learning Disabilities, Dying with Cancer*. London: Jessica Kingsley, 2009 (in press).

23 Tuffrey-Wijne I, Bernal J, Hubert J, Butler G, Hollins S. People with learning disabilities who have cancer: an ethnographic study. *British Journal of General Practice*, 2009; **59:** 503–509.

24 Tuffrey-Wijne I, Bernal J, Hollins S. Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, 2008; **36:** 185–190.

25 Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd edn. London: Sage Publications, 1998.

26 Bazeley P. *Qualitative Data Analysis with Nvivo*. London: Sage Publications, 2007.

27 Hollins S, Adeline P, Flynn M, Perez W, Towell D, Webb B. *Building Consumer Capacity in Primary Care Research and Learning Disability: Final Report*. London: St George's Hospital Medical School (Department of Mental Health), 2004.

28 Bloor M, Frankland J, Thomas M, Robson K. *Focus Groups in Social Research*. London: Sage Publications, 2001.

29 McClimens A, Grant G, Ramcharan P. Looking in a fairground mirror: reflections on partnerships in learning disability research. In: Nolan M, Hanson E, Grant G, Keady J (eds) *User Participation in Health and Social Care Research*. Maidenhead: Open University Press, 2007: 104–119.