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Older people and research partnerships

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ABSTRACT

Increasing consumer consultation is a priority for those involved in health and social care research and practice, with promoting greater public participation being widely accepted as 'a good thing' (Reason, 1994: 3). However, whilst such consultation may improve the quality of research and practice, there is a need to recognise the considerable investment of time and energy that is required for success (Baxter *et al.*, 2001). Given the extra resources needed, it is important to understand how consultation and user involvement can work to benefit all parties.

This paper describes our experiences of working together on a research project exploring people's involvement in decision-making processes when using care services in later life. When we started the project in March 2001 each of us could draw on a range of experiences that we hoped would make a valuable contribution. We have now worked together for over two years and this paper describes how our combined efforts have not only enhanced the overall quality of the research but also had personal benefits that we did not anticipate when we started out.

KEY WORDS

older people research advisory group participation

INTRODUCTION: STARTING THE PROCESS

When the research project described in this paper began in 2001, promoting consumer involvement in health and social care research

had become a major policy goal (DoH, 1999; DoH, 2000). Indeed, NHSE Trent, who funded the project, asked how I, as the researcher, planned to involve consumers in the research. I (Josie) was conscious that older people, the focus of the study, would traditionally have had research conducted 'on them' rather than

'with them'. However, having previously been involved in a project where older people had made an important contribution, I was aware that actively engaging users could enrich both the research process and its products (Tetley & Hanson, 2000). The literature supported such a view. For example, Whitmore (1994) recruited single parents as participants and co-researchers on a project set up to evaluate pre-natal programmes for single parents, and this article was particularly helpful in guiding my thoughts about effective ways of working with older people. Whitmore (1994) highlighted how the women drew on their own experiences to inform data collection, to identify the issues that they felt it was important to address and to ask questions in a way that maximised participants' involvement in the research. Actively seeking advice from older people about my proposed research, and the issues that they felt were important to explore, therefore seemed like a useful starting point.

In drawing up the project proposal I had identified three potential organisations providing care and services to a wide group of older people and their carers across Sheffield. One provided care and support for people with dementia and their carers, another ran a luncheon club and outreach service for black elders, and the third organisation offered a range of city-wide services for older people including luncheon clubs, social and activity clubs, and volunteer support services. These services were aimed at keeping older people active and healthy. I approached each organisation and asked if I could meet with some of the older people who used their services with a view to potentially recruiting them as advisors to the project. As a result of this request seven older people, including at least two from each organisation, expressed an interest. The first meetings to discuss the research took place between February and May 2001 and following these initial meetings all seven individuals said that they were happy to act as advisors to the project. At the outset I hoped that the people who agreed to work with me would also gain some benefit as a result of participating in the research. This paper therefore describes how we developed our working relationships so as to improve the quality of the research whilst also giving something back to the group members.

RESEARCH PARTNERSHIPS

In our initial meetings we spent time getting to know one another and sharing our thoughts on the issues that we felt affected older people. I talked about my research and asked the group members what they expected, and what they felt they could contribute to the study. I also asked if they had ideas about the type of training they would like to have in order to work effectively with me on the project. A range of issues came out of these discussions including the need for:

- training to refresh existing skills such as listening and communicating
- training to develop new skills such as:
 - skills in speaking out, especially in public fora
 - presentation skills
 - confidence building
 - computing skills
 - skills in reading and responding to public documents.

In order to meet these needs, I gave presentations at the meetings about policies and developments in service provision such as the *National Service Framework for Older People* (DoH, 2000), and the role of Primary Care Trusts (DoH, 1997; NHS Executive, 1999). Just as we were starting this work, I was asked if I would become a member of the Sheffield team taking part in a Trent-wide Health and Social Care Collaborative for Older People initiative. This group was established to undertake practice relevant work to explore how services for older people could be developed and improved (NHSE Trent, 2001). I asked the professional service providers if members of the advisory committee could be included in meetings and activities of the collaborative. As the involvement of older people in the activities of the group at a local and regional level was part of the initiative, this was readily agreed. Subsequently we attended meetings that enabled all the group members to comment on, and to gain insights into, how services are developed both at a local and national level. At the final conference of the Trent initiative, Joe, Maud and Vanlis were also asked to give service users' perspective on the collaborative. Training in

presentation skills was provided by a facilitator who had experience in working with patient and carer representatives across Trent.

All of these activities increased our confidence about the work we were doing and, in March 2002, I asked the group members how they would feel about presenting at the local 'Health Care Partnership in Action Conference' (Tetley *et al.*, 2002). The aim of this event was to promote and describe the partnership working that was taking place across Sheffield. Three members of the group (Joe, Maud and Lorna) said they would work with me and contribute to the conference. In our presentation we described some of the issues that we had worked on together. This presentation was well received and gave us confidence to think about presenting at future conferences. So when we were asked to present at the 'Planting Seeds' Conference, we felt able to share some of the experiences that we thought might be of benefit to other people. Because our work has covered a wide range of issues, we have chosen just a few examples to present here, these include how:

- the advice of the group helped Josie to work effectively and sensitively with different community groups
- the group's own experiences as service users benefited the research
- we developed reciprocities in our work that we did not initially envisage
- our engagement with a wide range of initiatives has benefited us as a group.

ADVISORY AND SUPPORT ROLE

At the outset I had asked the group members to act in an advisory and support role for the project, an activity that has enriched the study in a number of ways. Initially this related to the setting up of the study. Because I had to get permission from an ethics committee to conduct the research, the layout and content of the consent form and information sheets were quite tightly regulated. Having formatted the information in this way I was, however, concerned that older people might find the paperwork overwhelming. The group members read the consent form and advice sheets and reassured me that they understood them. They

also agreed to be named as contacts for their own organisation, if an older person or family carer wanted to talk to someone familiar about the research. This all seemed quite straightforward until I started working with the first study site with black elders in November 2001 and it was here that I hit my first barrier.

One part of my research was to work with people in the study sites and record my observations and informal conversations; however, before I could record anything I needed people to sign a consent form. Whilst people were happy to talk to me they were very reluctant to sign any form and I was not sure how I could move forward. At the next meeting of the advisory committee I shared this issue with the group. The African–Caribbean members of the group felt that this problem had occurred because the elders often worry that signing official-looking papers might in some way affect their benefits or rights. In order to overcome this, Maud, Vanlis and Vera (Vera had previous links with the elders through age active classes) said that they would come down to the centre and talk to people about the consent forms and explain why I needed their signatures. This proved to be very successful and, following their input, 26 people signed consent forms. At the 'Planting Seeds for the Future' Conference Maud talked about this. She said:

'I am Maud Hawthorne and I have been working with Josie as a member of the advisory committee from the day care centre for the Afro–Caribbean elders. Josie wanted to have an interview with the elders there but before doing so they have to sign a consent form.

'Vanlis and myself spoke to them about re-signing this form. They were very reluctant at first. Having visited the centre on a regular basis they trusted us, having known most of them over the years. We did not rush them, we explained that it would not affect their benefits or any service they were receiving and whatever they say to Josie it would be strictly confidential. Also we'll have nothing to do with the interview whatsoever. Finally they decided to sign and that was quite a

success. The key to that success was patience, trust and confidentiality.'

With the help of the group I had, therefore, been able to work more effectively as a researcher with the black elders. Maud, however, raised another important issue in this presentation. I had asked whether Maud, Vanlis and Joe wanted to be more involved in the research or help with any of the formal interviews that I planned to do later. They said that they did not feel this was appropriate, as some elders would be very wary of sharing their personal experiences with people they knew well for fear that any personal problems or issues might become more widely known within their community.

The advice of the group also helped me work more sensitively with people who I had interviewed. Whilst I was working with the black elders, I was keen to involve those who shared their experiences of receiving care as fully as possible. One way of doing this was by the use of individual narratives created from diary records and interviews. I discussed this activity with the research advisory group. During these discussions one of the black elders said it was important that the narrative stories were written sensitively and that any attempt by the researcher to reflect an African or Caribbean dialect into the written material would be seen as insensitive. We talked about this and I attempted to adhere to this advice. Therefore, whilst the narratives were accurate and contained quotes from the interviews, issues of style and language were carefully considered.

At the Planting Seeds Conference Vanlis said:

'Josie visited the centre while she was in the process of her research. She visited the care centre to familiarise herself with the users of the centre as she needed to build up relationships in order to gain their confidence. We informed Josie that the elders would be more willing to tell her their problems than ourselves as Afro-Caribbeans. We [also] gave her a few guidelines, how to handle the situation regarding their eloquence and their degree of intelligence and this she has mastered very well.'

RECIPROCITY IN RESEARCH

Whilst the above examples have illustrated how the advice of the group generally enriched the research process, I was less aware that taking part in the research had also resulted in gains for members of the group. Jeanne and Lorna had both been users of a wide variety of services whilst caring for their husbands with differing forms of dementia. I talked to them about their experiences to identify issues that might be raised by the participants in my second case study site; a service for people with dementia and their carers. However, when I met Jeanne at the start of the project she had recently been bereaved and I was concerned that working as an advisor should not put any undue pressure on her. Jeanne, however, reassured me that she enjoyed our meetings. Despite Jeanne's reassurances, I did not realise how much taking part in other activities, including the research, had helped until she gave the following presentation at the Planting Seeds Conference:

'My name is Jeanne Skinner and I'm a volunteer worker for the Alzheimer's Society. Ten years ago my husband was diagnosed to be suffering with Alzheimer's disease, at the age of 60. I was told that he must have had it for at least three years for it to have reached the stage that it was at. I cared for him at home for seven years, he died three years ago.

'Seven years is a long time and little by little you lose your own identity and freedom. I was helped by a 'Caring and Coping' course arranged by the Alzheimer's Society. It was wonderful to know I wasn't the only one in this situation. I knew very little about the illness at first but I was able to borrow books from the Society and learn as much as I could. I also received monitor telephone calls from carers support workers at the Society and I certainly appreciated the little chats we had. During the period of caring, I became very isolated and lost touch with everyday events and living.

'Friends and family visit but you rarely go anywhere just for yourself. It's hard to pick up the pieces and begin living again. After bereavement, a period of convalescence begins, your day-to-day routine needs re-planning, but you are really on your own now. You need to get out and find your way about again but how? Where do you begin? That was resolved by a monitor call from the Alzheimer's Society inviting me to visit the drop in on Tuesday mornings now I was able to do so. The welcome I got there reduced me to tears. Everyone there had been in the same situation and knew exactly how I felt. I have never felt such warmth and affinity from people I'd never met before and over the following weeks I began to feel I was coming alive again. I was with friends.'

'My involvement with the Society had filled a void left by my husband dying and I am now able to help in any way I can. So when I was asked to join Josie's research project I was glad to do so. I have met and become friends with some lovely people who are also members of the team. We chat and share day-to-day events and problems and we also have some laughs. We have had meetings at different venues, opening up new horizons, making life interesting again. We have met and talked to members of different services and had some very interesting discussions with them and aired our own views. So by helping Josie, I have also helped myself and I am grateful for the opportunity. Thank you.'

ENGAGEMENT WITH OTHERS

Earlier in this paper we described how the activities of the Trent Older People's Collaborative for Health and Social Care had helped to improve our understanding of health and social care services and policies for older people. We have continued with this work and invite guest speakers to our meetings. Joe is a particularly active member of our group and he often finds out about initiatives of which the

rest of the group are unaware. One of these was the NHS Patient Advice and Liaison Service (PALS). Through Joe we invited the local PALS representatives to one of our meetings. Jeanne and Lorna both found it useful to give the details of the PALS scheme when advising carers over the telephone who might have questions or concerns related to health services.

Again, the presentation by Lorna at the Planting Seeds Conference demonstrated how engaging with others outside of the study was not only important for the research but was also valued by the group:

'I am Lorna Haynes, a volunteer for the Alzheimer's Society. I looked after my husband for six years with Binswanger's disease and found it difficult to cope with his illness at the time. Since then I have been involved through the Alzheimer's Society with other carers. I have also taken part in other advisory groups. I have been very pleased to join Josie's group, especially with the wide range of opportunities to meet people from different parts of the Community in Sheffield and the Trent Region. I hope that the seeds which Josie's project has planted will help many other older people in the years to come.'

CONCLUSION

Our aim in writing this paper has been to demonstrate the ways in which user consultation/ involvement in research can have real benefits for research and also be enjoyable for the advisors themselves. Whilst our experiences were largely positive, it is important to recognise that this is not always the case. For example, if the process and mechanisms for involving people are not developed in a sensitive and appropriate way, or if the people taking the lead in the consultation are not fully committed, this can lead to problems such as tokenism and bad practice (Baxter *et al.*, 2001). We hope, however, that by sharing our experiences we might help others to avoid such mistakes and to engage more fully in participative work both in health and social care research and practice.

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