

How many different types of involvement can you fit into one study?

Eleni Chambers, Sue Shaw and others from the IQuESTS Study (Improving Quality and Effectiveness of Services, Therapies and Self-management of longer-term depression)

Research leadership by user researchers

Two experienced user researchers led a qualitative study within IQuESTS, working with a team of researchers of differing backgrounds and experiences, including another user researcher.

We both experience several different physical and mental health conditions that impact on our work and need to be managed, and that affected the whole team. Therefore we placed emphasis on developing a team culture where everyone's views and experiences were important and valued, and which enabled learning and development.

As all the team had to take account of health issues, we had to be more open and honest about our health within the team – sometimes this slowed down the work or made decision-making more complex. We also found that if the context we were working in was difficult or chaotic for some reason then our health difficulties amplified the effects on us.

In the leadership role, we complemented each other with our different skills and experience, and supported each other by negotiating a work plan that took account of our individual strengths and limitations. We believe that pairing up user researchers at a senior level in this manner is both productive and supportive.

Eleni Chambers and Sarah Cook, Co-leaders of qualitative study

Co-production of training materials

I work in a Community Mental Health Team and became involved in the development of the training resource because the training is aimed at both staff and carers. I was particularly interested in its unique development and the less traditional approach to training provision – targeting it at both professionals working with people with depression and their carers.

I found the development meetings inclusive and interesting. It was good to hear the varied views and opinions of the people involved. I felt having a range of people involved in the discussions meant that the training and associated materials hold a good level of richness, reflecting the views of a variety of interested parties. Attending the pilot course gave me a final opportunity to feedback about how it felt as a member of staff learning alongside carers and to offer my thoughts about the structuring of the course and teaching methods.

It has been an interesting project to be involved in and an opportunity to learn both more about research in practice and from the range of colleagues I worked with in the meetings.

Helen Stocks, Occupational Therapist

I was involved from a carers side of the equation, and having not been involved with anything like this before, it was rewarding and beneficial. Also, nobody from the group made me feel any the less able to contribute. It also was good to be able to listen and hopefully learn from professional people but not to be undermined. I would certainly do it again if I was approached and I hope that my contribution helped.

Christine Dilger, Carer

Consultation of users and carers during workshops

I attended a series of workshops aimed at different people. At the first workshop I felt it would have been better if there had been a separate meeting for service users as we didn't feel at all comfortable at this meeting. I felt it was just for professionals and not at all inclusive. The language used wasn't understandable and made me feel that we must be stupid. Fortunately I had someone who gave me support after the meeting so went home feeling a bit better. I would worry about anyone who went on their own as it could have a bad impact on their self-esteem.

I didn't like sitting at the same tables as professionals and felt out of my depth. I would have liked being with other service users or at least knowing who the other service users in the room were. I was afraid that I was going to be separated from the other person I was with, it didn't feel comfortable at all.

We gave feedback on the workshop afterwards including: there were few refreshments, need to use everyday language, would have liked to have known who everyone was, remember that people with depression or on certain medications can be extra sensitive.

At the second workshop, I felt much more comfortable. I think it was because we were sat in rows and I didn't have to talk to other people if I didn't want to - it didn't feel so intimidating as sat at tables with people you didn't know. I enjoyed the voting, it felt inclusive and by that I mean the language used when explaining things seemed to be aimed at everyone not just professionals. The day included plenty of breaks and refreshments. All in all I enjoyed the day.

Members of the group SODIT (Survivors of Depression in Transition)



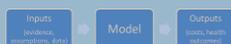
Consultation with users in quantitative research

I developed a mathematical model of the NHS for people with longer-term depression which shows how they go through the NHS system using different services in a "pathway". Users of services are the only people in the system that have experience of all parts of their pathway, and therefore it was crucial to meet with users and draw upon their knowledge and experience. Managers and providers were also consulted, however their experience is usually constrained by the area in which they work, and the mathematical model required a wider viewpoint of the system.

Jon and Eleni went to visit SODIT, a group for people with depression, where Eleni facilitated a focus group. We presented the IQuESTS study and learnt more about group members' experiences of longer-term depression and what it was like for them engaging with services in Sheffield.

It quickly became apparent that services were extremely complex and people's experiences were varied and often frustrating. They highlighted how groups like SODIT and other third sector organisations had a significant and positive affect on people with depression, and not representing these organisations formally in the mathematical analysis is a limitation of the study. However the group were enthusiastic about the research and engaged with the discussions. Meeting with users when undertaking quantitative research is surprisingly rare, and opportunities like this should be encouraged.

Jon Tosh, Research Fellow in Health Economics



Users educating students

The first thing to strike me was that the suggested meeting place was a café, so I immediately felt this meeting would be different from the academic lectures about research we had had so far, and different from the very hospital focussed medical model research placement I had recently had.

In retrospect, I realised I had been underprepared to get the most out of the meeting, since I hadn't thought enough about how service users can be involved in research and so didn't ask the questions that occurred to me afterwards. I was also unsure of what the "correct" terminology was, and didn't want to cause offence by using the "wrong words".

From the discussion I gathered that one of the service users had a research post with involvement at all stages of the research process. She seemed to have been instrumental in employing the other service user in a research capacity. I hadn't previously thought about the importance of employing service users in research posts, but clearly this potentially brings more status and power to the views of service users.

I was aware from lectures and reading that "Patient and Public Involvement" are buzz words in both health care and health care research currently but wasn't sure where the impetus to involve service users in research at the university was coming from; was it coming from the "top down" or from researchers "on the ground"?

Probably the most important learning for me from the meeting was the realisation that with sufficient support and training, service users can be involved in all stages of the research process, from designing and planning studies, to collecting and analysing data, writing up and dissemination. If this happens, this would be proper "public involvement" in health care research which I do believe is important in giving a valuable and different perspective on whatever is being researched. I'll need to think how to do this in both my usual health care role and any research I'm involved in.

Isabel O'Leary, Health Professional/MSc Clinical Research student