

Patricia Chambers' Presentation

**User research – opportunities and barriers.**

I have taken part in various pieces of research and enjoyed them all for different reasons. The first piece of research that I took part in was a hap-hazard affair that I conducted on my own. The results were an eye opener though and I learned that people want to tell their story. The research was about the different ways, pathways or reasons that young black men were coming into the mental health system. And that was way back in 1996 and now as then they are still coming in mainly through the judicial system. I knew very little about research then but later from being involved in official research I found that I had done the right thing.

The first piece of official research that I took part in was the study on mental health housing for my borough. I had joined the local user group and they were commissioned to do a study of the current provision for housing for mental health patients in the borough. This research turned out to be very exciting and very useful, not only to me but the borough.

For this piece of research we devised the questions, we were led by a facilitator who had experience in research and she helped us

put the questionnaire for the research together. Looking back it was very important to think of the way the questions were constructed. They had to be constructed in such a way as not to be misinterpreted and to get the right information from the interviewee in a concise manner and of course the questions couldn't be leading or racist or sexist or anything like that. It was very informative to learn and see what went on behind the scenes in research and what was needed to get it off the ground apart from funding. After we had got the questionnaire together we then had to sort out how we were going to reach our target audience. Luckily for us this wasn't too difficult as the LA wanted it done they worked with the housing providers to make themselves available. We worked from Mind and they were also a housing provider in the borough. Once we were armed with our questionnaire and had gone to some effort to make appointments with the interviewees, we went out and did the interviewing. This was fun as well as work. I found again that people were accommodating and didn't mind talking and telling their story. In fact some people took much longer to interview than the estimated time we had allotted for each interview. I found that people felt that once they were involved in something like research for improvement, they wanted to see results and quite often took part because they believed that taking

part was going to make a difference. I felt a responsibility to do the research right. Once the information was in we had to hand the completed questionnaires over to the facilitator and she collated all the information and put the statistics together. I wasn't the one from the group to help with that collation but got a chance to see what that involved in a later piece of research.

Some other pieces of research that I have taken part in were completely user led and conducted. I did a piece of research for a national user group that wanted to look at service user outcomes from the mental health services that they receive. This research was interesting in the way that it gave me the insight that we users can do important things like research and it can be conducted in a professional way and be meaningful. Everyone involved in the 'Outcomes' research was a service user. This research took the form of focus groups run on a monthly basis and then a report was written up afterwards. This research was interesting in the way that I found it was a lesson in self help. Service users finding out what service users wanted and putting this to the professionals in a professional way. This particular research took two years to complete and I took part in writing the final report. It gave me a sense of accomplishment to know that I had worked hard for two years and that the results had been published. It encouraged me

to stay well so that I could do the work and helped me to realise that suffering from mental illness is not the end of someone's life you can still do things that require a lot of mental agility and do them well.

After doing these pieces of research I began building my confidence in my ability to do research or take part in it and do it well. One of the next pieces of research that I took part in was the NIMHE report Making a Real Difference. This was one of the largest pieces of work that I have done. It was research into the affect that NIMHE was having on the mental health services and how well were they involving BME communities. Once again I was involved via focus groups but here I did the collating. It took months to collate all the information and accuracy was again a very important factor. This research was exciting after I saw the final report and have subsequently seen it being used in government policy. This has given me real confidence that what I'm doing is relevant and useful. This research was led by professionals but service users were included and I think that that was the right thing to do. Let service users see what the professionals are doing with our lives and how they are getting the information that is the basis for the decisions that they are making. Let us take part in shaping our mental health lives and futures.

Another piece of research that I have taken part in was the research that resulted in the 2005 Count Me in Census. I had no idea that this was going to be a major piece of work and cause ripples in all areas of the mental health system. This research was conducted in a very professional way and there was training that needed to be completed before you could participate. There was a briefing session before we went out to the interview sites and we did look at the questions again but we were not able to change or add anything or take anything away from what was given to us as the final questionnaire.

Going out to the sites was a lot of effort and we had to take trains to different parts of the country. It was interesting to see where people were being kept in the mental health system and it was a humbling experience to listen to the stories of fellow users and see them believe that what they were doing was making a real difference and it does. With the count me in census my involvement was just in the interviewing but I knew what the process was for collating the information and putting the report together.

I have also taken bit parts in research. I have been the interviewee as well as the interviewer or the person who runs the focus group or workshop that is part of the information gathering process. I have frequently run a focus group to gather information on a subject and one such group was for the white paper Our Health, Our Care, Our Say.

Lessons that I have learned from taking part in research over the years is that people don't mind telling their stories. Once they have agreed to take part they want to give the information and want to feel that they have been useful. They don't always want to know results but I feel that it is good to tell them that they can have a copy of the report or booklet or dvd or whatever format the results come in. I feel that it's important to let them know that what they are doing is important and valued.

I have learned that research is a work that is arduous and requires much effort and that it has to be accurate you cannot record at any stage what you think the interviewee is saying or what you think the interviewee should say. The work is detailed and painstaking.

I have also learned that the research needs to make a difference it needs to have meaning and be seen to do what it says it's going to do i.e. research to improve services. Needs to improve services.

I have taken part in research that is user led and research that is led by non-users and feel that both are carried out in my opinion with the same professionalism. Although it has to be said that user research is not giving the merit that professional research is given. Point in question is that after we finished the Count Me In Census in 2005 they said that the results were biased and for the following year they conducted the research with non-service users and professionals but they got the same results or statistics for the following year, 2006. This pleased me because it showed that service users can be as professional as professionals when it comes to research, after all we're all human. It also showed that we had been accurate and truthful. I was very pleased. It also adds to the argument that user led or user research should be given the same merit as non-user research.

Funding is another barrier that hinders research opportunities for service users, quite often funders don't want to fund service user research they either don't see the importance of the subject or they

don't believe it will be done to a professional standard or they still basically don't believe in the capability of the service user.

Another barrier to service users being involved in research is information. We often don't hear about the research opportunities that there are and if we do hear about them it's usually through a professional body and they're calling the shots.

Another barrier is, do the bodies that want research done know that there are service user organisations out there that can carry out the research. Information on us and our capabilities needs to be out there.

I have learned that I enjoy doing research and that it is good training for employment. I have learned that research does make a difference and that it's important for aiding the making of decisions and commissioning and policy making. I have learned to take research seriously. I had the belief before taking part in research, that research was just work for work's sake but I know now that it's important.

We must have access to the bodies that commission research so that they consider us in their first thoughts for who should do a piece of research and we should be given the opportunity to have first refusal. Service user led research or research that involves

service users is an opportunity for the service user to tell it like it is.

It's also an opportunity for the service user to be informed and therefore be more influential in the decision making process.

It's an opportunity for the service user to show their skills in this area and for want of a better word 'prove' capability.

I would definitely encourage other service users to take part in research from the conducting point of view because it's informative and it's interesting. It's a good experience and teaches you the value of information. It's on the job training for employment and is useful in people and communication skills. I feel that taking part in conducting research gives one important life skills.