Examples of user involvement in doing research

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Peer interviewers as research project team members[1]

Purpose: The researchers wanted to find out about the views and experiences of parents who use illegal drugs and are using health and social services. They planned to share the outcomes with local services so the needs of this group could be better met.

Setting up the project: The project covered two local areas. The researchers approached a Community Drug Team in one area who had a tradition of involving volunteers or 'user representatives' who were former drug users who were now leading stable lives. They discovered that some of the volunteers had already been involved in conducting surveys in the local area. They invited two to join the team. In the other area they asked for local service providers to suggest suitable people who were in control of their drug use and could have the skills to be peer interviewers. Two were nominated.

Roles of the user consultants: The peer researchers were asked to use their networks to encourage people to participate in the research who do not currently use services, as well as those that did. This increased the numbers, as the researchers could not reach all of these networks. They also interviewed all of the former drug users or people who did not use services, and some of the people currently using services. They assisted the researchers in analysing the information they gained in the interviews.

Support provided to user consultants: All peer researchers received:

- personalised training, either individually or in pairs

- were debriefed after every two or three interviews

- with their agreement the researchers stayed in contact with the peer interviewers' key workers to support them remaining drug free while in contact with other drug users

- a fee for each completed interview, and an hourly rate for attending training and meetings

Level of influence or decision-making: Peer researchers were involved throughout the research in discussions on the design of the interview guide and the themes coming out of the

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interviews. They influenced the analysis of the interview information using their personal expertise about being an illegal drugs user – the language and meanings commonly used. They did not have a strong role in the final report or other things written on the project.

Activities that happened: The whole project team did 52 interviews of drug-using parents, including people who did and did not use services. The researchers analysed this information with assistance from the peer interviewers. The researchers developed a report with recommendations for local services. They also wrote the article on which this case example is based, but with no input from the peer researchers.

Outcomes achieved: The project was able to:

▪ reach members of a hidden and reluctant group who would be difficult or impossible for the researchers to reach in any other way

▪ collect data quickly due to the peer researchers' local knowledge - this helped meet the needs of the health and local authorities who wanted to do something about the issue soon

Strategies for success:

- Choosing people who already had some experience in volunteer or research roles

- Investing time to build a relationship of trust between the peer researchers and the staff researchers

- The debriefing sessions were a valuable opportunity for the researchers to learn about the language and culture of drug-users from the peer interviewers

- Learning to negotiate roles and areas of expertise - which was less easy for the researchers to do as they were used to having a more powerful position in research

Problems that occurred:

- Peer researchers needed higher support than expected – this was mostly provided through the debriefing sessions, but the peer interviewers thought this could be improved through having regular project team meetings to share information and problem-solve

- Peer researchers did not insist on interviews being taped when participants were uncomfortable, while researchers found it difficult to not have this detail and just have notes because this reduced the quality of information –

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researchers had to accept the peer researchers judgement on this but thought in future they may have peer researchers as 'finders' who introduce the researchers to do the interviews (it is not certain what the peer researchers thought about that idea)

- Peer researchers knew that spending time with drug-users created a risk for them of wanting to start using again – they dealt with this on their own, or talked with their key worker, but recommended that in the future there was a peer support system where more experienced peer researchers were mentors for new people

- Difference of opinions on whether or not peer researchers would get a truer story from participants – this was not resolved, although the both the staff and peer researchers thought that they each might do better with some parts of the story than others

Benefits achieved:

- The project involved a diverse range of user consultants in terms of their personal backgrounds and where they lived

- Researchers learned about language and meanings in drug use that they may not understand and would limit the areas discussed during interviews

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- Improving the interpretation of the interview information using the expertise of the peer researchers

- Researchers learning about how much they and the peer researchers could share with each other

References

1.	Elliott, E., Watson, A. & Harries, U. (2002). Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations*, 5, 172-178.

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Case example analysis

Use what you have learned so far about user involvement to decide if what happened in this example was:

Poor   OK   Good   Excellent

Rate the 7 areas below. For some areas you may wish you had more information. Just do the best you can with what you have. After you rate each area give brief reasons for your decision.

- If you liked something, say why.

- If you think something was missing, then say what it was.

- Someone must record your decision and reasons for each area. Another person must be your group representative when we return to the large group.

1. A good **range** of users, carers or the public were involved

2. User consultants had meaningful **roles**

3. There were realistic **expectations** of what they would do

4. They received strong **support**

5. They had strong **influence** in the decisions

6. Their involvement had **benefits** for the organisation

7. Their involvement had **benefits** for other users, carers, and/or members of the public

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