

Training case study five

Research User Support Worker – Arthritis Research UK Primary Care Centre

Summary

The Primary Care Research Centre had a group of eight service users meeting regularly from 2006 (the Research User Group), but when the work of the Centre increased, it became necessary to support the group further. In addition, a larger pool of service users was recruited to become a virtual panel of 20 in addition to the Research User Group. At this point it was decided to employ a part-time support worker, initially for three days a week: someone with experience of a musculo-skeletal condition. In 2009 the post was developed into patient and public involvement (PPI) Coordinator and extended to 30 hours per week.

What does the support involve?

The PPI Coordinator, Carol Rhodes, liaises with both researchers and patients. The Research Centre has patients involved in 40 different projects, including clinical trials, qualitative research and PhDs. Carol supports less confident new members by attending meetings with them. When she first started she tried to go to all meetings with the patients, but now she has an assistant User Support Worker who performs this role. The Research User Group (RUG) meets four times a year and they also have an annual meeting for all 28 patients/service users.

Part of the role is as an intermediary in enabling patients to understand the research, which includes liaising with researchers to produce lay summaries. Carol has developed a

glossary of terms to help with this, which resulted from sitting in one of the larger steering groups and not understanding a great deal of what was said.

The Research Centre has a PPI request form for the researcher to fill in; this gives a framework with which all parties can understand the task involved. This document draws heavily on INVOLVE guidance and includes clear time scales for consultation and involvement so that service users are given time to read and absorb information. Carol then meets with the researcher and gets them to do a lay summary of the research. She also manages the process of feedback – to ensure that service users get feedback about their contribution whether a project is funded or not. Other issues include raising awareness among researchers of the best ways to communicate with service users. An example of this is to make sure that researchers know that service users do not necessarily open their emails every day. There can also be a lot of last minute requests which involve ringing round to find someone who can step in.

Much of the day-to-day support is now carried out by the User Support Worker. She organises all of the support needs for someone to attend a meeting (for example parking, payments, ensuring that people get breaks and refreshments) and attends meetings with them. Carol and her assistant consider it vital that more than one patient should attend a meeting.

Who developed this approach? Were members of the public involved?

The approach has evolved over time, starting with the eight-person user group and culminating in the present situation with one PPI Coordinator and one User Support Worker. Both of the workers have personal experience of a musculo-skeletal condition (the support worker is a former member of the RUG) and were active in developing the roles.

What are the benefits of this approach?

Benefits for service users

- This approach is particularly beneficial in helping to bridge the gap between patients and research clinicians in a field where the language and acronyms are often difficult to understand.
- Patients' lack of clinical and research knowledge helps the researchers to produce more patient-friendly paperwork for their research.
- Some service users have grown enormously in confidence through their involvement in research.

Benefits for researchers

- Researchers are guided by the PPI Coordinator to plan ahead and follow best practice as outlined in the framework.
- They can 'check out' their ideas with people who understand what it is like to live with a musculoskeletal condition through presenting draft protocols to the Research User Group.
- They have access to a group of people willing to be involved in a range of research tasks.
- Researchers' awareness of the positive value of service users' contribution to research ideas and the design of studies has been transformed.

Have you evaluated this approach?

There has been an evaluation of the whole PPI approach taken at the Centre. The response was very positive. Recommendations included: merging the virtual panel and the RUG to become one Research Users Group for clarity; developing an induction pack and/or workshop for new members; and having a regular annual survey of members' satisfaction. In addition, it was suggested that some PPI activities such as sitting on a steering committee need more support to develop a different set of

skills. So the PPI Coordinator is thinking of running a workshop just for those who sit on steering committees, as a training exercise but also as a way of letting them share their experiences with each other.

What are the learning points?

- It involves time, hard work and patience from all of those involved: researchers, patients and clinicians.
- People with musculoskeletal conditions need additional consideration when travelling to conferences, for example extra overnight accommodation may be required.
- Patients dislike tokenism and they need feedback on projects and regular updates in order to stay motivated.

“I love my job and I do think patients have a positive impact on the research projects they are involved in. It is not just the research that benefits, but researchers, clinicians and patients benefit by working together and sharing their individual areas of expertise. We can all learn from each other.”

Carol Rhodes, writing in the [INVOLVE newsletter, Winter 2011-12](#)

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