

Consumers take the initiative in patient and public involvement (PPI) training

By Peter Rainey and Carolyn Morris

In this article we report on how we, as two consumers, conceived, designed and delivered a training event aimed at improving the quality and effectiveness of patient and public involvement (PPI) by research teams.

COMPASS was one of two Supportive and Palliative Care Research Collaboratives funded by the National Cancer Research Institute (NCRI). It brought together research groups from 12 UK universities.

We were recruited as consumer members of the COMPASS Advisory Group, which provided guidance to the board on governance, strategy and consumer involvement. We also provided consumer input at COMPASS conferences and other regular meetings with research teams and, through membership of trial steering committees, contributed to individual studies.

While there were good examples of consumer involvement within COMPASS and a general awareness that PPI was a 'good thing to do', it became clear that there was no consistent approach and a lack of confidence and knowledge about how best to involve patients, carers and members of the public in COMPASS research studies.

Our goals

With the approval of the COMPASS board, we decided to take the initiative and design our own training event, to provide researchers with practical ideas and tools for involving consumers effectively. We had three critical design goals:

firstly, training should be practical and based on real-life settings; secondly, it should stimulate action; and thirdly, it should lead to consumer involvement, which improves the quality of the research through collaboration.

' It was about what's in it for them, rather than a moral imperative'

Crucially, we wanted to position PPI as 'part of the solution' to many of the problems research teams encounter as they navigate their way around the research cycle: generating ideas, refining the research question, ethics approval, securing funding, accrual to trials, and dissemination of results – all common hurdles faced by the research community.

' Make collaboration your default setting'

We designed and delivered an interactive workshop called 'Collaborate and Succeed'. The key message was that early engagement with consumers at every stage of the research cycle is the best way to ensure effective involvement and to add value to the research process. The workshop encouraged attendees to participate in practical problem-solving exercises based on their own real-life settings, to view challenges from a different perspective and to learn from each other. We hoped to show how a more collaborative approach with consumers could offer solutions and lead to better results. One significant benefit was that delegates left the workshop with an action plan.

We ran the workshop four times across three COMPASS locations and the feedback from research teams was very positive. Researchers liked the practical approach and the fact that consumers were the workshop facilitators. A good mix of researchers at every level attended the workshop with even the most senior staff learning something new. We could see confidence growing. Our researcher colleague, Marilyn Kendall, joined us for most of the workshops, so we were modeling

collaboration as well as advocating it.

Evaluating the training

After the final workshop, COMPASS commissioned a study to assess the impact of the training. Structured interviews were conducted with many of those who attended the event and with others within the COMPASS hierarchy. The findings were broadly consistent with the idea that a practical and action-oriented approach to PPI training is more effective as a means of learning. Most attendees learned something and were able to implement it immediately. Many felt that this form of training could become part of the curriculum for those building their careers in research and that perhaps major funders could provide this training as a means of ensuring there is good quality consumer input to the research proposals they receive.

One major conclusion which emerged from the study is that PPI training needs a champion at a senior level in research groups. We agree, and believe strongly that PPI provides an opportunity for leadership qualities to shine. We also believe that consumers should take a more active and prominent role in developing and designing PPI training for researchers and in actively marketing such training events. The evaluation showed us how important our role in the workshops was: 'They helped to demystify consumer involvement. They normalised it all and made it all OK.' Our backgrounds helped, but we can't be the only consumers with these skills.

More on what we did, what we learned and the evaluation's recommendations for consumer involvement training at: www.ncri.org.uk/default.asp?s=1&p=16

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