Training case study six

Planning training for involvement in a systematic review

Summary
This training was carried out by researchers at the Medical Research Council (MRC) Clinical Trials Unit (CTU), London and was funded through a post-doctoral grant in Evidence Synthesis. Some funding was also through Medical Research Council funding to the Meta-analysis group at the CTU. The training was not accredited.

What was the aim of the training?

The aim of the training was to enable patients to understand the principles of systematic reviews and meta-analyses so that they could participate in a systematic review being carried out at the MRC Clinical Trials Unit.

Who was the target audience?

The target audience was a small group of women who had experienced chemotherapy and / or radiotherapy for the treatment of cervical cancer, as this was the subject of the systematic review. The women were recruited through two main routes: the charity Jo’s Trust and Cancer Voices. They became known as Patient Research Partners.

What did the training involve?

Initially, a workshop style meeting was held with the women who had been recruited along with the lead researchers who were carrying out the systematic review. The purpose of the workshop was to take the Patient Research Partners through the process of carrying out a systematic review, covering issues

such as:

- What are clinical trials?
- What are systematic reviews and why might they be needed?
- The specific needs of this project
- The benefits of carrying out this systematic review.

The workshop was supported by an information pack.

Who developed the training? Were members of the public involved?

Initially, a small Reference Group was set up. This group included researchers, the Consumer Liaison Lead for the National Cancer Research Network, two experts in consumer involvement in healthcare research, the then Chief Executive Officer of **Jo's Trust** and one former cervical cancer patient. The Reference Group provided advice on the recruitment of women, provision of support and information and on the activities the women might undertake. From this we developed terms of reference and a role description for patients who were to get involved.

Workshop slides developed by the lead researchers were presented and discussed with the Reference Group members and were modified in response to their feedback. The Reference Group also provided initial comments and feedback on the information pack (drafted by members of the meta-analysis group). The information pack was further edited and extra sections were added, based on suggestions of the Patient Research Partners throughout the course of their involvement.

Who delivered the training? Were members of the public involved?

Researchers from the meta-analysis group delivered the training.

How did you support participants after the training?

Following the initial workshop, the Patient Research Partners were supported by regular meetings (approximately every six months for the duration of the project); and regular communication, usually by email.

What were the outcomes?

The Patient Research Partners became involved in a number of activities associated with the systematic review, including providing feedback on the detailed information folders; helping to trace contact details for trial investigators; learning about data management and analysis; and contributing to regular project newsletters. Their involvement also led directly to the researchers getting involved in another research project with a greater focus on late side effects of treatment. They were also involved in writing an editorial from the patient perspective. Another outcome was the further development of the information pack which may be used for similar projects in the future.

Have you evaluated the training?

The training itself has not been evaluated but the experiences of the Patient Research Partners and the researchers involved were evaluated at the end of the entire research project. The evaluation (published in the journal **Systematic Reviews**) showed that, for the most part, both researchers and patients appreciated the experience of involvement and the Patient Research Partners felt that the information provided had been thorough and had helped them to participate. There were some reservations about the involvement including: the time taken to manage the involvement of patients; the potential influence that patients can realistically have on a large-scale systematic review; and the need to be well prepared for what could be involved.

Learning points

- Training and supporting people well involves additional resources in terms of funding and time. This project was fortunate in that it had resources to do this, but this should not be overlooked in future projects.
- Preparing people for what might be involved is a vital part of training (for example the potential for research to take a long time; and dealing with discussion of topics or issues that may be sensitive or difficult).

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