

Making sense of study steering groups: the Approach study

By John Willmott

About the project

Approach was a three-year National Institute for Health Research Service Delivery and Organisation (NIHR SD0) funded study on integrated working between care homes for older people and primary care professionals, which has recently been completed. The study was complex in that it had two phases each with two components: in phase one, a systematic review of the research literature and a national care home survey; and in phase two, six care home case studies and a validation meeting to discuss the findings.

How and why I became involved in the project

The University of Hertfordshire Public Involvement in Research (PIR) Group was contacted to see if they knew of anyone who would be interested in taking part in the study. I volunteered as my wife had been in several different homes for respite care over many years and I felt that my experience with this would be helpful to the study.

My role in the project

Public representation was an integral part of the project at the case study phase and also within the study steering group which met twice a year. I was the University of Hertfordshire PIR Group public representative on the steering group. As a member of the study steering committee, I gave my views as a carer and member of the public on aspects of the study that required public input, for example I gave feedback on

summaries of the emerging findings from the systematic review and the survey. I was asked for my opinion on a proposed change to the data collection. I also attended the validation event at which the study findings were fed back to care home experts so that recommendations for the future health care of care home residents could be made to commissioners.

The difference public involvement made to the project

In the care home case studies phase, the study team felt that it might be more appropriate to interview relatives individually rather than in a focus group, as had been planned in the original proposal. The committee was asked to give its opinion on this, and I was happy to agree to this change as I felt it was a much more sensitive approach. This change was subsequently approved by the ethics committee. From my observations of the group, I am confident that the other members saw the benefit of having a lay member on board. They respected my contributions, I had an impact on changing some of the views in the group and I did not feel that my presence as a public representative was tokenistic.

Challenges and difficulties

Researchers took it for granted that all those sitting on steering groups are familiar with the role of committees, the way the project operates, who is involved, and how communication is maintained. I commented: "Different people seem to come and go to meetings." I suggested an organisational chart be devised to describe the structure of the Approach study to include the different management groups, who was involved and how they knitted together. This chart was a valuable tool for me and is now being used in another study on Falls in which I am involved, and would be of value, I am sure, in other studies.

Terminology was also problematic: for example, the word 'steering' did not explain the function of the group and

eventually I realised it meant 'advisory'. A big difference in my book! The steering group has now become more aware of the importance of using less jargon when including public representatives and will incorporate this into any future studies.

Advice to others

My advice for researchers is that they should always have in mind the need to use everyday language and be aware of the dreaded acronym.

And for members of the public, if you get the opportunity to contribute to research I would say: "Go for it." I learned that being prepared to listen at the beginning is preferable to thinking that you can influence everyone immediately. Find your feet, but don't be afraid to challenge and do it well!

For further information on the Approach study please contact:

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