Reviewer’s report

Title: ‘Is it worth doing?’ Measuring the impact of patient and public involvement on research.

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Reviewer: Paul Charlton

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This is an important article which will be welcomed by consumers involved in health and social care research, as well as by the wider research community. The author is critical of the drive to provide an empirical footing for positive value descriptions of consumer research involvement impact. She asserts that consumer involvement value is to be found in the specific research context and not by measuring how many or how much there is of any given consumer led outcome across research environments.

Having had five years of involvement with National Cancer Research Institute (NCRI) activity this conclusion is a welcome reassurance to the subjective anxiety experienced by many colleagues that their patient and carer led experience is not in itself enough to justify involvement. Rather it is – how many: trial management groups are you involved in; how many patient information leaflets have you contributed to; how many funding application reviews have you completed; or how many working parties or funding bodies are you contributing to. This approach may appear to indicate value added to the consumer funding body but it also generates an oppressive obligation on the consumer to demonstrate personal worth.

This article describes the extent to which research to date has tried to measure, with limited success, the output of research involvement of consumers. In asking – what difference has it made – the author describes how literature reviews reveal ten domains of activity or categories of consumer involvement research impact. These domains include, for example: impact on the people involved; impact on the researchers; impact on participants; and impact on the wider community. A case study example is of mental health research involvement where statistical analysis showed an association between consumer involvement and successful recruitment, even after other factors such as study design, study complexity and clinical group under investigation had been taken into account.

The article’s premise is, however, that even such an empirical finding cannot be generalised as an effect which is also likely to happen when recruitment to trials is supported by consumer involvement in other research contexts. It may be that altering the design of an invitation letter, or the band of appointment times at one location or in one trial design may achieve improved recruitment. But, the author points out, that will have been dependent on exactly what was going on with that trial.
A richer source of measuring the usefulness of consumer research involvement is instead to ask researchers what difference it has made to them. The author asks would not the researcher who experiences the impact of involvement be the best source of understanding the added benefit of consumer involvement in their research activity. It is, she says, ‘their thinking, planning, values and communication that are often challenged through involvement, a process that researchers describe as ‘a lightbulb moment’ or ‘reality check’[21]. For this reason, the impact of involvement could be more usefully conceived as a form of experiential knowledge.’

The article eloquently unpicks the current approach to understanding the positive value, or not, of consumer research involvement. There is a generous acceptance of involvement, in my own experience, by researchers but certainly there is also an uncertainty as to what exactly it is we are being asked to do. The author provides a ranging explanation of the extent of the empirical enquiry to answer that question to date and in so doing by that itself she provides a very welcome reference set to the positive benefits of consumer involvement. The uncertainty expressed in the article however, as to that not being sufficient to reveal the central beneficial impact of consumer involvement, is the author’s main assertion. Her alternative challenge is to go to the researchers themselves.

The author supports this conclusion by a framework for new research as beginning with where the researchers themselves started. That is, with their original plans, priorities, values, assumptions and to then investigate what the consumer led recommendations were and what changed in response. This will allow us, the author argues, to better understand why researchers adopted which recommendations and what outcomes were observed. More detailed accounts of this kind would, she says, provide a rich source of qualitative data that could be analysed to identify consistent themes in the way in which involvement works.

This is a very welcome article deserving of the widest publication across the research community, particularly into NIHR publications as well as by presentation to consumer research bodies like the cancer research community’s Consumer Forum.

Level of interest: An article of outstanding merit and interest in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests