Reviewer’s report

Title: Learning as an outcome of involvement in research: What are the implications for practice, reporting and evaluation?

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Reviewer: Hazel Thornton

Reviewer’s report:

This paper, proposing a new and better relationship between researchers, is very welcome. The authors set out to explore and promote a `thinking partnership` between all parties involved in conducting research, both to their mutual benefit and also the ultimate benefit to the quality of research and its use for patients and citizens.

Public and patient involvement (PPI) in research has come a very long way since it first began to be practised, and is by no means consistent from study to study, specialty by specialty, country to country; or indeed within a country such as the UK for example. It is thus difficult to cope with this variation when authoring a paper for a diverse readership where individual readers are likely to be at a different place on the path to achieving the relationship of `thinking partners` advocated here. In many cases now, it is preaching to the converted, but in others it will seem a more radical concept. I believe it is therefore necessary to adopt a confident stance in proposing this, since it has already been happening in some quarters for quite some time. In the business world, there is such a thing as `over-selling`: the seller must recognise the moment when the business is `in the bag` and tailor their language accordingly, otherwise the purchaser will be inclined to back off. I believe that, because thinking partnerships already exist, the language of writing or talking about it must be sufficiently authoritative and confident to encourage others to come on board what is an already productive relationship.

I felt that there was a degree of overselling in this paper, not only by language subtleties, but also by too much repetition and re-iteration. The readership will be as varied as those involved! Not all need converting from being absolute resisters to your concept; a more subtle wording, acknowledging that all those health-professionals are not out of the same mould, might well make a more persuasive, acceptable-to-more, case.

I would have liked to have seen a brief headed paragraph about ethics, aside from your mentions within the manuscript. As Archie Cochrane advocated back in the 1980s, research should be "everyone`s business". It is only right and proper that health and the people`s health should concern everyone, as Henry Sigerist proposed in the 1970s. See: https://www.ncbi.nlm.nih.gov/pubmed/765888 "Sigerist's account of the evolution of the physician and his discussion of the role of the people in the fight for health provide important new insights into current realities."

Which leads me on to say that I think it unfortunate that you began the introduction of the paper with a history of PPI, measured by recent precise dates. Unfortunate in several respects, firstly
because it was not entirely accurate, and secondly because it seeks to “measure” the unmeasurable by attempting to fix dates to introduction of these. Some work; some don’t. It was historically a longer, more piecemeal and scattered awakening of both Evidence-based-medicine (EBM) and PPI. Think of James Lind; or the randomised trial of streptomycin in 1948 [See: Iain Chalmers Why the 1948 MRC trial of streptomycin used treatment allocation based on random numbers J R Soc Med. 2011 Sep; 104(9): 383-386] - "There is a view among some medical historians that the emergence of the randomized clinical trial originated from statistical thinking, and that the modern era of controlled trials was essentially ushered in with the iconic randomized trial of streptomycin for pulmonary tuberculosis reported by the British Medical Research Council (MRC) in 1948”. And Archie Cochrane; for example.

And for PPI please see my brief (and incomplete!) history of (some) involvement. (Cannot see means of attaching a document, but would be pleased to forward on request.)

Some specific comments:

Page 7 Line 39 What do researchers learn from involvement?

Perhaps add

* Learn which outcomes matter most to patients, and abandon those that don’t matter


Line 51 - 54

I wonder if this last sentence should be a subtitle, or perhaps form part of a revised title which might more accurately describe the purpose of this paper?

Page 10. Line 56, l`evolve`

Again - see Cardiff paper above - about evolving not only `over time`, but also within one study. (See also the paper by Jenny Donovan et al about embedding qualitative research in a study about prostate cancer: https://www.bmj.com/content/325/7367/766 )

This chimes with and accords with you contention about the evolutionary aspects page 12, line 25.

There are several instances in your paper of the last line of a section succinctly conveying and important idea, e.g. page 13, line 29: "The answer is not always a committee." This would make a good strapline, or part of a title. Or good in a bullet-point boxed summary.
Page 14, again, last sentence of a paragraph: "This doesn`t relate to representativeness but to having specific experiences" - extremely important notion that badly needs addressing. It also conveys the uniqueness of each contributor to a research project, be they health professional or citizen/patient.

Page 15. Line 5. Prefer `about` rather than `as to`.

Lines 30-34: Again, another important final sentence that could be edited to go in a summary box.

And again end of next paragraph, lines 54-59.

You may find useful insight in the paper by Koops https://www.ncbi.nlm.nih.gov/pmc/articles/PMC119434/ where the involvement of carers/patients hastened the approval of the ethics committee in this difficult topic of stroke.

Page 17 top two lines somewhat ambiguous - needs rewording.

Line 41 - `implications for evaluation.

Historically, it was originally an intervention that was found to `work`. Now we have moved beyond that. There is now acceptance of patients and public as a valid part of `the team`; it has now moved on to the refinement stage - as explored in your paper.

Last line, second bullet point. `What are the benefits and harms?` OR `What are the benefits and risk of harm?`

Page 18. First paragraph.

This para doesn`t quite hang together logically

Line 32: rather than `need to be asked, would prefer ` are more appropriate`.

Last para: `Assessing the value of involvement will require…etc`

Page 19. Table 1.

Suggest behavioural rather than emotional;

`mostly descriptive stories`. This now popular use of the word `story` is inclined to make it seem like fiction. Would prefer perhaps `individual accounts, - experiential - qualitative?`

Page 21. First line, delete `as to`.

I think we must be careful not to be `absolute` about PPI data. Certain tabulations and facts and figures about PPI ARE helpful.
Page 22. Line 14-16.

Why state "This makes it uncertain [delete `as to`] whether evidence of the impact of involvement as defined in Table 1 will ever be obtained" when you’ve made a case against it??

Page 23. Line 22. Would prefer `study participants` rather than `recruitment`. What follows is ambiguous and needs re-wording.

Re recruitment - again see the Donovan prostate paper where recruitment improved (data to substantiate that!) during the course of the trial as a result of the embedded qualitative work.

|Line 49: delete `as to`.

Page 245. Methodological surely, not methodical?

Last sentence tentative - why not "leads to, etc.etc."

Lines54-56: Research reporting etc. Surely the writing group of researchers reports objectively? Have I misunderstood?

Page 25. Line 17 - `story` again. Might not `give an account` be better?

Your `Conclusions` paragraph final sentences. The Art and the Science of Medicine are both valid concepts that require different approaches, in tandem, rather than combined in a single report, when writing reports.

Final. Sentence: Health professional researchers also give accounts like anyone else, about what and who has shaped them: it is not the sole prerogative of involved non-health-professionals.

PAGE 26. First paragraph.

Surely, there are just different perceptions from different quarters, which is a common thing?

Line 27> `may be lost` - perhaps too tentative,

Line 39 - `echo-chamber`? perhaps re-word.

Line 42: `and may not work according to the rules… etc. Perhaps `who have their own way of working, unaccustomed to…`"

Line 49. `They` - which `they`? I was unhappy with the description of the variety of known behaviours of `ordinary` people - which I felt does nothing to enhance your case. And perhaps `Some researchers` - they are a varied bunch of people too!!

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