Reviewer’s report

Title: Patient and public involvement in health literacy interventions: A mapping review

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Reviewer: Roger Wilson

Reviewer's report:

I liked the key conclusion in the abstract. "Patient and public involvement were rarely reported in studies on health literacy interventions for older people. This could help explain why some interventions fail to improve health literacy in older people."

Twenty minutes later I asked myself is this borne out by the evidence? It is not one of the conclusions of the main paper. It is an attractive hypothesis to research but this study did not do it, and the authors admit that in their discussion. Re-writing the abstract Conclusion to match the paper's Conclusion is not an answer either as the latter does not say anything. It merely laments the paucity of evidence and affirms the general value of PPI.

I am intrigued by the report that "Involvement included volunteers, older people, patients, and community representative." Are these all exclusive categories? I can count myself in all four.

P6 line120: "we do not treat these observations as definitive". Wise caveat.

Background inventory (5561 studies screened, 1097 included) addressing issue of older people/patients in health literacy interventions. These were then screened further to identify 96. Then screened for indications of involvement. Of the 96, 43 were removed. 53 were read in full and 20 fulfilled inclusion criteria. This perhaps is the key issue, less than 2% of the starting number had an indication of PPI.

P7/8: Developed a taxonomy - nice and simple, could have further uses.

Most involvement in design and evaluation stages. None in prioritisation.

There is an extensive numerical analysis but I do not find the detail useful, it is rather meaningless in view of the small numbers involved and the lack of any clear trends or messages. What patients were involved in is very varied. The number of studies which did not use PPI is significant. They acknowledge no attempt to identify comparison studies with no PPI.

Failures in PPI in the studies are picked up with three examples identified:

Literacy level too high

Misaligned priorities between stakeholders involved in the intervention
Too much information on a website developed with patients

It is true that these practical issues highlight the need for PPI at the earliest level of research planning but they also highlight other failings which are not solely those of PPI or no PPI. Researchers can be guilty of other failings as well as not involving patients. Eg: where are the website editorial skills, why is the literacy level not checked (neither is a PPI issue).

The authors state that production of this article did not directly involve patients or public representatives - although consultations with such groups did inform the wider project that led to the creation of the larger inventory that was the starting point. This is a shame. Someone may have questioned what this study was for. It feels like a study which started with a hypothesis, faltered with the recognition that the data were just not there to approach answering it, was converted into a mapping exercise, and faltered again because the sparse data was coupled with substantial variations in detail and defied attempts to create a meaningful topography.

"Many of the studies discussed here pre-date increasingly widespread obligations from funding bodies to orientate research design using PPI. Thus, this mapping review may be considered prescient or premature."
True.

The hypothesis hinted at in the Abstract was:

"Patient and public involvement were rarely reported in studies on health literacy interventions for older people. This could help explain why some interventions fail to improve health literacy in older people."

Such a hypothesis is a worthy ambition and deserving of research. This was not the research to answer that question and as a mapping exercise I detected no emerging map.

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