Author’s response to reviews

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

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Author’s response to reviews:

COMMENT

All Referees: (many positive comments)

Ref#1:
Line 118 'Interventions that were' remove were.
Line 148 'who was involve' involved.
Line 225 'experiences or' replace or with of.
Line 234 'patients use website' websites or add the between patients and the.

Ref#1 It would have been interested to see the breakdown of the amount of Patient and Public involvement in the different countries.

Ref#2 Failures in PPI in the studies are picked up with three examples:
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

Authors’ Response

Thank you for taking time to read our paper and see value in it.

Thank you, these were all corrected.

We agree, however we are also mindful that we need to keep this paper concise, plus we must not over-interpret the meaning of data we found, the data were criticized by Ref#2 as too sparse for any significant conclusions to be made at all. Therefore, no changes were made.

We appreciate Reviewer 2 highlighting that these failures are not solely the result of failings in PPI and very much agree. It is certainly not our intention to imply that PPI could solve all problems in each of these or other health interventions, or that PPI operates in a vacuum, or is even a dominant reason why health literacy interventions have poor success rates.

The aim of the tone of our language overall about...
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 value of PPI is ‘deliberately’ not ‘definitive’. We carefully state that, for example lack of “PPI could help explain why some interventions fail” or PPI “can promote production of better health literacy”

By contrast we observed missed opportunities to use PPI in specific examples where it seemed like excellent use of PPI could have helped prevent these problems.

Ref#2 "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.

Ref#2 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.

We agree these categories are not mutually exclusive and have changed the last “and” to “and/or”

Ref#2 There is an extensive numerical analysis but I do not find the detail useful

We disagree with the Referee about “extensive”; these are not extensive numerical analyses but rather descriptions that enable some counting of what-where-who was involved. This is the core of a mapping review approach and we feel the paper would be remiss to not include such detail. We also compare to what Ref#1 said about wanting more detail (not less) about PPI in different countries. Hence, the counts we show are a compromise between the more and less detail asked for by different Referees.

Ref#2 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

This is an astute comment and partly a fair representation of how our research evolved. We originally had a bigger question in mind but scaled back our objectives when we realized the magnitude of the task in trying to collect suitable data that are largely incomplete.
variations in detail and defied attempts to create a meaningful topography.

We disagree that a meaningful topography must result from a mapping review (in spite of the name). The best mapping reviews may produce a visual graphic, but concept maps are not always required or even always desirable.

Sparsity of information is indeed one of our main findings. We dispute the assertion that because data are sparse, and because this limits confidence in conclusions, that the research is therefore pointless. That argument is similar to the Publication Bias that impacts upon scientific reporting whereby experimental or other evidence gathering exercises are conducted correctly to high standards, but fail to have significant results. This research may then never get published because it is seen as unimportant, and a bias results such that only “significant” results get into the literature. We strongly believe that our finding that data are sparse is extremely important to publicise and intend that it might help motivate researchers to believe that writing in detail about their PPI experience is worthwhile.

Our finding adds further evidence to the assertion made by Staniszewska et al 20017 (p. 2) that “…reporting of PPI in papers has often been inconsistent and partial, with little information about the context, process, and impact of public involvement and with limited reporting of conceptualization or theorization.” The authors’ development of GRIPP2 was based on a systematic review mapping gaps, weaknesses and deficiencies in the existing research designs. It is crucial that appropriate steps are taken to inform future research and policy decisions.

Ref#2 Background inventory (5561 studies screened, 1097 included) …less than 2% of the starting number had an indication of PPI.

Thank you, in essence this is the point of our paper. However, we considered but refrained from adding the 2% statistic to our paper to reflect the criticism from Ref#2 that the paper was already too numerical.

Ref#2 The hypothesis hinted at in the Abstract was:

We agree that our paper does not fully answer that question. However, we still hold that even an
"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.

Ref#3 I query the designation of '50 years' as 'old'. Some may be offended. Lifespan is increasing.

We are very much aware that no matter what threshold was used, someone will find reason to object to it. We have been transparent about the methods, also noting that this age threshold is becoming increasingly established in European research on how to better improve health outcomes in older adults. Justification why age 50 is an attractive target threshold for “older adults” are further included in our Limitations section. Therefore, no edits made.

Ref#3 You should cite and discuss validated evidence that improved health literacy improves health outcomes; and when it makes little difference. ... You should include validated evidence that health literacy declines in the elderly; chances are that if the elderly become ill, they will seek information to help resolve.

It doesn't help that information from health professionals is sometime contradictory.

Thank you for this suggestion, however, there are already 16 references in the background section about why health literacy is recognized as important to improve among all populations, and two references that address concerns about especially low HL among elderly people. We are mindful that to evaluate the merits of this evidence at greater length could significantly lengthen the paper, and go against the editors’ request to be concise and focused. Therefore, no action taken.

We agree that information from seemingly official sources can seem contradictory. Worse, efforts to improve that information over time means that new information contradicts some old information and then patients do not know what to believe. Again, these points are interesting but tangential. Therefore, to thoroughly cover them would not make our paper stay concise and focused, as requested by the editors.

Ref#3 Little is mentioned about the huge change in the availability of health information on the internet; and whether this incomplete answer can expose valid research worthy of dissemination.

We observe that other Referees were much more positive about the value of our research.

This is an interesting point on empowerment, but we are mindful that this is a tangential topic and we need to keep our paper concise and focused.
improves health literacy and health outcomes

Ref#3 You might mention that targeting health information on schoolchildren with the expectation that the health literacy would carry on through life, with an expectation of improved health outcomes.

This is another very valid observation, but we are mindful that it is a tangential topic and we need to keep the paper concise and focused. Therefore no changes made.

Ref#3 the paper confuses 'participation' (receiving an intervention) with 'involvement' (involvement in the research process/team; not the intervention) See NIHR, INVOLVE, RIAE guidance

We appreciate the distinction and that the referee has pointed out how the language could be confusing. We changed language about PPI participants to involvement or representatives.

Ref#3 As regards language (see trackchanges docx) I work on the basis that English should be in a form that those whose mother language is not English will understand. 'Impact' should sometimes be 'effect or affect'

Thank you, and we apologize for this not being up to scratch in the previous version of our paper. We followed the stylistic guides here: http://www.mit.edu/course/21/21.guide/affect.htm to make several changes.

Ref#4 There are many minor issues with expression, which need careful checking.

We interpret this to be a comment about proofreading needed (we have since carefully proofread & corrected some expressions).

Ref#4 I'd like to have seen more discussion related to the topics covered, including the concept of health literacy as it relates to perspectives of patients and members of the public. PPI discussions or direct contributions to the paper could help to make this a more substantial piece.

This expansion runs counter to the request by editors to make the paper more concise and focused, therefore no action has been taken.

Please see reference number 17 to our article which explored how patients and professionals view health literacy: Salter et al: Challenges and Opportunities: What Can We Learn from Patients Living with Chronic Musculoskeletal Conditions, Health Professionals and Carers about the Concept of Health Literacy. Using Qualitative Methods of Inquiry? PloS one 2014, 9(10).

Ref#4. a reference to the GRIPP2 work on reporting of PPI in research may be appropriate

GRIPP2 was already partly referenced (Wilson [20]), but we added an additional reference = Staniszewska et al 2017.