Reviewer’s report

Title: At the cross-roads of participatory research and biomarker discovery in autism: The need for empirical data

Version: 3 Date: 29 April 2015

Reviewer: Brian Lee

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Major compulsory revisions

1. The framing of the manuscript may require some revising to more clearly state the goal of the text as well as the takeaway message. In the Abstract, the authors state: “The extent to which principles of participatory research have been utilized in autism biomarker discovery specifically is largely unknown, despite significant claims to the contrary.” This makes it appear that the authors will be quantifying this unknown extent through their scoping review. The authors identify 6 of 342 articles that have involved stakeholders in biomarker discovery. The authors then conclude that “…CBPR principles have been clearly used in biomarker discovery..” This is not a particularly illuminating conclusion. Based on these numbers, I would conclude that nearly 99% of biomarker discovery studies do not incorporate CBPR principles, which is a somewhat different qualitative conclusion from that of the authors’.

2. More problematic is that the authors state that “Further research using participatory principles will be useful in accelerating the pace of discovery and the development of clinically meaning biomarkers.” However, the present text does not appear to contain evidence to support this assertion. If anything, given the challenges of participatory research, this would present additional obstacles to overcome.

Discretionary revisions

3. To me, the main point of interest in this article is not the scoping review, but the thought-provoking discussion. I suggest that limitations/challenges of participatory research for biomarker discovery be discussed in a standalone section(s), instead of scattered threads throughout. For example, the authors introduce early on that CBPR can be challenged by loss of validity, but neither explain how such a loss can occur or realistic solutions on how to address this (other than re-conceptualizing the loss of validity somehow as an advantage in other aspects, which does not address the core problem of loss of validity).

4. As an epidemiologist, a practical concern I might have is in potential harms of participatory research to the progress of science. For example, highly motivated groups not representative of the broader population would volunteer to participate in the study, resulting in a selection bias. This could cause both a loss of internal and external validity. I might also be more concerned about contamination between different groups if I were performing a randomized trial.
Another concern might be ceding control of a scientifically rigorous study to the demands of a less scientifically literate population. While paternalistic research should be avoided, the customer may not always be right and I might caution against advocating too strongly for participatory research.

5. Finally, the authors may wish to comment on whether it is possible that participatory research can pose potential harms to the community it is trying to involve. Not being an expert in this area, I could envision scenarios where translational science from bench to bedside takes so long and has so many false leads that prematurely involving the community may cause inadvertent harms. The harms may range from wasted time and energy; to false hopes being raised; or even to ill-advised family planning actions based on premature science.

**Level of interest:** An article of limited interest

**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