Author’s response to reviews

Title: "Is all the stuff about neurons necessary?" The development of lay summaries to disseminate findings from the Newcastle Cognitive Function after Stroke (COGFAST) study

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Author’s response to reviews:

Dear editorial team

Thank-you for the opportunity to resubmit our paper with further revisions. I have responded to your points as follows:

You state ethical approval is not required for this study but in parts it reads like a research paper. We would like you to emphasise that this study involved individuals as active collaborators. This is important because often such activity would have ethical approval if people are involved as study participants. In addition please review the terminology you use in relation to active involvement versus participation as a subject. For example the use of the term recruitment or bias suggests a research study. You also state data was collected (in author contributions). Once data collection is operating in a research context ethical approval is usually required.

We remain of the view that we were working to HRA guidelines on working “with” people rather than recruiting them as research participants (as explained in the ethical approvals section). We apologise that the most recent revisions the paper that we made did not clarify matters definitively enough. We accept that the terminology may appear ambiguous and have therefore made some changes to avoid concerns that our volunteers were research participants
(rather than collaborators). Although a number of PPI/E projects refer to collaborators as “participants” (e.g. Patients Participate) we accept your concern that the term may be associated with research participation. We have instead now used “volunteers” or “collaborators”.

We would expect you to include a patient as a co-author and wondered why you had not done this?

The project was initially written up as an undergraduate student’s dissertation. As this needed to be performed independently by the student, correspondence with the volunteers during this period was not felt to be appropriate. The article was subsequently created at a later date. The volunteers had only committed their time to the project discussion meetings and therefore we did not feel that it was appropriate to burden them with further requests, particularly as some volunteers have caring responsibilities. Further, as this was based on a student project, we did not have the funds or resources to adequately support volunteers to take part in academic writing.

We intend to disseminate a copy of the article to our collaborators and to the wider audience of VoiceNorth volunteers.

We would also like you to comment on any ethical aspects you considered in conducting the work, even if formal approval was not sought? If you do not believe there were any that is fine. Your ethical statement at the end about withdrawing suggests research study participation so please consider that wording too.

The only potential ethical issue that we highlighted was for collaborators verbal and written contributions should be anonymised for publication. We have explained this in the methods and consent for publication sections.

The terminology at the end of “ethical approval” section has been modified to “stop contributing”
All of the changes are highlighted within the manuscript. We look forward to hearing from you again.

Best wishes

Ellen Tullo