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 Editor

Thank-you for the opportunity to respond to reviewer comments on our paper. We provide an itemised response to comments (responses highlighted in bold below) and an amended manuscript with highlighting to indicate where changes have been made.

Two reviewers commented on the format of the supplementary material (currently png files). We may be able to supply these in an alternative format if the paper is accepted for publication – please could you advise us as to what might be the most suitable format for readers?

Thank-you for reconsidering our article

Ellen Tullo
<b>Reviewer #1</b>

I looked forward to reviewing this paper - I became keen on Plain English when writing my PhD; A lot of science and medical and health information is now written in Plain English - English that is simple, uses words that are easily understandable; and in such a manner that the informed public can understand the science/medicine/health subjects. I query that this paper does this:

1) 5 members of the public were selected from replies to an invitation; 4 attended on Focus Group 1 and 3 attended Focus group 2. that would not satisfy me as providing a strong evidence base

Members of the public were selected as a small convenience sample from a group of individuals known to have interest in participating in research. The project formed the basis of a dissertation for an undergraduate student with no allocated resources and a limited time frame. Unfortunately this meant that some individuals were unable to attend both of the focus groups. Although we cannot predict whether a larger sample would have led to more valid results, there were demonstrable changes made to the lay summaries and we feel this study shows that others could easily and inexpensively reproduce our methods. “It may be that purposive sampling of members of the public who comprise the most likely audience of a dissemination strategy is more fruitful than random sampling.”

2) The authors use of some words is not the normal or preferred usage - adaption and exemplar are two such; see Fowler.

Thank-you – these usage has been reviewed and changed

I have rarely (ever?) seen the Flesh metrics used for science or medicine - and after looking at relevant websites I wonder why the authors decided they were appropriate without further testing(this could be a separate project: 'Comparison of different readability metrics for science, medical and health writing...').

Whilst the Flesch tools were not designed specifically for assessment of scientific summaries, we chose to use the tools due to ease of access (available through word processing...).
software) and lack of specific alternative metric. We have added this information in the manuscript.

4) The weblink at the end of the paper did not take me to the website therefore I could not review the 'supplementary material'; on 2 occasions when attempting to connect to the site, my Acrobat reader (up to date) crashed meaning I could have lost hours of reviewer time. These experiences do not encourage the reviewer or 'the general public' to read on. The first time I tried, the ONS reference link took me straight to the site; the second time it came up with a '406 - site does not exist or has moved'; copying the link into Google did the same and a colleague found the same (I gave no other information to colleague) the ONS site needed searching to find article; I did not try the other reference links therefore they need checking.

We apologise that you had difficulty in accessing the websites via the links provided. We have checked the links from various different computers and have not found any problems. We are therefore unable to explain the root of the problem. We have asked the editor what would be the preferred format for the supplementary material.

I have added my comments to the pdf (in comment 'bubbles') which I ask the authors to consider.

Thank-you for these itemised suggestions annotated to the pdf. We have incorporated the majority of the suggestions (please see highlighted changes to the manuscript). In the cases that we have not made the suggested change, we present our rationale as follows:

1. Manuscript title (p1): Although you suggest that the first sentence of our title is confusing, as an in-vivo quotation from one of the participants we believe that it concisely illustrates the difference that academics and members of the public afford scientific terminology.

2. Explanation of “paradoxical increase” used in the abstract (p3): we do not think that there is enough space in the abstract to explain here. We feel that an explanation is given in the discussion section.
3. VOICENorth membership (p7): VN does not have any set criteria for membership so we cannot elaborate on demographics here.

Finally, writing Plain English does require lots of practice; it is hard work! I am not convinced that this paper - 7 years in the writing? - adds much to what is already available for writing in general, not just about specialist material. However, I have given my recommendation to publish because many people may not realise how important this is. Good Plain English should also help researcher reputation hence career.

The production of lay summaries was not an original part of the COGFAST project. It became clear following the outcomes of the various studies, that the results were important to disseminate to the wider public. We explain this in the “study setting” section. Thus, the lay summary project occurred beyond the scope of COGFAST and took place in Jan-April of 2016, not 7 years ago.

<b>Reviewer #2</b>

1) Interesting article but you are very coy about describing how the COGFAST study worked. You talk about paper and pen tests of memory function and then looking at their brains with a microscope after they died and had donated their brains for research by the brain bank. How does this process work ie how did they keep in touch with people so long and then persuade them to donate their brains! This is part of any lay research summary.

We did not feel that we had the scope to include detail about recruitment for the wider COGFAST initiative and the Newcastle Brain Bank in relation to the 4 specific sub-studies selected. We have endeavoured to add some more general information about the brain bank to our website: https://research.ncl.ac.uk/cogfast/contactusvolunteer/. Further, this was not highlighted by our participants.

2) I found having to download each of the formats was not easy and they were not clearly labeled with dates. Is going to be available in hard copy? as I prefer to print out what I read to digest it properly.
Our apologies that it was not easy to download each of the formats. We could not think of an alternative way to allow access to these pdfs if the article was accepted for publication. We have amended the document descriptions to make dates/sequence clearer.

3) I read that the research was old 1999 to 2003. You did not list separately the relevant journals articles from which the lay summaries were made. It would be nice to have that made clearer.

In the results section we identify why the four papers were prioritised by the group and the titles are referenced.

4) You talk about the general public but your focus groups seem to be some people with lived experience as users or carers or people with an interest in research. I do not think you mean the general public in this context.

Thank-you for this point. We acknowledge that the group are not necessarily representative of the “general public” due to their occupation and/or experience as a carer in the limitations section (p16). For example: “Consequently, our group of participants may not be representative of a typical ‘lay person’ (if such a thing exists). However, we argue that these individuals are representative of those most likely to access and benefit from the COGFAST website. It may be that purposive sampling of members of the public who comprise the most likely audience of a dissemination strategy is more fruitful than random sampling.”

5) You could have said more about dissemination of research findings and what the readership of the journals you chose was.

We do not think that there is sufficient scope within the article to consider the historical choices for dissemination of original COGFAST articles. We start from the premise that the findings are unlikely to be accessible to the general public when limited to academic journals.
1) It was clear that the authors wanted to test a method of creating lay summaries, although it was unclear why the end product was limited to four such summaries.

The project formed the basis of a dissertation for an undergraduate student with no allocated resources and a limited time frame. We hope in future to be able to produce similar summaries for the other papers. This project reports the process as we believe it may be of value to those wishing to do something similar.

2) The VOICENorth group which provided the five volunteers was clearly identified as a public contributor group and the attendance and meeting sequences were described and their interests/expertise were listed in their profiles. The process of working with the VOICENorth group (comments/drafts/focus groups) was quite clearly set out. The Flesch-Kincaid grading scheme for reading ease was described to the reader but no justification offered for its choice as the grading system in this case (for example, I don't know if there are other competing grading scales and this was identified as the best one, or how widely the FK scale is used.)

Whilst the Flesch tools were not designed specifically for assessment of scientific summaries, we chose to use the tools due to ease of access (available through word processing software) and lack of specific alternative metric. We have added this information in the manuscript.

3) On page 4, I would have expected to see reference to the fact that the NIHR Journals Library requires a plain English summary in all full reports that it publishes and that detailed author guidance has been developed for this purpose.

Thank-you – we have added this information and a reference to the manuscript.

4) The methods and sequencing of the project were broadly well set out, though I would have liked to see a definition of 'older people' in the 'study setting' section.

Thank-you – we have added a definition.
5) There was no particular discussion about the strengths and weaknesses of the methods - they were just stated. The inclusion of an example lay summary at each stage of the process was helpful and enables the reader to see the progression.

<b>We address the limitations of the methods in the discussion section, for example alternatives may be the use of one-to-one interviewing and ongoing feedback through online discussion.</b>

6) There were no major ethical considerations but the public contributors to the process appeared to have received clear instruction and have been treated considerately. It is not clear what provision would have been made had accessibility to the written material been a barrier to involvement.

<b>Although the participants chose to access the materials electronically, we also provided paper copies by post. We agree that visual impairment would have been a significant barrier to involvement in the process</b>

7) The plain English summary in the paper is clear and concise although I would have preferred it if it had been clearer that the conclusion stated at the end of the PES was the hypothesis that was being tested.

<b>Our conclusion in the plain English summary is repeated in the abstract background as an aim “This project aimed to select a series of studies from the Newcastle Cognitive Function after Stroke cohort (COGFAST) and create lay summaries comprehensible and accessible to the public.”</b>

8) The overall style and layout of the paper is acceptable but there are a number of distracting typographical errors which will require correction.

<b>Our apologies - These have been corrected.</b>
I thought this was a really well written and useful article. I enjoyed reading it and found the inclusion of examples of the lay summaries 'before and after' helpful. I think that the article makes a helpful contribution to discussions or how to write a good lay summary. My only concern is about the framing of the article. It raises some important questions which aren't currently in scope but which would I think help to take this work forwards.

1) The first of these concerns the approach taken. While this was thoughtful and clearly done with great skill, there is a long tradition of 'user testing' which has been developed in the field of web development which isn't referenced here but which would I think have opened up some useful alternative / additional approaches to involving the public in the process of developing the website and summaries. Another term for this is 'usability': here is a US website which provides an overview of some of the methods: https://www.usability.gov/ I think there is a real sophistication now in such methods which could really help people with the challenge of developing such resources in the future. I wonder if it would be helpful to reference this in the discussion section - making the point that the focus group approach is a first step, but that there is significant potential to draw on other methods?

Thank-you – we have included a reference to more systematic user testing techniques

2) My second concern is that the article frames the challenge as being about 'comprehensibility' whereas I felt that the challenge is broader than that: as someone who has a mother who has had a stroke and is living with dementia I was intrigued to find out more about the research and how it might help us make sense of her condition, so I read the summaries with great interest. I found they explained the science well but left me asking 'so what?' I suggest that focusing on 'comprehensibility' alone is too narrow - it is vital to also address purpose and motivation for reading.

Thank-you for this comment. The nature of the COGFAST project meant that it was more epidemiologically focussed, identifying risk factors rather than testing initiatives to improve life following stroke. We will consider whether we could link the information derived from COGFAST to other websites that concentrate on new treatments or support for patients and their families.
I wanted to share these reflections as I think they would help to take the work forward. Congratulations on writing such a thoughtful and lucid account. It really got me thinking!

<b>Thank-you for your positive response</b>