Author's response to reviews

Title: The care.data consensus? A qualitative analysis of opinions expressed on Twitter

Authors:

Rebecca Hays (rebecca.hays@manchester.ac.uk)
Gavin Daker-White (gavin.daker-white@manchester.ac.uk)

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The care.data consensus? A qualitative analysis of opinions expressed on Twitter

Response to reviewers

Referee 1
Reviewer: Amanda Lee Hughes
I have re-reviewed the document and found that the authors have adequately addressed the concerns I had with the first submission. The document is much improved!

Referee 2
Reviewer: Jonathan A Micieli
The authors have descriptively provided an overview of the tweets on this topic but it still lacks a clear scientific research question and enough of a quantitative component for this to be of interest to readers of a scientific journal. If the goal is to regurgitate the opinions expressed on twitter then one can easily go on twitter and type in #caredata and read tweets.

The authors use terms like "often", "some", "considerable" and "broadly". How did they come to these conclusions? Why did thy use these terms? How can we trust that these terms were selected correctly and what was the criteria for using these adjectives? Without this information we do not know how we can be sure there is no bias introduced by the authors.

Why are there examples of tweets under each heading? Why were these chosen and how reliably do they represent the general opinion?

Response to referee 2
Thank you for your comments. We agree that you raise an important point regarding the difficulty of evidencing the reliability and integrity of qualitative research. However, qualitative research does not rest on the same epistemological base as positivist science. It is an exploratory method, commonly used to highlight possibilities for further research, that focuses on subjective opinions and knowledge that cannot be captured by other methods, e.g. structured surveys. Qualitative studies are also increasingly "nested" within trials in order to make sense of why some interventions do (or don’t) work. Whilst qualitative methods come from a different tradition (arts and social sciences), they have their own well developed standards for application in applied health research. We believe that we have abided by these accepted standards for the conduct and reporting of qualitative research in this study.

Following the announcement about the care.data project at the beginning of 2014, various organisations conducted surveys to identify how many people supported or opposed the project, and how many people intended to opt out. However, these surveys did not explore people’s opinions about care.data in depth. Alongside this, there was intense debate about the project across social media. On Twitter, users were discussing the issue in detail. Therefore, we set out to explore the nature and range of opinions expressed about care.data on Twitter, and analyse the data in such a way as to provide insight into the strengths and flaws of the project. Further information has been added to the manuscript to reflect this (see page 2, lines 11-12; page 4, lines 11-18; page 6, lines 4-7).

By systematically collecting and coding tweets from the time period during which the delay to the care.data project was announced, we were able to familiarise ourselves with the Twitter discourse and characterise tweets in a more nuanced way than would be possible to garner by just reading through the search results for #caredata on Twitter or via automated methods. Thus, our methods enabled us to explore the content of tweets in-depth, describe the range of opinions expressed about the care.data project on Twitter, and provide an overview of the concerns people had about care.data and its implementation. Additional text has been added to the manuscript to emphasise this point (see page 6, lines 7-11; page 7, lines 17-20).

We have added a paragraph to the manuscript (see page 9, lines 5-10) which points to your concerns about the potential for bias through our use of terms such as “often” and “some”, the
presentation of illustrative tweets under each sub-heading, and the lack of a quantitative component. These practices are conventional in qualitative research studies, including those previously published in BMC Public Health. For example, the following manuscripts represent a selection of the highly accessed papers, published by BMC Public Health in 2015, that have used qualitative methods of data analysis, terms such as “some” and “many”, presented exemplar quotes, and have no quantitative component: