Author’s response to reviews

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

Authors:

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Author’s response to reviews: see over
Dear Editor,

**RE: MS: 1257629042140896**

Research article
The care.data consensus? A qualitative analysis of opinions expressed on Twitter
Rebecca Hays and Gavin Daker-White
BMC Public Health

Thank for your letter and the opportunity to respond to the reviewers’ comments on the above research article. Please find copies of the reviewers’ comments and our responses to each detailed below.

With best wishes,
Yours sincerely,
Rebecca Hays

**Response to reviewers**

**Referee 1**
**Reviewer:** Amanda Lee Hughes

**Major Compulsory Revisions**

<table>
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<th>Page 6, first paragraph -- The description of the Twitter data collection could be clearer. For example, why were tweets collected between 4-6pm only? What was the rationale for this choice? Does this mean only tweets that were created around this time period were collected? I also didn’t understand why the query was performed multiple times and only the one with the largest result was kept. If the queries returned different results (which it seemed like they did), wouldn’t it have been better to keep all results and aggregate them? The paper states, “The target number of tweets was reached on the fifth capture, which encompassed all tweets from the fourth capture. Thus, the fourth capture was deleted.” This raises lots of questions, such as, what was the target number of tweets? What happened to captures one, two, and three? Were five captures performed for every collection period? More clarity around the Twitter data collection process is needed.</th>
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<tr>
<td>Response:</td>
<td>The first two paragraphs of the methods (page 6, lines 8-22) have been revised to clarify how tweets were collected, including:</td>
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<td>• How NCapture works.</td>
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<td>• What the difference is between a capture (the act of capturing tweets) and a batch (a collection of captured tweets).</td>
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<td>• What the target number of tweets was.</td>
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<td>• Why only one capture was retained from each day.</td>
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<td>• How many batches of tweets were included in the final dataset and why this was the case.</td>
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‘Figure 1: When and how many tweets were captured’ has been added and referenced in the first paragraph of the overview section of the results (page 7, line 27) to show when and how many tweets were captured. The text in this paragraph (page 7, lines 25-29) has also been revised to clarify the time periods during which tweets were and were not captured.

Finally, text has been added to the discussion (page 23, lines 8-13) to highlight the advantages and limitations of the NCapture tool for NVivo 10 and the way we used this.
2 Page 6, “Data Analysis” section – This section needs more detail about the coding scheme, without this data the research is not reproducible. The paper states that the tweets were “coded in iterative fashion according to an evolving list of themes.” This is an appropriate approach, but what were these themes? In the “Results” section on page 2, it states that tweets were coded into one or more of 66 themes. However, I was unable to find these 66 themes in the paper. One way to address this concern would be to create a table listing these themes, along with an accounting of how many tweets were coded for each theme. This approach would be helpful for several reasons: 1) it would help the reader understand how frequently these themes occurred and 2) the paper can better demonstrate how the findings reported in the “Results” section of the paper were derived from the coded themes (right now that link is unclear).

Response – regarding the method and coding scheme:
Additional information has been added to the second paragraph of the data analysis section of the methods (page 7, lines 14-18) to clarify the roles of each author and how they collaborated to develop the coding scheme and reach a consensus.

The specified number of key themes and sub-themes in the results section of the abstract (page 2, lines 21-22) and the final paragraph of the overview section of the results (page 8, lines 19-24) has been updated to reflect final coding scheme.

Finally, ‘Table 1: List of key themes and sub-themes’ has been added and referenced in the final paragraph of the overview section of the results (page 8, line 21) to show this coding scheme in full.

Response – regarding how many tweets were coded for each theme:
Count data, regarding the number of tweets per theme, has not been added to the manuscript. However, text has been added to the discussion (page 23, lines 19-29) to explain the reasons behind the approach taken. Furthermore, a paragraph has been added to the end of the discussion (page 24, lines 12-19) that contains suggestions for how studies of this kind could be strengthened; highlighting methods that would have produced meaningful quantitative data and potentially offer a better way of representing the whole story in such a dataset.

3 Page 9, line 24 – “Tweets disclosed a lack of trust...” How many tweets? All tweets?

Response:
The word ‘often’ has been added to this sentence (page 10, line 1) to give an indication of how frequently the viewpoint was presented. Please see the response to the point above regarding how many tweets were coded for each theme.

4 Page 19, line 1 – The paper states that the themes discussed in the paper are related and then refers to Figure 1 for a conceptual model of how the themes are related. However, this model is never explained. If the conceptual model is going to be used in the paper, it needs to be explained in much greater detail. What do the arrows mean? What does the model tell us? If it is not going to be explained than it should be removed.

Response:
The first six paragraphs of the discussion (from page 20, line 6 to page 22, line 11) have been revised to integrate the summary of the findings with a more detailed description of the conceptual model (shown in Figure 2) and a clearer explanation of how the themes
are related.

5 Page 22, lines 11-16 – This last paragraph would be much stronger if it tied back to the findings of the paper. How did the study of Twitter messages around the care.data project contribute to a greater understanding of the issues and public opinion around the project? How might the project use these understandings to improve the project?

Response:  
An additional paragraph has been added to the conclusions (page 25, lines 1-8) that contains a reflection on the findings of the study and the implications for the care.data project.

**Minor Essential Revisions**

6 Page 6, line 9 – The word “protagonists” is problematic; it paints the Twitter authors in a particular light. For instance, the word “antagonists” could just have easily been used, but it would portray very different types of Twitter author. I would suggest removing “protagonists” and just say “authors.”

Response:  
The word “protagonists” was used alongside “authors” to refer to the subject of a tweet. To avoid confusion, the word “protagonists” has been replaced with the words “those mentioned” in the third paragraph of the methods (page 6, line 25).

7 Page 9, line 9 – The phrase “Users took to Twitter” seems to suggest that use of Twitter for this purpose was widespread by all users of Twitter. Unless this is true, it should be rephrased.

Response:  
The phrase “Users took to Twitter” has been changed to “Twitter users” in the last paragraph of the ‘Informed consent and the default ‘opt-in’’ section of the results (page 9, line 17).

8 Page 10, line 8 – “The third batch of tweets…” To what batches of tweets is this referring? I suspect this has something to do with the collection dates, but it is unclear.

Response:  
More details about the dates the batches of tweets were collected on and the time periods they cover have been added to in the first paragraph of the overview section of the results (page 7, line 25-29). This has also been depicted in ‘Figure 1: When and how many tweets were captured’, which has been linked to in the first paragraph of the overview section of the results (page 7, line 27).

9 Page 11, line 13 – The hashtags are on a separate line. They should probably be at the end of the line above them.

Response:  
The paragraph break has been removed from the tweet after the second paragraph in the ‘Privacy and data security’ section of the results (page 11, line 20).

10 Page 13, line 1 – “With the factual accuracy such statements, this debate again highlight
the...” should read, “with the factual accuracy of such statements, this debate again highlights the...”

**Response:**
The highlighted errors have been rectified in the first paragraph of the ‘Legal issues and GPs’ concerns’ section of the results (page 13, lines 9-10).

### Discretionary Revisions

| 11 | Page 5, paragraph starting on line 18 – This paragraph describes what was done and how it was done. The paragraph would also really benefit from a sentence that describes why this study was done and why the research is important. This will help motivate the research for the reader. |
| **Response:** | The final paragraph of the background (starting on page 5, at line 28) has been revised to clarify the aims and objectives of the study. The background section of the abstract has been revised accordingly (page 2, lines 9-11). |
| 12 | Page 5, line 4 – Consider changing “Twitter is being used to educate...” to “Twitter can educate...” |
| **Response:** | The wording of this sentence in the second to last paragraph of the background (page 5, line 14) has been changed. |
| 13 | Page 19, lines 2-5 – I’m not sure this tweet adds anything to the discussion. |
| **Response:** | The tweet following the first paragraph of the discussion (page 20, line 18) has been removed. |

**Referee 2**  
**Reviewer:** Jonathan A Micieli

### Major Compulsory Revisions

| 1 | In their qualitative report, the authors have several headings in the result section that discussion different aspects/opinions expressed on Twitter regarding care.data. However, there needs to be a more quantitative analysis for this paper to be informative to the scientific readers of this journal. For example, in the 3rd paragraph of the results the authors state "There was considerable confusion about what care.data involves". What makes the authors state that? Was there one person who expressed this opinion? 75% of people? 50% of people? How do they define considerable? Please analyze these tweets more scientifically so we can better understand people’s position. It is difficult to follow at present. The authors also state in their results that "Tweets that were broadly supportive of care.data appeared to be far fewer in number than those that were critical". How fewer? This would be best represented graphically so we can easily see how people feel about |

| **Response:** | The authors have several headings in the result section that discussion different aspects/opinions expressed on Twitter regarding care.data. However, there needs to be a more quantitative analysis for this paper to be informative to the scientific readers of this journal. For example, in the 3rd paragraph of the results the authors state "There was considerable confusion about what care.data involves". What makes the authors state that? Was there one person who expressed this opinion? 75% of people? 50% of people? How do they define considerable? Please analyze these tweets more scientifically so we can better understand people’s position. It is difficult to follow at present. The authors also state in their results that "Tweets that were broadly supportive of care.data appeared to be far fewer in number than those that were critical". How fewer? This would be best represented graphically so we can easily see how people feel about |
| Referee 3  

**Reviewer:** Tom H van de Belt 

**Major Compulsory Revisions** |
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Therefore, I advise the authors to add a research question and clearly choose between 1 or 2.

**Response:**
The final paragraph of the background (starting on page 5, at line 28) has been revised to clarify the aims and objectives of the study. The background section of the abstract has also been revised accordingly (page 2, lines 9-11).

A new ‘social media’ section has been added to the background (page 4, lines 18-24) to explain what social media is and that different sites are used for different purposes.

Finally, text has been added to the discussion (starting on page 22, at line 28) to highlight the limitations of collecting data from only one data source.

2 Second, I have a question about the methods used in this study. The authors used established methods of qualitative data analysis, which seems to be an acceptable solution. However, key in this methodology is that two reviewers independently code data, and discuss results until consensus is reached. I am aware that in some cases it accepted that only one author codes data, but then it should be clear that their level of agreement is very good to excellent. How was this done in the present study? I assume that the reviewers discussed differences and results. Please describe this as clearly as possible in a way it allows other researchers to reproduce equal results.

**Response:**
Additional information has been added to the second paragraph of the data analysis section of the methods (page 7, lines 14-18) to clarify the roles of each author and how they collaborated to develop the coding scheme and reach a consensus.

3 A third issue is related to the results section. The authors tend to quantify results e.g. ‘a very small number of people’, ‘a sizable proportion’ etc. This doesn’t make any sense thus should be avoided. I suggest that they provide it as follows: ‘% (n/n)’. However, one can question the value of numbers/proportions for this work since this is a qualitative study with the goal to identify a variety if topics/opinions. If proportions matter it would be better to disseminate a survey OR they could at least include the number of retweets as well cause this is a way to echo a persons thoughts and can reflect your own opinion (probably a good next step)?

**Response:**
Please see the previous response to reviewer 1, point 2 regarding how many tweets were coded for each theme.

4 In the discussion section, the authors provide new results. This should be avoided. Please transfer to results section or remove.

**Response:**
A new ‘Potential of care.data and the ideal model of implementation’ section has been added to the results (starting on page 18, at line 21). This includes the content of two paragraphs previously in the discussion that concerned support for the care.data project and suggestions for improvement, and the content of two paragraphs from the overview section of the results that also concerned support for care.data. These changes mean the contents of the results now more accurately reflect the thematic framework shown in
‘Table 1: List of key themes and sub-themes’ (which is referenced in the final paragraph of the overview section of the results (page 8, line 21).

The first six paragraphs of the discussion section (from page 20, line 6 to page 22, line 11) have been revised to reflect these changes.

5 The authors should clearly discuss all limitations of this work. I recommend a comparison to other sources such as other social media channels (there was a lot of debate about #caredata on Facebook), surveys, interviews, etc. Furthermore, it is clear that the very large majority of the individuals it concerns are not on Twitter. I am also interested in the limitations of NCapture in combination with NVivo 10: The number of tweets seemed to vary a lot? Did the authors compare the performance with other tools? Eg: there is an abundance of social media monitoring tools. If so, they could also describe this in the methods section. If they did not, I see this as an important limitation. Regarding their analysis, I would like to hear their thoughts about not including retweets since they drastically improve the reach of a tweet and when a tweet gets retweeted: it is clear that more people support it OR disagree with it.

**Response:**

As noted in response to point 1 above, a new ‘social media’ section has been added to the background (page 4, lines 18-24) to explain what social media is and that different sites are used for different purposes. Text has also been added to the discussion (starting on page 22, at line 28) to highlight the limitations of collecting data from only one data source.

Text has been added to the discussion (page 23, lines 9-13) to highlight the advantages and limitations of the NCapture tool for NVivo 10 and the way we used this.

Retweets were not included because our aim was to identify and describe the range of opinions expressed, and retweets only reiterate information. Thus, they would not add anything to our analysis.