

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Insights into the London Cancer Patient Experience: Framework analysis of free text data from the National Cancer Patient Experience Survey 2012/2013 from the two London Integrated Cancer Systems
AUTHORS	Wiseman, Theresa; Lucas, Grace; Sangha, Amrit; Randolph, Anuska; Stapleton, Sarah; Pattison, Natalie; O'Gara, Geraldine; Harris, Katherine; Pritchard-Jones, Kathy; Dolan, Shelley

VERSION 1 - REVIEW

REVIEWER	Mary Wells NMAHP Research Unit, University of Stirling, UK I know two of the authors well
REVIEW RETURNED	26-Feb-2015

GENERAL COMMENTS	<p>The free text responses included in the National Cancer Patient Experience survey are extremely important, and shed light on aspects of patients' experiences that may not be captured in a multiple choice questionnaire. Understanding the experiences of patients in NHS Trusts that did not perform well in the survey is important for policy and care provision.</p> <p>This short paper provides some genuine insights into the areas of care that need attention, as well as the positive aspects of care that are particularly important to cancer patients. Although I would recommend that the paper is published, I do have a number of suggestions that would significantly enhance the clarity and relevance of the paper to the wide audience of BMJ Open.</p> <p>The background section provides some context but would be improved by a brief explanation of the purpose, aims and methods used in the National Cancer Patient Experience survey, as this will not be known by all readers of BMJ Open. Also - this explanation would make it possible for some of the questions in the score sheet to be ticked 'yes'. At the moment, there are details missing e.g. ethics of the CPES, so it is impossible to say that these have been addressed in the paper.</p> <p>Methods</p> <p>The rationale and potential for analysing free text responses from survey could be strengthened by referring to other studies that have done this e.g. Corner et al (2013) PROMS survey http://bmjopen.bmj.com/content/3/4/e002316.full and indeed the authors own work (Ref 11).</p> <p>Table 1 would make more sense in the data paragraph.</p> <p>Could the authors provide a little more detail about the framework developed for the 2012/13 data and whether information about this is published elsewhere?</p> <p>Findings</p>
-------------------------	---

	<p>Were the 10,262 positive comments all in response to question 1 and the negative comments all in response to question 2 or were some answers to question 3? This is not currently clear, and it would be helpful to include a breakdown of where the free text responses were located in relation to the three open ended questions. If the total number of comments was 15603 (made up of positive and negative comments), are the additional comments about the ambiguity of the questionnaire not included in this total?</p> <p>Percentages in Tables 2 and 3 are unclear. In Table 2 these add up to 99% but in Table 3 they add up to 51%. Further explanation needs to be given.</p> <p>It would be helpful to include some further details on the distinction between themes (or an acknowledgement that there is some ambiguity between them) e.g. poor care and poor communication, as some of the quotes describing poor care also seem to be about poor communication.</p> <p>The final paragraph before the section on ambiguity (page 7) contains some alarming details - rather than presenting these as a list, some of these could be explained more fully.</p> <p>For positive and negative comments, it would also be helpful to understand whether there was a tendency for the same patients to make several comments or whether most were primarily single comments.</p> <p>Do the responses about ambiguity provide any detail of which questions or areas of the questionnaire people found confusing? (other than the issue related to care across a range of trusts)</p> <p>Discussion</p> <p>This is rather short. Greater analysis of the key themes would be welcome here. Additionally, some further discussion of the core features of positive and negative experiences of cancer care, with reference to the literature, would enhance the paper overall.</p> <p>Abstract</p> <p>I would suggest that the overall objective could be re-framed, as the analysis of free text comments from a questionnaire survey is unlikely to reveal the 'in-depth experiences' of patients</p> <p>Editorial comments to be addressed:-</p> <p>P3 line 20 the following sentence is a little confusing - "The ten poorest performing NHS trusts were ranked by Macmillan based on the number of questions where patient scores fell within the bottom 20% of results for all trusts over 63 questions" and would be clearer if it read "The ten poorest performing NHS trusts were ranked by Macmillan, based on the number of questions (out of 63) for which patient scores fell within the bottom 20% of results for all trusts"</p> <p>P3 after line 24 I would suggest providing a sentence listing the number of hypotheses before giving the longer explanation e.g. including patient characteristics, environment and organisation, staffing and treatment issues</p> <p>P3 line 48 - if in quotations - is there a reference for this?</p> <p>P4 first paragraph, p8 - data are plural</p> <p>P4 line 38 sentence saying that content analysis should be interpreted with caution- it would be clearer to say that this form of analysis is unable to reflect whether the number of responses pertains to the size of the trusts, percentage of patients....etc etc.</p> <p>P6 line "most" number of negative comments should read "greatest"</p> <p>Please can the authors check the url's for references - several of these do not seem to work and direct the reader to 'page cannot be found'</p>
--	--

REVIEWER	Mike Bracher
----------	--------------

	University of Southampton, UK
REVIEW RETURNED	17-Mar-2015

GENERAL COMMENTS	<p>Many thanks to the authors for their submission. The project represents a potentially illuminating contribution to understanding cancer patient experiences in London, an area which (as the authors point out) appears to lag behind other areas of the country in patient experiences of cancer care. The authors point to some potential areas of interest beyond those arising from the closed questions in the survey. In addition, they also highlight issues with the survey itself, in terms of ambiguities in the questionnaire and difficulties in identifying patients with specific sites. Both of these are important issues that have the potential to contribute to knowledge, and to our understanding of the uses and limits of free-text data in developing cancer services.</p> <p>Unfortunately, I am unable to recommend the paper for publication at this time. The central problem is the apparent lack of depth in the analysis, which hampers the authors' ability to present specific insights that could inform policy decisions (a key aim of the paper). Two important claims that underpin the paper are the strengths of free-text responses as a way of exploring 'in-depth' experiences of cancer treatment, and that analysis of these can help to inform policy by providing such insights that are not visible in the quantitative analyses. In my view these claims need to be supported much more clearly in the findings, and developed in the discussion. Below are the main areas which I believe require attention.</p> <p>***1 – Depth of the analysis –</p> <p>The analytical framework as presented in the paper appears very thin, given the size of the data set. Many of the themes highlighted in the article are general and lacking in substantive discussion, and it is unclear as to how they could inform in any detailed way a policy response. Welcome attempts are made to 'drill down' deeper into specific areas of care (i.e. in relation to poor care at night, and waiting for treatment in chemo and radiotherapy facilities – p.6-7). However, these observations need to be bolstered by better discussion, a clearer sense of the coverage of these comments (i.e. what percentage of negative respondents they represent), and better integration with existing debates around cancer care (i.e. indicating to whom/where and how these findings may be of value).</p> <p>With respect to the depth of the analytical framework, as a comparator our research team recently completed analysis of free-text data from the Welsh Cancer Patient Experience Survey (WCPES), involving 4,672 patients who had provided free-text comments. Our thematic framework (which can be found in the report cited at the end of this review) comprised approximately 250 codes at 5 levels of specificity, developed through a process of multi-stage coding. Whether the framework used here is bigger/more complex or smaller/less complex than this comparator is not the issue – rather, the framework needs to be of a sufficient depth to highlight particular problems and give an indication of their representation within the data set. If, as the authors claim at P4:L42-44, '...thematic counts would help [trusts] prioritise areas of greatest need for improvement', then this information becomes especially crucial. Counts on numbers of comments in each area would not contribute massively to the word count, even if presented in a large table, and yet would (as the authors note) significantly strengthen the paper if the results were broken down into more specific areas. The report linked below may be helpful in illustrating how this might look.</p> <p>My initial reaction having read the paper was to sympathise with the relatively small space (i.e. 4,000 words) that they authors have to work with for a data set comprised of text. In principle I would even support (if justified by the article) the editors granting more space due to the nature of the analysis and need to give space to illustrate patient narratives through quotes. However, after seeing the word count, I was extremely surprised to see that the article is only 2431 words in length. I would encourage the authors to make use of the available space in future revisions.</p>
-------------------------	---

***2 - The status of the 'in-depth' nature of the comments –

Apart from the generality of the analysis, there remain questions about how 'in-depth' the free-text data from the NCPES actually are. My view is that the authors need to be more nuanced in their claims about this, and in particular about the status of this as qualitative data and its ability to give such insights. To claim that free-text comments provide information which often goes beyond what is visible in quantitative measures, and that it has the potential to reveal aspects of experience that are not covered by closed questions, is clearly justifiable. However, our own work with both the WCPES and NCPES data for patients with cancer of unknown primary (CUP – forthcoming) for 2010, 2011-12 and 2013, suggest that the detail given by patients, and the quality of descriptions, is highly variable. For example, in the WCPES data, we found that the average number of words used was 46.78, with a standard deviation of 60.06, indicating a high level of variance (this reflected our experience in terms of qualitative analysis). While it is certainly true that there are detailed and extremely valuable descriptions within the data, these are highly variable, and if (as seems likely) this persists in the London data, then this should be acknowledged (or if not, similar analysis should be undertaken to demonstrate this difference). They also need to acknowledge the limitations of this material as qualitative data – this need only be one sentence, but material of this type would not typically be seen as 'in-depth' when compared with other forms of qualitative material such as semi-structured interviews or notes from ethnographic observations. In my view the paper would be improved if a better sense were given of how 'in-depth' the material is, in terms of its strengths and limitations relative to other forms of qualitative data

***3 - Reporting of 'comments' instead of 'respondent' numbers –

The authors have chosen to report numbers of 'comments' in each theme/area, as opposed to number of 'respondents' who provided comments in each area. This is not necessarily a barrier to publication, but I believe that reporting numbers of respondents is preferable. Respondents may give more than one comment in a given area across different boxes, and so it is not possible to see how many individual participants fall into each category. This risks distortion because participants can and do write multiple comments across boxes that may pertain to one area (i.e. a comment in both the 'positive' and 'improve' boxes that is subsumed into one area). In our own work, we found that in a large number of cases in both the WCPES and CUP NCPES data, participants wrote in a narrative style that cut across boxes, mixing negative and positive comments across boxes. Our solution to this was to 'clean' the data by reading through all positive, negative and other comments and assigning them to categories once it was confirmed that they actually belonged to each. One respondent may have many opinions, but our interest here is surely in 'who said what about what/whom', rather than adding up the numbers of different opinions present. Reporting numbers of respondents would establish more clearly the direct link between numbers of participants and the weight of themes.

***4 - Development of the thematic framework –

4.1 - The authors state that the initial framework was developed for analysis of the 2011/12 NCPES data. The related report is not referenced in the article, and while I see a reference to it on the London Cancer Alliance website, I cannot see a link to it at the present time. This report needs to be referenced so that readers can see how the framework was developed initially (i.e. how the sample was constructed for building the survey, inter-rater reliability statistics etc.).

4.2 - The authors report their 'Top five' themes for both positive and negative comments – it is unclear why five was chosen, and this may be an arbitrary number. It should be possible, without much impact on the word count, to publish the entire thematic

framework and associated counts as a single table.

***5 - Lack of specific areas for improvement –

Lack of depth of the analysis hampers the authors' ability to engage in significant discussion and thereby present implications for policy focused on specific areas of need. For example, at P8:L40-47 the link appears to be simply that (my terms) poor staffing is bad for patient experiences. The analysis presented does not add anything substantial to the material which the authors themselves have cited. The areas of discussion are vague, reflecting the generality of the analysis. I am confident however that a deeper and more focused analysis/discussion would allow the authors to make more substantive contributions.

***6 - Lack of demographic information –

The authors provide no detail on demographic information in terms of the sub-set of NCPES respondents in London providing free-text comments. Were they substantially different from the total respondent group in London or not? Such data should be available together with the comments provided by Quality Health, and need to be reported so that readers can tell who is speaking, and whether they are representative of the general set of respondents.

***7 - Link between findings and discussion re: 'Ambiguity of questionnaire' –

The authors have reported what I believe to be a very significant finding relating to identification of patients with specific sites, or even hospitals within London. This is a serious limitation of the current survey design, and one that we have encountered in work in Wales and with CUP NCPES data from England. The kinds of ambiguity which they highlight simply aren't visible in the quantitative data, and as such I would encourage the authors to add a comment highlighting this as a strength of free-text analysis (i.e. that it can help provide correctives to quantitative measures and how results are organised).

However, the discussion in my view stretches this somewhat, by claiming that 'reported issues with the questionnaire itself suggest that the picture for London might not be as troubling as the quantitative data suggest' (P8:L49-53). In order to substantiate this claim, the authors would need to provide a breakdown of how many positive and how many negative respondents expressed difficulties with the questionnaire, and/or indicated that most or part of their care had taken place outside of London. As it stands, one could claim equally that cancer care may actually be worse, as positive respondents may also be included whose care took place largely outside of the London area.

***8 - Better links with the quantitative data –

It would be useful to have some sense of how the free-text findings compared (where relevant) with responses to relevant closed questions (if applicable). In our own work with the WCPES, we were able to identify 13 questions that mapped directly to themes emerging from the free-text comments. It may be that the authors wish to explore only those areas which do not map to these questions, but I suspect that some areas of interest will be relevant.

***9 – other areas

9.1 – Ethics - There is no acknowledgement of the ethical procedures (in any) that accompanied the study, and or issues relating to the use of the data.

	<p>9.2 – Limitations - There is no substantive discussion of study limitations present – this links back to pt.2, regarding the in-depth nature of the comments.</p> <p>I have left off other minor issues (e.g typos etc.), as I believe that the paper and the analysis that informs it will require substantial revision before this paper is ready for re-review, and such many of these may become redundant. Examples of the suggestions I have made in terms of reporting standards are reflected in this report: http://www.macmillan.org.uk/Documents/Fundraising/InYourLocalArea/Wales/WCPESR_eportFINALpdf.pdf - which I hope will be of value to the authors. As indicated at the beginning of my review, I believe that the project undertaken by the authors has the potential to reveal insights which will be of value in targeting policy. I hope that these comments will prove useful in further development of this work, and I am happy to be contacted by the authors if they have any questions or if I can be of assistance.</p>
--	---

VERSION 1 – AUTHOR RESPONSE

Reviewer 1: Mary Wells

1. The background section would be improved by a brief explanation of the purpose, aims and methods used in the National Cancer Patient Experience survey, as this will not be known by all readers of BMJ Open.

Our response: Thank you for this important contextual point. We have now added in an explanation of the purpose, aims and methods of the NCPES into the Background section. And, as advised, we have added in information about ethical approval for the NCPES to the study information for BMJ Open.

2. Methods

The rationale and potential for analysing free text responses from survey could be strengthened by referring to other studies that have done this e.g. Corner et al (2013) PROMS survey <http://bmjopen.bmj.com/content/3/4/e002316.full> and indeed the authors own work (Ref 11)

Our response: Thank you, this makes a lot of sense and we have added this into the methods section and linked to the reference you suggest (now reference 28) as well as the other paper you refer to which is now reference number 6.

Table 1 would make more sense in the data paragraph.

Our response: Thank you, we agree and this has been now been moved.

Could the authors provide a little more detail about the framework developed for the 2012/13 data and whether information about this is published elsewhere?

Our response: This section has been expanded with more detail about the framework provided in the text and how it was developed from 2011/12. In the analysis section:

“The initial framework was developed for the 2011/12 free text analysis by two researchers – TW and AR – based on a review of the patient experience literature and a preliminary analysis of the data. In this process, both researchers independently looked at comments from three trusts. Following identification of potential themes, the researchers discussed and compared the themes and TW devised the framework. The framework was then piloted by the research group with data from the first trust. A few minor changes were then made before using the framework as a basis for analysing all the data. Data from the first question, ‘Was there anything particularly good about your NHS cancer

care?’ was inserted into a framework for ‘positive’ responses while data from the second question populated a framework containing ‘comments for improvement’. Data from the third question ‘Any other comments?’ was found to fall into either a positive comment about care or a comment for improvement; hence all the comments from this question were subsumed into either the ‘positive’ or ‘improvement’ framework. This positive/negative binary is consistent with the rest of the survey data, which is also reported in this way.[18] Within the framework, researchers also coded findings to be able to look at services by tumour group as well as by trust.”

A summary of the framework was fed back in a report to the two integrated cancer systems, London Cancer and the London Cancer Alliance, for their use but these organisations have not made it available online hence not including a specific reference.

3. Results

Were the 10,262 positive comments all in response to question 1 and the negative comments all in response to question 2 or were some answers to question 3? It would be helpful to include a breakdown of where the free text responses were located in relation to the three open ended questions.

Our response: Thank you for this. The point did need some extra clarification. The comments came from all three questions. In response to question 3 (any other comments) people made comments which were classed as either positive or negative. These were checked by researchers to agree where the comments would be classified. Therefore unfortunately, we do not have the separate numbers of comments for each question available, as all comments were counted and distributed to either positive or negative frameworks. We would need to re-count all the comments in order to provide this and with over 15,000 it is not possible at the moment to do this. Any comments about the ambiguity of the questionnaire were treated outside of the framework and they are therefore in addition to the total number of comments reported within the framework. We have tried to clarify this within the paper by referring to the comments in the framework separately from those on the issue of ambiguity.

Percentages in Tables 2 and 3 are unclear. In Table 2 these add up to 99% but in Table 3 they add up to 51%. Further explanation needs to be given.

Our response: Thank you for this. We have now provided the full list of themes so that these do add up to the full amount of comments. Please see tables 3 and 4. We have re looked at the data and made a small correction as there was an error in reporting here. We have now made it clear throughout that we are reporting on the numbers of comments within the frameworks and for each theme and both tables add up to 100%. We have also included a new table (2) which shows the comments and numbers of respondents.

It would be helpful to include some further details on the distinction between themes (or an acknowledgement that there is some ambiguity between them) e.g. poor care and poor communication, as some of the quotes describing poor care also seem to be about poor communication.

Our response: This is correct there is some ambiguity and cross over. We have now further explained that all the data was cross checked by two researchers to reach a consensus on where comments should be attributed. We have also acknowledged the ambiguity of themes and how this was systematically approached as well as the natural crossover between themes in a sentence both in the

Analysis section: "There was some cross over and natural relationship between the themes – i.e. in the themes for improvement between poor care and poor communication. To make sure there was consistency of approach, each data set was examined by two researchers to ensure a consensus was reached as to how comments were attributed to each theme."

The final paragraph before the section on ambiguity (page 7) contains some alarming details - rather than presenting these as a list, some of these could be explained more fully.

Our response: We appreciate this comment and have added and fleshed out the detail of this theme to expand as follows:

"The detail of how and why patients experienced poor communication emerges clearly in the free text data. Although a further detailed full sub-analysis of each theme has not been conducted on the data, some clear areas arose within the communication theme. These included insensitive communication such as bad news broken badly and patients not being informed about their diagnosis or treatment. Other communication issues stemmed from poor administration such as letters not being sent; patients being sent details of the wrong appointment; confusing information such as different information being given by healthcare professionals and information not being given in plain English.

The communication theme also related to two other overlapping themes: 'Information' and 'Liaison between departments'. Within both of these themes, poor communication played a role in patients' sense that information was confusing or lacking, and that departments within the hospitals were not working in an integrated manner."

For positive and negative comments, it would also be helpful to understand whether there was a tendency for the same patients to make several comments or whether most were primarily single comments.

Our response: We have now included a table (2) showing numbers of respondents completing the free text data against the number of comments. We also write to this point: "The relationship between the number of free text comments and the number of respondents can be seen in table 2. An average of two thirds of patients (66%) who returned their NCPES provided free text responses across the 27 trusts; some questionnaires included several comments written across the three free text questions and others were left blank."

Do the responses about ambiguity provide any detail of which questions or areas of the questionnaire people found confusing? (other than the issue related to care across a range of trusts)

Our response: Thank you we have tried to address this point by providing more detail about the different ways in which people commented about the questionnaire in the section on ambiguity.

4. Discussion

Greater analysis of the key themes would be welcome here. Additionally, some further discussion of the core features of positive and negative experiences of cancer care, with reference to the literature, would enhance the paper overall.

Our response: Thank you. We have expanded the whole Discussion section to re-focus on the key findings of the paper. We have also referenced some wider analysis of cancer care in the UK into both the background and discussion sections.

5. Abstract

The overall objective could be re-framed, as the analysis of free text comments from a questionnaire survey is unlikely to reveal the 'in-depth experiences' of patients

Our response: Thank you. This has been amended in line with your suggestion.

6. Editorial comments

:

P3 line 20 would be clearer if it read "The ten poorest performing NHS trusts were ranked by Macmillan, based on the number of questions (out of 63) for which patient scores fell within the bottom 20% of results for all trusts"

Changed as per reviewer's suggestion

P3 after line 24: provide a sentence listing the number of hypotheses before giving the longer explanation e.g. including patient characteristics, environment and organisation, staffing and treatment issues

Changed as per the reviewer's suggestion

P3 line 48 - if in quotations - is there a reference for this?

Yes, reference as per the next sentence – have added to clarify

P4 first paragraph, p8 - data are plural

Changed, thank you for spotting this

P4 line 38 sentence saying that content analysis should be interpreted with caution- it would be clearer to say that this form of analysis is unable to reflect whether the number of responses pertains to the size of the trusts, percentage of patients....etc etc.

Changed as per the suggestion

P6 line "most" number of negative comments should read "greatest"

Thank you again. Changed as per suggestion.

check the url's for references

All the URLs have been re-checked and are working. Thank you

Reviewer 2: Mike Bracher

1. Depth of the analysis

The analytical framework thin, themes general lack depth. Welcome attempts are made to 'drill down' deeper into specific areas of care (i.e. in relation to poor care at night, and waiting for treatment in chemo and radiotherapy facilities – p.6-7). However, these observations need to be bolstered by

better discussion, a clearer sense of the coverage of these comments (i.e. what percentage of negative respondents they represent) and better integration with existing debates around cancer care (i.e. indicating to whom/where and how these findings may be of value). If, as the authors claim at P4:L42-44, '...thematic counts would help [trusts] prioritise areas of greatest need for improvement', then this information becomes especially crucial. Counts on numbers of comments in each area would not contribute massively to the word count, even if presented in a large table, and significantly strengthen the paper if the results were broken down into more specific areas.

Our response: We thank the reviewer for his in-depth comments which have been very useful. We have amended the language so as not to talk about 'drilling down' but instead have clarified that the objective was to shed light on some aspects of patient experience and that this was primarily to inform patient experience working groups and tumour working groups within the London Cancer Integrated Systems.

While a more in depth analysis would be welcomed, due to the resourcing of this project this was not possible to do a full sub-analysis on each theme within the framework. This means that beneath the overarching positive and improvement themes we are unable to give percentages on sub themes. However, we have now provided the full set of themes alongside counts for each of those themes within the tables, which we hope provides much more context and clarity. Furthermore, comments within each theme were read in detail and patterns within those themes have been expanded upon and discussed within the revised manuscript (please see table 3 and 4 as well as the findings section).

2- The status of the 'in-depth' nature of the comments –

Need to be more nuanced in claims about 'in depth' nature of free text comments. detail given by patients, and the quality of descriptions, is highly variable. Actually question how 'in-depth' the material is, in terms of its strengths and limitations relative to other forms of qualitative data (i.e interviews, ethnographic etc)

Our response: Thank you. We agree that the language needs refining. As per the reviewer's suggestion, we have now revised this point to state that free-text comments provide information which may go beyond what is visible in quantitative measures, and that it has the potential to reveal aspects of experience that are not covered by closed questions, as opposed to talking about the 'depth'. We have removed the 'in depth' and 'drilling down' language and have noted the potential limitation within the strengths and limitations section. We have also referenced papers which refer to the relative benefits of free text v survey v narrative interviews.

3. Reporting of 'comments' instead of 'respondent' numbers

Reporting numbers of respondents is preferable, as opposed to numbers of comments; participants write positive and negative across boxes. One respondent may have many opinions, but our interest here is surely in 'who said what about what/whom', rather than adding up the numbers of different opinions present. Reporting numbers of respondents would establish more clearly the direct link between numbers of participants and the weight of themes.

Our response: We have now included a table showing both the numbers of respondents and the numbers of comments per trust overall. When it came to the thematic counts, it was decided to look at the number of comments per theme because people made different comments within the text they provided over a number of thematic areas and it was important to capture all of these. Please see table 2 which we hope goes some way to answering this point.

4 - Development of the thematic framework

4.1 - the initial framework was developed for analysis of the 2011/12 NCPES data. link needs to be provided. This report needs to be referenced so that readers can see how the framework was developed initially (i.e. how the sample was constructed for building the survey, inter-rater reliability statistics etc.).

Our response: We have now included more detail and thorough explanation of the how the framework was constructed and comments attributed (see above comment to Reviewer 1 and highlighted text from the paper which expands on this).

4.2 - publish the entire thematic framework and associated counts as a single table (not just top 5)

Our response: Thank you. This has now been done and hope it provides the detail which was missing the earlier version.

5 - Lack of specific areas for improvement –

Lack of depth of the analysis hampers the authors' ability to engage in significant discussion and thereby present implications for policy focused on specific areas of need.

P8:L40-47 the link appears to be simply that (my terms) poor staffing is bad for patient experiences. The analysis presented does not add anything substantial to the material which the authors themselves have cited. The areas of discussion are vague, reflecting the generality of the analysis.

Our response: Although the frameworks only contain the top line themes for positive and negative comments, these have been reported per trust and therefore each trust has gained specific insights into their own areas of need. Furthermore a comparable analysis was done for the London Trusts in 2011/12 and was fed back into action groups. The analysis was requested again in the same way for the 2012/13 data by the London Integrated Cancer Systems. It is understood that a more detailed sub analysis would strengthen the research and this has been acknowledged in the limitations section.

With regards to the point on staffing, clearer links have been made to the relevant literature as this emerged as a potential reason for poorer experience in London, we felt it was important to show what the free text data said on this issue. See Discussion and reference 21.

6 - Lack of demographic information –

The authors provide no detail on demographic information in terms of the sub-set of NCPES respondents in London providing free-text comments. Were they substantially different from the total respondent group in London or not? Such data should be available together with the comments provided by Quality Health, and need to be reported so that readers can tell who is speaking, and whether they are representative of the general set of respondents.

Our response: Thank you this is an important point. This data was not made available to us. We were only provided with individual trust free text data by the trusts themselves. We could not link this to the survey data or accompanying demographics. This would have further strengthened the research and we have acknowledged this as a limitation as you have rightly pointed out.

7 - Link between findings and discussion re: 'Ambiguity of questionnaire' –

The authors have reported what I believe to be a very significant finding relating to identification of patients with specific sites, or even hospitals within London. This is a serious limitation of the current survey design, I would encourage the authors to add a comment highlighting this as a strength of free-text analysis (i.e. that it can help provide correctives to quantitative measures and how results are organised).

Our response: Thank you. This has now been addressed with much more within both the Background and Discussion about the benefits of free text analysis e.g.

“If the NCPES does not cover all parts of the patient experience, free text data might suggest where the survey can be refined or expanded in the future and therefore how the survey can be better developed for quality improvement purposes.[6, 30] The design of the 2012/13 survey (and carried into the 2013/14 survey) is limiting in terms of the difficulty in identifying patients with specific sites. This seems to be particularly problematic for London with patients reporting a complex care pathway with variable experiences across different trusts. Future research could be strengthened with the inclusion of questions about cancer patients’ pathways through different hospitals to allow for the variation in fragmented versus consolidated care pathways.[15]”

The discussion in my view stretches this somewhat, by claiming that ‘reported issues with the questionnaire itself suggest that the picture for London might not be as troubling as the quantitative data suggest’ (P8:L49-53). In order to substantiate this claim, the authors would need to provide a breakdown of how many positive and how many negative respondents expressed difficulties with the questionnaire, and/or indicated that most or part of their care had taken place outside of London. As it stands, one could claim equally that cancer care may actually be worse, as positive respondents may also be included whose care took place largely outside of the London area.

Our response: Thank you, the discussion has now been refined and this point has been removed in line with your comments.

8 - Better links with the quantitative data – It would be useful to have some sense of how the free-text findings compared (where relevant) with responses to relevant closed questions

Our response: Although we would like to be able to undertake this comparison, this was not in the remit of our research. We have highlighted this as a limitation and discussed how this could add to future research in the Discussion.

9.1 – Ethics - There is no acknowledgement of the ethical procedures (in any) that accompanied the study, and or issues relating to the use of the data.

Our response: This has now been addressed and we have added in information to the BMJ Open form to explain the ethical approval for the NCPES.

9.2 – Limitations - There is no substantive discussion of study limitations present – this links back to pt.2, regarding the in-depth nature of the comments.

Our response: The limitations section has been expanded in light of these comments.

VERSION 2 – REVIEW

REVIEWER	Mike Bracher University of Southampton, UK
REVIEW RETURNED	27-May-2015

GENERAL COMMENTS	<p>Many thanks for the opportunity to review this second submission. This draft represents a significant improvement over the first submission, and the authors have made substantial efforts to address my comments, including indicating the resource constraints and limitations of the project as well as its original objectives more clearly (i.e. why they undertook this analysis and for whom, vis, LCIS working groups). The suitability of this paper for publication rests on its ability to provide a significant original contribution to knowledge, which is dependent on its objectives (i.e. how it is positioned and what authors claim that it is offering). As far as I can see, there are two possible contributions that this paper can try and make:</p> <p>(1) To provide original insights that extend or deepen our of cancer patient experiences in general.</p> <p>(2) Provide an exemplar for how this type of data can be used to inform policy and provide specific guidance for improvements at the local level, above and beyond what you get from the quantitative analyses.</p> <p>From our discussion thus far, the limitations of the paper, and the refined focus that the authors have set out in their revisions, it is now clear that the second option is where the paper is positioned, i.e. as a write up of how the authors used this data to help inform care improvement within context of the London Working Groups. In addition, the authors have highlighted a significant limitation of the NCPES survey which has direct implications for service improvement and utility of the data, and which they would (to my knowledge) be the first to report. The question then becomes to a large extent – ‘how far and how well does the current paper demonstrate these contributions’, and in my view only a few minor changes and additions are needed to satisfy publication requirements. These are given below in relation to the sub-headings discussed in previous correspondence, with a couple of additions at the end, and some minor comments (e.g. typos, clarifications) at the end.</p> <p>Once again I would be happy to look at other revisions of this paper, and believe that it will make a significant original contribution to understanding the utility of free-text data in relation to service improvement.</p> <p>Regards,</p> <p>Mike Bracher.</p> <p>***1. Depth of the analysis</p> <p>The new tables provide a much better sense of the coverage of the themes, and the addition of the full thematic framework gives a much better sense of what is covered. With regard to the text in the ‘Findings’ section, there have been significant moves to illustrate the kinds of information that may be useful in improving care (e.g. P11:L3-13). The fact that in this study the authors did not have the time or resources to code for sub-themes has been addressed significantly, and could be resolved without too much additional effort. The claim that the authors make regarding the specific areas within the themes identified is that they represent ‘specific actions for trusts...which can be acted on and ‘owned’ by staff’ (P11:L5-7). What the paper now needs is evidence to support</p>
-------------------------	--

this claim. Sub-thematic counts would have gone some way to showing us the relative weight of each area, and so might have provided evidence of information that trusts could use to target more specific areas when planning improvements. However, as this has not been possible due to resource constraints, the alternative is to demonstrate or give some exemplary evidence how these areas that were highlighted translated into information that trusts and/or people involved in working groups could use. This could be something as simple as a few comments (even anonymised from private correspondence) from people who've used the comments to target improvements in their area – just an indication that lets the reader know that what was given was in fact of value in practice. Given what the authors have indicated about the previous analysis (2011/12) and request for further information, I doubt that this will be a problem. It would also strengthen the paper by giving audiences an idea of the pathway that this analysis followed in order to make its impact, meaning that interested readers may be able to replicate this elsewhere.

***2- The status of the 'in-depth' nature of the comments –

With the exception of one or two observations that I've noted in the 'Minor Comments' section below, the authors have addressed my concerns here.

***3. Reporting of 'comments' instead of 'respondent' numbers

In my view, reporting of comments over participants is not a barrier to publication, but I am still not convinced that reporting of participant numbers would not have been a better option. I am also uncertain as to how fully the authors' response addresses my point. Reporting of participant numbers would in no way risk 'missing' responses, nor reducing the impact of statements; what it would do however is avoid the problem present in comment reporting, where a respondent writing about the same thing across different boxes would be double counted. The units of analysis in this survey are individual patients – not the number of boxes that they wrote in or number of different opinions that they expressed. If you are a trust trying to assess the weight of a particular theme, surely you want to know how many people a particular observation affected, not how many different boxes they wrote in.

When the authors write in their response that 'because people made different comments within the text they provided over a number of thematic areas and it was important to capture all of these', do they mean that participants wrote across a number of sub-areas within the themes, or just that they wrote comments corresponding to the general themes in table 2? If the former, then an argument could be made in favour of their choice, that in the absence of counts for sub-themes, the authors wished to preserve a sense of each theme's relative importance by indicating the diversity of comments within each theme. If the latter, then I see no reason why comment counts are preferable, as they convey the same information as participant counts, but with the added risk of doubling up on respondents who have written across boxes.

I think that the authors need to be clearer about the rationale for why they chose this, and the limitations of their choice (i.e. as I've indicated above).

Also, one other question that isn't clear is whether 'comments' refer only to the individual responses in each box (i.e. 1 box = 1 comment) OR whether this refers to individual fragments within boxes (e.g. 2 separate sentences within 1 box that relate to 2 themes count as 2 comments). Clarification on this in the text (just a sentence or footnote) would be welcome.

Both points I think can be resolved with little difficulty or additional work.

***4 - Development of the thematic framework

**4.1 - the initial framework was developed for analysis of the 2011/12 NCPES data. link needs to be provided. This report needs to be referenced so that readers can see how the framework was developed initially (i.e. how the sample was constructed for building the survey, inter-rater reliability statistics etc.).

The authors have addressed this point significantly and, notwithstanding the following points, I am satisfied with their response. Lack of inter-rater reliability statistics is a limitation, and should be noted in the methods or limitations section.

****4.2 - publish the entire thematic framework and associated counts as a single table (not just top 5)**

This has now been addressed and in my view strengthens the paper significantly.

****4.3 – Process of handling the data **NEW****

The authors have provided a detailed account of how the data were handled during the framework analysis, and as such the process is much clearer; however, there are one or two points which I think might benefit from further clarification. The first is just to report what system was used to produce the thematic analysis (i.e. was it NVivo, Excel, other software?). This would help make the process as set out clearer and more readily reproducible.

P5:L44-50 – the authors describe the process of ‘inserting’ positive and negative comments into corresponding frameworks for analysis. However, given that they have acknowledged that respondents may write across different boxes, and that this means positives may end up in the ‘improvement’ response box (or vice versa), were the data cleaned (i.e. read and sorted to ensure that comments in the positive/improve boxes did in fact correspond to those categories). If so this should be stated, and if not this should be acknowledged as a limitation of the positive/negative counts.

*****5 - Lack of specific areas for improvement –**

Given the discussion at the start of my reply re: the contribution of the paper, the authors appear to have addressed this in the following part of their response to me:

“Furthermore a comparable analysis was done for the London Trusts in 2011/12 and was fed back into action groups. The analysis was requested again in the same way for the 2012/13 data by the London Integrated Cancer Systems.”

Inserting this statement (or similar) into the paper, and perhaps some additional indications of the benefit of this work, would be sufficient to address this for me. The comment on staffing has been resolved, given the acknowledgement of study limitation and clarifications given.

*****6 - Lack of demographic information –**

If data have not been made available by the source (i.e. the trusts) then this is a completely valid response with respect to this study; however, I would suggest a small change to how this is reported in the paper. At the moment in the ‘limitations’ section (P3:L6-11), the impression is given that demographic data are not available, rather than that these were not made available to the authors by their source. This should be changed to reflect the latter, as the data are available from QH as publicly available data. This is simply to avoid readers who may be thinking of using the data taking away the idea that it is not possible to get this.

*****7 - Link between findings and discussion re: ‘Ambiguity of questionnaire’ –**

The paragraph added into the discussion (P15:L17-36) addresses my concern from the previous version and strengthens what is a very significant finding of the authors’ paper. If anything, I wonder if the authors are still underselling themselves here; they are the first to be able to put a figure (albeit for one area, i.e. London) on potential sources of recording error as indicated by patients respondents (i.e. 9% for the study group). The fact that this was found to vary from 3% to 25% within different trusts poses an

additional problem, which is that as we move down from the national picture to the trust level, where the information will actually be actioned, the potential for error may increase due to clustering. I state 'may', because at the moment the only thing I can see lacking here is a quantification of how many people said something about reporting across trusts (P13 – i.e. what percentage of respondents in total said this, and what was the range of values across trusts). If there was any way that this could be reported it would be a very significant strength, because it would be the first time that anyone would have shown a clear indication of the potential size (and variation in size) of this error. I would also be more explicit about the potential implications of their finding, which in my view could be summarised as follows:

(i)The CPES data are being used nationally to inform policy. MDTs are obligated to report on these data annually, and to plan service improvement accordingly.

(ii)The analysis from London indicates that there are a significant number of people in a large population who indicate that their comments may not match the areas with which they are identified in the data.

(iii)Variations across trusts indicate that these errors may cluster in different areas, which may reflect, for example, different areas of cancer specialty (i.e. people coming from outside area for treatment at specialist centres within particular trusts).

(iv)It is therefore vital that action is taken to ensure that patients are identified with their correct areas of care, in order to avoid wasting time and resources responding to data which may be incorrect or misattributed (as well as professional and public confidence risks relating to misattributed complaints, given that negative comments tended to be more specific than positives). The risk of this increases as the population decreases (i.e. as we go from national or regional level to trust or MDT level).

This would also be beneficial in terms of focusing the efforts of the survey provider in improving the survey, and extend the potential for impact from the published article

My previous comment about observations relating to the quantitative data has also been addressed by removal of this observation from the present draft.

***8 - Better links with the quantitative data – It would be useful to have some sense of how the free-text findings compared (where relevant) with responses to relevant closed questions

Now indicated as a limitation, so in my view resolved.

***9.1 – Ethics - There is no acknowledgement of the ethical procedures (in any) that accompanied the study, and or issues relating to the use of the data.

This appears to have been resolved.

***9.2 – Limitations - There is no substantive discussion of study limitations present – this links back to pt.2, regarding the in-depth nature of the comments.

Notwithstanding my comments elsewhere in this response, this concern has been addressed.

***10 – Links with the WCPES (2013) report (NEW)

Bracher, M., Wagland, R., & Corner, J. (2014). Exploration and analysis of free-text comments from the 2013 Wales Cancer Patient Experience Survey (WCPES). Southampton, UK. Retrieved from <http://www.macmillan.org.uk/Documents/Fundraising/InYourLocalArea/Wales/WCPESR>

eportFINALpdf.pdf

I was surprised to find that the authors had chosen not to cite the above report. While as an author I should obviously declare an interest in this, there appear to be sound reasons why this particular study should be cited in this paper. The report represents the first time (to our knowledge) that a national survey of cancer patient experiences has been subjected (in their entirety) to free-text analysis, and many of its findings map directly to aspects of cancer patient experience that the authors have discussed here. This text could be used to support claims made in relation to many of the sub-areas that they discuss within the themes identified, but were not able (due to time and resource constraints) to sub-code and quantify. Attendant counts within the WCPES report should be useful as proxy indicators for the potential weight of sub-areas that you have discussed in your paper. Once again, the citation (or not) of this report is not a barrier to publication, and if other sources could be found that would do the same job then this would be equally acceptable; however, we have been unable to find such a study. I have indicated some exemplary areas of overlap in the minor comments below.

***Minor comments:

P2:L18-21 – Add in that the framework was adapted from earlier work (i.e. 2011/12)

P2:L21-29 – Add numbers and counts for reported themes in the abstract.

P2:L51-53 – Not sure about ‘clear linkages’ here: please clarify or remove (in my view the description is fine if this is removed).

P2:L55-57 – Switches tense and talks about what free-text comments ‘provide’ (potential), as opposed to what they did provide (actual) in this study. Please amend.

P3:L18 – Change ‘data is’ to ‘data are’ – please check remainder of document.

P3:L13 – No bullet point on this point.

P3:L39-43 – Please clarify or remove the following: ‘Indeed, patient experience matters as much to most patients as clinical outcomes and safety.[3, 4] When the performance of healthcare systems is being assessed, patients’ experiences are increasingly important.’

P3:L55 – Please give the actual number of questions on the survey.

P5:L9 – I’m not sure that the claim about getting close to the ‘meanings’ attached to care is adequately supported here (to do this I think you’d need a slightly more developed discussion the different data sources. But I don’t think it’s an issue for this study either – as far as I can see, what we’re after in the NCPES are more detailed descriptions of experiences than we get in the closed questions, and a space for patients to tell us things that are important to them. Both of these are clear relative strengths of both interviews and free-text responses over closed questions. If the authors agree, I would recommend a small amendment here.

P7:L7-12 – Header of the first column reads ‘Number of Trusts’, indicating an amount of trusts – I assume that the number is an ID number used to anonymise the trust – if so please change to ‘Study ID for Trust’ or similar.

P8:L25 – Just a little more nuance on the claim of ‘consensus’ among respondents – i.e. was it broad, total etc.?

P8:28-29 – Suggestion: the WCPES report cited in pt.10 above also supports this finding (or positive comments being more generic than negatives, and so might be good to include an observation that this is consistent with previous studies).

P9:L3-4: would change ‘relating to services from’ to ‘relating to services ranging from’ or ‘such as’ etc...

P11:L7: ‘Open comments’ – maybe stick to ‘free-text’? Terms are perfectly interchangeable but might be better to use consistent terminology?

P11:L25-27: Suggestion – Poor care at night/weekend is one example of a strong sub-theme in the WCPES may help to bolster the observation/discussion. Can be found in section 4.2.7 with relevant figures in table 33 of the referenced report. Other sub-themes may also be useful.

P11:L45-46: Change ‘number of staff who had a poor level of English’ to ‘number of staff who were reported to have a poor level of English’.

P12:L1-30: Suggestion - this would seem the ideal place to compare findings here with those from WCPES for identified sub-themes, as the latter would give indications as to

	<p>coverage and weight in a national survey.</p> <p>P12:L32 – P14:L10 – I would add two sub-headings to reflect the two main observations in relation the ambiguity of the questionnaire (i.e. not reflecting the complexities of patient journeys, and other more general comments about lack of clarity – I'd also put the first of these up front).</p> <p>P14:L39-40: Please clarify – the most important issue in relation to what?</p> <p>P14:L41-43: Suggest changing to 'Free text data can help to reveal..' or similar, rather than 'can reveal', which would suggest that we can completely access patient voice in its entirety and complexity through this method.</p> <p>P15:L44-45: May be redundant now as QH have been given the contract.</p>
--	---

VERSION 2 – AUTHOR RESPONSE

Overall: Our response: The authors thank the reviewer for his detailed insights and comments which the authors agree have helped to strengthen the paper. Please see below the individual responses to each point. Changes have been made via tracked changes in MS word.

***1. Depth of the analysis

Our response:

Thank you for this suggestion. We have highlighted two examples of how the working groups used the data to (a) reduce agency staff and (b) to target clinic waiting times. This has been added into the discussion section.

***2- The status of the 'in-depth' nature of the comments –

Our response: Many thanks, the minor comments have now been addressed.

***3. Reporting of 'comments' instead of 'respondent' numbers

Our response: Thank you for the comments again. We have clarified that we mean that 'comments' refer to individual thematic issues. So if someone made two comments in question 1 – i.e. one about food and one about care, these would be distributed to the two separate themes. However, if someone wrote two positive sentences about a communication issue, for example, this would be only one 'comment'.

With regards to the first point about reporting comments instead of participants we have tried to develop this further by highlighting that participants wrote across a number of sub-areas within the themes, and in the absence of counts for sub-themes, we therefore as you suggest, decided to try to retain a sense of each theme's relative importance by indicating the diversity of comments within each theme.

***4 - Development of the thematic framework

Our response: We have not included this as a limitation as we did not set out to have multiple coders working separately but working collaboratively to come to a consensus about where comments should be put within the thematic framework. We do not think it would not be appropriate to cite this as a limitation to this approach.

**4.2

Our response: Thank you

4.3 – Process of handling the data **NEW

Our response: Thank you, we have now added in that this was done using tables in Microsoft Excel.

P5:L44-50 –Our response: With thanks, we have now explained how we cleaned the data and made sure that the positive and improvement comments were reported in the correct areas no matter where they were written.

***5 - Lack of specific areas for improvement –

Our response: Thank you. We have added in a sentence to this effect and additionally tried to address it in our response to Point 1.

***6 - Lack of demographic information –

Our response: Thank you. We have amended this to clarify as you suggest.

***7 - Link between findings and discussion re: 'Ambiguity of questionnaire' –

Our response: Many thanks for this constructive suggestion and additional focus. We have added in further detail in line with this in an extended Discussion. Although it would have been useful to report the 'error' numbers within sub-sections of the 'ambiguity/problems with the questionnaire' section, we feel that this might be the basis of a different paper. We aimed for this paper to focus on a wide range of insights into cancer care in London.

***8 - Better links with the quantitative data –

Our response: thank you

***9.1 – Ethics

Our response: thank you

***9.2 – Limitations –

Our response: thank you; hopefully this has now been addressed relating to your other points

***10 – Links with the WCPES (2013) report (NEW)

Our response: Thank you, we have now added in references to this relevant report.

***Minor comments:

P2:L18-21 – Our response: although this would have been good, we are at maximum word limit for the 300 word abstract so cannot add this in.

P2:L21-29 Our response: As there is a 300 word limit on the abstract we are unfortunately not able to fit this in

P2:L51-53 –Our response: Done thank you

P2:L55-57 –. Our response: This has been addressed thank you

P3:L18 – Our response: This has been addressed and changes made where indicated, thank you

P3:L13 – Our response: Thank you this has now been added

P3:L39-43 –Our response: Thank you. The first sentence has been clarified and the second removed.

P3:L55 – Our response: There were 70 questions on the survey excluding the free text and demographics, so we have amended this to read '70'

P5:L9 – Our response: Thank you. This has been amended in line with the suggestion.

P7:L7-12 –Our response: Thank you this has been amended

P8:L25 – Our response: Thank you. We have changed this to 'a broad consensus'

P8:28-29 –Our response: This has now been added in and referenced, thank you for sharing.

P9:L3-4: Our response: Thank you this has been amended

P11:L7: Our response: Makes sense and have changed this to free text.

P11:L25-27: Our response: Thank you this has been referenced here

P11:L45-46: Our response: Thank you, this has been changed

P12:L1-30:.. Our response: We thank the reviewer for highlighting the omission of the WCPES paper. We have now cited this report and agree it is a very helpful reference. However, we don't feel it appropriate refer to it for each thematic area given that this is a London-focused paper and deals with the specifics of the London area.

P12:L32 – P14:L10 –Our response: Thank you for this valuable suggestion; this has now been amended

P14:L39-40: Our response: This has been clarified.

P14:L41-43: Our response: Thank you. This has been changed

P15:L44-45: Our response: Thank you for this. We have removed the final reference point.