

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Consent and widespread access to personal health information for the delivery of care: a large scale telephone survey of consumers' attitudes using vignettes in New Zealand
AUTHORS	Whiddett, Dick; Hunter, Inga; McDonald, Barry; Norris, Tony; Waldon, John

VERSION 1 - REVIEW

REVIEWER	Chrysanthi Papoutsi University of Oxford, UK
REVIEW RETURNED	13-Mar-2016

GENERAL COMMENTS	<p>This paper presents findings from a quantitative survey on public preferences towards access to health records by different professional groups in New Zealand. The authors have done a great job in summarising what must have been a significant amount of data in clear and concise messages that are topical for policy-making. Although the findings are interesting, the paper needs to be further developed before it is ready to be considered for publication. It would also be useful to understand the differences between the previous paper published out of the same study (on a sample of around 1800 respondents in Hunter et al 2009 [10]) and the current paper submitted for publication (with the full sample of 2400 respondents), especially in relation to the conclusions drawn out of the analysis.</p> <p>1. The abstract states that the study question is: 'How willing are consumers to consent to sharing their personal health information with different people involved in the provision of care? Which factors influence their decision? Can the design of information systems increase their willingness to share?'</p> <p>It might be worth revising the question/making it more specific to better reflect the findings presented here, i.e. it is the first question that this paper attempts to answer – perhaps in terms of whether members of the public would consent, rather than if they are willing – and includes pre-specified factors to partly respond to the second question as well. It is not clear whether the factors taken in account (socio-demographics, health condition, sensitive information) derive from previous literature.</p> <p>2. There is a mismatch between the policy context provided in the paper, which draws heavily on the UK setting, and the study setting which is New Zealand. The authors only mention in passing that there is a similar strategy proposed in New Zealand, but do not provide any further details. Without more information on the technological landscape of the health service and policy context of the country where participants were recruited, it is difficult to situate the findings and judge their relevance.</p>
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	<p>3. The methods section does not mention the year the survey was carried out and there is no description of consent taking processes or data management. I understand the methods are presented in a previous paper reporting on preliminary findings, but it might be worth adding some information here as well to strengthen the paper.</p> <p>4. Two questions were asked as part of the telephone survey: whether people would feel comfortable and whether they would consent to use of their information. The paper only presents findings on the latter. Presenting findings from both questions would allow a richer discussion on public preferences and the extent to which people feel they have any actual choice over whether their records can be withheld or not. Results need to explain the tables and diagrams fully, to avoid presenting new findings in the discussion section.</p> <p>5. The results of the study could be discussed in relation to more recent literature and the New Zealand policy context. A very similar study (of which I have to declare I am a co-author) was carried out recently in the UK and findings are reported here in case this is of help: http://www.sciencedirect.com/science/article/pii/S1386505615000118 http://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-015-0202-2 http://wwwf.imperial.ac.uk/blog/electronichealthrecords/ (unpublished data)</p> <p>6. The limitations would also need to be expanded to include further consideration of representativeness, whether respondents understood different things when talking about a 'summary of medical history', whether people who are already privacy sensitive would accept to participate in a telephone survey etc. The proportion of participants without chronic conditions and those who do not consider their medical records to contain sensitive details are only one quarter and one fifth of the sample respectively, therefore any conclusions drawing on this data need to be carefully considered.</p> <p>7. Language in the discussion section needs to be revised (e.g. first sentences of first two paragraphs).</p> <p>8. There also needs to be a distinction between findings deriving from the survey as presented in this particular paper and suggestions the authors are making on the basis of interpreting these data. The discussion mentions that the 'analysis has identified two techniques which could be incorporated...' and the abstract also notes that: 'the study suggests that the use of summary records and enabling consumers to control access to some of their information is likely to increase consent for sharing information'. Although this is well established in previous literature, it is not something that seems very strongly supported in this study (only 5% difference between summary and full record) and the question on enabling control of information has not been directly considered by participants.</p>
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REVIEWER	David Grande University of Pennsylvania United States
REVIEW RETURNED	22-Mar-2016

GENERAL COMMENTS

Summary

The authors report on a telephone survey of New Zealand residents where respondents were asked to evaluate vignettes that described different members of the health care team having access to their health care information that would be used in their own medical care. The question is important as many nations and public and private organizations are seeking to develop new models of information sharing to advance clinical, public health and research goals.

Critiques

1. Introduction: The context is well presented for this research but the study questions should be more clearly presented at the end of the introduction. In its current form, the study questions are more implied rather than clearly stated. The abstract implies broader study questions than they actually answer in their methods and results.
2. Methods: The authors do not state when the data was collected. The methods reference a paper from 2009 so it is not clear if they are saying they replicated these methods and collected data recently (when?) or if this is a new analysis of previously collected data. More details are needed. If it is from 2009 (and therefore collected even earlier) – the results would be somewhat outdated given changes in information technology during the intervening years.
3. Methods: The authors presented participants with a many possible permutations of information sharing attributes but only report on two (users, level of detail of personal information). They should at least describe in greater detail what those other attributes were and why they are only presenting the results of a subset here.
4. Methods: The authors state that a series of questions were asked following each vignette but only describe two. Were additional questions asked? If so, what were those questions? More detail is needed about the script from the survey to allow for interpretation by the reader.
5. Methods: The authors used logistic regression to model their results which is a good approach. However, they do not describe how many vignettes each participant evaluated and therefore how they addressed within respondent correlation in the model.
6. Methods: They were interested in how the level of clinical detail might influence willingness to share information. However, they do not provide much context for the participant on what exactly is a “full medical history” vs. a “summary.” So it is not clear how we should interpret this since it’s hard to say what the respondent thought that meant. It would have been helpful to describe this further. This should be added to limitations. In general, the vignettes did not provide much context or detail (similar to the point made above about use and how the use related to actual medical care).
7. Methods: Other studies have found that use is a more significant driver of willingness to share than other attributes such as user– this study didn’t seem to explore that. The authors held use constant and at the same time didn’t provide much context or specificity to the nature of information use. So the respondent may wonder why a pharmacist or community health worker needs access to their information. Knowing the answer to that question may have a large effect on willingness to share if it was seen as potentially useful for their care. Instead, the respondent may be guessing as to what that person’s role might be in their care.

	<p>8. Methods: Why did the authors conduct a stratified analysis (which seems post-hoc) based on self-report of “sensitive” information rather than include it in a single model and perhaps model as an interaction?</p> <p>9. Discussion: The results do not support one of their main conclusions. The authors state that their data show that giving people control over their own data will lead to more people consenting to share. I don't know how their data speaks to that conclusion. They might say controlling access might lead to greater levels of trust in the overall system but it could actually lead to fewer people consenting. I think previous studies would actually suggest that if people are given the choice – many will opt out of sharing.</p>
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REVIEWER	Merle Spriggs (1) University of Melbourne, Australia (2) Murdoch Childrens Research Institute, Australia
REVIEW RETURNED	04-Apr-2016

GENERAL COMMENTS	<p>I agreed to review this manuscript. Now that I have read it I am unsure how to proceed. I am unable to complete the review checklist in a meaningful way and I doubt the paper will be published in its current form. This paper addresses an important topic and the abstract led me to believe that it was reporting on the results of a large scale telephone survey. That is not quite the case. The authors have previously conducted a large scale telephone survey (their reference 10, published in 2009 i.e. preliminary results from a national study). The paper submitted to BMJ Open takes as its starting point a 2014 NHS document (Personalised health and care 2020: a framework for action). The authors rightly think that the results of their telephone survey highlight major challenges to what is being proposed in the NHS document. In my view, this is the basis for a valuable and interesting commentary or for debate type article. It is odd that it is presented as a study with method, sample, analysis etc, admittedly based on a subset of vignettes from the original study. (It's also curious as to why only the preliminary results are cited)</p> <p>Also, while the author's previous study highlights challenges, the techniques they suggest which may lead to more people consenting to share their health information would benefit from some discussion of the UK Summary Care record and the Australian Personally Controlled Electronic Health Record (PCEHR) - now called the My Health Record. These are systems that incorporate the aspects being recommended and are not without problems.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Chrysanthi Papoutsi

Institution and Country: University of Oxford, UK

Competing Interests: None declared

This paper presents findings from a quantitative survey on public preferences towards access to health records by different professional groups in New Zealand. The authors have done a great job in summarising what must have been a significant amount of data in clear and concise messages that are topical for policy-making. Although the findings are interesting, the paper needs to be further developed before it is ready to be considered for publication. It would also be useful to understand the differences between the previous paper published out of the same study (on a sample of around 1800 respondents in Hunter et al 2009 [10]) and the current paper submitted for publication (with the full sample of 2400 respondents), especially in relation to the conclusions drawn out of the analysis.

Thank you for your positive comments in the introduction. Thank you also for the very useful comments below which have focussed our attention on areas which could do with improvement, We hope we have now produced a better paper which responds to your concerns.

The original paper (Hunter et al 2009) simply presented a broad summary of our initial analysis and descriptive statistics of the first responses (less than half of the total number of respondents) and it did not really draw out the implications.

In contrast, this paper has a much clearer focus and draws on the data to address contemporary policy issues; it presents the findings from a more sophisticated statistical analysis (using logistic regression) of a subset of data from the completed data set.

1. The abstract states that the study question is: ‘How willing are consumers to consent to sharing their personal health information with different people involved in the provision of care? Which factors influence their decision? Can the design of information systems increase their willingness to share?’

It might be worth revising the question/making it more specific to better reflect the findings presented here, i.e. it is the first question that this paper attempts to answer – perhaps in terms of whether members of the public would consent, rather than if they are willing – and includes pre-specified factors to partly respond to the second question as well. It is not clear whether the factors taken in account (socio-demographics, health condition, sensitive information) derive from previous literature.

The Abstract has been rewritten in a different format, in the process it has been made more specific to the findings.

2. There is a mismatch between the policy context provided in the paper, which draws heavily on the UK setting, and the study setting which is New Zealand. The authors only mention in passing that there is a similar strategy proposed in New Zealand, but do not provide any further details. Without more information on the technological landscape of the health service and policy context of the country where participants were recruited, it is difficult to situate the findings and judge their relevance.

A good point, sorry for being so egocentric. From a New Zealand perspective it is clear that our structures and systems are similar to the UK, but it is much less likely that anyone outside of New Zealand would be much aware of what goes on here.

We have added a comment in the Introduction paragraph 1 to explain that they are similar and given reference.

3. The methods section does not mention the year the survey was carried out and there is no description of consent taking processes or data management. I understand the methods are presented in a previous paper reporting on preliminary findings, but it might be worth adding some information here as well to strengthen the paper.

These points are clarified in Methods section, Subsection sample, paragraph 1.

4. Two questions were asked as part of the telephone survey: whether people would feel comfortable and whether they would consent to use of their information. The paper only presents findings on the latter. Presenting findings from both questions would allow a richer discussion on public preferences and the extent to which people feel they have any actual choice over whether their records can be withheld or not. Results need to explain the tables and diagrams fully, to avoid presenting new findings in the discussion section.

We agree that the relationship between comfort and consent is interesting and relevant, but unfortunately the current paper is already over the word limit, so we focussed on the issue of consent.

We are planning to publish an exploration of the relationship based on the full dataset in a future paper.

5. The results of the study could be discussed in relation to more recent literature and the New Zealand policy context. A very similar study (of which I have to declare I am a co-author) was carried out recently in the UK and findings are reported here in case this is of help:

<http://www.sciencedirect.com/science/article/pii/S1386505615000118>

<http://bmcmmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-015-0202-2>

<http://wwwf.imperial.ac.uk/blog/electronichealthrecords/> (unpublished data)

Thank you for the links to your interesting study, which I have cited in the Discussion section.

We have also expanded the Discussion Section, subsection Summary Care Records, to give more links to policy initiatives in this area.

6. The limitations would also need to be expanded to include further consideration of representativeness, whether respondents understood different things when talking about a 'summary of medical history', whether people who are already privacy sensitive would accept to participate in a telephone survey etc. The proportion of participants without chronic conditions and those who do not consider their medical records to contain sensitive details are only one quarter and one fifth of the sample respectively, therefore any conclusions drawing on this data need to be carefully considered.

The point about respondents understanding of 'summary of medical history' is addressed in Discussion section paragraph 3.

Other limitations of the sample, including the point about the limited sample size of subgroups, are addressed in Discussion section paragraph 4.

7. Language in the discussion section needs to be revised (e.g. first sentences of first two paragraphs).

These have been revised.

8. There also needs to be a distinction between findings deriving from the survey as presented in this particular paper and suggestions the authors are making on the basis of interpreting these data. The discussion mentions that the 'analysis has identified two techniques which could be incorporated...' and the abstract also notes that: 'the study suggests that the use of summary records and enabling consumers to control access to some of their information is likely to increase consent for sharing information'. Although this is well established in previous literature, it is not something that seems very strongly supported in this study (only 5% difference between summary and full record) and the question on enabling control of information has not been directly considered by participants.

We have rewritten the Abstract (which is totally restructured), Introduction (which now only introduces the context and outlines the research focus) and the Discussion sections to clarify the distinction between the specific findings from the research and the conclusions which we draw by interpreting the data. We have also expanded the discussions of our conclusions to acknowledge their limitations.

Reviewer: 2

Reviewer Name: David Grande

Institution and Country: University of Pennsylvania, United States

Competing Interests: None declared

Summary

The authors report on a telephone survey of New Zealand residents where respondents were asked to evaluate vignettes that described different members of the health care team having access to their health care information that would be used in their own medical care. The question is important as many nations and public and private organizations are seeking to develop new models of information sharing to advance clinical, public health and research goals.

Thank you for agreeing with the importance of the issue and for the useful critiques of the paper. We hope that we have adequately addressed the issues within the limited space of the paper.

Critiques

1. Introduction: The context is well presented for this research but the study questions should be more clearly presented at the end of the introduction. In its current form, the study questions are more implied rather than clearly stated. The abstract implies broader study questions than they actually answer in their methods and results.

The Abstract has been rewritten and is much more concise about what we report, similarly the Introduction has been rearranged to clarify the focus – see final paragraph.

2. Methods: The authors do not state when the data was collected. The methods reference a paper from 2009 so it is not clear if they are saying they replicated these methods and collected data recently (when?) or if this is a new analysis of previously collected data. More details are needed. If it is from 2009 (and therefore collected even earlier) – the results would be somewhat outdated given changes in information technology during the intervening years.

We have clarified when the data was collected (2008) in the Methods subsection Sample. The data presented is a new analysis of a subset of the entire dataset collected for the project.

The original paper (Hunter et al 2009) simply presented a broad summary of our initial analysis and descriptive statistics of the first responses (less than half of the total number of respondents) and it did not really draw out the implications. In contrast, this paper has a much clearer focus and draws on the data to address contemporary policy issues; it presents the findings from a more sophisticated statistical analysis (using logistic regression) of a subset of data from the completed data set.

Although some aspects of technology have advanced since the survey, as we point out in the Discussion section, paragraph 3, New Zealand has a very level of use of EHRs for some time, with 100% of GP practices now using such systems, so respondents should be familiar with the concepts being researched.

3. Methods: The authors presented participants with a many possible permutations of information sharing attributes but only report on two (users, level of detail of personal information). They should at least describe in greater detail what those other attributes were and why they are only presenting the results of a subset here.

We have outlined the other attributes and values in Methods section, paragraph 4.

We focus on the subset which relate specifically to the policy issues which we wish to address which are outlined in the introduction, otherwise we end up with a very long and unfocussed paper.

4. Methods: The authors state that a series of questions were asked following each vignette but only describe two. Were additional questions asked? If so, what were those questions? More detail is needed about the script from the survey to allow for interpretation by the reader.

We have rewritten that section to clarify that respondents were asked the two questions.

5. Methods: The authors used logistic regression to model their results which is a good approach. However, they do not describe how many vignettes each participant evaluated and therefore how they addressed within respondent correlation in the model.

This is a fair point, we have clarified the number of vignettes which were evaluated by participants, firstly overall in the Methods section, paragraph 5, and secondly in our subset in the subsection Sample, paragraph 2.

We also clarify in the subsection Analysis paragraph 1, that the nlme package uses a mixed effects logistic model to adjust for the correlation between answers to multiple scenarios by the same respondent.

6. Methods: They were interested in how the level of clinical detail might influence willingness to share information. However, they do not provide much context for the participant on what exactly is a “full medical history” vs. a “summary.” So it is not clear how we should interpret this since it’s hard to say what the respondent thought that meant. It would have been helpful to describe this further. This should be added to limitations. In general, the vignettes did not provide much context or detail (similar to the point made above about use and how the use related to actual medical care).

We agree that this is a limitation of the vignette methodology (or indeed any survey methodology) however, we do address the point in the Discussion section, paragraph 3.

Note that the interviewers were provided with scripts to clarify issues for respondents.

7. Methods: Other studies have found that use is a more significant driver of willingness to share than other attributes such as user— this study didn’t seem to explore that. The authors held use constant and at the same time didn’t provide much context or specificity to the nature of information use. So the respondent may wonder why a pharmacist or community health worker needs access to their information. Knowing the answer to that question may have a large effect on willingness to share if it was seen as potentially useful for their care. Instead, the respondent may be guessing as to what that person’s role might be in their care.

We now explicitly mention (Method paragraph 4) that our survey covered a range of uses other than care (the other four secondary purposes, which are not discussed here, were ‘Quality audit’, ‘Financial Audit’, ‘Improving the health of New Zealanders’, ‘Assessing eligibility for financial assistance’). However, we are focussing on the use for care because it relates to the policy issues we are addressing in this paper. Attempting to cover the other purposes as well would lead to a much longer and less focussed paper, and this one is already at the word limit.

The issue about how well the respondent understood the reason for access is again part of the problem of external validity raised in point 6 above.

8. Methods: Why did the authors conduct a stratified analysis (which seems post-hoc) based on self-report of “sensitive” information rather than include it in a single model and perhaps model as an interaction?

It was not a stratified analysis, it was a single model as suggested. “SensitiveNYR” was a factor with three levels where effects for the contrasts Yes-No and Refused-No were estimated as shown in the output. As for interactions, these were checked for but were all non-significant or non-estimable due to the smaller numbers who Refused to say whether they had sensitive information.

Figures 1 and 2 might have given the impression that the analysis was stratified by "sensitive". In the actual model stratification was not done, but the graphs are presented as they are just to help readers make visualise of the raw effect of "sensitive", "type of information" and "role". We hope that the wording has now been revised to clarify this.

9. Discussion: The results do not support one of their main conclusions. The authors state that their data show that giving people control over their own data will lead to more people consenting to share. I don't know how their data speaks to that conclusion. They might say controlling access might lead to greater levels of trust in the overall system but it could actually lead to fewer people consenting. I think previous studies would actually suggest that if people are given the choice – many will opt out of sharing.

This is a good point and we have acknowledged this in Discussion section, subsection Ability to control.. , paragraph 2.

Reviewer: 3

Reviewer Name: Merle Spriggs

Institution and Country: (1) University of Melbourne, Australia; (2) Murdoch Childrens Research Institute, Australia

Competing Interests: No competing interests

I agreed to review this manuscript. Now that I have read it I am unsure how to proceed. I am unable to complete the review checklist in a meaningful way and I doubt the paper will be published in its current form. This paper addresses an important topic and the abstract led me to believe that it was reporting on the results of a large scale telephone survey. That is not quite the case. The authors have previously conducted a large scale telephone survey (their reference 10, published in 2009 i.e. preliminary results from a national study). The paper submitted to BMJ Open takes as its starting point a 2014 NHS document (Personalised health and care 2020: a framework for action). The authors rightly think that the results of their telephone survey highlight major challenges to what is being proposed in the NHS document. In my view, this is the basis for a valuable and interesting commentary or for debate type article. It is odd that it is presented as a study with method, sample, analysis etc, admittedly based on a subset of vignettes from the original study. (It's also curious as to why only the preliminary results are cited)

Thank you for your comments; it is good to see that you feel that the issues raised are worthy of debate and that our data is relevant.

We felt that it was worth presenting the findings as a complete study as the original paper had a number of limitations. The original paper (Hunter et al 2009) simply presented a broad summary of our initial analysis and descriptive statistics of the first responses (less than half of the total number of respondents) and it did not really draw out the implications.

In contrast, this paper has a much clearer focus and draws on the data to address contemporary policy issues; it presents the findings from a more sophisticated statistical analysis (using logistic regression) of a subset of data from the completed data set.

Also, while the author's previous study highlights challenges, the techniques they suggest which may lead to more people consenting to share their health information would benefit from some discussion of the UK Summary Care record and the Australian Personally Controlled Electronic Health Record (PCEHR) - now called the My Health Record. These are systems that incorporate the aspects being recommended and are not without problems.

The problems with the implementation of these systems is a very good point, which we have incorporated in the Discussion section, subsection Summary Care Records, paragraph 1.

VERSION 2 – REVIEW

REVIEWER	Chrysanthi Papoutsis University of Oxford, UK
REVIEW RETURNED	02-Jun-2016

GENERAL COMMENTS	<p>Although the paper raises interesting issues I would be uncomfortable to suggest publication unless there are significant revisions to include data or analysis that has not been published previously. It is still unclear what the similarities and differences are between this work and the paper published in 2009 (I have been found it difficult to complete the review checklist). The original paper presents data from 1828 respondents, this paper presents data from 2438 respondents. The findings of the original paper seem to be similar to the findings of this paper. It might be worth considering an additional data collection element to bring the data presented in the new paper up-to-date or perhaps introduce a longitudinal dimension.</p> <p>Some of the statements in the paper remain inadequately supported by data or are presented more strongly than the data would support (I have outlined specific points in my previous review). The authors have added a few comments on limitations but the strength of the conclusions drawn on the basis of this data has not changed. The paper still contends that ‘findings suggest two techniques which could be incorporated into the design and implementation of future health information systems ... summary care records ... [and] ability to control access to information’. I don’t think this study has directly produced findings that support the latter statement – respondents have not been asked whether having the ability to control access to information would change their willingness to share their record. This is an interpretation of the researchers based on their findings. This also needs to be changed in the abstract and strengths bullet points.</p> <p>There needs to be further reflection on whether the difference between groups is only statistically significant or whether it is significant in practice (about 5% difference in most cases). This could also inform a policy discussion on the level of proportionality of the investment justified to produce the conditions which may extend the proportion of patients consenting to share their records. The sentence added to the paragraph on Summary Care Records (Discussion) may also need to be reviewed to clarify the argument made.</p> <p>It is still unclear whether the characteristics taken in account (socio-demographics, chronic condition, sensitive information) were chosen because they were deemed to be important in previous literature and findings specifically contradict/confirm previous work.</p> <p>The abstract will need to clarify the year the survey was carried out. Same for the methods section.</p> <p>There is little explanation as to what full and brief record would mean, both in the context of the project, and in terms of respondent perceptions. The paper suggests ‘respondents should have seen such systems being used and be familiar with the concepts being researched’. Is this something that came out of the phone interviews? The original paper from 2009 states a third level of detail: ‘information relevant to the current health problem only’. This is not mentioned here. It is difficult to make sense of people’s</p>
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	<p>responses if it is unclear what questions were asked overall.</p> <p>The way the policy context is framed remains largely UK-centric. It might be worth re-framing the introduction to start with the NZ policy context, citing relevant grey literature of the country's national strategy (such as [4] cited already), and then consider similarities and differences with the UK or other countries to provide an international perspective.</p> <p>Figure 1 & 2 headings need to be revised for language. It would also be useful to have respondent numbers rather than just percentages) in table 1.</p> <p>The paper mentions: 'Since we are only considering a subset of all vignettes in this paper the majority of respondents only answered 2 vignettes with 95% answering 4 or less of the selected vignettes.' I am not absolutely clear what this means and how it corresponds to information provided in the first part of the Methods section ('the median number of vignettes per interview was 7...').</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Chrysanthi Papoutsis

Institution and Country: University of Oxford, UK

Competing Interests: none declared

1. Although the paper raises interesting issues I would be uncomfortable to suggest publication unless there are significant revisions to include data or analysis that has not been published previously. It is still unclear what the similarities and differences are between this work and the paper published in 2009 (I have been found it difficult to complete the review checklist). The original paper presents data from 1828 respondents, this paper presents data from 2438 respondents. The findings of the original paper seem to be similar to the findings of this paper. It might be worth considering an additional data collection element to bring the data presented in the new paper up-to-date or perhaps introduce a longitudinal dimension.

This paper is significantly different from the previous paper as it is based on a much larger dataset, uses different statistical techniques and presents previously unpublished results from some completely new analysis that examines the impact of the presence of sensitive information within respondents' records.

In contrast, to the original paper (Hunter et al 2009) this paper draws on the full dataset from the 4209 respondents (rather than the initial sample of 1828 respondents). It presents the findings from a more sophisticated statistical analysis (using logistic regression) of a subset of data from the complete data set with a clearer focus and to address contemporary policy issues.

Both papers do present some similar findings in that they both illustrate the importance of the role of the recipient and the level of detail on respondents' willingness to agree to share their information.

However, this paper does contain some completely new analysis and makes an important additional contribution as it also examines, quantifies and illustrates the impact that the presence of sensitive information in the record can have on respondents' willingness to share their information. This analysis has not been done before and it is a valuable contribution to the literature which can help to inform debate about EHR implementation policies and strategies.

We have added a note about the limitation of the age of the data and the suggestion for additional data collection to the paragraph in the Discussion which considers the limitations of the research (para 4).

1. Some of the statements in the paper remain inadequately supported by data or are presented more strongly than the data would support (I have outlined specific points in my previous review). The authors have added a few comments on limitations but the strength of the conclusions drawn on the basis of this data has not changed. The paper still contends that 'findings suggest two techniques which could be incorporated into the design and implementation of future health information systems ... summary care records ... [and] ability to control access to information'. I don't think this study has directly produced findings that support the latter statement – respondents have not been asked whether having the ability to control access to information would change their willingness to share their record. This is an interpretation of the researchers based on their findings. This also needs to be changed in the abstract and strengths bullet points.

In the Discussion/Conclusion section, we have changed the wording within the paper away from "controlling access" to referring to "the need to find ways to manage sensitive information".

Similarly, in the Abstract we have changed the wording to:

"We suggest that providing summaries and co-designing ways to address the management of sensitive information within EHRs might increase rates of consent."

We have changed the strength section to the point:

- *The findings quantify the extent to which the presence of sensitive information reduces consumers' willingness to consent to share their information.*
We have also changed the wording at various other places throughout the paper to be more circumspect in our interpretation of the data.

2. There needs to be further reflection on whether the difference between groups is only statistically significant or whether it is significant in practice (about 5% difference in most cases). This could also inform a policy discussion on the level of proportionality of the investment justified to produce the conditions which may extend the proportion of patients consenting to share their records. The sentence added to the paragraph on Summary Care Records (Discussion) may also need to be reviewed to clarify the argument made.

These issues are now raised in the fourth to last and the final paragraph of the Conclusion, we raise them as issues for further discussion and do not attempt to answer these questions within the paper.

3. It is still unclear whether the characteristics taken in account (socio-demographics, chronic condition, sensitive information) were chosen because they were deemed to be important in previous literature and findings specifically contradict/confirm previous work.

The rationale for asking for specific respondent characteristics is now clarified in the Methods section.

The findings are compared with previous research in the Discussion section, paragraph 2.

4. The abstract will need to clarify the year the survey was carried out. Same for the methods section.

We have included the date of data collection in the Abstract under Design.
The date was already in the Methods section, subsection Sample.

5. There is little explanation as to what full and brief record would mean, both in the context of the project, and in terms of respondent perceptions. The paper suggests 'respondents should have seen such systems being used and be familiar with the concepts being researched'. Is this something that came out of the phone interviews? The original paper from 2009 states a third level of detail: 'information relevant to the current health problem only'. This is not mentioned here. It is difficult to make sense of people's responses if it is unclear what questions were asked overall.

The rationale for using full and brief records is that they correspond to issues considered within the NZ Health Information Strategy Document. The wording used for the <content of medical information> is given in paragraph 10 of the Methods section.

We did not include the third option 'information relevant to the current health problem only' in this analysis and presentation as it does not correspond with options which are under currently discussion at a policy level. We feel that we can simply omit this option from the analysis as the vignettes which are presented to the respondents were independent of each other and were randomly selected

Interviewers were asked ensure that respondents were confident that they understood the vignette and interviewers were able to explain the terms in more detail if asked.

6. The way the policy context is framed remains largely UK-centric. It might be worth re-framing the introduction to start with the NZ policy context, citing relevant grey literature of the country's national strategy (such as [4] cited already), and then consider similarities and differences with the UK or other countries to provide an international perspective.

We have changed the first paragraph of the Introduction to refer to the New Zealand Strategy rather than the UK one.

7. Figure 1 & 2 headings need to be revised for language. It would also be useful to have respondent numbers rather than just percentages) in table 1.

*The titles and the figures have been revised.
Table 1 now contains counts as well as percentages.*

8. The paper mentions: 'Since we are only considering a subset of all vignettes in this paper the majority of respondents only answered 2 vignettes with 95% answering 4 or less of the selected vignettes.' I am not absolutely clear what this means and how it corresponds to information provided in the first part of the Methods section ('the median number of vignettes per interview was 7...').

This point has been moved to the 12th paragraph of the Methods section. It now comes just after the part of the paper where we define the subset of data used in this paper.

We hope it is now clear that selecting a subset of the vignettes results in the use of a subset of the responses for each respondent.