Author’s response to reviews

Title: Development of an eHealth information resource for family carers supporting a person receiving palliative care on the island of Ireland.

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Version: 1 Date: 18 Jan 2019

Author’s response to reviews:

Dear Sir/Madam

We would like to thank the reviewers for taking the time to read our paper and providing such valuable comments, questions and suggestions. We believe that responding to these has further improved our paper.

I have responded to each of the reviewer’s comments below. I hope this is satisfactory.

David

Reviewer One.

Point 1. Thank you for identifying this potential source of confusion. It was never our intention to suggest that the website should be considered as an educational resource. To avoid confusion, we have removed all references to education from the manuscript. In addition, we have stated throughout the paper that our aim was to develop a website, which would provide ‘core
information’ to assist carers to provide care. For example, lines 10-12 and lines 66-67; 69; 71-72; 82.

You also ask us to clarify what we mean by evidence based resources. In this context, we simply mean that the content we wished to provide should be supported by research, we did not want to provide links to anecdotal evidence which did not have any scientific support. We have added a clarifying statement to this effect on lines 80 - 82.

Point 2. The authors did review existing websites but did not look at the specific research evidence to guide website design, development or formative evaluation. This project was developed on an extremely tight budget and we would have been unable to complete these activities in the timeframe available to us. In terms of the website design; the carers’ website will be hosted by the All Ireland Institute for Hospice and Palliative Care (AIIHPC).

The AIIHPC already host a number of palliative care websites (e.g. for professionals and children). In terms of design, it was always the intention that the ‘carer’s website’ would look and function in a similar way to the existing ‘portfolio’ of websites hosted by the AIIHPC.

The AIIHPC will continue to consult with members of the VRG on the future development of the site to ensure that it meets with the developing need of carers. This work will be completed through an ongoing programme of consultative meetings with user groups, which take place on a quarterly basis.

Point 3. The systematic reviews did not state if the contributing papers took into consideration the views and perspectives of all types of family carers across the community – we now acknowledge this in the study limitations lines336-345). The need to be inclusive was recognised within our study and was discussed by the VRG. We actively recruited members of the VRG to reflect the current portrait of communities in Ireland (we have included a statement to this effect on lines 102-103 and again on lines 337 – 345). This allowed the widest representation of people possible to comment on the relevance and appropriateness of the website content.

Point 4. We have added additional information on the VRG on lines 99 - 103.

Point 5. We have tried to be more reflective of the process we employed in the discussion section and in particular the importance of the virtual reference group in contributing to the final content of the website (e.g. lines 313-317; 333-345).
Point 6. The layout and design of the webpages was informed by our web developer, Gareth Westcott, who is a co-author of this paper. Gareth developed the pages to be in keeping with the other AIHPC content. In addition, we shared the pages with members of the VRG and the study steering group for approval before launching the final website.

Point 7. Readability of content was discussed among members of the VRG. We were also aided by a carer advocacy group (a member of whom sat on the project committee) who commented on the readability of the proposed content. We did not undertake a formal assessment of readability.

Point 8a. Again, a formal quality appraisal of external resources was not undertaken. Rather, all external content was initially examined by members of the Project team and subsequently by the VRG for approval. Again, members of the VRG were invited to examine the website and all linked resources prior to the website being launched.

Point 8b. Usability was again assessed by the Project team and the VRG prior to launch. The web development process also employed software designed to identify and provide an alert if there were any issues with external linked content.

Point 9. We have now added this information on lines 278-279.

Point 10. The downloadable factsheets are supplementary content to the webpages. In working with the web developer we found that writing for a web page requires a concise writing style that often, did not complement detailed description. Rather than overwhelm the reader we decided to, where appropriate, provide summary information on the webpage with a link to the downloadable factsheet if the reader wanted to access more detailed information.

Reviewer Two.

Point 1, Background: We have added additional references supporting the point that home-based palliative care services are a policy goal in the Northern Ireland and Ireland on line 42.

Point 2, Background: We have expanded on the challenges facing policy makers and service planners and the role of technology: lines 43-49 and lines 76-79.

Point 3, Development process: All authors were members of the project team. The team included: Two palliative care consultant clinicians; a professor of palliative care whose background is as a registered nurse with 25 years’ experience in palliative care practice, education and research (PH); A palliative care educator with expertise in e-learning (CP); The director of the All-Ireland Institute of Hospice and Palliative Care – an organisation that is driving change in palliative care on the island of Ireland and which is working in partnership with 9 Hospices, the Irish Hospice Foundation, 8 Universities and 5 health and social care trusts
a web development specialist currently working with the AIIHPC (GW). GW has specialist knowledge on developing palliative care websites; a professor of nursing with a background in palliative care research; a health services researcher (DS); two directors of carer organisations on the island of Ireland; two PPI representatives. We have added the initials of the co-authors to the manuscript as requested. We have clarified this on lines 89 - 91.

Point 4, Development process: The initial ‘development process’ paragraph was included to provide a brief summary of the tasks undertaken. We therefore did not feel it would be appropriate to go into detail about the iterative process undertaken with the Virtual Reference Group here. We have discussed this in more detail in later sections of the manuscript – see for example line 211-214; 313-317; 333-336; 359-360). In short, we provided written summary information to the VRG and invited them to respond via email or telephone. We then convened a meeting of the VRG where we discussed the information provided and any responses we had received. We audio recorded and transcribed these meetings and created a list of action points. These action points were circulated around the VRG and the amendments were made to the draft content. This would again be circulated to the VRG for approval.

Point 5, Review of reviews: We feel that, given the time constraints involved we were extremely thorough in carrying out the review of reviews. In developing the search strategy, we worked closely with a specialist Information Scientist. In order to identify the terms of interest for the search strategy, a brief pilot search or ‘scoping review’ of the literature was undertaken. Identified studies were examined and ‘key descriptors’ extracted to assist in the development of the search strategy.

The scoping review showed that this area was not well defined and, therefore, that a tightly constrained or ‘sensitive’ search strategy would result in the non-identification and exclusion of potentially relevant reviews. Consequently, we employed a broad search strategy which resulted in the identification of a large number of items. We felt that, whilst this may be resource intensive it provided the greatest opportunity for identifying the largest number of relevant reviews. In addition, ‘key word’ searches were completed on a range of internet search engines whilst the reference lists and bibliographies of all retrieved papers were also searched for further potentially relevant papers.

The review of reviews was undertaken to provide us with evidence of the ‘core information needs’ of carers. Having identified these needs they were shared with the Virtual Reference Group in an iterative process to ensure that they were appropriate for presentation using a website.

We accept that it would have been very useful to look at the evidence describing online resource development but due to budgetary and time constraints this was not possible.

Point 6, Review of reviews – We screened titles rather than titles and abstracts. This step was undertaken as it is a recognised method and there is a strong argument that screening titles first is
a more efficient method of screening particularly if the subject area is not well-defined and the search terms are broad (for example see, Mateen et al, ‘Titles vs Titles and abstracts for initial screening of articles for systematic reviews.’ Clinical Epidemiology; 2013; 5: 89-95). For this piece of work, we were only interested in identifying reviews – it was often obvious from the titles whether the identified studies were reviews and if they were of a topic of interest. We state in the text that any ambiguous titles were retained for title and abstract screening.

Point 7, Review of reviews: We have not provided a Prisma flowchart and checklist. In retrospect this was a mistake however, we do not state that we have undertaken a systematic review and we hope that we have not given that impression. Rather we sought to undertake a review of existing reviews in as thorough a way as possible given the time and resource constraints that we faced. We hope that in recognising this the information presented in the flowchart and the text in page 6 (lines 137-148) is sufficient to illustrate the process we undertook.

Point 8 Review of reviews: We limited the search strategy to articles after the year 2000. This decision was made as, again due to time constraints we had to limit the number of articles we would review. The team felt that articles after the year 2000 would point to the most up-to-date research. Further we recognise that research builds on other research and that articles published after the year 2000 would be informed by the research that pre-dated this time.

Point 9, Review of reviews: Professional and academic colleagues were asked to identify additional published reviews based on their professional knowledge and experience. No additional review papers were identified using this method.

Point 10, Review of reviews: Core information was identified through reading the review articles and tabulating the information contained in the reviews. Due to their summary nature we did, on some occasions, have to refer to the original papers contained in the reviews in order to identify core information. This data was tabulated and we used these tables to look for common themes across the studies. This summary information was provided to the VRG. This process is explained in brief on lines 205-243).

Point 11, Development of content: VRG has been changed to read Virtual Reference Group on Page 9 (line 202).

Point 12, Development of content: The audio recordings of meetings were used to maintain a record of the VRG’s views and to develop action points that would be used to shape content development and demonstrate the meaningful involvement of this group. We have added information to clarify why we recorded the VRG meetings on lines 213 -214.

Point 13, Website development: The website developer is a co-author on this paper and his initials have been added (GW) line 250.
Point 14, Website development: We have amended this section of the paper and removed references to face validity (line 260). We were simply trying to describe a process whereby subject experts reviewed existing established websites to examine content and determine if they were relevant to our website. The international websites were assessed according to the criteria listed in the paper (evidence based, easy to understand, relevant to the core information needs we had identified and, relevant to carers on the island of Ireland) and a summary of this information was shared with the VRG. We did not undertake a formal face validity assessment and the amended text reflects this.

Point 15, Discussion: We have added additional references to citing international standards that mandate the need to provide sufficient information to support carers – lines 295-298.

Point 16, Discussion: We have added additional references highlighting the lack of evidence based resources for family carers and providing a framework to guide future research - lines 306-308.

Point 17, Discussion: As is recognised in the literature, the evidence base supporting many palliative care interventions is currently inadequate and this can act as a barrier to the development of services (e.g. Morrison, 2017). In this study we sought to identify review articles which would summarise the best-available evidence, we supplemented this with expert knowledge both nationally and internationally, and presented findings to a Virtual Reference Group of health care professionals, carers and relevant members of the voluntary sector. In identifying core themes, we sought to achieve a consensus from these contrasting groups. The themes identified are broadly reflective of international studies and, as such, we do believe they have relevance beyond the immediate membership of the VRG. The uptake of the website would further support that content is of interest to a wide group of carers both within and beyond the island of Ireland. We acknowledge this point in the study limitations lines 331 – 345.