Author’s response to reviews

Title: The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision

Authors:
Anne Finucane (anne.finucane@mariecurie.org.uk)
Anna Bone (anna.bone@kcl.ac.uk)
Catherine Evans (catherine.evans@kcl.ac.uk)
Barbara Gomes (barbara.gomes@kcl.ac.uk)
Richard Meade (richard.meade@mariecurie.org.uk)
Irene Higginson (irene.higginson@kcl.ac.uk)
Scott Murray (scott.murray@ed.ac.uk)

Version: 1 Date: 28 Oct 2019

Author’s response to reviews:

Yvonne Engels, PhD (Reviewer 1)

This is a very essential, well-written paper about possible death scenario's, based on trends in the past. By making such a proactive analysis, anticipating on such scenario's is possible. I have some remarks and questions:

Authors: We thank Reviewer 1 for the very positive comments.

1. what was the reason not to choose for a scenario where the capacity of hospital death is frozen, in favour of death at home, in care homes or hospice? This scenario would help to show, if combined in a next economic paper, that such a scenario might be more feasible in terms of growing health care costs: dying outside the hospital is not only an indicator for quality, but is also cheaper.

Authors: We take Reviewer 1's point that it would also be useful to compare a scenario where hospital capacity is frozen. However, we believe that the four scenarios we have chosen best reflect current and future capacity for palliative care in the community in Scotland. The chosen scenarios also allow comparison with other international data based on these scenarios. We agree with Reviewer 1 that examining such a scenario in a future paper might be interesting and informative and we now note this is the discussion. (p11, line11).
2. page 5: why is chosen for these age categories? (as they are not distributed equally)

Authors: The categories used reflect how age data is organised in our national datasets provided by the national records of Scotland. The same age categories were used in the original Bone et al. study (2017) so allow comparison with trends and projections in England and Wales.

3. On page 9, it is stated that the number of care homes decreased in the past years; did also the number of beds decrease? And might it be an additional scenario that this trend continues?

Authors: Yes, registered places also decreased, we mention the actual numbers on p9 now. See p9, Line 29

4. Also on page 9, the percentage of care home deaths in the Netherlands is mentioned. What is essential to add, is that a care or nursing home in the Netherlands is very unique, when compared to those in other countries, as we have 'elderly care physicians' in these settings. They are specialised in care for elderly, and contribute to high quality care. What is even more interesting, is the low and further decreasing percentage of hospital deaths in the Netherlands (around 32% of deaths).

Authors: Thank you very much for this very helpful information which we have now added: “In the Netherlands, there are ‘elderly care physicians’ specialised in care for the elderly who contribute to high quality care in care home settings”. See Page 9, Line 35. We also add a reference to support this statement (Varenso 2015).

5. In the recommendations, I would add a suggestion to add an estimation of costs of the scenario's, as this is also important to use the current paper for the planning of future health care.

Authors: Thank you. We have now inserted: “Other scenarios are possible, e.g. fixed hospital capacity; and could be usefully considered alongside an economic analysis of each scenario in future studies”. See p11, Line 11.

Sarah Mitchell (Reviewer 2):

Thank you for asking me to review this paper. It is well written and makes and important, relevant contribution to the international evidence base to inform the delivery of palliative care in the future.

Authors: We thank Reviewer 2 for the very positive comments.

I have a few suggestions for discretionary changes, which I hope are helpful.

Background

Line 21/22 states "most people express a preference to die at home if circumstances allow" - this is a widely accepted narrative in palliative care research and policy, but is still based on a limited evidence base. We have much more to learn about what this means, as alluded to in the discussion page 11 "care to feel safe and secure", so I wonder if it would be better to state "many people" instead of "most".

Authors: Thank you – we have now made this change, page 4, line 21

The final paragraph of the discussion provides important detail about what "integration of palliative care" means, and explains the situation in different countries. This could be edited and moved to the introduction, paragraph three, which refers to "the degree of palliative care integration" but does not provide any more clarity. This is important as "integration of palliative care" can be interpreted in many different ways.
Data sources
Does "care home" include both nursing and residential?
Authors: Yes, we have now clarified this. See p5, line 7: ‘care home’ (includes nursing homes and residential homes without nurses).

Projections of place of death
Adding the numbers of care home deaths in Scenario 3 to the percentages would be very helpful to understand what this means in the real world, as would adding numbers to the percentages provided for hospital, care home and home deaths in scenario 4.
Authors: We have now inserted these data in this section (page 7, scenario 3&4), which are also described in Table 1.

Discussion
Page 9 line 22 - refers again to "palliative care integrated with existing services" - I am unclear about whether this means a palliative care approach delivered by all, or the integration of specialist services. This could be addressed by moving the paragraph which provides detail from the discussion to the introduction (as suggested above).
Authors: We agree and have moved this paragraph to the Introduction as suggested. Thank you. Page 4, line 24

The point (lines 27-28) about a fall in the number of care homes is very important for future consideration, as is the suggestion for training to support GPs to deliver good emergency care at the end of life (line 58).
Authors: Thank you. We have also expanded this point to include figures for care home places which are also declining, as per Reviewer 1’s comments.

I wonder if there are references about project ECHO that could be added - page 10, lines 4-5
Authors: We already include a reference to ECHO. Reference 37 is a reference to an ECHO evaluation, page 10, line 5. Due to space limitations we have not described ECHO specifically, but agree it is important so have noted it here.

Page 10 line 8 consider "many people" instead of "most" (as above)
Authors: We have amended this – thank you.

Conclusion
The conclusion could be strengthened with a bit more detail around the sentence "However, this is very unlikely" - it would be interesting to hear the authors view on why this is very unlikely. This would provide important context for the clear recommendations provided.
Authors: Thank-you. We have added some context: “However, this is very unlikely without additional investment in community-based care including care home capacity” Page 11, line 24

Cecila Larsdotter (f Håkanson), PhD, associate professor (Reviewer 3):
Dear authors,
This in an overall interesting and highly relevant study that I think is highly needed in order to take the place of death discourse to a new level in terms of informing future policy in all countries.
I have only minor comments to this well written manuscript, mainly about some unclarities that I think will be helpful for the readers to see revised.

Authors: We thank Reviewer 2 for the very positive comments.

In the background section you describe the worldwide demographic shift. You also mention that the number of deaths in Scotland has increased but you present no numbers about the ageing progression in the country, which you do about the world - this would provide sense-making information.

Authors: Good point. Thank you – we have now added a sentence on this:
“People aged 85 and over accounted for one-third of all deaths in 2017; this is projected to rise to 45% by 2040”. See page 4, line 17.

You also in one section describe the changes (and continuity) related to causes of death, but you have, as far as I can see not included diagnosis in any of your analyses, so this information seems less relevant. I would rather have seen information about the current infrastructure related to the ageing population and to palliative care/place of death in the country, i.e. what’s the situation regarding number of nursing home beds/hospital beds and nursing home/hospital deaths for example? This is a major part of your discussion and as well the focus of your scenario analyses, and in the discussion, you relate to the situation in other countries, so this information is really lacking in my opinion.

Authors: Thank you. We have now added detail on the Scottish context to the introduction to increase the relevance of this paragraph (see paragraph 4 in the Introduction). We have added data on the number of people aged 85 and over who die in Scotland. We provide information on where people die in Scotland in the results section (recent trends in place of death in Scotland) (page 7, Ln1).

There is some unclarity about the way data was derived from the experts, and analyzed, i.e. were they individually interviewed regarding personal recommendations? And, was this during the same occasion when all other experts were present? And what did you do with the group discussions? The presentation of the findings suggest that the text is a summary of some kind of qualitative analysis more than what is described about the prioritizing and flip charting. Please clarify this part of the method section.

Authors: We have now added further detail in the methods to clarify. Page 6, paragraph on design and data analysis). The process is also clarified in Supplementary Table 1.

In the discussion you claim the home death preferences, previously shown in studies as a reference when discussing your results. However, one could question how relevant this is, as we know for a fact that most of these studies do not target older people's preferences, and certainly not people with cognitive deficiencies (which is a large and growing group of individuals of direct relevance for forecast projections and future palliative care needs. In fact, these people have rarely been voiced about their preferences.

Authors: Thank you. We take your point, which also reflects that of reviewer 2. We have amended our wording to state that ‘many’ as opposed to ‘most’ people express a preference to die at home if the circumstances allow. See page 10, Line 8.

Finally, you refer to the need for a realistic debate -I think you need to be more clear about what a realistic debate implies.

Authors: We have added further detail in the discussion, and a reference on Realistic Medicine, which is aligned with the idea of a realistic approach to care in Scotland. See page 10, Line 36 and also page 8, line 53.