PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	How many people will need palliative care in Scotland by 2040? A mixed method study of projected palliative care need and recommendations for service delivery
AUTHORS	Finucane, Anne; Bone, Anna; Etkind, Simon; Carr, David; Meade, Richard; Munoz-arroyo, Rosalia; Moine, Sébastien; Iyayi-igbinovia, Aghimien; Evans, Catherine; Higginson, Irene; Murray, Scott

VERSION 1 – REVIEW

REVIEWER	Heidrun Golla, MD University of Cologne, Faculty of Medicine and University Hospital of Cologne Department of Palliative Medicine Kerpener Strasse 62 50924 Cologne, Germany
REVIEW RETURNED	03-Jul-2020

GENERAL COMMENTS	Thank you very much for the invitation to review this overall carefully thought out and interesting manuscript which I received on July 2, 2020. Comments: Abstract: clear, well-written, no remarks Bullet points: 5 strengths and 1 limitation, the latter with respect to Covid-19 which -in my view- does not fit the aim and scope of the manuscript very well. I would prefer a balanced strengths and limitations ratio and suggest to eventually remove the Covid-19 discussion from this manuscript. Background: It was a pleasure to read the background section, it smoothly leads into the following manuscript. Methods section: also largely well-thought-out and well-written. However, in all sections changes are assumed to be „linear“. Why? What is the rationale behind this? In my opinion, the expert composition is not optimal: What was the rationale behind the selection of the sample? Rather few persons and sometimes only one representative was involved (e.g. from volunteers), the number of researchers was equal to the number of GPs (4 each), only two physicians specialized in palliative care and two palliative care nurses, no representatives of other essential professional groups such as e.g. psychotherapists, physiotherapists, representatives of spiritual care or consultants

	from other disciplines confronted with the diagnoses chosen from ICD 10 (e.g. neurologist, internal physician). Is the chosen sample really capable of formulating and deciding on such far-reaching and important recommendations? Are key representatives not missing or only represented by a rather small sample? On which basis, how and who developed the recommendations? This does not become particularly clear to me (but this seems to be an important point, at least in my humble opinion). Results: My major concern in the results section (as in the discussion section) is that the results obtained with the less conservative method are more stressed than those obtained with the more conservative methods. E.g. page 14 ll33-35 „By 2040, we estimate that between 74% and 95% of those who die might benefit from a palliative care approach (Table 1)“. On the one hand this is not wrong, on the other hand it is left out that with method 1-2b the relative share of deaths with PC needs does not change at all from 2007-2040 (always about 75%); only with method 3 the jump to 95% occurs. This way of presenting the results continues (to give only one further example page 17 section „proportion of people dying with multimorbidity associated with… „). I would prefer a more balanced representation and discussion of results found with the different methods used. Figure 2: It does not seem clear to me why there should be fewer "other diseases" in 2040, which include per definition of the authors long-term neurological conditions. Here it is to be expected that these will increase significantly in the future. Unfortunately, this is not discussed. Discussion: See comment regarding the results section (i.e., suggestion for a balanced representation and discussion of results). E.g. page 21 ll.3-6: Yes it is right that the vast majority will profit from the palliative care approach but using the more conservative approaches the percentage constantly remains around 75%. Minor: page 18 ll54-56: „…. more people may need palliative care….“ (more people than / compared to?) Page 19 ll 15-17.: “it is recommended to invest in digital systems”. Please explain a little bit more at that point what do you mean with digital systems. Increase in digital systems may not make sense in general, especially if you anticipate a significant increase in the number of demented people as shown e.g. in Figure 2. Page 21, ll 52/53: „Primary care providers will be trained …. and will work… „ I wonder whether it is clear that this will happen or isn't this rather a desire/proposal which should then be worded as such (e.g. should). Strengths and limitations section: please add some of the aspects I mentioned in this section. Moreover, at least in my opinion the discussion on Covid-19 in the discussion section seems to me to be a bit deliberate. I doubt that this is really helpful in this manuscript. Conclusion: Something like „Depending on the model used“ should be added as introductory phrase to the sentence „by 2040, we

	project that many more people in Scotland will die with palliative care needs,…."

REVIEWER	Ana Isabel González-González Institute of General Practice. Goethe University. Frankfurt am Main. Germany.
REVIEW RETURNED	29-Sep-2020

GENERAL COMMENTS	RECOMMENDATION: Minor revisions required. REVIEWER COMMENTS TO AUTHOR Thank you for your submission, it was good to see that you have planned a study to estimate the need for palliative care in the multimorbid patients in your region. I am sure this should make a good contribution to the literature and support the planning of future resources needed to face the more need for palliative services. My comments are mainly (very minor) suggestions for details and clarification. I hope that the following review will support your ongoing work: - Title – Titles should mention the study design. - Methods – When defining multimorbidity, please specify if you are only considering chronic conditions. - Methods – How were the participants in the expert consultation approached? Which were the selection criteria for such a group? How was the response rate? - Discussion – Why the different methodologies reached different numbers? I think it would be advisable to comment in the discussion section on the differences or similarities in the number of deaths due to the use of different methods to estimate. I wish you all the succes for your manuscript and the overall work.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Reviewer Name: Heidrun Golla, MD
Institution and Country: University of Cologne, Faculty of Medicine and University Hospital of Cologne
Department of Palliative Medicine
Kerpener Strasse 62
50924 Cologne, Germany

Reviewer 1 Comment	Authors Response
Thank you very much for the invitation to review this overall carefully thought out and interesting manuscript which I received on July 2, 2020.	Thank-you for your considered and thoughtful feedback. We have revised our manuscript in response to your suggestions below. This has added clarity, and we are very grateful to you for this.

Abstract: clear, well-written, no remarks	Thank-you
Bullet points: 5 strengths and 1 limitation, the latter with respect to Covid-19 which -in my view- does not fit the aim and scope of the manuscript very well. I would prefer a balanced strengths and limitations ratio and suggest to eventually remove the Covid-19 discussion from this manuscript.	We have removed the bullet point on COVID. We moved the bullet point stating that trends were drawn on data over the previous 11 years. We added 2 limitations and now have 3 strengths and 2 limitations.
Background: It was a pleasure to read the background section, it smoothly leads into the following manuscript.	Thank-you
Methods section: also largely well-thought-out and well-written. However, in all sections changes are assumed to be „linear“. Why? What is the rationale behind this?	Thank-you. We applied linear models as we were primarily interested in projections of what may occur if recent trends in cause of death continue linearly. This is in line with a previous publication on projections of palliative care need (Etkind et al, 2017) Our projections should not be interpreted as a forecast of what will happen, rather they provide a starting point for discussions around what might happen, and what actions might be advocated for if recent trends continue. We have added a sentence in the strengths and weakness section noting this.
In my opinion, the expert composition is not optimal: What was the rationale behind the selection of the sample? Rather few persons and sometimes only one representative was involved (e.g. from volunteers), the number of researchers was equal to the number of GPs (4 each), only two physicians specialized in palliative care and two palliative care nurses, no representatives of other essential professional groups such as e.g. psychotherapists, physiotherapists, representatives of spiritual care or consultants from other disciplines confronted with the diagnoses chosen from ICD 10 (e.g. neurologist,	As outlined in the Methods section (under ‘expert consultation and consensus survey’), we sought a purposive sample of stakeholders from palliative care, primary care and social care along with commissioners, service providers, government representatives, researchers, patient/ carer groups and charities. We focused primarily on those involved in palliative care service design as we wanted to advocate to policy-makers in this area. We agree that it would have been even better to have included a neurologist, internal physician, or those from other professional groups. We

internal physician). Is the chosen sample really capable of formulating and deciding on such far-reaching and important recommendations? Are key representatives not missing or only represented by a rather small sample?	have now noted this in the strengths and weakness section (first paragraph). Overall, our participants were capable of formulating recommendations for our targeted policymakers and funders. We have been clear and transparent in providing details on the general roles of these individuals without compromising confidentiality; so it is clear where the recommendations have come from.
On which basis, how and who developed the recommendations? This does not become particularly clear to me (but this seems to be an important point, at least in my humble opinion).	We have added further detail to the section "expert consultation and consensus survey" clarifying who developed the recommendations and how.
Results: My major concern in the results section (as in the discussion section) is that the results obtained with the less conservative method are more stressed than those obtained with the more conservative methods. E.g. page 14 ll33-35 „By 2040, we estimate that between 74% and 95% of those who die might benefit from a palliative care approach (Table 1)". On the one hand this is not wrong, on the other hand it is left out that with method 1-2b the relative share of deaths with PC needs does not change at all from 2007-2040 (always about 75%); only with method 3 the jump to 95% occurs. This way of presenting the results continues (to give only one further example page 17 section „proportion of people dying with multimorbidity associated with… „).	We present all the data in the results section so readers can clearly see the outcomes given different scenarios. Our analysis of palliative care need both by age and disease group is based on Method 2b – a more conservative method. However, in response to the reviewers point, we have added a section in the discussion drawing attention to the finding that the overall % of people with palliative care needs did not increase for Method 2A/B. See 'findings in relation to existing evidence'. In all areas of this paper we report the range given different models and have provided the data so readers can see the differences in % and numbers under different scenarios. We have stressed the less conservative results as the method we used then, method 3 we believe is a more detailed projection of future need as it innovatively identifies palliative care needs from both main cause of death and contributing causes We have inserted this in the text p12 Estimate 3:

	"Thus, Method 3 should yield the most accurate and comprehensive estimate of deaths associated with palliative care need in a calendar year.
I would prefer a more balanced representation and discussion of results found with the different methods used.	We have added a section in the discussion drawing attention to the reviewers point that the overall % of people with palliative care needs did not increase for Method 2A/B. See 'findings in relation to existing evidence'.
Figure 2: It does not seem clear to me why there should be fewer "other diseases" in 2040, which include per definition of the authors long-term neurological conditions. Here it is to be expected that these will increase significantly in the future. Unfortunately, this is not discussed.	Thank-you for noting this which we agree deserves some discussion. Our category, "other diseases" , include cerebrovascular diseases (mainly stroke) and HIV. Other research has shown that while the number of people living with stroke will rise in the years to come, the number of people dying with the condition is projected to fall. See: Wafa HA, Wolfe CDA, Emmett E, et al. Burden of Stroke in Europe. *Stroke* 2020;51(8):2418-27. Similarly, in Scoltand the number of people diagnosed with HIV has fallen over the last decade. The projected fall in mortality due to cerebrovasular disease and HIV is likely to be one reason why those dying of 'other diseases' are projected to decrease. We now have added a sentence on this in the Discussion – under 'findings' in relation to existing evidence.
Discussion: See comment regarding the results section (i.e., suggestion for a balanced representation and discussion of results). E.g. page 21 ll.3-6: Yes it is right that the vast majority will profit from the palliative care approach but using the more conservative approaches the percentage constantly remains around 75%.	As above - we have added a section in the discussion drawing attention to the reviewers point that the overall % of people with palliative care needs did not increase for Method 2A/B. See 'findings in relation to existing evidence'
Minor: page 18 ll54-56: „…. more people may need palliative care…." (more people than / compared to?)	Thank you. We have added "compared to 2017".
Page 19 ll 15-17.: "it is recommended to invest in digital systems". Please explain a little bit more at that point what do you mean with digital systems. Increase in digital systems may not make sense in general, especially if you anticipate a significant increase in the number of demented people as shown e.g. in Figure 2.	We have now added an example: "Experts recommended sustained investment in digital systems*, such as electronic care co-ordination systems that are accessible to patients, carers and professionals*, alongside prioritisation of person-centred approaches.

Page 21, ll 52/53: „Primary care providers will be trained …. and will work… „ I wonder whether it is clear that this will happen or isn't this rather a desire/proposal which should then be worded as such (e.g. should).	Thank you – we have now reworded this sentence: "Primary care providers need to be trained as 'expert generalists' and need to work more closely with palliative care specialists…."
Strengths and limitations section: please add some of the aspects I mentioned in this section. Moreover, at least in my opinion the discussion on Covid-19 in the discussion section seems to me to be a bit deliberate. I doubt that this is really helpful in this manuscript.	We believe that some discussion of COVID-19 is relevant in this paper. We clarify that our projections did not account for COVID – and we believe that this should be stated under the strengths and weaknesses. We provide the latest data at the time of writing, on COVID deaths in the older population in Scotland, and we refer to our recent publication on changing patterns of mortality during the COVID pandemic. We acknowledge that COVID may result in a change in the patterns of deaths in the coming year, but we also note that it does not change our overall message that palliative care need is projected to increase in the coming decades.
Conclusion: Something like „Depending on the model used" should be added as introductory phrase to the sentence „by 2040, we project that many more people in Scotland will die with palliative care needs,…."	Many thanks. We have changed this to: "By 2040, irrespective of the estimation method used, we project that many more people in Scotland will die with palliative care needs, particularly in the oldest age groups; and care complexity will increase."

Reviewer: 2
Reviewer Name: Ana Isabel González-González
Institution and Country: Institute of General Practice. Goethe University. Frankfurt am Main. Germany.

Reviewer 2 Comment	**Authors Response**
RECOMMENDATION: Minor revisions required.	Thank you.
Thank you for your submission, it was good to see that you have planned a study to estimate the need for palliative care in the multimorbid	Thank-you very much,

patients in your region. I am sure this should make a good contribution to the literature and support the planning of future resources needed to face the more need for palliative services. My comments are mainly (very minor) suggestions for details and clarification. I hope that the following review will support your ongoing work:	
Title – Titles should mention the study design.	We have amended the title to include the study design.
Methods – When defining multimorbidity, please specify if you are only considering chronic conditions.	Yes – we have added 'chronic' in the section "Defining, estimating, and projecting multimorbidity." so this is now clear.
- Methods – How were the participants in the expert consultation approached? Which were the selection criteria for such a group? How was the response rate?	We have added detail on this – see response to reviewer 1. However, we could not provide a response rate to the consultation invitation as those contacted were invited to forward the invitation to interested colleagues.
- Discussion – Why the different methodologies reached different numbers? I think it would be advisable to comment in the discussion section on the differences or similarities in the number of deaths due to the use of different methods to estimate.	We have revised our manuscript to discuss this further in the section 'Findings in relation to existing evidence' (Under Discussion).
I wish you all the success for your manuscript and the overall work.	Thank you very much.

VERSION 2 – REVIEW

REVIEWER	Heidrun Golla, MD University of Cologne, Faculty of Medicine and University Hospital of Cologne, Department of Palliative Medicine Kerpener Strasse 62 50924 Cologne
REVIEW RETURNED	29-Nov-2020

GENERAL COMMENTS	Thank you, no further comments.