Author’s response to reviews

Title: Development of quality indicators for the measurement of the organisation of palliative care in Europe: The Europall project

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Version: 4 Date: 16 July 2012

Author’s response to reviews: see over
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Dear Natalie Pafitis,

Thank you for giving us the opportunity to re-submit our paper (MS: 2050296145621786): “Development of a set of process and structure indicators for palliative care: the Europall project”, and for the helpful comments of both reviewers, who considered it an interesting and relevant paper.

We adapted the paper accordingly, and hereby react on each comment of the reviewers. We hope that this first international study on process and structure QIs will be accepted in your paper.
Reviewer 1. (Roeline Pasman)

Although interesting and relevant, I think this paper lacks sufficient detail to assess the quality of the development procedure and developed QI set. According to me, this paper needs at least further explanation on the concepts and methods used, which can be seen as Major Compulsory Revisions.

*As general remark she asks for further explanation on the concepts and methods, which we did (see track changes document).*

The authors focus on the organisation of palliative care specifically, and define this as: “systems to enable the delivery of good quality in palliative care”. The authors give no further operationalization of this definition, or aspects of organisation of palliative care. What for instance means “good quality”? In the methods where they describe the QI selection they say that project members were asked to indicate whether the suggested QI was a criterion for the organisation of palliative care. But it is not clear which criteria were used.

*We changed ‘the organization’ in ‘processes and structure’ to make it clearer and link it to the usual wording of quality indicator (QIs). We consider those QIs as good, that were found in literature and were accepted by the experts. (p.3, l.26 p.4, l.21-22)*

At several points the authors mention the recommendations for palliative care of the European Council, and that for measuring the quality of the organisation of palliative care this should meet the recommendations. However, the authors do not elaborate on these recommendations, nor reflect in the discussion on them by stating to what extent the QI set covers the recommendations of the European council. I would suggest a framework with the aspects of organisation of palliative care maybe combined with recommendations of the European council (and aspects of the definition of palliative care of the WHO) to classify the QI set. The authors use a previously developed framework, and it is possible that this meets the above mentioned classification, but that does not become clear in the paper. Such a framework based on used concepts is also necessary to determine which QIs are lacking.
We agree that we did not give any further details on the content of the recommendations we referred to. We added them, and also added information that the framework we used to categorize the QIs contains the elements of the recommendations. (p.3, l.14)

Methods:
The title of the paper suggests a systematic review, but the paper describes a development process of QI sets, with a review as part of this.

We agree and adapted the title accordingly. (p.1, l.1)

Review part:
The authors state that they used as inclusion criterion publication date from December 2007 to May 2009, as a previous systematic review ran until December 2007. However, it is not clear to me if and how they used the results of this previous review in their review.

As your systematic review was published within the search period, it has been included.

Above that, the previous review used less databases than the authors used in their review. Shouldn’t they have used a broader date range for these additional databases?

We used your review as a starting point. It has been peer reviewed, published and contained a good overview of the existing QIs at that moment. We did not feel the need to search the same period again. Yet, for the period we focused on, we decided to include more databases as we wanted to be as complete as possible. (p.5, l.2)

Furthermore, they state that they used the search strategy of the previous review, but they also state that they were not only interested in papers describing QIs, but also interested in publications that describe characteristics of the organisation of palliative care, in order to develop QIs that are not available yet. Was this search strategy suitable to systematically find publications that describe characteristics of the organisation of palliative care?

We were not clear enough in the methods section and adapted this. In the literature review, we collected (sets of) QIs. In the grey literature search we searched characteristics for the
organization of palliative care, if no suitable QIs on a relevant topic were found in the main search. (p.5, l.21)

What exactly were the inclusion and exclusion criteria for this review? Information is given in the different subparagraphs in the methods section, and it would be much clearer to give a clear list at one point in the methods section.

We changed the text about in- and exclusion criteria accordingly. (p.5, l.8)

Developmental process

It is not clear to me how exactly the QI selection went: Which criteria for the organisation of palliative care were used? This is not operationalized.

As mentioned before, we included structure and process QIs.

Was there a special procedure for suggesting new QIs (how was it assessed to be relevant?) and adaptations of found QIs? In the results is mentioned that 20 new QIs were developed based on important organisational aspects found in the literature. This needs further explanation and I would suggest a table with the found important organisational aspects and the QIs developed based on this found important organisational aspects. Also 90 (of the 110) found QIs were adapted. Please give more insight in this procedure. What is meant by “adaptations of an existing framework” (point 3 indication each QI)

As more clearly mentioned in the adapted paper, we categorized the QIs found in literature in the framework. This is a framework based on a previous European project. We changed it in order to complete it with the recommendations of the Council of Europe.

After the search, some domains or subdomains did not contain sufficient QIs. Therefore we performed a grey literature search to be able to develop QIs ourselves. This is one of the accepted methods to develop a set of QIs. We adapted so many QIs found in literature, because sets of QIs are often developed for a specific group of patients or a specific ward (e.g. ICU), that could quite easily be adapted to make them more general. (p.7, l. 20)
Why is QI 2 in table 3 excluded?

This QI has been excluded after a long discussion. There was no consensus whether it is a quality criterion if the own GP is available out of hours for his own patients, or whether it is better that the out of hours service has all the information of each palliative care patient. Besides, this was not a QI that fits in all participating countries.

General comments
The paper lacks any reflection on the differences between European counties regarding organisation of palliative care, nor whether the developed QI set is suitable for all European countries. For instance, in the grey literature only ‘policy’ papers from Belgium, The Netherlands and the UK were found. And are the found QI’s originally developed in different European countries? In other words: how European is this QI set? In the last paragraph about further research it is stated that a modified Rand Delphi group procedure is done and pilot tests in 26 countries. I think this paper would be better if this RAND procedure is integrated in current paper.

In this study, we did not focus on differences between countries regarding palliative care organization. We did this in a previous study, and the results have been published in a book (Sam H Aahmedzai, Xavier Gómez-Batiste, Yvonne Engels et al.: Assessing Organisations to Improve Palliative Care in Europe. Vantilt Publishers, Nijmegen, the Netherlands & Martien Frijns, Doetinchem, the Netherlands, 2010, ISBN 978-94-91024-01-6).
As the development of the final set of structure and process QIs was a multi step procedure, we did not include the Delphi and pilot in the same paper. We would not have been able to give all details if we would have.
We added as a limitation that the experts were only from 7 European countries. (p. 8, l.25)

The authors state in the discussion that the use of the QI set is partly comparable to Claessen et al. This makes me wonder what the current paper adds to this Claessen study.

We agree that this was a strange sentence. What we meant to say is that as well Pasman as we did not focus on one specific setting or sub population of palliative patients, like in many QI-sets (ICU set). Anyhow, we adapted the text and made clear that we focused on structure and process and on another period. (p. 4, l. 23-25)
Reviewer 2. (Katja Hermann)

1. Results section: I was a bit confused by the paragraphs on QI development. To understand the performed procedure it could be helpful if the authors provide a flow chart for the development of the indicators in addition to the flow chart demonstrating the included/excluded studies.

   *We agree that adding a flow chart makes the steps much clearer. We added it. Thank you for this suggestion.* (p. 6, l. 18)

   Maybe you could also restructure the paragraphs since it is not always clear which indicator set is referred to, i.e. 3rd paragraph, last sentence: The 14 excluded QIs mentioned do not belong to the n=110, do they belong to the n=142? What about the other 18 excluded QIs, then?

   *We adapted the text to make it clearer and gave the information in the flow chart.* (p. 18)

   Wouldn’t it generally be better to include the reasons for exclusion with the statement “resulted in a reduction from 142 to 110 QIs” in the second paragraph? (Discretionary Revision)

   *We added this in the text and gave an example.* (p. 7, l. 11)

2. The manuscript describes that 20 QIs were newly developed (Results, QI development, 4th paragraph). However, Appendix C shows 24 QIs with the description “New developed” – Among the first 15 QI in the appendix (all new developed), no. 1, 8 and 9 are missing in table 4.

   *We adapted this.* (p. 19)

   As I understood, some of the QIs (i.e. no. 1, 9) are more general QIs (a summary of the following). Do you want to treat them as a single QI or rather as a heading for a group of QIs
(which is not measurable in itself)? This should be described more clearly. The QI about bereavement support (no. 8) is completely missing in the manuscript without reasons given. Again, a flow chart might also help.

Indeed, it was discussed within the steering group meetings whether a QI with several sub QIs should be mentioned to be one QI or more ones. We made a pragmatic decision to mention them in the overview as one QI, but in the next steps (Delphi and pilot study) they of course were operationalised as different QIs. As this is a next step in the development process, this will be described in the pilot study paper.

3. The new developed QIs in table 4 are phrased differently than in the appendix (and than the other QIs). Could you please explain why you used a different wording? It is difficult to measure “should” (as phrased in table 4) – do you have an approach for that? Otherwise you could use the expressions from the appendix.

We adapted this.

Minor Essential Revisions:
1. To get a good overview of the setting specific QIs in table 2 and to follow the description in the manuscript, the setting should be specified in the table.

We agree that this was missing. We added it in the table (p.19).

2. There is a spelling mistake in reference 46 (Pronost et al. 2008): “haematology-oncology”. In addition: isn’t this a French publication (full text) and should therefore have been excluded from the analysis?

Thank you for this. We adapted it.