Author’s response to reviews

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

Authors:

Kathrin Woitha (k.woitha@anes.umcn.nl)
Karen van Beek (karen.vanbeek@uzleuven.be)
Nisar Ahmed (n.ahmed@sheffield.ac.uk)
Jeroen Hasselaar (j.hasselaar@anes.umcn.nl)
Jean-Marc Mollard (Jm.mollard@reseau-ensemble.org)
Isabelle Colombet (Isabelle.Colombet@spim.jussieu.fr)
Lukas Radbruch (Lukas.Radbruch@malteser.org)
Yvonne Engels (y.engels@anes.umcn.nl)
Kris Vissers (k.vissers@anes.umcn.nl)

Version: 2 Date: 24 November 2011

Author’s response to reviews: see over
Quality indicators for the measurement of the organisation of palliative care in Europe: a systematic review

Kathrin Woitha1, Karen Van Beek2, Nisar Ahmed1, Jeroen Hasselaar1, Jean-Marc Mollard5, Isabelle Colombet6,7, Lukas Radbruch4, Yvonne Engels1, Kris Vissers1

1. Radboud University Nijmegen Medical Centre, Department of Anaesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands
2. University Hospital Leuven, Department of Radiotherapy-Oncology and Palliative Medicine, Leuven, Belgium
3. Academic Unit of Supportive Care, School of Medicine and Biomedical Sciences, The University of Sheffield, Sykes House, Little Common Lane, Sheffield S11 9NE, UK
4. University of Bonn, Malteser Hospital Bonn/Rhein-Sieg, Department of Science and Research in Palliative Medicine, Bonn, Germany
5. Réseau de Santé, Paris Sud, France
6. Santé Publique Informatique Médicale, Faculté de Médecine de Paris 5, Paris
7. DIH-Evaluation et Gestion des Connaissances, Hôpital Européen G Pompidou, Paris

Kathrin Woitha
Radboud University Nijmegen Medical Centre
Department of Anaesthesiology, Pain and Palliative Medicine
Geert Grote Plein 10,
6500 HB Nijmegen
The Netherlands
k.woitha@anes.umcn.nl
T +31 (0) 24 3613793
F +31 24 3613585
ABSTRACT

Background: By measuring the quality of the organisation of palliative care with quality indicators (QIs), caregivers and policy makers are able to monitor to what extent recommendations are met, like those of the council of the WHO on palliative care and guidelines. This will support the implementation of public programmes, and will enable comparisons between organisations or countries.

Methods: As no European set of indicators for the organisation of palliative care existed, such a set of QIs was developed. A previously applied search strategy was used and several scientific databases searched. Additionally grey literature in the individual countries was screened. Further, reference lists of obtained papers were studied and hand searches were performed. Evidence of existing QIs was obtained from scientific databases, grey literature and hand searches in the time range from December 2007 till May 2009. In two project meetings the QI development process was finalised.

Results: The searches resulted in 142 indicators, which were discussed in steering group meetings. Of those QIs, 110 were eligible for the final framework.

Conclusion: We developed the first European set of QIs for the organisation of palliative care. This article is the first step in a multi step project to identify, validate and pilot QIs.

Keywords: Quality indicator, organisation, Europe, Public Health, Palliative care, Europall
Background

Following the 2002 definition of the World Health Organisation (WHO), [1] palliative care is no longer restricted to patients with cancer; it should be available for all patients with life-threatening diseases. Furthermore, palliative care is applicable early in the course of the disease and can be delivered in conjunction with therapies that aim to prolong life. Palliative care needs a team approach in order to relieve not only pain and other somatic symptoms but also to provide multi-dimensional care including psychosocial and spiritual care and support for patients and their proxies. This wider definition implies an increase of the number of patients eligible for palliative care. Due to successful medical interventions, the aging population and improved survival of patients with chronic diseases or with cancer, the demand for palliative care will increase too. [2,3]

In 2003, the Council of Europe launched recommendations for the organisation of palliative care. This included further development of cooperation between European countries. [4] As most scientific studies focus on clinical outcomes, it is unclear whether these recommendations and the WHO definition have been implemented in the organisation of palliative care in Europe. By measuring the quality of the organisation of palliative care, caregivers and policy makers can monitor whether in their country, specific settings and networks for palliative care meet the recommendations of the council of Europe and of the WHO. This information would give better insight, which is needed for the measurement of the impact of palliative care programs. [5]

A valid and reliable method for assessing the quality of the organisation of care is the use of quality indicators (QIs). QIs are ‘explicitly defined and measurable items referring to the outcomes, processes or structure of care’. [6,7] In a systematic review published in 2009,
clinical indicators appeared to be widely overrepresented over indicators that assess organisational issues of palliative care, and most QIs were developed in and for one specific country and setting. [8]

Therefore, we aimed to develop a scientifically sound European set of QIs, which can be used to assess the quality of the organisation of palliative care settings regarding all aspects of the WHO definition in all European countries.

Methods

The study, undertaken by partners from seven collaborating countries (Belgium, United Kingdom, France, Germany, Netherlands, Poland and Spain), ran from October 2007 till September 2010. [9] It was co-funded by the European Executive Agency for Health and Consumers (EAHC).

The initial phase of this project was a systematic review aiming to find already existing QIs in literature or aspects of the organisation of the palliative care for which QIs would be useful. QIs were operationalized as ‘measurable items referring to the outcomes, processes or structure of care’. [6,7] Organisation of palliative care was defined as ‘systems to enable the delivery of good quality in palliative care’. [11] Besides publications that describe the development or use of QIs for the organisation of palliative care, publications were used that describe characteristics of the organisation of palliative care, in order to develop QIs if not available yet.
Main database search

The following bibliographic databases were searched: Medline, Scopus, PsycINFO, Social Medicine, CINAHL, the Cochrane Database, Embase, SIGLE, ASCO, and Google Scholar by a previously applied search strategy (Appendix A). [10] If applicable, Mesh terms were changed, as these are database-specific.

Inclusion criterion was a publication period from December 2007 to May 2009, as a previous systematic review ran until December 2007.

The initial selection process was based on title and/or abstract, followed by a selection based on full text. Additionally, reference lists of obtained papers were studied and hand searches were performed (Current Opinion in Supportive and Palliative Care, Journal of Pain and Symptom Management, Palliative Medicine and Quality and Safety in Health Care journal).

Papers describing indicators about palliative care for children, clinical outcome indicators, patient outcome, treatment, as well as papers about assessment and reliability of symptom performance scales were excluded. Clinical outcome indicators were excluded because Pasman et al. cover them in their paper and we put the focus on structure and process indicators. [12] Also scientific papers that were not written in English were excluded.

Grey Literature Search

Grey literature was defined as ‘literature which has not been formally published in the peer-reviewed literature’ (REF COOK). [13] Inclusion of grey literature was restricted to reports from government agencies or scientific research groups, white papers or websites from national organisations and limited to the seven participating countries. Finally, the network of the Europall research group was used to identify relevant papers.
Methods of screening and article selection
The steering group of the Europall project planned two meetings in September and October 2009 with all project members (Appendix B). Before the first meeting titles and abstracts were screened independently by three researchers. Full papers of relevant papers were accessed and again independently assessed.

Data extraction
Of each paper, study results, author, year of publication, study design, study population, and QIs were documented.

QI selection
The resulting draft QI set was presented to the whole research group during the first steering group meeting in September 2009. Academic experts from several disciplines in palliative care, all from one of the seven participating European countries were present. Each QI was discussed.
The project members indicated 1. whether the suggested QI was a criterion for the organisation of palliative care, 2. whether it overlapped with other proposed QIs, 3. to which domain of an adaption of an existing framework it belonged. [87] and 4. for which settings it was applicable.

Additionally, the project partners could suggest new QIs about aspects that were relevant but not yet operationalised as QIs.
The researchers captured individual comments and suggestions concerning the QIs. Adaptations were made and a new draft QI set was presented in the second steering group meeting in October, where the same procedure was followed.
Results

Search flow

The literature search resulted in 527 papers. After identification of 16 duplicates of 511 papers, title and abstract were screened. Of these, 389 documents were excluded, as they did not contain QIs. Full papers were obtained of 122 publications, from which 63 papers were included; 57 resulting from the database search [14-70] and another six papers from the additional hand searches. [71-76]

Results Grey literature search

The grey literature search added nine papers, deriving from Belgium, the Netherlands and the UK. [77-86] These sources included government sites, national health organisations or national institutes.

QI development

Six-hundred-thirty-five candidate indicators were derived from this literature review. After screening of duplicates, deleting outcome indicators and combining indicators covering the
same topic, the remaining 142 QIs were organised in a framework and presented in the first steering group meeting.

The two steering group meetings resulted in a reduction from 142 to 110 QIs (Appendix C). These QIs were distributed in the theoretical framework. [87] The framework consisted of 10 domains with specific subcategories (table 1).

The majority of the 110 QIs were process indicators (n=76), the other structure indicators (n=34). Some of the QIs (n=24) were only applicable in specific settings; ten in primary care, thirteen in inpatient settings and one in home care (table 2). The others can be used in all settings that deliver palliative care. Fourteen QIs were excluded, as they had no relation to palliative care, were too comprehensive or not clear (table 3).

Further, 20 QIs were developed based on important organisational aspects found in literature (e.g. There should be the facilities for a relative to stay overnight.) (table 4). Finally, several QIs, originally developed for other settings like the intensive care unit, were rephrased to make them appropriate for palliative care settings (n= 90) (e.g. Palliative care services should work in conjunction with the referring professional/team.).


Discussion

We were able to develop a European framework with 110 QIs to assess the organisation of palliative care in several kinds of settings and on national policy levels. To our knowledge, this study presents the first systematically developed European set of QIs on this topic. Part of the QIs are setting specific, whereas others will be applicable in all kind of settings that deliver palliative care.

Strength and limitations

We chose an approach with several consecutive methodological steps to develop a set of QIs. Of those aspects that were considered important for the organisation of palliative care but of which no QIs could be found, we developed QIs ourselves. Defining QIs in a consensus procedure is a good option if scientific literature is not yet available, [88] particularly because it combines several methods to improve validity. Using a group approach has the advantage that participants can share their expertise and experience. Besides, groups often make better decisions than individuals. [89] Yet, we do realise that the project meetings reflected the opinion of a certain group.

As health care systems and palliative care change, indicators need to be evaluated and updated regularly, and new QIs need to be developed accordingly.

The naming of QIs as process or structure indicators can be discussed. Not all designed QIs clearly belong to one of these groups. For example, ‘All volunteers have training in palliative care’ could be considered as structure but also as process indicator. Yet, this only influences the categorisation and not the content, importance or use of a QI.
Another strong aspect of this literature search is the inclusion of grey literature, which created the possibility to include documents in other languages than English, and from important although not scientific sources. (REF Genet)

Comparison with existing literature

Where Pasman et al. performed a systematic review on all kind of QIs for palliative care, and Pastrana et al. focused on outcome indicators for Germany, we focused on the organisation, and not on the content of care itself. [90,91] By using an European perspective and by not limiting ourselves to symptom control, our study follows the recommendations of Ostgathe et al. [92] Additionally the use of our QI set is partly comparable to Claessens et al. set. [93] Their set is applicable in all kind of palliative care settings as ours.

Further research

This is the first step in a multi step project to develop a valid, acceptable, feasible and reliable set of QIs for the organisation of palliative care. In next steps, this set of QIs was face-validated in a modified Rand Delphi group procedure, and pilot-tested in 26 countries. These steps will be described separately. The final set can be used to provide feedback to settings or countries to reflect on their performance, for supporting quality improvement activities, accreditation, research, and enhancing transparency about quality. They can be used to evaluate the implementation of the WHO definition and the recommendations of the council of Europe. [94,95]
From 2011 to 2015, a follow-up project to Europall called IMPACT (funded by the EU 7th framework) will develop and test strategies to implement these QIs.

**Conclusion**

This review resulted in the first comprehensive framework of QIs for the organisation of palliative care.

**Competing interest**

This work was partly funded by EAHC (Executive Agency for Health and Consumers, grant: 2006111 PPP ‘Best practices in palliative care’). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. The authors have no financial disclosures.

**Disclosure and acknowledgements**

The authors are grateful to the EAHC (Executive Agency for Health and Consumers) for funding the Europall project. We would like to thank Hristina Mileva from EAHC specifically for her help and support. Further our thanks also go to the many individuals and organisations in
the seven countries that contributed information to the project. We are especially grateful to all those who shared their views with us.

Belgium: Johan Menten

England: Sam Ahmedzai, Bill Noble

France: Jean-Christophe Mino

Germany: Eberhard Klaschik, Birgit Jaspers

Poland: Wojciech Leppert, Sylwia Dziegielewska

Spain: Xavier Gomez Batiste Alentorn, Silvia Paz, Marisa Martinez Munoz

**Funding**

3-year EU project (2007-2010), co-funded by EAHC- Executive Agency for Health and Consumers
Reference List


4. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care


13. [http://www.biblio.uottawa.ca/content-page.php?g=en&s=rgn&c=src-litgris]


59. Teno JM, Connor SR: Referring a patient and family to high-quality palliative care at the close of life: "We met a new personality... with this level of compassion and empathy". JAMA 2009, 301:651-659.


61. Torres-Vigil I, Aday LA, Reyes-Gibby C, De LL, Herrera AP, Mendoza T, Cleeland CS: Health care providers' assessments of the quality of advanced-cancer care in Latin


70. The American Society of Clinical Oncology (ASCO) and the European Society for Medical Oncology (ESMO): ASCO-ESMO Consensus Statement on Quality Cancer Care. *Journal of Clinical Oncology* 2010, 24:3498-3499.


77. Plan van Aanpak Palliatieve Zorg 2008-2010 [http://www.palliatief.nl/LinkClick.aspx?fileticket=yX68iRdBUjw%3d&tabid=3997&mid=10542]

78. Quality and outcomes framework Guidance – Updated August 2004


80. Europall Project [http://www.europall.eu/]

81. End of Life Care Strategy Quality Markers and measures for end of life care


83. Externe indicatoren voor pijn bij kanker [http://www.cbo.nl/thema/Richtlijnen/Overzicht-richtlijnen/Oncologie/]


85. Studie inzake de ontwikkeling van een registratie-instrument voor palliatieve zorg


94. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care

95. World Health Organisation [http://www.who.int/cancer/palliative/definition/en/]
Records identified through database searching (n = 57)

Records identified through reference screening/hand search (n = 6)

Records identified through grey literature search (n = 9)

Studies identified (n = 527)

Records after duplicates removed (n = 511)

Records screened (n = 511)

Records excluded (n = 389)

Full-text articles assessed for eligibility (n = 122)

Full-text articles excluded, with reasons (n = 15 no full papers obtained)

Studies included in qualitative synthesis (n = 72)
Table 1: Quality indicator framework

<table>
<thead>
<tr>
<th>Definition of a palliative care service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to palliative care</td>
</tr>
<tr>
<td>1. Access and availability</td>
</tr>
<tr>
<td>2. Out of hours</td>
</tr>
<tr>
<td>3. Continuity of care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infrastructure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. All settings</td>
</tr>
<tr>
<td>2. Inpatient setting (hospital, palliative care unit, hospice, nursing home)</td>
</tr>
<tr>
<td>3. Home care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assessment tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personnel palliative care services</td>
</tr>
<tr>
<td>1. Staff</td>
</tr>
<tr>
<td>2. Education and training for staff/ volunteers</td>
</tr>
<tr>
<td>3. Support systems</td>
</tr>
<tr>
<td>4. Organisation of care</td>
</tr>
<tr>
<td>5. Information sharing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Documentation of clinical data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Clinical record</td>
</tr>
<tr>
<td>2. Timely documentation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality and safety issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality policies</td>
</tr>
<tr>
<td>2. Adverse events</td>
</tr>
<tr>
<td>3. Complaints procedure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reporting clinical activity of palliative care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
</tr>
<tr>
<td>1. Local level</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
</tr>
</thead>
</table>
Table 2: Setting specific QIs

1. Palliative care is available for the patient and their family by: Phone
2. Palliative care is available for the patient and their family by: Visiting the patient
3. Palliative care is available for the patient and their family by: Bringing the patient to the service
4. For a palliative patient in a crisis, the following can be arranged within 24 hours: Admission
5. For a palliative patient in a crisis, the following can be arranged within 24 hours: An urgent discharge to patients home
6. For a palliative patient in a crisis, the following can be arranged within 24 hours: Transfer to another setting of care
7. The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Opioids and other controlled drugs
8. The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Anticipatory medication for the dying patient
9. The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Syringe drivers
10. General practitioners (GP’s) are routinely called when a patient is being discharged home or transferred to another setting
11. The discharge/transfer letter of palliative care patients contains a multidimensional diagnosis, prognosis and treatment plan (see indicator 48 Clinical record)
12. The primary care out-of-hours service has handover forms (written or -electronic) with clinical information of all palliative care patients in the terminal phase at home
13. Consultations with the patient and/or family / informal caregivers are done in an environment where privacy is guaranteed (e.g. there is a dedicated room)
14. Dying patients are able to have a single bedroom if they want to
15. There are facilities for a relative to stay overnight
16. Family members and friends are able to visit the dying patient without restrictions of visiting hours
17. There is a private place (e.g. dedicated room) for saying goodbye to the deceased
18. For a palliative care patient staying at home there is the possibility, if needed, to provide someone (a volunteer or professional) to stay overnight if needed
19. Palliative care services work in conjunction with the referring professional/ team
20. All relevant team members are informed about patients who have died
21. Within 24 hours of admission there is documentation of the initial assessment of: Prognosis, Functional status, Pain and other symptoms, Psychosocial symptoms, The patient’s capacity to make decisions
22. There is documentation that patients reporting pain or other symptoms at the time of admission, had their pain or other symptoms relieved or reduced to a level of their satisfaction within 48 hours of admission.

23. There is documentation about the discussion of patient preferences within 48 hours of admission.

24. A discharge/transfer summary is available in the medical record within 48 hours after discharge/transfer.

---

Table 3: Excluded QIs

1. Advance directives are available across care settings, while protecting patient privacy, for example by internet-based registries or electronic personal health records.

2. The General Practitioner is available out-of-hours for his palliative care patients in the terminal stages of illness.

3. Percentage vacancies of total employees (full time equivalents).

4. Percentage employees that enter and leave the service within one year (turnover).

5. Illness days as percentage of patients total working days (excl. pregnancy leave).

6. Written goals and aims for quality improvement have been defined or updated.

7. There is a designated person responsible for implementing quality improvement.

8. The following quality improvement methods were used at least once in the past year:
   a. Clinical training
   b. Case discussions
   c. Supervision

9. Number of peer-reviewed publications in the past five years (impact factor).

10. There is a national cancer register.

11. There is a national register of causes of death.

12. The national register of causes of death contains information about place of death.

13. Percentage of cancer deaths who died at home.

14. Percentage of all non-acute deaths who died at home.
### Table 4: New developed QIs

1. The following facilities should be available as part of a comprehensive palliative care service: Day care
2. The following facilities should be available as part of a comprehensive palliative care service: Home care support team
3. The following facilities should be available as part of a comprehensive palliative care service: Hospice beds
4. The following facilities should be available as part of a comprehensive palliative care service: Hospital support team
5. The following facilities should be available as part of a comprehensive palliative care service: Inpatient hospital beds (e.g. palliative care unit)
6. The following facilities should be available as part of a comprehensive palliative care service: Outpatient clinic
7. A palliative care team should be available at the request of the treating professional/team in all of the following settings: Day care
8. A palliative care team should be available at the request of the treating professional/team in all of the following settings: At home
9. A palliative care team should be available at the request of the treating professional/team in all of the following settings: Hospital
10. A palliative care team should be available at the request of the treating professional/team in all of the following settings: Hospice
11. A palliative care team should be available at the request of the treating professional/team in all of the following settings: Nursing home
12. A palliative care team should be available at the request of the treating professional/team in all of the following settings: Outpatient clinic
13. There should be a dedicated room where multi-disciplinary team meetings within one setting takes place.
14. Dying patients should be able to have a single bedroom if they want to.
15. There should be the facilities for a relative to stay overnight.
16. There should be a private place (e.g. dedicated room) for saying goodbye to the deceased.
17. Palliative care services should work in conjunction with the referring professional/team.
18. From the database the service should be able to derive: Time from diagnosis to referral to palliative care
<table>
<thead>
<tr>
<th>Metric</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from referral to initiation of palliative care</td>
<td></td>
</tr>
<tr>
<td>Time from initiation of palliative care to death</td>
<td></td>
</tr>
<tr>
<td>Frequency of unplanned consultations with the out-of-hours service</td>
<td>for palliative care patients who are at home</td>
</tr>
<tr>
<td>Frequency of unplanned hospital admissions of palliative care patients</td>
<td></td>
</tr>
<tr>
<td>Percentage of non-oncological patients receiving palliative care</td>
<td></td>
</tr>
</tbody>
</table>

19. All health and social care professionals should have standardised learning objectives for continuing basic training in palliative care.

20. There should be a program for specialised training in palliative care for professionals working in a service that provides specialised palliative care.