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Quality Indicators for the Organisation of Palliative Care in Europe



KATHRIN WOITHA

**QUALITY INDICATORS FOR THE
ORGANISATION OF PALLIATIVE CARE
IN EUROPE**

Kathrin Woitha

Colophon

The studies in this thesis have been performed at the Department of Anesthesiology, Pain and Palliative Medicine of the Radboud University Medical Center.

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QUALITY INDICATORS FOR THE ORGANISATION OF PALLIATIVE CARE IN EUROPE

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“Everything will be all right in the end... if it's not all right then it's not yet the end.”

Sonny (Best Exotic Marigold Hotel)

Dedicated to my godmother Dorle

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CHAPTER 1



GENERAL INTRODUCTION AND OUTLINE OF THE THESIS

1.1. FRAMEWORK

This thesis presents prospective evaluation methods relating to the organisation of palliative care (PC) in Europe. The scientific work presented in this PhD book is the result of a large European collaborative project built around an EU co-funded project from the Executive Agency of Health and Consumers (EAHC) on defining best practices in the organisation of PC.¹ This European research project was called Europall, and ran between 2008 and 2011. The consortium consisted of partners from seven European countries: Belgium, France, Germany, the Netherlands, Poland, Spain, and the UK. The project was coordinated by the research team from Radboud University Nijmegen Medical Center in the Netherlands. In this research project we used qualitative and quantitative approaches to outline and evaluate the organisation of PC in Europe.

1.2. WHAT IS PALLIATIVE CARE?

1.2.1. DEMOGRAPHICS

The European population is progressively ageing.² As a consequence, health care in general and specifically the organisation of health care in particular face huge challenges. Health systems therefore need to adapt in order to provide appropriate health care at all levels for all citizens, and financial sustainability.³ Alongside this ageing population, the number of patients with medical problems where curative treatment is indicated is also increasing. This is expected to result in a 20% increase in the need for palliative care (PC) programmes for the European countries.⁴

PC encompasses holistic and integral treatment for both terminal cancer patients and patients in the advanced stages of other progressive and incurable chronic diseases like chronic obstructive pulmonary disease (COPD), heart failure or dementia. In Europe, over two million people per year die from one or more progressive chronic diseases.⁵ In 50% of the cases, symptoms such as fatigue, pain, lack of energy, weakness, and loss of appetite occur in terminal cancer patients.⁶ Patients with advanced congestive heart failure (CHF), COPD, kidney failure, Alzheimer's disease, Parkinson's or Amyotrophic Lateral Sclerosis (ALS) also need of PC. In response to this dramatic increase in the number of patients requiring PC, high quality PC services and professionals need to be integrated into health care systems. However,

due to the lack of specific implemented indicators to evaluate the quality and need for PC programmes, appropriate quality indicators (QIs) for PC services and programmes in the different countries were unclear at the start of this research project.

1.2.2. HISTORY AND DEFINITION OF PALLIATIVE CARE

The first hospices were set up in England in the 1960s. The aim was to forego futile high-tech medicine for patient-centred care and provide appropriate treatment of critically ill and terminal cancer patients. Having trained as a nurse, social worker and doctor, Cicely Saunders launched the hospice and palliative care (PC) movement which is now known all over the world. She is best known for introducing the concept of total pain management and addressing of encompassing physical, psychological, social, spiritual and practical problems.⁷⁻¹³

This concept was transmitted to Canada and Australia before the hospice and PC movement began to take root in the rest of Europe. The accepted global definition of PC (World Health Organisation, WHO) from 2002 is as follows

”Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹⁴

1.3. ORGANISATION IN PALLIATIVE CARE

1.3.1. TERMINOLOGY OF THE ORGANISATION OF PALLIATIVE CARE

Different terms, models and frameworks describing the organisation of palliative care (PC) exist. Because of the expansion and rapid development of PC, it is essential to understand these different models. The organisation of PC has evolved in different ways, influenced by local or national health care systems, socioeconomic factors and resources, cultural issues, as well as educational levels of health care professionals.¹⁵ Consequently, several countries developed organisational PC structures. Within the European countries, models vary not only between the countries but also even between different regions. In this thesis, we will provide a comprehensive definition of the organisation of PC. We therefore describe the organisation of PC on the basis of collected country-specific features, settings and domain characteristics reported by the different research partners in this Europall project.

At the start of this Europall project in 2008, the partners were aware of the importance of using the same definitions and descriptions all over Europe. At that time, the European Association of Palliative Care (EAPC) had not yet published its recommended definitions. As established in the literature, no comparison is possible if partners do not interpret the terms in the same way.¹⁶⁻¹⁸ With the knowledge of that time and to create a collective terminology, all project members contributed to the development of a glossary of essential terms used throughout the entire project. With the assistance of the glossary, an overview of PC situation in each European country participating in the Europall project was published in a separate book.¹⁹ In line with many other European projects or the EAPC Atlas, the inventory covered topics such as the organisation of care, models of PC, legislation, volunteers, research and education in PC.^{18,20-23}

1.3.2. IMPROVING PALLIATIVE CARE OVER COUNTRIES

The introduction of palliative care (PC) bringing national organisations together in an European umbrella organisation started in 1988. The European Association of Palliative Care (EAPC) platform was established by 42 individual founding members from nine countries.²⁴ In 1999, the Eastern and Central European Palliative Task Force (ECEPT) joined.^{25,26} In 2008, the EAPC consisted of 41 national associations with collective collaborative members from 25 European countries. The aim of these organisations is to promote PC in Europe. Due to centralisation, the understanding of PC and resulting work routine became more consistent. This resulted in White Papers describing and advising on aspects of the organisation of PC. All the information was distributed through the EAPC website, newsletters and alternating biannual research based and general European congresses.²⁴

Besides this scientific network, the European Parliament provided support with resolutions on counselling and care of the terminally ill in 1989 and the mission and vision of PC in Europe in 1992. The initiative of the Council of Europe promoted a report by the European Health Committee on 'Problems related to death: care for the dying'.²⁵ Experts developed a 'Recommendation (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care', which was translated into 17 languages.^{4,27} The recommendation describes the huge differences in the availability and quality of PC throughout Europe. National plans for PC in close collaboration with professionals and representatives of patients and families were proposed. The establishment of one national centre of excellence as a minimum and reporting of essential topics, e.g. opioid availability or medical and nursing curricula, were also included in these recommendations. Several of these recommendations were further explored and resulted in the EAPC White Paper on standards and norms for hospice and PC in Europe, an official position paper of the EAPC.¹⁶

The commitment to achieve the political and own objectives of the EAPC caused qualitative and quantitative studies in PC all over Europe.²⁸ In addition to the EAPC Research Network, research collaboratives in the UK emerged (the Cancer Experience Collaboratives (CeCo) and Collaborative Complex Assessment, Trials and Implementation of Services (COPASS)). International projects like the European Palliative Care Research Collaborative (EPCRC) were launched, focusing on the response to opioid treatment for pain and methods for assessing and classifying of

pain, fatigue (cachexia) and depression or the International Observatory on End of Life Care, describing and comparing PC development in over 60 countries and areas in Europe.^{29,30} Furthermore, in a European collaborative research project (EURELD) studies exploring attitudes towards medical end-of-life decisions contributed to the improvement of PC in Europe.³¹ EU co-funded programmes included the PRISMA and the OPCARE projects, aimed to implement best practices, harmonising research in end of life care for cancer patients and improving care for cancer patients during the last days of their lives.³²⁻³⁴

In line with some of the above-mentioned European projects, Europall started with country inventories to capture the state of art of PC in the participating countries.^{17,20,35} Part I of this thesis presents the organisation of PC in the seven countries, focussing on national legislation and regulations (chapter 2) and non-professional team members and volunteers (chapter 3).

1.3.3. IMPROVING PALLIATIVE CARE IN DIFFERENT SETTINGS

Palliative care (PC) comprises many different options for supportive care, end-of-life care and the optimal place of dying. The majority of people in the European region still do not die at home, although most people would prefer to do so.³⁶ As quality of life must prevail until the end, it is essential to inform patients and family members about good practices and the range of care options at the end of life.

PC is provided in different settings: domiciliary, quasi-domiciliary and institutional. A distinction can be made between specialist and non-specialist PC services. Specialist PC settings include e.g. palliative care units (PCU), or hospice care, whereas non-specialist PC services include the palliative home care support team, home care or nursing home (Table 1). Another distinctive feature is that in specialist PC services care is organised in cooperation with other services, care is structured and a multidisciplinary team approach is used.^{16,37} The team providing PC must per definition consist of doctors and nurses and may include pharmacists, social workers, spiritual worker, physiotherapists, psychologists, occupational therapists, complementary therapists and volunteers. Ideally, to support the multidisciplinary team approach, specific defined procedures and guidelines are developed (e.g. Liverpool Care Pathway), which e.g. explain the content, roles and specific tasks of each team member in relation to the trajectory of the disease state in the patient.³⁸

Meanwhile the procedure of the Liverpool Care Pathway was controversially and critically discussed in 2013.^{39,40}

Table 1 Conceptual framework used in the EAPC Atlas of Palliative Care⁴¹

Location where palliative care is provided	Resources and services providing basic level of palliative care	Specialized palliative care services		
		Basic level of palliative care	Specialized palliative care services or supportive palliative care services	Other specialized palliative care services
Patient care in acute hospitals	General Hospital	Volunteer hospice team	Hospital palliative care support team	Mixed palliative care support team Palliative care units in tertiary hospitals (Acute, university or general hospitals)
Patient care (medium and long term) in places other than general hospitals	Nursing homes and other residential facilities			Palliative care units in hospitals or residential non-general hospitals Unidades de cuidados paliativos en centros hospitalarios o residenciales distintos del hospital general
Patient care is provided at home	Assistance is provided by general or family physician and nurses in primary care teams		Home care support team (the family physician has primary responsibility for the patient)	Palliative care unit in an inpatient hospice Day hospice or day-care center for palliative care Home palliative care team (primary responsibility for patient within the palliative care team)

All these different types of settings have their specific structure and criteria of quality improvement. To improve the quality of PC in Europe generally and further harmonise health care services for the provision of good PC, it is vital that specific measurement tools are developed to evaluate the quality of care provided.

This thesis defines and identifies best practices of PC in Europe by developing structure and process quality indicators (QIs) which can be implemented in all settings across Europe in order to compare and measure the quality of the organisation of PC, hopefully resulting in improved quality of life for patients in a palliative trajectory all over Europe.

1.3.4. IMPROVING PALLIATIVE CARE OVER DOMAINS

The aim was to establish a quality indicator (QI) framework in different domains of care describing the organisation of palliative care (PC).⁴² The literature provides some early examples of frameworks in PC.^{15,43-45} Three manuscripts include QI sets,

whereas one paper only presents domains. The areas of interest of these studies were general practice management (international, six countries), cancer care/ end-of-life care or generally expressed for PC.

Although studies show different approaches, some recurring domains were found. Essential aspects are physical treatment, ethical/ legal aspects, cultural issues, or psychosocial components. By contrast, symptom-oriented or assessment/ screening sections remain specific.

The domains for the Europall QI framework emerged whilst preparing the literature review (chapter 4) and the international meetings of the project group. QIs were clustered according to content in nine different domains agreed by the project group (definition of a palliative care service, access to PC, infrastructure, assessment tools, personnel in palliative care services, documentation of clinical data, quality and safety, reporting clinical activity of palliative care services and education).

1.4. QUALITY INDICATORS IN PALLIATIVE CARE

1.4.1. DEFINITION OF QUALITY INDICATORS

Large-scale changes in the health care landscape lead to an increase focus of quality.⁴⁶ These changes include rising costs and limited resources. As a consequence the idea of measuring and improving quality of health care rose.⁴⁷ Nowadays health care professionals describe this development as daily routine.⁴⁶ The outcomes are of importance for several parties such as patients, health care providers, politicians and insurance companies.⁴⁶ However, standardised clinical data collection is lacking in many countries, in particular for palliative care (PC). The most common issues described are a lack of documentation about how major illnesses are treated in most health care systems; a lack of systematic outcome assessment; a lack of resource evaluation related to quality for specific diseases; persisting variations among providers in care for similar patients; and the fact that few formal monitoring systems are used by health care providers or regulators.⁴⁸⁻⁵⁰

The literature provides different definitions of quality indicators (QIs). Donabedian states that QIs make it possible to improve quality in care by providing insight into the structure and process aspects of care which are related to outcome and as a tool to guide the process of QI in health care.^{46,51} Worning et al. indicate that QIs are

parameters “assessing a particular health care process or outcome”.⁵² The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) describes QIs as “quantitative measures that can be used to monitor and evaluate the quality of important governance, management, clinical, and support functions that affect patient outcomes”.⁵³ The Canadian Council on Health Services Accreditation defines QIs as “measurement tools, screens, or flags that are used as guides to monitor, evaluate, and improve the quality of patient care, clinical support services, and organisational function that affect patient outcomes”.⁵⁴ We chose the definition of Campbell’s et al. “Quality indicators are explicitly defined and measurable items referring to the structures, processes, or outcomes of care”.^{55,56}

1.4.2. TYPES OF QUALITY INDICATORS

Similar to the many existing definitions of quality indicators (QIs), distinctions are made between types of QIs. Two categorisations systems are mainly used. The first one divides QIs into rate-based or sentinel QIs. A rate-based QI describes information occurring on a regular basis. Typically, rate-based indicators are expressed as ratios, e.g. proportions or rates. They may be calculated as mean values of a sample population. The structure of a rate-based QI consists of a numerator and denominator specifying what to measure. By contrast, the sentinel QI is designed to evaluate individual incidences, e.g. numbers of patients who die during surgery. The reason for measuring single facts is to capture poor performance which is used for risk management.⁴⁶

Donabedian et al. suggest a different division. QIs in health care are based on structures, processes or outcomes:⁵¹

- Structure QIs represent the characteristics of settings where care is delivered, e.g. “type and amount of resources used by a health system or organisation to deliver programmes and services and they relate to the presence or number of staff, clients, money, beds, supplies and buildings”^{51,57}
- Process QIs evaluate the activities and tasks in patient episodes of care, e.g. the practitioner’s activities in making a diagnosis, recommending or implementing treatment or other interactions with the patient.
- The last type of QIs, relating to outcomes of health care, describes the effects health care on the individual patient or society as a whole. In a general sense this can be compared to the gradation of contentment of the patient.

This thesis uses Donabedian's categorisation of QIs. Maintained through several successful published projects, this approach seemed more fitting for our aims.⁴⁴ Furthermore, the focus in this thesis is on the development of structure and process QIs. This decision was based on the aim of the project. As the QIs were developed to measure the organisation in PC, the development of outcome measures was not a part of this thesis.⁴⁶

1.4.3. EVIDENCE-BASED DEVELOPMENT OF QUALITY INDICATORS

Two procedures are described in literature about how evidence-based quality indicators (QIs) can be developed.⁵⁸ The first approach comprises searches, such as Cochrane Collaboration literature syntheses, meta-analyses or randomised controlled trials.^{59,60} The alternative is the use of an experienced expert panel of health care professionals deciding in a consensus process. The combination of both methods is recommended due to the lack of evidence of indicator development in palliative care (PC).^{57,61-63}

Consensus methods are defined as structured facilitation techniques exploring opinions of a group of experts. Established consensus techniques are consensus development conferences, the Delphi technique, the nominal group technique, the RAND appropriateness method and iterated consensus rating procedures.^{55,64-67}

The RAND appropriateness method is described in detail, as this was the approach chosen in this thesis (chapter 5). This method combines characteristics of the Delphi and nominal group techniques. In addition, the RAND appropriateness approach integrates expert opinion and systematic evidence. After conducting a systematic literature review to develop QIs, experts were chosen for the group meeting. They receive a postal survey to rate the developed QIs. In face-to-face meetings, panellists then discuss and re-rate each QI.

1.4.4. TESTING QUALITY INDICATORS

Following the evidence-based development with a consensus technique further quality criteria have to be taken into account. Before implementation the quality indicators (QIs) have to fulfill the standards of acceptability, feasibility, reliability, sensitivity to change, and validity.^{68,69}

Box: Evaluation criteria (adapted from NQF)⁵⁵

Importance: The extent to which the indicators capture key aspects of care that require improvement.

Scientific Acceptability The degree to which the indicators produces consistent and credible results when implemented. This includes aspects such as:

- **Validity:** The degree to which the indicators accurately reflect the quality of care.
- **Evidence to improve outcomes:** Evidence that changes as measured by the indicators lead to changes in outcomes.
- **Reliability:** The extent to which the indicators can measure the construct consistently.
- **Responsiveness:** The indicators' ability to detect change from interventions.
- **Variability:** The extent to which the indicators' scores demonstrate sufficient variability between populations for useful comparisons.
- **Usability:** The extent to which intended audiences (e.g. consumers, clinicians) can understand the results of the indicators and are likely to find them useful for decision- making.
- **Feasibility:** The way in which data can be obtained within the normal flow of clinical care and the extent to which the indicators can be implemented.
- **Ready data sources:** The extent to which the data required can be assessed or determined from available data sources or measurement tools.

Typical approaches used are assessing measures' psychometric properties, conducting surveys, or clinical/organisational audits. Frequently used measures to asses the psychometric properties include factor analyses. To realize quality measurements with the help of surveys regularly patient or practitioner or even both groups are recruited. In order to test acceptability, feasibility, reliability, sensitivity to change, or validity via clinical/ organisational audits researchers tend to use interviews or focus groups.

In this thesis the quality measurement is only applied to a certain extent. In preparation for the prospective audit we tested our QIs for applicability across European countries (chapter 6). We conducted an online survey with representatives of palliative care (PC) services and used factor analyses with the intention to minimize our QI set.

1.5. RESEARCH OBJECTIVES OF THE THESIS

The present thesis consists of two main parts. The first part of the thesis explores the state of palliative care (PC) in seven European countries from a descriptive perspective. The second part is directed at the development and testing of structure and process quality indicators (QIs) to measure of the organisation of PC in Europe.

The specific research objectives of this thesis are as follows:

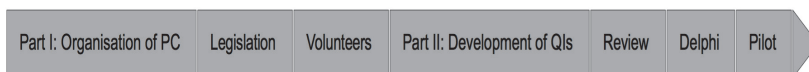
Part I:

- To prepare a glossary of terms to ensure identical use of terminology in Europe
- To explore the existence and implementation of legislation and regulation in palliative care in seven European countries
- To compare the organisation of informal workers (volunteers) in palliative care in seven European countries

Part II:

- To identify and develop structure and process quality indicators (sets) measuring the organisation of palliative care
- To evaluate clarity and usefulness of the identified/developed quality indicators by using a two-round modified RAND Delphi process
- To perform a feasibility test of the developed QI set in a European/ international context using an online survey method.

Figure 1 Research phases



1.6. OUTLINE OF THE THESIS

Quality indicators (QIs) have been developed within certain countries and for different purposes. The Europall project aimed to develop a European set of QIs especially for the organisation of palliative care (PC). As the development of PC is very dynamic, we started to generalise terminology (Appendix Addendum Glossary) to ensure common understanding of all term used throughout the project. Subsequently we took stock of the PC organisation in the contributing countries concerning national legislation and regulation in the seven participating countries were summarised in **chapter 2**. In **chapter 3**, the organisation of volunteers in the seven countries is presented. After an illustration of each countries' PC organisation the development of QIs for the organisation of PC is described in **chapter 4**. **Chapter 5** outlines the two-round modified RAND Delphi process conducted to rate the usefulness and feasibility of the proposed QI. **Chapter 6** comprises a pilot test of the final QI set in a wider European context. With the help of an online module, we investigated the applicability of the QI set in 25 European countries. Finally all studies presented in this thesis are discussed in **chapter 7**.

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PART 1: ORGANISATION OF PALLIATIVE CARE



CHAPTER 2



COMPARISON OF LEGISLATION, REGULATIONS AND NATIONAL HEALTH STRATEGIES FOR PALLIATIVE CARE IN SEVEN EUROPEAN COUNTRIES (RESULTS FROM THE EUROPALL RESEARCH GROUP): A DESCRIPTIVE STUDY

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2.1. ABSTRACT

According to EU policy, anyone in need of palliative care should be able to have access to it. It is therefore important to investigate which palliative care topics are subject to legislation and regulations in Europe and how these are implemented in (national) health care plans. This paper aims to deliver a structured overview of the legislation, existing regulations and the different health care policies regarding palliative care in seven European countries.

In 2008 an inventory of the organisation of palliative care was developed by the researchers of the Europall project. Included were two open questions about legislation, regulations, and health policy in palliative care. This questionnaire was completed using palliative care experts selected from Belgium, England, France, Germany, the Netherlands, Poland and Spain. Additionally, (grey) literature on palliative care health policy and regulations from the participating countries was collected to complete the inventory. Comparative analysis of country specific information was performed afterwards.

In all countries palliative care regulations and policies existed (either in laws, royal decrees, or national policies). An explicit right to palliative care was mentioned in the Belgium, French and German law. In addition, access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, opioids and the role of volunteers.

Although all included European countries have policies on palliative care, countries largely differ in the presence of legislation and regulations on palliative care as well as the included topics. European palliative care policy should support palliative care policy and access across Europe.

2.2. INTRODUCTION

With the aging of the European population and an expected increase in mortality rates, a vision on palliative care development at a European level is increasingly important.¹ The Council of Europe and the WHO formulated recommendations for the integration of palliative care into the national health care systems.^{2,3} They concluded that any person in need of palliative care should be able to access palliative care without undue delay, in a setting which is, as far as reasonably feasible, consistent with his or her needs and preferences and regardless of cultural, ethnic or other background. Public health policy must acknowledge people's right to high-quality palliative care whatever the nature of the disease they suffer from and this should not depend on the financial abilities of patients or their informal caregivers. Because several European countries already have national initiatives regarding palliative care; it is relevant to consider to what extent European countries succeed to incorporate the advices from the Council of Europe and the WHO in their health care systems. This also points to the importance of the development of quality indicators for palliative care as several studies have attempted to define outcome or quality parameters in palliative care.⁴⁻⁷ However, also the health system development in a certain region largely influences quality improvement in palliative care.⁸ As part of an integral quality approach to palliative care, investigating (European) differences in health policy are pivotal, for example legislation and policy regulations. This paper therefore focuses on regulations, legislation and national health care strategies concerning palliative care in seven European countries to answer the following research questions:

1. What kinds of laws or other regulations (national/regional) regarding palliative care exist in the participating European countries?
2. Is there a national and/or regional health policy regarding palliative care and how is this implemented?
3. What palliative care topics are subject to health policy regulation and plans?

2.3. MATERIAL AND METHODS

The design and performance of this study comprised four phases. As a first step, in 2008, an inventory for the organisation of palliative care was developed including a questionnaire with open questions. A careful process of agreement on definitions and terms, including the preparation of a concise glossary of terms preceded the

questionnaire to allow for the comparison of data between the different countries.⁹ The glossary and the questionnaire were completed during several project work conferences with all participating partners. In summer-fall of 2008 the partners of each participating country were asked to complete the inventory for his/her country, including two questions about legislation and national policy on palliative care.

Secondly, the partners contacted national palliative care experts in their country. In total, 6 to 12 key persons per country were consulted to further complete the questionnaire, taking into account the glossary of terms (professors in palliative care, professional care providers as well as policy makers/developers and palliative care organisations). Experts were approached using the network of the Europall research group.

Thirdly, (grey) literature was performed to further add to the information provided by the experts. This literature search focused on specific information per country because regulations and health policy are likely to be published in national or regional reports from official bodies (e.g. palliative care reports in each country, publications of palliative care organisations). In addition, experts handed over policy reports. 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. Internet databases such as Medline, PubMed and Google scholar were searched for extra information about palliative care policies in the participating countries, using snowball sampling which has been considered fruitful for the inventory of complex policy interventions.⁵

Fourthly, a comparative analysis of the completed surveys was performed. Because the analysis of answers to the sub-question on finances turned out to be a complex separate study field, it was decided not to include this in the analysis for this manuscript. Phases are summarized in Table 1.

For the involved countries, ethical approval was not required as this study was based on reviewing published and unpublished literature and consultation of experts.

Table 1 Palliative care inventory study design

Development of the inventory	
Phase I	<ul style="list-style-type: none"> -development of glossary of terms -development of questionnaire on organization of palliative care <ul style="list-style-type: none"> > including two questions on legislation and regulation of palliative care in Europe <ol style="list-style-type: none"> 1. What kinds of laws regarding palliative care do exist? (Plus year established) (Please specify: regional or national; name and summary of content. We do not mean laws about volunteers etc., although it might be linked to palliative care; laws about euthanasia etc. Can be mentioned if they also mention palliative care) 2. Is there a national and/or regional health policy regarding palliative care in your country? <ol style="list-style-type: none"> a. If yes, please describe (development, budget, aims) b. Describe the implementation of the plan, regarding the organization of service c. Is there a national/regional palliative care association/federation/organization in your country? Please describe on national and regional basis d. How is palliative care financed? Please describe, also relevant budgets: Public/private/voluntary Is it dedicated for palliative care? Differences between settings?
Phase II	Consultation with 6 to 12 key persons per country to further complete the questionnaire,
Phase III	(grey) Literature study -Collecting of palliative care policy documents per country -Additional snowball sampling based on pubmed search, expert consultation, internet search.
Phase IV	Comparative analysis based upon the country specific information.

2.4. RESULTS

2.4.1. PALLIATIVE CARE REGULATIONS

Germany was the first country to have specific laws concerning palliative care; Social Code Book XI as well as V/§39a (introduced in 1997) covers regulations for palliative care.¹⁰ In 1997, insured persons were entitled to allowances for inpatient or day care in hospices. In 2001, these regulations were extended to the delivery of outpatient palliative care by hospice services, including the services of hospice palliative care volunteers visiting the patients at their homes or elsewhere. Following the Statutory Health Insurance Competition Strengthening Act (SHI-CSA) of April 2007, new paragraphs were inserted in the Social Code Book V, entitling patients, including children, to outpatient specialist palliative care when needed.¹¹ The German guidelines for specialised palliative home care services (SAPV), developed by G-BA (Federal Joint Committee) came into force in March 2008. They include the aims of SAPV, requirements of the teams (qualification, multi-professionalism, organisation), content and extent of services, and quality assurance. SAPV teams and the delivery of care must fulfill detailed criteria in order to receive remuneration from statutory health insurers.

In France, law 99-477 of 9 June 1999 was designed to ensure the right to adequate access to palliative care and supportive care for any citizen requiring this care.¹² All

hospital units and other healthcare institutions are obliged to provide pain and palliative treatment. Patients are allowed to refuse further investigations or treatment. Caregiver's leave is stipulated for any ascendants, descendants or persons living in the home of a patient requiring palliative care (this measure has been applied only since 2010). The law 2005-370 of 22 April 2005 (concerning patient rights and the end-of-life) allows, at the terminal or advanced phase of an incurable and serious disease, the possibility, after informing the patient or the patient's representative ("person of confidence"), to relieve the patient's suffering by a treatment which, as a side effect, can shorten the patient's life.¹³ It authorises "advance directives" indicating the person's wishes concerning his/her end of life and defining the conditions of limitation or discontinuation of treatment. The doctor is required to take these wishes into account when they have been expressed during the previous three years. The law also specifies that hospitals and other healthcare establishments must identify the departments in which palliative care is dispensed. In addition, every department needs to define how many employees have had specific training in palliative care and how many beds are identified as palliative care beds. A circular published in March 2008 by the French Ministry of Health contain regulations for dedicated palliative care beds, mobile hospital support teams, palliative care units, home hospitalisation and palliative care networks.¹⁴ In the French system, which clearly distinguishes between hospital (predominantly public/quasi-public) and primary care (predominantly private), palliative care networks are important to maintain continuity between healthcare organisations and home care.

The Belgian law concerning palliative care, enacted in 2002, declares that every citizen has the right to receive palliative care (and/or information about it), to receive information about his illness and warrants the accessibility to palliative care.¹⁵ The law defines palliative care as the total care provision for patients whose life threatening disease no longer responds to curative therapies. The major aim is to offer the patient and his/her next of kin as much quality of life as possible and a maximum of autonomy. For the support of these patients, multidisciplinary care on physical, psychiatric, social and moral level is considered pivotal. A broad commission has to report the implementation and the improvement of different palliative care deliveries to the government every second year, and annual progression reports are delivered by the Minister of Public Health and Social Affairs. The same year 2002 euthanasia was legalised in specific circumstances.¹⁶ One

precondition for the use of euthanasia is that the physician always needs to inform the patient about palliative care. Since 1993 many initiatives have been undertaken in Belgium at a federal and at community level to enable and support palliative care. There are Royal Decrees about palliative care, which can be considered as detailed guidelines for palliative care networks, hospital support teams and palliative home care teams. They stipulate what services are necessary, their geographical distribution, conditions and minimum criteria for staff, the content of their work, and sometimes funding of different palliative care services.¹⁷

England, the Netherlands, Poland and Spain do not have specific palliative care laws, but palliative care is mentioned in general health care laws. In Spain the care for the chronically ill and terminally ill is mentioned in a law about the National Health System and in Poland insured persons are entitled to palliative care in the law on Universal health insurance.¹⁸ In the Netherlands palliative care is considered a part of the regular health care legislation (e.g. the Dutch Act of Agreement on Medical Treatment; WGBO).¹⁹ A Euthanasia law exists (Termination of Life on Request and Assisted Suicide; published in 2002), stating amongst others that no reasonable alternative should be available for patients (although palliative care is not explicitly mentioned). In Poland there is a statement in the Code of Medical Ethics that obliges doctors to care for patients with incurable diseases and that offers patients the possibility to resign from intensive care at the end stage of incurable diseases. In England the Mental Capacity Act of 2005 is an act of the Parliament of the United Kingdom which applies in England and Wales and came into force in April 2007.²⁰ Its primary purpose is to provide a legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves. In Poland there is a statement in the Code of Medical Ethics that obliges doctors to care for patients with incurable diseases and that offers patients the possibility to resign from intensive care at the end stage of incurable diseases.²¹

In Spain, a Royal Decree (1030/2006) determines the specific (not only palliative care) services to be provided in each health care sector as well as the mechanism for their modernisation and improvement.²² It defines the fundamental principles to guarantee the availability and equal access to palliative care at both the primary and secondary levels of care. An overview of the palliative care regulations is presented in Table 1.

2.4.2. NATIONAL PLANS ON PALLIATIVE CARE

As palliative care and its provision is defined in the Belgian legislation and several Royal Decrees act as healthcare organisation guidelines for the different palliative care services, there is no separate national palliative care policy.¹⁶ The National Cancer Plan (March 2008) however states that the expansion of palliative care shall be actively supported.²³ Palliative care has gained increased recognition within the policy arena in the United Kingdom. The so-called 1995 Calman-Hine Report was crucial in influencing plans for service development in cancer. Since the year 2000, several important national and regional initiatives have been launched to promote access to end-of-life care and to improve quality of care, including the NHS Cancer Plan of September 2000; an action plan to include palliative care in 34 regional cancer networks; the 'NICE clinical guidance on supportive and palliative care for adults with cancer (2004)The End of Life Care initiative (launched 2003) incorporating the Gold Standards Framework (GSF), the Liverpool Care Pathway (LCP) for the dying patient, and the Preferred Place of Care tool (PPC); The End of Life Care Programme comprising a comprehensive framework aimed at improving high quality care across the country for adults in the last phase of life; and the initiative "Better care: Better Lives" improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions".²⁴⁻²⁶

According to the palliative care law of 1999, structures and organisation of palliative care and pain management must be described in the French regional health organisation plans (SROS).¹² The SROS must determine the resources (such as mobile palliative care teams, palliative care units, home hospitalisation beds, palliative care networks) necessary to achieve the set objectives. In addition, palliative care was the subject of three governmental plans in France (1999-2001, 2002-2005 and 2008-2012). Following the Law of April 2005, the Ministry of Health created a national surveillance committee on the development of palliative care and end of life supportive care in 2006.¹³ In 2008, this committee proposed a national policy for the development of palliative care, accompany the implementation and deployment of this policy, and evaluate application of legislative and regulatory texts concerning palliative care and end of life supportive care. A third Governmental plan for the development of palliative care (2008-2012) was launched in 2008 for the further development of intra- and extramural palliative care, to pursue the

development of training and research in palliative care and to improve the development of support and training for the paramedics.²⁷

In 2005, the German Bundestag officially declared the improvement of palliative care as a priority. The coalition treaty (Christian Democrats and Social Democrats) mentioned palliative care for the first time stating “that there is a particular need for improvement in the care and treatment of people in the final stages of their lives. Many people, even patients with serious illnesses, would like to be cared for at home to the very end, so the offered services should take this need into account. For this reason, the legal provisions governing the services, the contractual rights and obligations and the funding of statutory health and long-term care schemes must include rules designed to guarantee better palliative care”.²⁸ Health care reform was declared one of its top priorities for 2006 and in November 2005 they stipulated, among others, the promotion of incentives for better coordination of care, to raise efficiency and to improve quality of care.²⁹ As a result the entitlement to out-patient specialist palliative care was implemented in a law in the next electoral term (Statutory Health Insurance Competition Strengthening Act (SHI-CSA)).

For 1998-2003 the Dutch Minister of Health, Welfare and Sport initiated a stimulation programme. The underlying principle was that palliative care should be provided as much as possible by doctors, nurses, care workers and other care providers who work in regular non-private facilities. In this way access and availability to palliative care should be improved. The stimulation programme encompassed encouragement of research and innovative projects, promotion and guidance of palliative care and stimulation of the integration of hospice facilities. In 2007 the secretary of the Ministry of public health, welfare and sports did a proposal for a new national program 2007-2010 Palliative care Plan' (Plan van Aanpak Palliatieve Zorg') with three main topics: the organisation and finance of palliative care, the improvement of quality and transparency of palliative care and education and palliative care competencies (extra training).³⁰

There is no separate national palliative care plan as such in Poland. For the years 2005-2010 palliative care is included into the National Cancer Program, which allows the development of palliative care in-patient and out-patient services included into oncology units by financing support. Each oncology centre (usually situated in each capital of the province) should have a palliative care inpatient and outpatient unit or at least a hospital support team when formation of a separate palliative care unit is

impossible. Although there is no national policy, the person responsible for the organisation of palliative care is the National Consultant of palliative medicine with regional consultants in each province (Voivodes). The National Consultant of palliative medicine (a physician with a specialty in palliative medicine) focuses on developing palliative care in each administrative district with access to at least an out-patient unit and home care. The Spanish regulations about palliative care have followed most principles and recommendations made by international organisations. This resulted in the National Palliative Care plan which was enacted in 2001 and conceived to care for all patients in need of palliative care within the public sector.³¹ According to the vision of the plan, palliative care is to be nationwide available, on a free basis, and with no distinctions of territory, economic resources or accessed information.³² The National Palliative Care Plan also regulates the use of opioids for symptom control in the incurably ill and pays attention to non-cancer patients. A regional palliative care plan exists, or is under development, in several autonomous communities (15 of the 17 autonomous communities have some type of regional palliative care plan). On March 17th 2007 the Palliative Care Strategy of the National Health System, conceived as a tool for implementing the national plan and to support Autonomous Communities in the implementation of their regional programmes, was approved by the Inter-territorial council.³³ The National Strategy seeks to reduce differences between regions in order to make palliative care thoroughly available within the national health system across the country. An overview of the palliative care policy plans can be found in Table 1 and Table 2.

Table 2 Legislation and other national/regional regulations about palliative care

	Belgium	England (UK)	France	Germany	Netherlands	Poland	Spain
Laws regarding PC	Law 14 June 2002 to ensure the right of access to palliative care	/	Law 99-477 9 June 1999 designed to ensure the right of access to palliative care Law 2005-370 of 22 April 2005 concerning patient rights and the end of life	National level, Social Code Book V (introduced 20. December 1988) and Social Code Book XI (introduced 26 May 1994) § 39a covers in- and outpatient hospice services Amendment § 39a deals with special requirements for the care in children's hospices The Statutory Health Insurance Competition Strengthening Act (SHI-CSA), April 2007: Incentives for better coordination of care	/	/	/
Other regulations concerning PC	Royal Decrees concerning minimum service provision requirements in different PC settings and funding, free medical care for PC patients at home and palliative caregivers leave		Circulars published in 2008 by the French Ministry of Health: Healthcare organisation guidelines for palliative care services	2007, GB-A : new regulations on specialised palliative home care services	Agreement palliative Terminal Care Funding and regulations of specific PC settings	Point in Code of Medical Ethics: obligation for care for patient with incurable diseases and the possibility of resign from intensive care at the end stage of incurable diseases.	1030/2006 Royal Decree, on September 15 defines the fundamental principles to guarantee the availability and equal access to PC

2.4.3. CROSS-NATIONAL COMPARISON

In this study covering seven European countries, the following topics appeared as subject to regulations and palliative care plans: definition of palliative care, rights to palliative care, access to palliative care, palliative care provision, quality assurance, patient allowances, palliative care leave, advanced directives, funding of services, palliative care research and training, and opioids availability. Three countries (Belgium, France and Germany) have specific laws on palliative care mostly to ensure the right of access to palliative care. An explicit right to palliative care was mentioned in the Belgium and in the French law. Access to palliative care and

palliative care provision was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries have a national policy on palliative care, although sometimes mainly related to national cancer plans (Table 3). Of the seven investigated countries, five countries have specific national palliative care plans, although the content differs (Table 4). Similarities in England, Germany, Netherlands and Spain are that they deal with quality assurance whereas research in palliative care is mentioned in the French, Dutch and Spanish policies. Differences relate to policy on access to and use of opioids. Variations in palliative care training for staff and volunteers as well as funding of palliative care also exist. In all countries there are regulations (either in laws, royal decrees, national policies) about patients' financial contribution to palliative care (usually almost free of costs). Other regulations exist on planning and financing of palliative care services (Belgium and Spain), or treatment relationship, as does the 'Agreement Palliative Terminal Care' in the Netherlands. In Poland, the national consultant of Palliative Medicine guards the presence of at least one inpatient unit and home care in each administrative district. A palliative care leave was mentioned in three countries, Belgium, France, and Germany. Additional note of the authors: after closure of our study, in May 2011, the Spanish government approved a law dedicated to palliative care and the right to a dignified death.³⁴

	Belgium	England (UK)	France	Germany	Netherlands	Poland	Spain
		-The Scottish Partnership for Palliative Care				-Regional consultants of palliative medicine in each province	
		-All-Ireland Institute for Hospice and Palliative Care					
National Palliative Care organisation	3 Federations of PC: FPZV (Flanders), FWSP (Walloon region), FBSP (Brussels)	- NCPC (national council for PC England-Wales-Northern Ireland) - The Scottish partnership for PC	SFAP (Société d'Accompagnement et de soins palliatifs)	DHPV (Federal Hospice Working Group) DGP (German Association for Palliative Medicine)	AGORA (Landelijk Ondersteuning s-punt Palliatieve Zorg)	Polish Association for PC Polish Association for Palliative Medicine	SECPAL (Spanish Society for PC)

Table 4 Overview palliative care laws, regulations, national palliative care plans

	Belgium	Netherlands	England	France	Poland	Spain	Germany
Specific PC laws	X			X			X
General health care laws with mentioning of PC		X	X		X	X	
Other regulations concerning PC	X	X		X		X	X
National PC plan		X	X	X		X	X
National cancer plan including PC	X		X		X		

Table 5 Coverage of existing legislation, regulations and health care plans regarding palliative care

	Belgium	England (UK)	France	Germany	Netherlands	Poland	Spain
Definition of PC mentioned	A				D		
Right to PC	A		A	A			B, D
Access to PC	A	E	A	A, B, D	D	E	B, C, D
PC provision	A, B, E	E	A, B, D, E	A, B, D	B, D	E	B, D
Quality assurance	A	D		A, B, D	D		D
Patient allowances	B	C	C	D	C	C	C
PC leave for informal caregivers	B		A	B			
Advance directives	C	C	A			C	
National funding PC services	B, E		E	A, B, D	B, D	A	
PC Training		E	B, D	A, C	D		D
Research			D		D		D
Opioids			D				D
PC volunteers			D	A, B, C	C		

- A. Palliative care laws.
- B. Palliative care regulations.
- C. General health care laws/ system.
- D. National palliative care plans.
- E. National cancer plan.

2.5. DISCUSSION

This study investigated and compared the legislation, regulations and national palliative care plans regarding palliative care in seven European countries.

European countries differ considerably in their policy on palliative care, partly due to cultural differences and historical influences. A right to palliative care is established in Belgium, France, and Germany, whereas all countries have policies on access to palliative care, palliative care provisions, and patient allowances. Differences exist in policies covering palliative care leave, advance directives, national funding, palliative care training, research, opioid regulations, and volunteering. Although a thorough method was used to complete the inventory, it remains difficult to get a complete and actual overview of a whole country. In France, United Kingdom, Poland, Germany and Spain, different regions may have developed regional health care policies. In this article, this was solved by giving a general overview with some details for regions with specific regulations. As every country had their own appointed researcher, there are differences in the way the key persons were contacted, how many key persons responded and how the grey literature was consulted. As countries have different health care systems and different cultures conclusions should be interpreted carefully.

In the light of European recommendations on palliative care it should be remarked that palliative care can be concluded a crucial part of health care at a policy level in all countries investigated.^{1,2} Considering that national palliative care programs are part of cancer care in some countries, the status of palliative care in non-cancer care needs further attention in policymaking. The access of patients to palliative care provisions is addressed in all national policies on palliative care. Palliative care training, research priorities, palliative care leave, advance directive procedures, and national funding, however, vary largely between countries and receive future attention. The regulations concerning opioids is explicitly addressed in two national care plans. This calls for future research as a recent ESMO/EAPC study concluded wide variation between (Eastern and Western) European countries in opioid availability.³⁵ Considering the wide variation in topics addressed in palliative care plans and regulations, it is recommended that a European quality indicator set for palliative care not only addresses outcome parameters but also health policy items. An advantage of such an approach will be that health policy indicators can measure to what extent appropriate preconditions for palliative care delivery to patients are

available in a country. Such health policy indicators are relatively easy to establish if one has access to health policy evaluation documents in a certain country. This also offers the opportunity for so-called resource-poor countries to participate, which has been considered a challenge.³⁶

A European strategy to stimulate palliative care provision and policy is recommended, provided that differences in cultural and historical backgrounds are taken into account. A 2008 policy report on palliative care in Europe mentioned three possibilities to further develop palliative care: a) an approach in which further developments are considered the sole responsibility of national bodies, b) an approach in which the European Parliament formulates policy recommendations, c) an approach in which the European Union formulates legislation about palliative care.³⁷ Our study revealed important differences in palliative care policy at national levels at several points. The European Association for Palliative Care (EAPC) can have an important role in developing and comparing quality indicators for patients in the last phase of life to prepare (European) health policy for palliative care. This can be considered as first steps to reach consensus on what is good palliative care and how we can make sure that in Europe every patient in need of palliative care has adequate access to it.

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CHAPTER 3



VOLUNTEERS IN PALLIATIVE CARE - A COMPARISON OF SEVEN EUROPEAN COUNTRIES: A DESCRIPTIVE STUDY

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3.1. ABSTRACT

In Europe, volunteers have an important role in the delivery of palliative care. As part of the EU co-funded Europall project, four aspects of volunteering in palliative care were studied for seven European countries (Belgium, England, France, Germany, Netherland, Poland, and Spain). These were (1) involvement of volunteers in palliative care, (2) organization of palliative care volunteering, (3) legal regulations concerning volunteering, and (4) education and training of palliative care volunteering.

A literature search combined with an interview study. Information from the scientific literature and country-specific policy documents was obtained and completed with the data of consecutive semi-structured interviews with experts in the field of palliative care in the participating countries. In all countries, volunteers appeared to be involved in palliative care, yet their involvement across health care settings differed per country. England, for example, has the highest number of volunteers whereas Spain has the lowest number. Volunteering is embedded in law and regulations in all participating countries except for England and Netherlands. In all participating countries, volunteers are organized, both on a national and a regional level and in all countries training programs are available.

This study provides a descriptive overview of volunteer work in palliative care in seven European countries, with a focus on the organizational aspects. Further research should concentrate on the roles and responsibilities of volunteers in the care for the terminally ill in different European health systems.

3.2. INTRODUCTION

The presence and activities of volunteers in palliative care are widely acknowledged.¹ Their role in a multidisciplinary team is valuable and they provide important support for patients, families and professionals in the last phase of life.^{2,3} In palliative care, volunteers not only assist in patient care but also add a unique personal dimension. Their input is based on psychosocial, spiritual and practical needs of the palliative patient, and adds to what the health care professional or family caregivers can offer.^{2,4} Nevertheless, from a European point of view, the role and position of volunteers in palliative care is not clearly outlined.

In most European countries, the organisation of palliative care related activities for volunteers has improved during the past decades. For example by offering training programmes in palliative care, introducing coordinators and using management protocols.⁵ However, research on volunteering in European countries is scarce and mostly concentrates on motives for volunteering, volunteers' roles and responsibilities, their personal characteristics and their satisfaction.⁶ Until recently, only limited information was available on their organisational set-up and the integration of volunteers in specific palliative care programs.

As most European countries face the challenge of a growing population with an increased number of patients with advanced stages of life-shortening, chronic diseases, in combination with limited financial resources, volunteering will be an important source of aid in caring for people in the last phase of life. An international overview of the organisation of volunteering in palliative care might contribute to sharing best practices.

As part of a EU co-funded study, the Europall project, that ran from 2007 to 2011, we studied in the seven participating countries (1) whether and how volunteers are involved in palliative care, (2) whether volunteering is nationally or rather regionally organised, (3) which legal regulations concerning volunteering exist and (4) whether these volunteers receive training and education.

3.3. MATERIAL AND METHODS

3.3.1. DESIGN

The study was divided into four steps, namely (1) development of a semi-structured questionnaire, (2) performance of a (grey) literature search (3) interviews with palliative care experts to complete the questionnaire and literature search, and (4) comparison of the data from the seven participating countries, being Belgium France, Germany, the Netherlands, Poland, Spain and England.

During the Europall steering group meetings, with experts in palliative care and researchers in this field, consensus was reached on aspects of volunteering that were relevant for the organisation of palliative care. These concerned the involvement of volunteers in palliative care, whether and how they are nationally or regionally organised, the existence of legal regulations concerning volunteering and whether and how volunteers are trained. These aspects were integrated into a semi-structured questionnaire (Appendix A). Additionally, an explanatory glossary consisting of 23 pages including 93 terms was prepared. Concepts and words were explained to facilitate a reliable comparison of the countries' data.⁷⁻⁹

3.3.2. GREY LITERATURE SEARCH

The (grey) literature search focused on specific information per country. Scientific databases such as Medline, PubMed and Google scholar were searched to answer the research questions. The search strategy included combinations of MESH terms "palliative care" OR "hospice" "terminal care" OR "bereavement" OR "end of life" AND "name of country" OR "region" or "city" AND "volunteers" (Appendix B).

The (grey) literature search focused on specific information per country. It was defined as 'documents obtained from other than the above mentioned electronic research engines, official sources of publication and distribution, but limited to reports and websites from nationally acknowledged organisations'.¹⁰ These included policy documents, reports from professional associations, the national governments, other competent health authorities or a well-constituted European organisation (Appendix C). In addition the official national websites of the volunteer organizations in palliative care of the participating countries were studied. Data concerning general health care volunteers were excluded.

3.3.3. EXPERTS

In each country the project partners were invited to interview experts (n=6-12, per country) face to face to deliver additional information to the (grey) literature search (Appendix D). Inclusion criteria to be consulted as an expert were having at least five years of experience and being acknowledged on a national level in the field of palliative care. Persons considered for inclusion were professors in palliative care, professional care providers as well as policy makers. The chairman of the national society of palliative care of each country proposed and confirmed the experts who were chosen by the Europall research group.¹¹

3.3.4. ANALYSIS

Per country, first the questionnaires were filled with the information provided by the literature search, and completed with additional information from the experts' interviews. In case of conflicting information, data was checked again by the Europall group and adapted accordingly.

3.3.5. ETHICAL APPROVAL

Ethical approval was not required, as this part of the study was based entirely on searching and reviewing both published and unpublished literature, consulting with colleagues, regional and national palliative care organisations and experts opinions in the field.

3.4. RESULTS

3.4.1. INVOLVEMENT OF VOLUNTEERS IN PALLIATIVE CARE

Although no data about the total number of volunteers in **Belgium** was available, volunteers appeared very essential for palliative care. In 2005, in 14 home care teams in Flanders, about 350 volunteers were involved. Different types of settings use the support of volunteers. Volunteers are involved in intramural and extramural palliative care and added to settings not predominantly dedicated to palliative care (personal communication, September 2008). Volunteers can be found in hospitals, palliative care units, home care teams, residential homes (but not particularly dedicated to palliative care (personal communication, September 2008), hospital support teams and day care centres. Preferred inclusion of volunteers is in home

care teams, palliative care units, day care centers and residential homes. In case of shortage of volunteers in home care, they can be backed up by volunteers of the health insurance funds. (personal communication, August 2008) In Belgium volunteers are complementary to the professionals; they have more time to spend with the patients. Family members report that their concerns about their beloved ones are listened to (personal communication, August 2008) and that the volunteer provides an important link for the relatives (personal communication, September 2008).

In **France**, the total number of volunteers for palliative care in 2009 was about 5,000. This estimate summarizes the data of all palliative care organisations and additional associations. The organisations claim that the support given by the volunteers can hardly be dispensed with.

In **Germany** approximately 80,000 volunteers participate in palliative care. They cover in- and outpatient care in a range of different settings. Volunteers are present in hospices, palliative care units and home care hospice services, the so-called 'ambulanter Hospizdienst'. Particularly hospice home care relies to a great extent on volunteers. For example in the state of North Rhine Westphalia, half of the 400 outpatient hospice services consist entirely of volunteers, beside the professional coordinators paid from the reimbursements from the sickness funds (personal communication, June 2008). In contrast, problems are reported from the in-patient sector. Staff often delegate tasks to volunteers, as a cheap solution. It is unclear for staff as well as for volunteers which tasks can be delegated to or performed by volunteers (personal communication, June 2008). Volunteers consider their contribution to palliative care as very essential because they have the feeling that "they represent society around the dying person and that their work evokes the neighbourly solidarity of the past".

The Netherlands has about 8,000 registered volunteers (personal communication, August/September 2008). A large part of the volunteers are assembled in the Association of High Care Hospices (up to 1000 members) and in the National Patient Association (NPV, Nederlandse Patienten Vereniging, 2000 members) and the rest belong to the Volunteers in Palliative Terminal Care (VPTZ, Vrijwilligers Palliatieve Terminale Zorg). They most often volunteer in hospices, but also in palliative care units, nursing homes, elderly care homes and hospitals. In low care hospices, they

often have a key role and cover 24/7, while professionals are only there part of the day and on-call. Regarding terminal home care, volunteers provide 75% of the work. In **Poland**, four million persons provide volunteer services in all kinds of health care settings. About 2,500-3,000 volunteers participate in the palliative care sector, but clear figures are not available. Volunteers support nearly all public hospice services. In non-public hospices volunteers provide the full scope of patient care. The distinction between public and non-public hospices that a certain amount (n=73) have a contract with the health ministry. The rest are supported from the church and official partners, like the Caritas.

Regarding **Spain**, it is unknown how many volunteers contribute to palliative care. Volunteer collaboration is provided in hospitals and socio-health centres. Hardly any volunteers contribute to terminal home care.

In **England** professionals are supported by a network of 70,000 volunteers. They are included in in-patient services, out-patient services and home care. Volunteers are particularly active in hospice settings, as these are predominantly based on charity funding. Besides, over 200 palliative care teams have included volunteers in their multidisciplinary team.

3.4.2. ORGANISATION OF VOLUNTEERS

Belgium does not have an umbrella organisation of palliative care volunteers. In the Walloon region e.g. seven different palliative care volunteer organisations exist. In addition smaller initiatives exist. For example, volunteers in the local organisation PANAL (palliative network Leuven and surroundings), have organised themselves in "Pallium" (personal communication, September 2008). In Pallium, the internal organisation is discussed in monthly meetings including capacity decisions about the required number of volunteers. Such initiatives are not present in all Belgian regions. Instead, volunteers are recruited from other services (e.g. the health insurance funds) (personal communication, September 2008).

In **England** there exists one organisation concerning volunteers in palliative care is the Association of Voluntary Service Managers (AVSM). This association provides a network of managers for the volunteers. The other existing organisation dealing with volunteers is Help the Hospice. They represent hospice services involving palliative care volunteers.

In **France**, palliative care voluntary work is organised in a hierarchical structure. A legal body organises voluntary work, and two organisations closely collaborate with the health care services: the Association Jusqu' à la Mort Accompaner la Vie (JALMALV) and the Union Nationale Association pour le Développement des Soins Palliatifs (UNASP). Both organisations, being the largest ones in the country, represent volunteers in palliative care. In addition, over 100 smaller networks exist, all member of the Société Française d'Accompagnement et de soins Palliatifs (SFAP), the umbrella organisation concerning palliative care.

In **Germany**, a distinction is made between organisations initiated by volunteers themselves and run by professionals. The latter is the Deutsche Hospiz- und PalliativVerband e.V. (DHPV, German Hospice and Palliative Care Association), an umbrella organisation representing volunteer and professional organisations and associations, founded in 1992. Over 1000 hospice and palliative care services are a member of this organisation.

In the **Netherlands** volunteer work in palliative care is organised on as well a national level as on regional levels. The national volunteer organisation of the Netherlands is the VPTZ, the Vrijwilligers Palliatieve Terminale Zorg (Volunteers in Palliative Terminal Care). The VPTZ is divided in 210 local organisations, of which 140 are involved in home care and 70 in hospice care. The VPTZ is responsible for managing the work setting of volunteers including their tasks, their education and their public manifestation. Similar to England, every local VPTZ organisation has its own paid volunteer coordinator. In addition, other organisations like for example the high care hospices (Association of High Care Hospices) and the patients themselves (Dutch Patient Association, NPV, Nederlandse Patienten Vereniging), exploit volunteers too.

Poland does not have a volunteers organisation, but a centre for volunteers. This centre manages volunteers on the national level since 1983. The institution is located in Gdansk Hospice and coordinated by a catholic priest (Piotr Krakowiak), the National Priest for Palliative and Hospice Care in Poland. Training for volunteers is provided in hospices.

In **Spain** non-governmental organisations are responsible for volunteers in palliative care. The most prominent are the Spanish Association Against Cancer (AECC, 1953), The Red Cross and the Order of San Juan de Dios. More recently, some autonomous communities incorporated volunteering in their palliative care plans.

Currently, the Psychosocial Support Teams belonging to the 'La Caixa' Programme are developing a national volunteering programme.

3.4.3. LEGISLATION CONCERNING VOLUNTEERS

A decision of the Flemish (**Belgium**) government in 2008 states that 'a volunteer organisation involved in palliative care and existing of at least 20 volunteers is entitled to receive reimbursement from the Flemish government' (personal communication, September 2008).

In **France** the legislation includes statements on the management of volunteer organisations. It concerns the respect of personal opinions, dignity, privacy, discretion, confidentiality and absence of interference with health care.

Each patient has the right for a palliative care treatment. Besides, support from a volunteer is part of palliative care. A volunteer has to be member of an organisation to be allowed to work with patients.

In **Germany**, the Sozialgesetzbuch V, §39a (Code of Social Law, 1997) includes palliative care from the legal perspective. As a first step, in 1997, insured persons that did not require inpatient treatment in hospitals but for whom appropriate home care was no longer possible, were entitled to treatment in inpatient hospices or day care in hospices. Next, in 2001, regulations for these patients were extended to include the delivery of palliative home care, including the services of hospice palliative care volunteers at the patients' home, in their families, or in inpatient services. The respective hospice home care service must ensure, among others, that their services are delivered by trained volunteers and that the service is coordinated by a qualified professional.

Poland has a law concerning volunteers since 2003 (a decree was launched on the 24.04.2003, last change on 01.01.2012, Dz. U. 2010.234.1536). The palliative care volunteers are not specified separately. The law declares that volunteers should have the insurance provided by the institution where they "work" and they should have access to the protective measures similarly to health care professionals. Volunteers may "work" in hospices, at home and in the out-patient clinics but only in the public health (not private sector). Additionally they get reimbursements for public transport and education.

In **Spain** the care for terminal-stage patients is organised under the Spanish law. The Catalan Statute recognises access to good palliative care as a human right for citizens, but volunteers are not explicitly mentioned.

England does not have a specific legislation on palliative care or volunteers. Implementation of a palliative care policy is determined locally. Although the Gold Standards Framework (GSF) is a tool, which shall help to improve the care and consultation with the patient and family. In addition, the End of Life Care Strategy aims „to develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society“.

The Netherlands, like England and Spain, do not have any legislation concerning palliative care or volunteers.

3.4.4. TRAINING AND EDUCATION OF VOLUNTEERS

In **Belgium** training courses are organised per setting and region. In Flanders training for volunteers in palliative care is divided in basic training, refresher courses and evaluations. Furthermore, some networks offer supervision (personal communication, September 2008).

In Brussels only basic and continuing education is offered. Continuous education requires a monthly appointment for the volunteers. In the Walloon region the organisations advice to do an internship to prepare for work. Home care teams offer training courses of 30-40 hours. In addition, night shifts can only be done by volunteers with nursing skills (personal communication, August/September 2008).

Aside from the palliative care organisations other organisations also provide training for volunteers. The ‘Cancer et Psychology’, for example, is an acknowledged association to train volunteers (personal communication, September 2008).

Volunteers working in **France** obtain education supported from a budget of the National Health Insurance. This concerns initial training and refresher courses. The initial training program takes three days. Training is refreshed on a yearly basis. Up to 83% of the volunteers had a personal interview in combination with their basic training. Most of the candidates were obliged to sign a contract.

With the growing palliative care development in **Germany** training programs for volunteers have become accepted. Initially, curricula for coordinators were designed as the coordinators are the access points for volunteers for training. The curricula included volunteers’ tasks in hospice palliative care and in communication and

attitude skills. The recommendations of the *Federal Ministry of Work and Social Affairs* suggested a basic course with emphasis on reflection on personal experiences, and an advanced course focussing on knowledge and skills for practical work. In total, the courses compromise up to 140 course sessions of 45 minutes (personal communication, June 2008). The advanced course, with 15 to 20-hours, includes aspects of 'basic nursing' at the patients' homes, such as: What can I do when a patient is sick? What can I do when a patient needs help to get out of bed? Often hospices adopt training modules regarding special needs of the patients. Supervision on a regular basis by an external professional is recommended.

The training of volunteers in the **Netherlands** is mandatory before they are allowed to work with palliative patients. The volunteer organisation VPTZ and the Association of the High Care Hospices offer training courses, although the content of the High Care Hospices training programs varies between institutions (personal communication, August 2008). Similar to Germany, the VPTZ training programme is based on a curriculum. The curriculum is delivered in introductory courses and continuing education. On a national level the content is structured in 16 different modules (personal communication, August/September 2008). Beside the national training programs, hospices often train their volunteers individually according to their specific needs.

In **Poland** education of volunteers is provided on a local level. The training programs are available for volunteers and for coordinators. The education programs are located in palliative care units.

As the models of palliative care volunteering differ vastly in **Spain**, each setting has its own principles. There are differences in guidelines of organisation, establishing agreements etc. Yet, the training of volunteers concerning initial and continuing training are the same everywhere.

In **England** volunteers often have a brief induction and occasional training. Especially volunteer bereavement counsellors provide counselling under supervision. However training varies according to role and setting.

3.4.5. COMPARATIVE ANALYSIS

The results from our survey demonstrated similarities and differences of availability, tasks, legislation and training of volunteers in palliative care in seven European countries.

The most striking country variations became evident in the data availability on the contribution of volunteers to palliative care, which are summarised in Table 1. Whereas England has the highest estimates of volunteers presence, Belgium is not able to present a total figure (Table 1). Often there was a correlation of present data with the existence of national volunteer organisations.

Table 1 Availability of volunteers

Country	Number of Inhabitants	Number of volunteers	Volunteers/ 1.000 inhabitants
Belgium	6,000,000	354	0.06
Germany	82,046,000	80,000	0.98
Spain	46,661,950	14,203	0.3
France	65,073,482	4,169	0.45
Netherlands	16,493,156	8,300	0.5
Poland	38,153,389	2,500	0.07
England	60,587,000	70,000	1.160

The overall usage of volunteers across settings is different (Table 2). Belgium, the Netherlands, and UK have volunteering in most settings of palliative care delivery. For Germany, Poland, and France palliative care volunteering is less widespread across settings.

Table 2 Usage of volunteers across settings

	Home care	Palliative care unit	Nursing home	Hospital	Day care centre	Hospice	Care home
Belgium	+	+	+	+	+	+	-
Germany	-	+	-	-	-	+	-
Spain	+	-	+	+	-	-	+
France	+	-	-	+	-	-	-
Netherlands	+	-	+	+	-	+	+
Poland	-	-	-	-	-	+	-
England	+	+	-	+	+	-	-

The seven countries differed in the coordination of volunteers on a national or a local level (Table 3).

Table 3 Organisation of volunteers

Country	Organisation: national	Organisation: regional
Belgium		PANAL
Germany	DHPV (1992)	
Spain		AECC (1953/ 1994) Red Cross Order San Juan de Dios
France	JALMALV (1993/ 2007) UNASP (1984/ 1992/ 1995)	SFAP (1990)
Netherlands	VPTZ	Association of high care hospices NPV (1983)
Poland		Gdansk Hospice
UK		AVSM Help the Hospice

In the studied countries legislation regarding volunteering in palliative care varies. However, three countries do not include volunteers in their legislation, namely England, the Netherlands and Spain.

The objective of inclusion of palliative care volunteers in the national health care systems might go along with their national or regional commitment. As reported, some countries have strong regional organisations, which perform management of volunteers to higher (national) level whereas others remain on regional level (Table 3).

Data concerning volunteer training is comparable in all countries and the need for volunteer basic and continuing training, seems to be accepted nation-wide. Only in France, specific advanced training for volunteers has been explicitly mentioned in the questionnaire.

3.5. DISCUSSION

This paper provides a first comparison of the organisation of volunteers in seven European countries to gain a better understanding on an international level. The evaluation provides an overview of the organisation of volunteer work, the usage of volunteer work and the availability of training courses. This will stimulate the discussion about clear definitions and concepts for the contribution of volunteers to palliative care in Europe.

Combining a (grey) literature search and expert interviews allows for triangulation strengthening the research design. The approach to identify experts differed between the countries involved in the survey, as each country team individually performed

their national part of the survey. However, the number of key persons involved and the methodology of the grey literature search were used uniformly in all countries.

Differences in the health care systems, the state of development of palliative care, the need to use English as the project language among mostly non-native speakers and the workforce capacity of the research team all may have influenced the level of details per country.

Although we concentrated on seven countries in our study, these countries represent different regions of Europe, different health care systems and different cultures. It appeared difficult to find data that were covered in each of the participating countries as volunteering in Europe has not been subject of extensive research so far. We tried to take regional differences into account where possible. Based on these findings, proposals for standards for the organisation of volunteers in palliative care in Europe have been developed and will be published elsewhere.

There are only few comparable studies in the literature. Fusco-Karmann and Tinini evaluated, in cooperation with the European Association of Palliative Care (EAPC), volunteer organisations (non-profit organisations, NPOs) in 18 European countries.⁵ In that survey it appeared that volunteers received training via their associations, and also were mainly occupied in home settings and hospices.

A few years later, in 2004, Gronemeyer et al. compared palliative care in 16 European countries. This report was mainly in congruence with the findings of the Europall project, for training of volunteers, the organisation of volunteers as well as for volunteer tasks, even though their study covered partly different European countries than the countries involved in Europall.¹²

Outside Europe, volunteering in the Middle East has been studied as part of a larger study by Bingley and Clark.¹³ Similar to our survey, in Cyprus, Jordan and Israel volunteers receive initial basic training. In these countries, home hospice organisations are established and run by volunteers, almost like the hospice home care services in the Netherlands and in Germany.

In summary, our study adds important knowledge to the organisation of volunteers in hospice and palliative care in seven European countries. The study indicates that there is a cultural aspect to volunteering, which was not mentioned in previous studies. The interrogated experts describe less recognition of volunteer work in Spain.

3.5.1. IMPLICATIONS FOR PRACTICE AND POLICY

The education of volunteers might be of particular interest as institutions obtain an obvious benefit of educated volunteers. Trained staff improves the quality of care and the patients' quality of life. However, the integration of specific curricula and the supervision of volunteers remain different. The security provided through contracts with volunteers might be considered beneficial. Tasks and working conditions can be described to avoid the use of volunteers as cheap substitutes for paid professional caregivers. However, the formal way might have a discouraging effect and stop volunteers from supporting.

Aspects of best practices could be merged and presented to volunteer organisations and to EAPC. Furthermore, the establishment of a European platform for palliative care volunteering, with participation from volunteer organisations, could serve to tackle various challenges named in this article, e.g. the varieties in training programs or differences in funding, and cultural differences in the usage of volunteering in palliative care. A benchmarking process could be used to improve quality of care. Finally, this could facilitate an easier data exchange for international comparisons and benchmarking with consideration of cultural differences to stimulate research in this area. To share good practices, quality indicators and standards will be further developed based on the results of our study. This should further stimulate the discussion about clear definitions and concepts for the contribution of volunteers to palliative care in Europe.

3.6. ACKNOWLEDGEMENTS

The authors are grateful to the EAHC (Executive Agency for Health and Consumers) for funding the Europall project which ran from 2007 till 2010 and consisted of collaborative research partnership of scientists and caregivers from Belgium, France, Germany, the Netherlands, Poland, Spain, and the United Kingdom. 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.

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PART 2:
DEVELOPMENT OF QUALITY INDICATORS
FOR THE ORGANISATION OF PALLIATIVE
CARE



CHAPTER 4



DEVELOPMENT OF A SET OF PROCESS AND STRUCTURE INDICATORS FOR PALLIATIVE CARE: THE EUROPALL PROJECT

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4.1. ABSTRACT

By measuring the quality of the organisation of palliative care with process and structure quality indicators (QIs), patients, 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.

As no European set of indicators for the organisation of palliative care existed, such a set of QIs was developed. An update of a previous systematic review was made and extended with more databases and grey literature.

In two project meetings with practitioners and experts in palliative care the development process of a QI set was finalised and the QIs were categorized in a framework, covering the recommendations of the Council of Europe.

The searches resulted in 151 structure and process indicators, which were discussed in steering group meetings. Of those QIs, 110 were eligible for the final framework.

We developed the first 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.

4.2. INTRODUCTION

Following the 2002 definition of the World Health Organisation (WHO), palliative care is no longer restricted to patients with cancer; it should be available for all patients with life-threatening diseases.¹ Furthermore, palliative care is applicable early in the course of the disease and can be delivered in conjunction with interventions 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 regarding settings and services, policy and organisation, quality improvement and research, education and training, family, communication with the patient and family, teams and bereavement. This included further 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, patients, 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 structure and process 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 or setting.⁸

Therefore, we aimed to develop a scientifically sound European set of structure and process QIs, as a first step in quality measurement and improvement.

4.3. MATERIAL AND 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).

QI sets can be based on existing sets of QIs, recommendations from clinical guidelines, scientific literature, best practice or expert consensus.⁶ We used a combination of these.

As palliative care, being a relatively young field within health care is changing rapidly. The initial phase of this project was an update and extension of a previous review aiming to find already existing QIs in literature or aspects of the organisation of the palliative care for which QIs would be useful.⁸ Quality indicators 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', which made us focus on processes and structures.⁷ Besides publications that describe the development or use of QIs for the organisation of palliative care, publications were used that describe the structure or process of good palliative care, in order to develop QIs if not available yet.

4.3.1. MAIN DATABASE SEARCH

As an update and extension of an existing systematic review, the following bibliographic databases were searched: Medline, Scopus, PsycINFO, Social Medicine, CINAHL, the Cochrane Database, Embase, SIGLE, ASCO, and Google Scholar by an existing search strategy (Appendix A).⁸ If applicable, Mesh terms were changed, as these are database-specific.

Inclusion criteria were a publication period from December 2007 to May 2009, as the systematic review ran until December 2007 and containing information about the development or use of (sets of) QIs.

Papers describing QIs about palliative care for children, clinical outcome indicators, patient outcome and on treatment were excluded, as well as scientific papers that were not written in English.

The initial selection process was based on independent screening by three researchers of 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).

The QIs derived from the search were categorized in a framework. It was based on (1) a previously developed framework for evaluation of the organisation of general practice and adapted for palliative care and (2) the recommendations of the Council of Europe.^{4,10} It contains the domains 1. Definition of a palliative care service, 2. Access to palliative care, 3. Infrastructure, 4. Assessment tools, 5. Personnel, 6. Documentation of clinical data, 7. Quality and safety issues, 8. Reporting clinical activity of palliative care, 9. Research and 10. Education.

4.3.2. GREY LITERATURE SEARCH

If a domain or subdomain of the framework was not covered with QIs found in the literature search, an additional grey literature search was performed. Grey literature was defined as 'literature which has not been formally published in peer-reviewed literature'.¹¹ Inclusion of grey literature was restricted to reports from government agencies or scientific research groups, white papers and websites from national organisations of the seven participating countries. Finally, the network of the Europall research group was used to identify relevant papers.

4.3.3. 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).

4.3.4. QI SELECTION

The draft set of structure and process QIs was discussed 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 invited. Consensus was based on 1. whether it considered a process or structure QI 2. whether it overlapped with other proposed QIs, 3. to which domain of the framework (Table 1) it belonged and 4. for which settings it was applicable. Based on the grey literature search, the project partners could suggest new QIs about aspects that were relevant but not yet operationalised as QIs.¹⁰

Based on this meeting, adaptations were made and a new draft QI set was presented in the second steering group meeting in October.

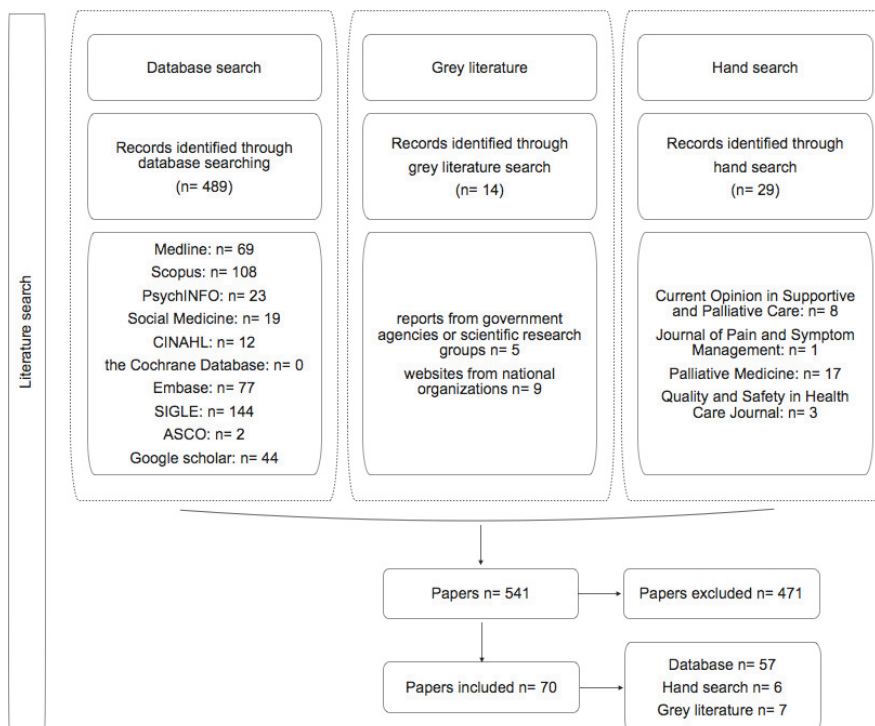
4.4. RESULTS

4.4.1. SEARCH FLOW

The literature search resulted in 541 papers, including a previous systematic review on quality indicators for palliative care.⁸ Most of the papers came from the database search (n=527), followed by the hand search (n= 29) and least of grey literature search (n=14).

In the screening process 16 duplicates were identified, and titles and abstracts of 511 papers were searched. 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 search¹²⁻⁶⁸ and another six papers from the additional hand searches (Figure 1).⁶⁹⁻⁷⁴

Figure 1 Flow chart literature search



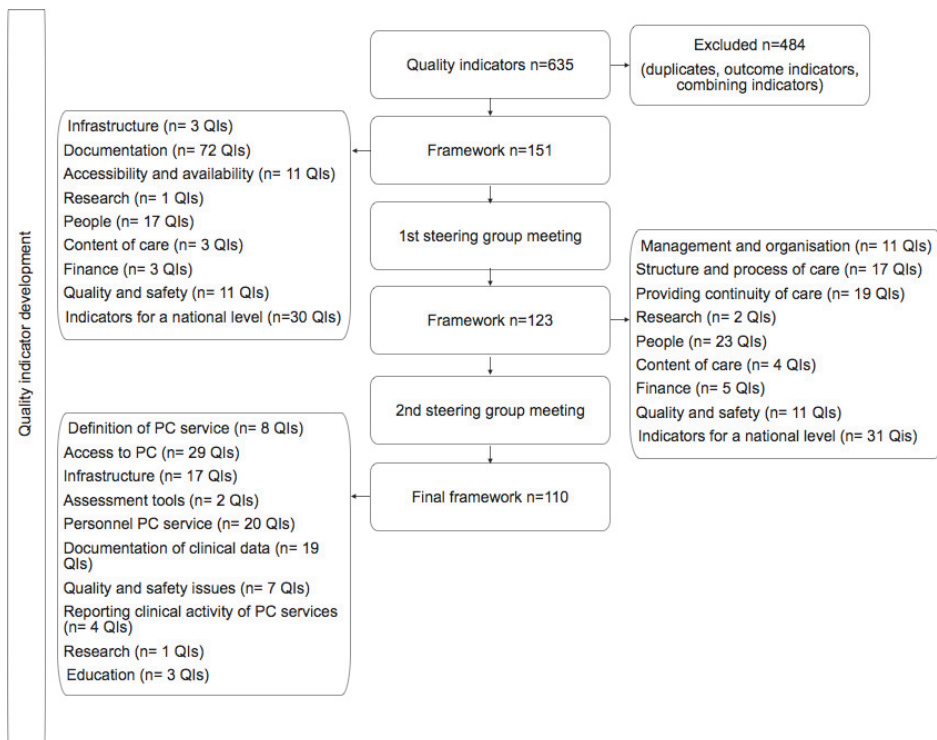
4.4.2. RESULTS GREY LITERATURE SEARCH

The grey literature search yielded seven papers, deriving from Belgium, the Netherlands and the UK.^{9,75-80} These sources included government sites, national health organisations and national institutes (Figure 1). This additional search resulted in the development of 53 QIs, divided over almost all domains (Appendix B).

4.4.3. QI DEVELOPMENT

Six hundred-thirty five QIs were derived from this literature review. After screening of duplicates, selecting process and structure QIs and combining QIs covering the same topic, the remaining 151 QIs were organised in the framework and discussed in the first steering group meeting. The two steering group meetings resulted in a reduction from 151 to 110 QIs (Appendix C) (Figure 2). For instance the domain about finance QIs was excluded for the final set as the QIs were more useful on national level than in the setting specific palliative care institutions.

Figure 2 Flow chart quality indicator development



The rest of the QIs were distributed over the framework (Table 1).¹⁰

The majority of the 110 QIs were process QIs (n=76), the other structure QIs (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. The others were meant for all settings that deliver palliative care.

Twenty-four QIs were developed based on organisational aspects found in literature (Table 1, QI 51). Finally, several QIs (n= 86), were changed in their presentation of text during the procedure. For example, originally developed QIs for other settings like the intensive care unit, were adapted to make them appropriate for palliative care settings.

Table 1 Quality indicator set

Quality indicator set				
Definition of a palliative care service				
1	All the services below are part of a comprehensive palliative care service: Palliative day care, Palliative home care support team, Hospice beds, Palliative hospital support team, Inpatient palliative care hospital beds, Palliative care outpatient clinic, Bereavement support	Structure indicator	All settings	New developed
2	All the services below are part of a comprehensive palliative care service: Palliative day care	Structure indicator	All settings	New developed
3	All the services below are part of a comprehensive palliative care service: Palliative home care support team	Structure indicator	All settings	New developed
4	All the services below are part of a comprehensive palliative care service: Hospice beds	Structure indicator	All settings	New developed
5	All the services below are part of a comprehensive palliative care service: Palliative hospital support team	Structure indicator	All settings	New developed
6	All the services below are part of a comprehensive palliative care service: Inpatient palliative care hospital beds (e.g. palliative care unit)	Structure indicator	All settings	New developed
7	All the services below are part of a comprehensive palliative care service: Palliative care outpatient clinic	Structure indicator	All settings	New developed
8	All the services below are part of a comprehensive palliative care service: Bereavement support	Structure indicator	All settings	New developed
Access to palliative care				
A. Access and availability (All settings)				
9	A palliative care team is available at the request of the treating professional/team in all of the following settings: Day care, at home, Hospital, Hospice, Nursing home, Outpatient clinic, Day care	Process indicator	All settings	New developed
10	A palliative care team is available at the request of the treating professional/team in all of the following settings: Day care (excluding palliative day care)	Process indicator	All settings	New developed
11	A palliative care team is available at the request of the treating professional/team in all of the following settings: At home (or home replacing institution s.a mental institution, prison)	Process indicator	All settings	New developed
12	A palliative care team is available at the request of the treating professional/team in all of the following settings: Hospital	Process indicator	All settings	New developed
13	A palliative care team is available at the request of the treating professional/team in all of the following settings: Hospice	Process indicator	All settings	New developed
14	A palliative care team is available at the request of the treating professional/team in all of the following settings: Care home	Process indicator	All settings	New developed
15	A palliative care team is available at the request of the treating professional/team in all of the following settings: Outpatient clinic (excluding palliative care outpatient clinic)	Process indicator	All settings	New developed
16	For every professional/team specialised palliative care advice is available 24 hours a day, 7 days a week	Process indicator	All settings	Changed
17	Patients in need of palliative care and their families have access to palliative care facilities: Throughout the entire duration of their disease	Process indicator	All settings	Changed

Quality indicator set				
18	Patients in need of palliative care and their families have access to palliative care facilities: With no extra financial consequences for the patient	Process indicator	All settings	Changed
19	Patients receiving palliative care have access to diagnostic investigations (e.g. X-rays, blood samples) regardless of their setting	Process indicator	All settings	Changed
Primary care (Home, Nursing home)				
20	Palliative care is available for the patient and their family by:Phone	Process indicator	Primary care indicator	Changed
21	Palliative care is available for the patient and their family by: Visiting the patient	Process indicator	Primary care indicator	Changed
22	Palliative care is available for the patient and their family by: Bringing the patient to the service	Process indicator	Primary care indicator	Changed
23	For a palliative patient in a crisis , the following can be arranged within 24 hours: Admission	Process indicator	Primary care indicator	Changed
24	For a palliative patient in a crisis , the following can be arranged within 24 hours: An urgent discharge to patients home	Process indicator	Primary care indicator	Changed
25	For a palliative patient in a crisis , the following can be arranged within 24 hours: Transfer to another setting of care	Process indicator	Primary care indicator	Changed
B. Out of hours (All settings)				
Staff				
26	A member of a palliative care team is available 24 hours a day, 7 days a week: For palliative care consultation by phone	Process indicator	All settings	Changed
27	A member of a palliative care team is available 24 hours a day, 7 days a week: To provide bedside care in a crisis	Process indicator	All settings	Changed
Drugs				
28	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Opioids and other controlled drugs	Structure indicator	Primary care indicator	Combined/ Changed
29	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Anticipatory medication for the dying patient	Structure indicator	Primary care indicator	Combined/ Changed
30	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Syringe drivers	Structure indicator	Primary care indicator	Combined/ Changed
C. Continuity of care (All settings)				
31	There is a procedure for exchange of clinical information across caregivers, disciplines and settings	Process indicator	All settings	Changed
32	Before discharge/ transfer/ admission there is information transfer to the caregivers in the next setting regarding care and treatment	Process indicator	All settings	Changed
33	There is a professional caregiver per individual palliative patient nominated as responsible 'key worker' who coordinates care	Process indicator	All settings	Combined/ Changed
34	The responsible 'key worker' pays special attention to continuity of care within and across settings	Process indicator	All settings	Combined/ Changed
Inpatient setting (Hospital, Palliative care unit, Hospice)				
35	General practitioners (GP's) are routinely called when a patient is being discharged home or transferred to another setting	Process indicator	Inpatient setting indicator	Changed
36	The discharge/ transfer letter of palliative care patients contains a multidimensional diagnosis, prognosis and treatment plan (see indicator 48 Clinical record)	Structure indicator	Inpatient setting indicator	Changed
Primary care				
37	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	Structure indicator	Primary care indicator	Changed
Infrastructure				
A. All settings				
Infrastructure				
38	Specialist equipment (e.g. anti decubitus mattresses, aspiration material, stoma care, oxygen delivery, special drug administration pumps, hospital beds, etc.) is available for the nursing care of palliative care patients in each specific setting	Structure indicator	All settings	Changed
39	There is a dedicated room where multidisciplinary team meetings within one setting takes place	Structure indicator	All settings	New developed
40	There are dedicated facilities for multidisciplinary communications across settings: A dedicated room for meetings	Structure indicator	All settings	Changed
41	There are dedicated facilities for multidisciplinary communications across settings: Facilities for video or telephone conferences	Structure indicator	All settings	Changed
Information about care				
42	There is an up to date directory of local caregivers and organisations that can have a role in palliative care	Structure indicator	All settings	New developed

Quality indicator set				
43	There are dedicated information about the palliative care service: A website	Structure indicator	All settings	Changed
44	There are dedicated information about the palliative care service: Leaflets or brochures	Structure indicator	All settings	Changed
45	Patient information should be available in relevant foreign languages	Structure indicator	All settings	Changed
46	Appropriately trained translators should be available if professional caregivers and patient or family members do not speak the same language	Process indicator	All settings	Changed
47	There is a computerised medical record , to which all professional caregivers involved in the care of palliative care patients have access: Within one setting	Process indicator	All settings	Combined
It systems				
48	There is a computerised medical record , to which all professional caregivers involved in the care of palliative care patients have access: Across different settings	Process indicator	All settings	Combined
B. Inpatient setting (Hospital, Palliative care unit, Hospice, Nursing home)				
49	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)	Structure indicator	Inpatient setting indicator	Changed
50	Dying patients are able to have a single bedroom if they want to	Process indicator	Inpatient setting indicator	New developed
51	There are facilities for a relative to stay overnight	Structure indicator	Inpatient setting indicator	New developed
52	Family members and friends are able to visit the dying patient without restrictions of visiting hours	Process indicator	Inpatient setting indicator	Changed
53	There is a private place (e.g. dedicated room) for saying goodbye to the deceased	Structure indicator	Inpatient setting indicator	New developed
C. Home care				
54	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	Process indicator	Home care indicator	Changed
Assessment tools				
55	There is a holistic assessment of palliative care needs of patients and their family caregivers (e.g. SPARC)	Process indicator	All settings	Changed
56	There is an assessment of pain and other symptoms using a validated instrument	Process indicator	All settings	Changed
Personnel palliative care services				
A. Staff				
57	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Physician	Structure indicator	All settings	Changed
58	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Nurse	Structure indicator	All settings	Changed
59	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Spiritual/ religious caregiver	Structure indicator	All settings	Changed
60	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Psychologist/Psychiatrist	Structure indicator	All settings	Changed
61	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Social worker	Structure indicator	All settings	Changed
62	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Physiotherapist	Structure indicator	All settings	Changed
63	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Occupational therapist	Structure indicator	All settings	Changed
64	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Dietitian	Structure indicator	All settings	Changed
65	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Bereavement counselor	Structure indicator	All settings	Changed
66	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Pharmacist	Structure indicator	All settings	Changed
B. Education and training for staff/ volunteers				
67	New staff receives a standardised induction training	Process indicator	All settings	Changed
68	All team members have certified (accredited?) training in palliative care, appropriate to their discipline	Process indicator	All settings	Changed
69	All volunteers have training in palliative care.	Process indicator	All settings	Combined/ Changed

Quality indicator set				
C. Support systems				
70	All team members have an annual appraisal	Process indicator	All settings	Changed
71	All team members who professionally deal with loss have access to a program for care for the carers	Process indicator	All settings	Changed
72	Satisfaction with working in the team is assessed (e.g. Team Climate Inventory)	Process indicator	All settings	Changed
D. Organisation of care				
73	Palliative care services work in conjunction with the referring professional/ team	Process indicator	Inpatient setting indicator	New developed
74	There is a regular interdisciplinary/ multi-professional meeting to discuss palliative care patients: daily meetings to discuss day-to-day management of palliative care patients	Process indicator	All settings	Combined/ Changed
75	There is a regular interdisciplinary/ multi-professional meeting to discuss palliative care patients: weekly (inter- and multidisciplinary) meeting to review palliative care patients referrals and care plans	Process indicator	All settings	Combined/ Changed
E. Information sharing				
76	All relevant team members are informed about patients who have died	Process indicator	Inpatient setting indicator	Changed
Documentation of clinical data				
A. Clinical record (All settings)				
77	For patients receiving palliative care a structured palliative care clinical record is used	Process indicator	All settings	Changed
78	The palliative care clinical record contains evidence of documentation of the following items: Clinical summary	Process indicator	All settings	Changed
79	The palliative care clinical record contains evidence of documentation of the following items: Physical aspects of care	Process indicator	All settings	Changed
80	The palliative care clinical record contains evidence of documentation of the following items: Psychological and psychiatric aspects of care	Process indicator	All settings	Changed
81	The palliative care clinical record contains evidence of documentation of the following items: Social aspects of care	Process indicator	All settings	Changed
82	The palliative care clinical record contains evidence of documentation of the following items: Spiritual, religious, existential aspects of care	Process indicator	All settings	Changed
83	The palliative care clinical record contains evidence of documentation of the following items: Cultural aspects of care	Process indicator	All settings	Changed
84	The palliative care clinical record contains evidence of documentation of the following items: Care of imminently dying patient	Process indicator	All settings	Changed
85	The palliative care clinical record contains evidence of documentation of the following items: Ethical, legal aspects of care	Process indicator	All settings	Changed
86	The palliative care clinical record contains evidence of documentation of the following items: Multidimensional treatment plan	Process indicator	All settings	Changed
87	The palliative care clinical record contains evidence of documentation of the following items: Follow up assessment	Process indicator	All settings	Changed
B. Timely documentation				
Inpatient setting (Hospital, Palliative care unit, Hospice, Nursing home)				
88	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	Process indicator	Inpatient setting indicator	Changed
89	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	Process indicator	Inpatient setting indicator	Changed
90	There is documentation about the discussion of patient preferences within 48 hours of admission	Process indicator	Inpatient setting indicator	Changed
91	A discharge/ transfer summary is available in the medical record within 48 hours after discharge/ transfer	Process indicator	Inpatient setting indicator	Changed
All settings				
92	There is documentation of pain assessment at 4 hour intervals	Process indicator	All settings	Changed
93	The discussion of patient's preferences is reviewed on a regular basis (in parallel with disease progression) or on request of the patient	Process indicator	All settings	Changed
94	There is documentation that within 24 hours after patient transfer, the responsible physician in the receiving setting has visited the patient	Process indicator	All settings	Changed
95	There is documentation that within 24 hours after patient transfer, the new palliative care team in the receiving setting has visited the patient	Process indicator	All settings	Changed
Quality and safety issues				
A. Quality policies				

Quality indicator set				
96	The palliative care service has a quality improvement program	Process indicator	All settings	Changed
97	There is documentation whether targets set for quality improvement have been met	Process indicator	All settings	Changed
98	Clinical audit are part of the quality improvement program	Process indicator	All settings	Changed
99	The setting uses a program about early initiation of palliative care (e.g. the Gold Standards Framework)	Process indicator	All settings	Changed
B. Adverse events				
100	There is a register for adverse events	Process indicator	All settings	Changed
101	There is a documented procedure to analyse and follow up adverse events	Process indicator	All settings	Changed
C. Complaints procedure				
102	There is a patient complaints procedure	Process indicator	All settings	Changed
Reporting clinical activity of palliative care services				
103	The palliative care service uses a database for recording clinical activity	Process indicator	All settings	Changed
104	The following is part of the database: Diagnosis, Date of diagnosis, Date of referral, Date of admission to the palliative care service, Date of death, Place of death, Preferred place of death	Process indicator	All settings	Changed
105	From the database the service is able to derive: Time from diagnosis to referral to palliative care, Time from referral to initiation of palliative care, Time from initiation of palliative care to death, Frequency of unplanned consultations with the out-of-hours service for palliative care patients who are at home, Frequency of unplanned hospital admissions of palliative care patients, Percentage of non-oncological patients receiving palliative care	Process indicator	All settings	New developed
106	Based on the database, an annual report is made about the service	Process indicator	All settings	Changed
Research				
107	There is evidence that the palliative care service is involved in research in palliative care (e.g. authorship of publications, research grants)	Process indicator	All settings	Changed
Education				
108	All health and social care students have standardised learning objectives for basic training in palliative care	Process indicator	All settings	Changed
109	All health and social care professionals have standardised learning objectives for continuing basic training in palliative care	Process indicator	All settings	New developed
110	There is a program for specialised training in palliative care for professionals working in a service that provides specialised palliative care	Process indicator	All settings	New developed

4.5. DISCUSSION

We were able to develop an international framework with 110 QIs to assess the organisation of palliative care in several kind of settings. To our knowledge, this study presents the first systematically developed international 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.

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 process and structure QIs.^{8,81} By using an international perspective and by not limiting the study to symptom control, our study follows the recommendations of Ostgathe et al.⁸² Our set also contains two QIs that are linked to the World Health Assembly's proposed global health indicator 'Access to palliative care assessed by

morphine-equivalent consumption of strong opioid analgesia (excluding methadone) per death by cancer', but without the restriction to patients with cancer.⁸³

4.5.1. 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.⁸⁴ Of those QIs that were developed for a restricted group of patients or setting (e.g. ICU or vulnerable elderly) we checked whether we could rephrase them into QIs for more types of settings or palliative patients. Defining QIs in a consensus procedure is a good option if scientific literature is not yet available, particularly because it combines several methods to improve validity. Using a group approach has the advantage that participants can share their expertise and experience.⁷ Groups often make better decisions than individuals.⁸⁵

The naming of QIs as process or structure indicators can be discussed. Yet, this only influences the categorisation and not the content, importance or use of a QI.

Another strong aspect of our procedure is the inclusion of grey literature, which created the possibility to include documents from important although not scientific sources.⁸⁶

As the Europall project was a collaboration of seven European countries, only experts of these countries were represented in the steering group meetings. Other European countries, with different health care and financing systems, cultures and palliative care, were not involved at this stage.

This first step resulted in a set of structure and process QIs, that can help professionals or settings to measure the quality of care of their setting. In a next step, a subset will be developed of which each QI is applicable in the seven participating countries.

Based on a modified RAND Delphi method the following set will be interesting for international comparison. The advantage of this comprehensive set enables each country and each setting the opportunity to see all QIs that are available on this topic. The last step will describe a pilot study to test the set of QIs on face-validity, applicability and discriminative power. This includes almost all (26) European countries. These studies will be published separately.

4.5.2. FURTHER RESEARCH

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.^{1,4}

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.

4.5.3. CONCLUSIONS

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

4.6. ACKNOWLEDGEMENTS

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CHAPTER 5



VALIDATION OF QUALITY INDICATORS FOR THE ORGANIZATION OF PALLIATIVE CARE: A MODIFIED RAND DELPHI STUDY IN SEVEN EUROPEAN COUNTRIES (THE EUROPALL PROJECT)

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5.1. ABSTRACT

Validated quality indicators (QIs) can help health care professionals to evaluate their medical practices in a comparative manner to deliver optimal clinical care. No international set of QIs to measure the organisational aspects of palliative care settings exists. To develop and validate a set of structure and process indicators for palliative care settings in Europe. A two-round modified RAND Delphi process was conducted to rate clarity and usefulness of a previously developed set of 110 QIs. Twenty multi-professional palliative care teams of centres of excellence from seven European countries. In total 56 QIs were rated as useful. These valid QIs concerned the following domains: the definition of a palliative care service (2 QIs), accessibility to palliative care (16 QIs), specific infrastructure to deliver palliative care (8 QIs), symptom assessment tools (1 QI), specific personnel in palliative care services (9 QIs), documentation methodology of clinical data (14 QIs), evaluation of quality and safety procedures (1 QI), reporting of clinical activities (1 QI), and education in palliative care (4 QI). The modified RAND Delphi process resulted in 56 international face-validated QIs to measure and compare organisational aspects of palliative care. These QIs, aimed to assess and improve the organisation of palliative care, will be pilot tested in palliative care settings all over Europe and be used in the EU FP7 IMPACT project.

5.2. INTRODUCTION

With an aging European population and a growing number of persons dying from cancer or chronic diseases, the number of people in need for good palliative care increases too.¹ Decision makers have to assess where and when palliative care services should be developed, but also how they should be equipped and how care should be organized to guarantee high quality of palliative care. To provide optimal palliative care to patients, not only medical care should improve but also the quality of the organisation of palliative care settings should improve.^{2,3} Comparable data on organisational aspects of settings delivering palliative care in individual countries should be available in order to guarantee high quality palliative care for all citizens, as well as its efficiency and effectiveness.

To assess specific components of the organisation of health care systems or settings, quality indicators (QIs) can be used. A QI is 'a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care provided and can reveal potential problems that might need addressing'.⁴ QIs are measurement tools for evaluation, monitoring, and improvement of patient care, clinical support services and organisational functioning.⁵

To categorize QIs, Donebedian's classification in structure, process and outcome indicators is frequently used.⁶ Additionally, QIs can be subdivided into internal and external indicators. Health care providers can use internal indicators to monitor and improve care processes in their own setting. External indicators can be used by governments, patient organisations and payers, to assess the quality of care of a health care provider, and to compare health care providers.^{6,7}

In practice, outcome QIs are more common and accepted than structure or process QIs.⁸ Therefore, the purpose of this study was to develop and validate a set of structure and process QIs to measure the organisation of palliative care in different health care systems and countries, taking geographical, historical, political and cultural aspects into account.⁹

This study was co-funded by the European Executive Agency for Health and Consumers (EAHC) and part of the Europall project, in which experts in palliative care from seven European countries (Belgium, United Kingdom (UK), France,

Germany, Netherlands, Poland and Spain) participated. The Europall project ran from October 2007 till September 2010.

5.3. MATERIAL AND METHODS

5.3.1. DESIGN

A two-round modified RAND Delphi process was conducted in 2009/2010 on a previously developed concept set of process and structure QIs.¹⁰ This method is used to determine the extent of agreement on an issue, and is a validated method for developing QIs. It allows the consultation of a large number of geographically dispersed experts in a short period of time.¹¹ Instead of individuals, who usually participate in Delphi studies, palliative care teams were invited to participate as a group, to represent the multi-professional character of palliative care.

5.3.2. PARTICIPANTS

In spring 2009 nationally acknowledged experts in the Netherlands, Belgium, Germany, UK, Poland, France and Spain were invited to identify three centres of excellence in palliative care. 'Experts' were defined as (1) having at least five years of experience in the field of palliative care; (2) being recognized as opinion leaders at a national level, and (3) having a good overview of palliative care in their country. Centres of excellence needed to exist for at least five years and to be acknowledged nationally as examples of good practice, with a high standing educational program and strong organisational aspects.

A number of three centres of excellence was determined in a steering group meeting. It was considered that three centres within a country would be representative for geographical spread, different models of palliative care and organisational structures. Besides, a panel of 21 teams in total (3 teams in each of the seven participating countries) is appropriate.^{11,12} Per centre of excellence, the multi-professional palliative care team was invited to participate. We asked them per Delphi round to arrange a meeting with preferably a representative of each discipline.

5.3.3. RATING PROCESS

After delivery of the essential documents (questionnaire, glossary and instruction sheet) each centre organized a meeting with the multi-professional team. The teams

were instructed to rate each QI, based on group consensus. If no consensus could be reached on a QI, they were asked to put the ratings of each team member in the comment field.

The teams rated the previously developed 110 structure and process QIs on clarity and usefulness. Usefulness was defined as: the proposed indicator corresponds with (1) a basic level of quality, that should be present in all settings of palliative care in all participating countries, (2) a higher quality level in agreement with the settings of good practice of that country, or (3) an innovative quality level, that is exceptional at the moment but that could become the optimal quality level in the coming years.¹² Ratings were performed on a scale of 1 (not clear/not useful) to 9 (very clear/very useful). Besides, each QI had an open comment field.

Following Delphi round one, each team received feedback on its own ratings compared to the median ratings of all teams. QIs with high ratings and no comments in round one were not added in round 2. Based on comments in round 1, several QIs were rephrased, resulting in an adapted list of QIs. In a second meeting, the adapted set of QIs was rated again. After the second rating a final QI set was prepared.

5.3.4. ANALYSIS

Analysis was based on the modified RAND appropriateness method. This method has been developed at the University of California at Los Angeles (UCLA) to synthesize the scientific literature and expert opinion on health care topics.¹³

The RAND method defines agreement for a 9-members team as having no more than two team members who rate the QI outside the 3-point region (the 1-3 range classified as inappropriate, the 4-6 range as uncertain, and the 7-9 range as appropriate).¹³ Hence, in this study, at least 18 of the 20 participating teams had to rate a QI with a median score of 7-9 to be considered useful and included in the final list. A higher number of low-rating teams resulted in rejection of the proposed QI.

5.3.5. ETHICAL APPROVAL

In none of the participating countries ethical approval was required. In the UK clearance and approval to proceed was obtained from the Service Evaluation, Clinical Effectiveness Unit in Sheffield. In the information letter for the participating teams, confidentiality and anonymity of the research findings was guaranteed. As no

personal information of the participating professionals was collected, no informed consent was questioned.

5.4. RESULTS

Of all countries except for Spain, all eighteen teams that were approached participated in Delphi round one. In Spain, selection of centres of excellence was delayed; they were not able to participate in round one. The teams existed of one to seven persons (Table 1).

Table 1 Participants

Country	Team	Delphi 1		Delphi 2	
		team size	participants*	team size	participants*
Belgium	a	6	Ph,Nu	4	Ph,Nu
	b	3	Ph,Nu	3	Ph,Nu
	c	5	Ph,Nu	5	Ph,Nu
UK	a	4	Ph	3	Ph
	b	1	Ph,Nu	1	Ph,Nu
	c	6	Ph,Nu	6	Ph,Nu
Germany	a	3	Ph,Nu	3	Ph
	b	4	Ph	4	Ph
	c	7	Ph,Nu,So	8	Ph,Nu,So
Netherlands	a	4	Ph,Di,Vo,Ma	1	Ph,Di,Vo,Ma
	b	5	Ph,Nu,Ps,Di	3	Ph,Nu,Di
	c	5	Nu,Di,Re	5	Ph
Poland	a	3	Ph,Ma,So	2	Ph,Ma,So
	b	2	Ph,Re	2	Ph
	c	3	Ph	3	Ph
France	a	5	Ph,Nu,So	5	Ph,Nu,So
	b	5	Ph,Di,Vo	4	Ph,Nu,Di,Vo
	c	5	Nu,Ps,Di,	5	Ph,Ps
Spain	a	0		6	Ph,Nu
	b	0		3	Ph,Nu,Ps
Total		76		76	
Mean		3,8		3,8	

*Ph = physician, Nu = nurse, So = social worker, Ps = psychologist, Vo = volunteer, Di = director, Ma = manager, Re = researcher

Based on clarity ratings, 15 of the 110 proposed indicators in this first round were rephrased. Six indicators were rated high (7-9) by all teams in round 1 and already considered face-valid. (Table 2).

Table 2 Indicators with ratings of high agreement (7, 8, or 9) by all teams in Delphi round 1

Indicators with ratings of high agreement (7, 8 or 9) by all teams in Delphi round 1
1. Family members and friends are able to visit the dying patient without restrictions of visiting hours.
2. The multidisciplinary team that provides palliative care consists of at least a physician.
3. The multidisciplinary team that provides palliative care consists of at least a nurse.
4. New staff receives a standardized induction training.
5. All health and social care students have standardized learning objectives for basic training in palliative care.
6. All health and social care professionals have standardized learning objectives for continuing basic training in palliative care.

Two QIs were deleted in the domain of Access/ Availability, such as a specialized palliative care being available for the patient by bringing the patient to the service. Three QIs were added (e.g. for a palliative care patient staying at home there should be the possibility, if needed, to provide a volunteer or professional to stay during the day). One QI was divided in two new indicators. Furthermore, the explanation of four QIs in the glossary was adapted and definitions for six QIs were added. One QI was mistakenly not rated in the second round (all relevant team members should be informed about patients who have died). For this QI the ratings of the first round were used in the final analysis.

The second Delphi round was performed by the same teams plus two from Spain (Table 1). In the Netherlands one centre was exchanged in Delphi round 2, due to changes in the management. The Belgian teams had the highest agreement (most QIs rated 7-9); the UK teams the lowest (intra-country agreement being 91% for Belgium and 50% for UK, respectively). Eleven indicators (10%) were rated 7-9 by all teams (Table 3).

Table 3 Indicators with ratings of high agreement (7, 8, or 9) by all teams in Delphi round 2

Indicators with ratings with high agreement (7, 8 or 9) by all teams in Delphi round 2
1. Opioids and other controlled drugs are available for a palliative patient 24 hours a day, 7 days a week.
2. Anticipatory medication for the dying patient is available for a palliative patient 24 hours a day, 7 days a week.
3. Before discharge/ transfer/ admission there is information transfer to the caregivers in the next setting.
1. 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).
5. All volunteers have training in palliative care.
6. For patients receiving palliative care a structured palliative care clinical record is used.
7. The palliative care clinical record contains documentation of psychological and psychiatric aspects of care.
8. The palliative care clinical record contains documentation of social aspects of care.
9. The palliative care clinical record contains a follow up assessment.
1. There is a program for specialized training in palliative care for professionals working in a service that provides specialized palliative care.
1. There is a program for continuing specialized training in palliative care for professionals working in a service that provides specialized palliative care.

After two Delphi rounds the teams reached consensus for 56 of the 110 QIs (50%) (Tables 4 and 5). These were considered as useful and clear measures for the evaluation of the organisation of palliative care. One QI was rated 1-3 by all 20 teams (a occupational therapist is necessary for the multidisciplinary team).

The largest number of useful QIs remained in the domains of Access and Availability (15), Documentation of clinical data (14), Personnel (9) and Infrastructure (8) (Table 5). None of the rated QIs in the Research domain appeared useful, and only one in the domains about Assessment tools, Quality and safety, and Reporting clinical activity.

Table 4 Final validated indicator set

Domain	Final set
Definition of a PC service (2)	A comprehensive palliative care service consists of <ol style="list-style-type: none"> 1. a palliative home care support team. 2. a palliative hospital support team.
Access to PC (16)	<ol style="list-style-type: none"> 3. A palliative care team is available at the request of the treating professional/ team at home. 4. A palliative care team is available at the request of the treating professional/ team in a hospital. 5. A palliative care team is available at the request of the treating professional/ team in a care home. 6. For every professional/ team specialized palliative care advice is available 24 hours a day, 7 days a week. 7. Patients in need of palliative care and their families have access to palliative care facilities throughout the entire duration of their disease. 8. Palliative care is available for the patient and their family by phone. 9. Palliative care is available for the patient and their family by visiting the patient. 10. For a palliative patient in a crisis, an admission can be arranged within 24 hours. 11. A member of a palliative care team is available 24 hours a day, 7 days a week for palliative care consultation by phone. 12. Opioids and other controlled drugs are available for a palliative patient 24 hours a day, 7 days a week. 13. Anticipatory medication for the dying patient is available for a palliative patient 24 hours a day, 7 days a week. 14. There is a process for exchange of clinical information across caregivers, disciplines and settings. 15. Before discharge/ transfer/ admission there is information transfer to the caregivers in the next setting. 16. General practitioners are routinely called when a patient is being discharged home or transferred to another setting. 17. The discharge/ transfer letter of palliative care patients contains a multidimensional diagnosis, prognosis and treatment plan. 18. The primary care out-of-hours service has handover forms (written or -electronic) with clinical information in the terminal phase at home.
Infrastructure (8)	<ol style="list-style-type: none"> 19. Specialist equipment (e.g. anti-decubitus mattresses, aspiration material, stoma care, oxygen delivery, special drug hospital beds, etc) are available for the nursing care of palliative care patients in each specific setting. 20. There is an up to date directory of local caregivers and organizations that can have a role in palliative care. 21. The palliative care service has a website. 22. There is a computerized medical record , to which all professional caregivers involved in the care of palliative care patients have access within one setting. 23. 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). 24. Dying patients can have a single bedroom if they want to. 25. Family members and friends can visit the dying patient without restrictions of visiting hours. 26. There is a private place (e.g. dedicated room) for saying goodbye to the deceased.
Assessment tools (1)	<ol style="list-style-type: none"> 27. There is an assessment of pain and other symptoms using a validated instrument.

Domain	Final set
Personnel in palliative care services (9)	<p>28. The multidisciplinary team that provides palliative care consists of at least one physician and nurse.</p> <p>29. A social worker is essential to have in a multidisciplinary palliative care team.</p> <p>30. A psychologist is essential to have in a multidisciplinary palliative care team.</p> <p>31. A physiotherapist is essential to have in a multidisciplinary palliative care team.</p> <p>32. New staff receives standardized induction training.</p> <p>33. All team members have certified/ accredited training in palliative care, appropriate to their discipline.</p> <p>34. All volunteers have training in palliative care.</p> <p>35. Palliative care services work in conjunction with the referring professional/ team.</p> <p>36. There is a weekly inter- and multidisciplinary meeting to review palliative care patients' referrals and care plans.</p>
Documentation of clinical data (14)	<p>37. For patients receiving palliative care a structured palliative care clinical record is used.</p> <p>38. The palliative care clinical record contains a clinical summary.</p> <p>39. The palliative care clinical record contains documentation of physical aspects of care.</p> <p>40. The palliative care clinical record contains documentation of psychological and psychiatric aspects of care.</p> <p>41. The palliative care clinical record contains documentation of social aspects of care.</p> <p>42. The palliative care clinical record contains documentation of spiritual, religious, existential aspects of care.</p> <p>43. The palliative care clinical record contains documentation of cultural aspects of care.</p> <p>44. The palliative care clinical record contains documentation of care of the imminently dying patient.</p> <p>45. The palliative care clinical record contains documentation of ethical, legal aspects of care.</p> <p>46. The palliative care clinical record contains a multidimensional treatment plan.</p> <p>47. The palliative care clinical record contains a follow up assessment.</p> <p>48. Within 24 hours of admission there is documentation of the initial assessment of prognosis, functional status, pain and other symptoms, psychosocial symptoms and the patient's capacity to make decisions.</p> <p>49. 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 24 hours of admission.</p> <p>50. When a palliative care patient is discharged/ transferred, a discharge/ transfer summary accompanies the patient.</p>
Quality and safety (1)	<p>51. There is documentation whether targets set for quality improvement have been met</p>
Reporting clinical activity of PC services (1)	<p>52. The palliative care service uses a database for recording clinical activity.</p>
Education (4)	<p>53. All health and social care students have standardized learning objectives for basic training in palliative care.</p> <p>54. All health and social care professionals have standardized learning objectives for continuing basic training in palliative care.</p> <p>55. There is a program for specialized training in palliative care for professionals working in a service that provides specialized palliative care.</p> <p>56. There is a program for continuing specialized training in palliative care for professionals working in a service that provides specialized palliative care.</p>

Table 5 Number of indicators rated valid per domain

Aspects / items rated	Round 1	Valid (%)	Round 2	Valid (%)
Definition of a palliative care service	8	8 (100%)	9	2 (22%)
Access to palliative care	29	27 (93%)	27	16 (59%)
Infrastructure	17	17 (100%)	17	7 (41%)
Assessment tools	2	2 (100%)	2	1 (50%)
Personnel in palliative care services	20	19 (95%)	19	8 (44%)
Documentation of clinical data	19	19 (100%)	19	14 (74%)
Quality and safety	7	7 (100%)	7	1 (14%)
Reporting clinical activity	4	4 (100%)	4	1 (25%)
Research in palliative care	1	1 (100%)	1	0 (0%)
Education in palliative care	3	3 (100%)	2	2 (100%)
Total	110	107 (97%)	107	52 (49%)

5.4.1. QIs PER DOMAIN

Definition of a palliative care service

The teams agreed that a palliative home care support team and a palliative hospital support team need to be part of a comprehensive high quality palliative care service.

5.4.2. ACCESS TO PALLIATIVE CARE

It was agreed that all patients in need of palliative care, as well as their family, should have access to palliative care facilities throughout the entire duration of their disease. Patients staying at home or in another primary care setting, should have the possibility to consult a palliative caregiver by phone 24 hours a day, or to be visited by a caregiver. If needed they should be admitted in time to another palliative care setting. A palliative care team that is available at the request of professional caregivers of palliative care patients was considered an important quality criterion, as well as 24 hours, seven days a week availability of advice by a palliative care specialist. Opioids, other controlled drugs and anticipatory medication for the dying patient need to be available for a palliative care patient day and night. Another quality criterion that appeared important was having standard operating procedures for the transfer within due time of medical information transfer across settings, caregivers and disciplines, including the out-of-hours service.

Examples of QIs in this domain on which no consensus was reached are the accessibility of diagnostic investigations regardless of the setting, and having a professional caregiver per individual palliative care patient who is nominated as responsible case manager to coordinate care.

5.4.3. INFRASTRUCTURE

Privacy of patients in in-patient settings including the possibility to die in a separate (single bed) room, facilities for relatives to stay overnight and no restrictions of visiting hours were considered important. Furthermore, specialist equipment, such as anti-decubitus mattresses, oxygen delivery and special drug administration pumps, need to be available in all settings. Finally, directories of local caregivers and organisations as well as websites of the respective services were considered relevant.

No consensus was reached on having patient information in foreign languages, and having a computerized medical record to which professionals across settings can have access.

5.4.4. ASSESSMENT TOOLS

Consensus was reached on the availability of a validated instrument to assess pain and other symptoms.

No agreement was reached on the necessity of a holistic assessment of palliative care needs of patients and their family caregivers.

5.4.5. PERSONNEL IN PALLIATIVE CARE SERVICES

The participating expert teams agreed on QIs regarding the composition of the palliative care teams, introductory training for new staff, continued training for staff and volunteers, and an annual appraisal of functioning for all staff. Weekly meetings to review referrals and specific care plans were also considered important, as well as a good cooperation between a palliative care service and the referring professionals. Teams agreed that a spiritual caregiver, a psychologist or a physiotherapist should participate in the multi-professional palliative care team.

Rejected QIs were that all team members who professionally deal with dying patients have access to a program for 'care for the carer's, that the satisfaction of working in a palliative care team are assessed or that all relevant team members are informed about patients who have died.

5.4.6. DOCUMENTATION OF CLINICAL DATA

The participating expert teams had the opinion that a structured palliative care medical record adds to quality, and that it contains a clinical summary and information about the physical, psychosocial and psychiatric, social, spiritual and cultural aspects. Also aspects regarding care for the imminently dying patient were considered important. A multidimensional treatment plan should be described as well as information about follow up assessments. This information needs to be written down in the medical record timely. After transfer, information for the caregiver in the receiving setting should be immediately available.

No consensus was reached on reviewing patients' preferences on a regular basis (in parallel with disease progression) or on request of the patient. The same applied to

requiring documentation within 24 hours after patient transfer that the new palliative care team in the receiving setting has visited the patient.

5.4.7. QUALITY AND SAFETY

The only useful QI in this domain was that there is documentation whether targets set for quality improvement have been met.

5.4.8. REPORTING CLINICAL ACTIVITY

It was considered important that palliative care services use a database for recording clinical activities, but no consensus was reached on what kind of data is collected, or the importance of writing an annual report based on the database.

5.4.9. EDUCATION

QIs regarding standardized learning objectives for basic and continuing training were considered essential, as well as a program for specialized training for professionals working in palliative care.

No QIs in this domain were rated invalid.

Table 6 Number and professions of participants in the Delphi process

Participants	Delphi 1 (%)	Delphi 2 (%)
Physician	35 (46%)	37 (48.7%)
Administrator-manager	9 (11.8%)	7 (9.2%)
Nurse	21 (27.6%)	21 (27.6%)
Nursing home specialist	1 (1.3%)	0 (0%)
Psychologist	2 (2.6%)	4 (5.3%)
Researcher	1 (1.3%)	0 (0%)
Social worker	2 (2.6%)	3 (3.9%)
Volunteer coordinator	3 (3.9%)	3 (3.9%)
Volunteer	2 (2.6%)	1 (1.3%)
Total	76 (100%)	76 (100%)

5.5. DISCUSSION

As result of the two-round modified Rand Delphi procedure with 20 teams of seven European countries, we developed a set of 56 structure and process QIs, all considered important for the measurement and evaluation of the organisation of palliative care across settings. The QIs cover eight domains. In total 49% of all QIs

selected from the previously published literature review and experts meetings were clear and considered useful.¹⁰

The study has several strengths. First, we performed an international study. For that reason, the set of QIs can be used in the seven participating countries, and probably in more. Next, in palliative care, all kind of professionals in several kind of settings are involved. Therefore, we asked each participating expert centre to compose a multidisciplinary team to rate the concept QIs, a team in which all kind of professionals with expertise in as well primary as secondary palliative care collaborated.

This study shows also several weaknesses. First, although an established definition for QIs was used, we did not provide a numerator and denominator.^{4,5,14} Such a format is useful for QIs in which a proportion of a certain feature should be met, like the percentage of patients of all hospitalized patients in a certain period of whom pain has been measured with a visual analogue scale. Our QIs concern structures and processes of care, and consequently are presented in the format of a standard. Second, the procedure to perform a multi-professional team approach instead of using individual experts has not been described in a modified RAND Delphi process before. Thirdly, the specific composition of each team may have influenced the results. Physicians and nurses were overrepresented in the meetings (Table 1). In combination with hierarchical influences probably the physicians' opinion may have weight strongest which might have influenced the ratings. Fourthly, a low rating might have other causes than considering a QI to be unimportant. For instance, in the UK specific QIs about finance or national regulations for palliative care were rated low. Probably, these QIs were not considered relevant for quality assessment by the English teams as these aspects are already realized in their daily practice. Finally, teams rating the lowest number of useful QIs like the Netherlands or the UK, had a greater influence on the final QIs than those rating the highest useful number like the Belgian or French teams. For example, the teams of Belgium were the only ones estimating a key worker for the coordination of palliative care and a bereavement counselor as essential members of a palliative care team. And the French teams considered a 'hospital at home' as an important part of a comprehensive palliative care service, and a dietician as a member of the palliative care team. Therefore, we recommend that each country, apart from the international set, also uses those QIs that were rated high in their own country but are not in the international set.

The aim of this study was to develop a set of QIs that can be used to compare the quality of the organisation of palliative care within and across settings on a European level. A modified RAND Delphi process to develop a set of QIs for the organisation of health care has been used in previous studies.¹⁴⁻¹⁶ For example, Huebner-Bloder et al. developed QIs for hospital information systems, Engels et al. for the management of general practice and Campbell et al. for the management of cardiovascular diseases.^{12,14,15,17} Van Lieshout et al. encouraged their participants to develop QIs based on their experience with management of cardiovascular diseases.¹⁶ In this study some QIs were developed and proposed not only from the literature review by the experts in palliative care participating in the research group.

The usefulness of this set of QIs needs to be further assessed for validity, acceptability and feasibility. Discriminative power has to be determined and case mix adjusters need to be described on national and international levels. Therefore, the Europall QI set should be considered as a first step in the whole process of developing, testing and implementing QIs to improve the organisation of palliative care in Europe. For those reasons, this set of QIs has been pilot tested in 28 European countries. This will be published separately. Also the optimal way to motivate countries, settings and professionals to use our QIs as a first step to improve the quality of their organisation needs to be studied. In general practices, providing oral and written feedback, in combination with a quality improvement project guided by an external facilitator appeared successful.¹⁸ In the EU FP7 funded IMPACT project, that runs from 2011 till 2015, such implementation strategies are currently being tested.¹⁹

5.6. ACKNOWLEDGEMENTS

Thanks to the participation of national experts and international renowned opinion leaders in palliative care it was possible to develop this international set of 56 indicators for the evaluation of the organisation of palliative care. This can be an important contribution to the promotion and improvement of the quality of the organisation of palliative at a national and European level.

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CHAPTER 6



TESTING VALIDITY AND FEASIBILITY OF A SET OF QUALITY INDICATORS TO EVALUATE THE ORGANISATION OF PALLIATIVE CARE ACROSS EUROPE: A PILOT STUDY IN 25 COUNTRIES

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6.1. ABSTRACT

A well-organised palliative care setting or service is a prerequisite for offering good palliative care. Valid, reliable and feasible quality indicators (QIs) are needed to assess and monitor the quality of their organisation.

To validate a previously developed set of QIs and its feasibility in settings and services that provide palliative care across Europe.

38 QIs, applicable in all types of settings, and derived previously from a RAND Delphi process were used, and operationalised into 38 yes/ no questions. The questionnaire was meant to be self-completed by professionals of the settings and services. Descriptives statistics, factor and reliability analyses, ANOVA and chi-square analyses were used.

Questionnaires were sent to representatives of 217 palliative care settings in 25 countries. Included settings were hospices, inpatient dedicated palliative care beds, palliative care outpatient clinics, palliative care units, day care centers for palliative care, palliative care home support teams, inpatient palliative care support teams, care homes, and nursing homes.

All invited 25 EAPC countries took part with in total 107 participants (57%). The QIs were reduced to four coherent subscales, being 'equipment and continuity of care', 'structured documentation of essential palliative care elements in the medical record', 'training and appraisal of personnel' and 'availability of controlled drugs'. No significant differences in quality criteria between the different types of settings and services were identified.

The reduced QI set needs a structured implementation program to guarantee future use.

6.2. INTRODUCTION

Today, many Europeans die due to cancer and chronic diseases.¹ Often, care for vulnerable patients in the last phase of life is focused on maintaining or improving the quality of their life. Hence, palliative care receives increasing interest both at the level of patient care and consequently, at the organisation of the care level. Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2002) Information on the organisation of settings that provide palliative care, collected with valid and reliable instruments, would enable professional health caregivers to improve the quality of their own services. Besides, standardisation, measurement and reporting contributes to transparency of care for patients.² The use of quality indicators (QIs) is a common approach to measure quality of care.³⁻⁵ QIs are 'measurable elements of practice performance for which there is evidence or consensus that they can be used to assess quality and hence changes in the quality of care provided'.⁶

In previous publications, we described how health care professionals from seven European countries, taking part in the EU co-funded Europall project, were involved in developing and face-validating QIs in a modified RAND Delphi process.⁵ The result comprised a comprehensive set of specific structure and process QIs for the assessment and the comparison of the organisation of palliative care across Europe. In this study, this set of structure and process QIs was tested for its feasibility, validity and reliability in different palliative care settings across Europe.⁷⁻⁸

6.3. MATERIAL AND METHODS

6.3.1. DESIGN

A cross-sectional design was used to test feasibility, validity and reliability of the QIs in palliative care settings across European countries.

6.3.2. RESEARCH POPULATION

Each of the seven collaborating Europall partners approached experts in centers of excellence of their own and 2-3 additional European countries. These experts identified palliative care services in their countries (hospices, inpatient dedicated palliative care beds, palliative care outpatient clinics, palliative care units, day care centers for palliative care, palliative care home support teams, inpatient palliative care support teams, care homes, and nursing homes).⁷⁻⁸ In case a partner was not able to fulfill the criteria of 2-3 additional countries, members of the European Association of Palliative Care (EAPC) were approached.

6.3.3. DEVELOPMENT OF THE QUESTIONNAIRE

In a Europall steering group meeting in April 2010, the 56 previously face-validated QIs were transferred into one questionnaire.⁵ Only QIs that were measured in all kinds of palliative care settings were included in this paper (38). The questionnaire that was filled in by all types of settings comprised 38 items in a yes/ no format. This questionnaire was pre-tested in three palliative care settings with different disciplines and revised accordingly. All items were added into an online tool (Monkey Survey). Concerning the content, the questionnaire was structured in different parts. Starting with some demographic parameters, a representative of each setting was asked to fill in the questionnaire. The items concerned access to palliative care, infrastructure, assessment tools, personnel, documentation of clinical data, reporting clinical activity, and education (Table 2).⁵

6.3.4. PROCEDURE

A standard invitation letter, with definition of terms and an informed consent form, was sent to 217 palliative care services in 25 countries.

Next, emails were sent to the representatives with the questionnaire attached via an online tool (Monkey Survey). Per QI, the representative had to indicate if this quality criterion was met in one's own palliative care setting. After completion by the representative the research team received an automatic notification that the questionnaire was uploaded successfully.

6.3.5. STATISTICAL METHODS

Frequencies and descriptive statistics are presented.

Factor analysis was used to explain the variability among the observed items of the questionnaire in terms of fewer unobserved variables, the so called factors. We performed factor analysis using principal axis factoring as the extraction method. The varimax rotation with Kaiser normalization was used to simplify the interpretation of the factors. Extraction of the factors was based on the Kaiser's criterion for Eigenvalues of equal to or greater than 0.7. The Cronbach's alpha was used to calculate the internal consistency of the factors constructed. The value of the Cronbach's alpha >0.60 is generally considered acceptable.⁹ The mean and the standard deviation of all factors is presented.

Analysis of variance (ANOVA) was used to study the differences between types of settings and services for each factor separately. The dependent variable was the specific factor. The independent class variable was the types of settings and services. For those QIs that could not be included in scales, chi-square analysis was used to study differences between types of settings and services. For these purposes only those types of settings and services of which more than ten participated in the study were used.

Statistical analyses were performed using SPSS® 20.0 for Windows (IBM, SPSS Inc., Chicago, IL, USA). The critical level for statistical significance was set at $p < 0.05$.

6.3.6. ETHICAL APPROVAL

As there were no patient data included, ethical approval procedures were not indicated in the participating countries.

6.4. RESULTS

6.4.1. DEMOGRAPHICS

Representatives from 107 of the 217 approached health care organizations (57%) across 25 EAPC member states (100%) completed surveys of 123 palliative care settings. Some respondents filled in questionnaires for more than one palliative care setting as one organization may have several palliative care services. Eight questionnaires were excluded because of missing data.

All parts of Europe were represented, namely Northern (24%), Western (28%),

Southern (20%) and Eastern Europe (12%).¹⁰ In addition, respondents from Armenia, Israel, and Cyprus answered the questionnaire.

Two questionnaires (16%) could not be listed due to missing country names. (Table 1)

Table 1 Participant characteristics

Division***	Countries	Country (n)	%	Settings (n)	Types of settings (n)
Northern-Europe	Finland, Ireland, Latvia, Norway, Sweden, UK	6	24	27	care home (3), home care (1), hospice (7), pcu*(4), inpatient (2), psth**(4), outpatient (2), other (1)
Western-Europe	Austria, Belgium, France, Germany, Luxembourg, the Netherlands, Switzerland	7	28	49	Care home (2), home care (7), hospice (4), pcu (3), inpatient (2), psth (6), day care (3), other (4)
Southern- Europe	Croatia, Greece, Malta, Serbia, Spain	5	20	9	home care (2), hospice (1), pcu (4), day care (1), other (1)
Eastern- Europe	Bulgaria, Czech Republic, Poland	3	12	26	care home (2), home care (4), hospice (7), pcu (3), inpatient (1), psth (4), outpatient (4), day care (1)
Other	Armenia, Cyprus, Israel, no ID	4	16	12	care home (3), hospice (3), pcu (1), inpatient (1), outpatient (1), other (1)
Totals		25		125	

*pcu= palliative care unit; **psth= palliative support team in hospital, *** 10

Most often, respondents represented palliative care units (PCU) (27%, n=33), followed by hospices (19%, n=23), home care (11%, n=14) and inpatient palliative care support teams (PST) (11%, n=14), palliative care home teams (8%, n=10), day care (7%, n=8), outpatient clinics (6%, n=7), inpatient palliative care beds (5%, n=6), remaining a rest category of 7% (n=8). No nursing homes were represented (Table 2). Of the participating settings, 74% were part of a comprehensive palliative care service, and 68% of a palliative care network. Palliative care teams often consisted of nurses (84%) and physicians (77%), but also quite often of a social worker (71%), psychologist (62%) or a spiritual caregiver (59%).

6.4.2. REDUCTION OF QUALITY INDICATORS

Factor and reliability analyses resulted in the composition of four reliable scales. Four factors were extracted, which accounted for 73% of the variance among the items. 'Equipment and continuity of care' consisted of 10 QIs ($\alpha=0.92$), 'structured documentation of relevant aspects in the medical record' of 11 QIs ($\alpha=0.93$), 'training

and appraisal of personnel' of 9 QIs ($\alpha=0.88$), and 'availability of controlled drugs' of 3 QIs ($\alpha=0.87$).

The remaining 5 QIs could not be combined in a factor (having an up-to-date directory of local caregivers and organizations; working in conjunction with the referring professional/team; having a written procedure for exchange of clinical information across caregivers, disciplines and settings; assessment of pain and other symptoms with validated instruments; using a database for recording of clinical activities). (Table 2 and 3)

Table 2 Aspects of the scales on the organisation of palliative care settings and services

	Quality components (factor loadings*; Cronbach's alpha)	Number of questions	Cronbach's alpha	Eigenvalue	% of variance	Mean	Standard deviation
1	Equipment and continuity of care (0.49-0.89; 0.92) 1. anti-decubitus mattresses 2. aspiration material 3. stoma care material 4. oxygen 5. drugs administration pumps 6. hospital beds 7. website with dedicated information 8. 24/7 pc consultation by phone 9. timely transfer patient information next setting 10. discharge/transfer information accompanies the patient	10	0.92	6.98	49.85	0.74	0.33
2	Structured documentation in medical record (0.42-0.77; 0.93) 1. using a prestructured medical record 2. clinical summary 3. physical aspects of care 4. psychological and psychiatric aspects 5. social aspects 6. spiritual, religious, existential aspects 7. cultural aspects 8. care aspects for dying patient 9. ethical, legal aspects 10. multidimensional treatment plan 11. follow-up assessment	11	0.93	1.53	10.90	0.61	0.36
3	Training and appraisal of personnel (0.40-0.83; 0.88) 1. program specialized training 2. program continuing specialized training 3. physicians trained in pc 4. nurses trained in pc 5. volunteers trained in pc 6. newly employed physicians induction training 7. newly employed nurses induction training 8. physicians get annual appraisal 9. nurses get annual appraisal	9	0.88	0.98	7.00	0.61	0.32
4	Availability of controlled drugs (0.42-0.69; 0.87) 1. 24/7 availability of opioids 2. 24/7 availability of other controlled drugs 3. 24/7 availability of anticipatory medicine for the dying patient	3	0.87	0.76	5.45	0.76	0.38

*: extraction method: Principal Component Analysis. Rotation method: Varimax with Kaiser Normalisation.

Table 3 Aspects of the remaining separate QIs on the organisation of palliative care settings and services

Quality indicators	Percentage 'yes'	Standard deviation
a Up-to-date directory of local caregivers and organisations	0.74	0.44
b Working in conjunction with the referral	0.81	0.40
c Having a written procedure for exchange of clinical information	0.60	0.49
d Assessment of pain and other symptoms	0.74	0.44
e Using a database for recording clinical activities	0.62	0.49

6.4.3. COMPARISON OF SERVICES AND SETTINGS

In the comparison of settings and services, hospices, palliative care units, home care and palliative care hospital support team were included, based on number of respondents. We found no significant differences in meeting the quality criteria between the different types of settings and services.

In all types of settings, the nine quality criteria had a mean or a percentage 'yes' of lower than 0.90 or 90%, which means that there is room for quality improvement.

6.5. DISCUSSION

We were able to collect pilot data of 123 palliative care settings and services in 25 European countries. Apparently, respondents were highly interested to complete and return our questionnaire; within one month we were able to have a response rate of 57%. This is comparable to other international studies with palliative care professionals.^{11,12}

Of the 38 concept QIs that were applicable in all kind of settings and services, 33 could be reduced to four scales, being 'equipment and continuity of care', 'structured documentation of essential palliative care elements in the medical record', 'training and appraisal of personnel' and 'availability of controlled drugs'. The other five were QIs that could not be combined to scales. Such data reduction, well known in the development of questionnaires or QIs has the advantage that QIs are combined in coherent sub scales.^{13,14}

The aim of our study was to further validate the questionnaire and test its feasibility in practice. For that reason, we used small convenience samples of settings and services. And as the number and type of participants differed per country, it is not

appropriate to use this pilot to compare countries and make judgments about the differences and similarities. For that reason, we restricted the comparisons to check whether the instrument was able to find differences between types of settings and services, which was not the case. Data collection in a larger number of settings and eventually case mix adjustment will be necessary to compare countries, settings or services, or to report changes over time.

Our study concerned QIs for the organisation of palliative care. Several sets of QIs that measure the quality of care or consumer quality have been developed before.¹⁵⁻²² Our set of QIs does not concur with these, but adds an extra dimension. Developing and publishing a set of QIs is not a guarantee that they will be used in practice. A structured implementation program is necessary.

6.5.1. STRENGTHS AND LIMITATIONS

In this study, an existing set of QIs was tested in practice, and reduced to a limited number of scales. To our knowledge this is the first time that such an analysis has been performed in research on developing QIs in palliative care. Besides, in contrast to many other QI development programs, the entire process of QI development took place in an international context. This will contribute to the applicability in all European countries, in order to make comparisons between countries, and to the successfulness of international implementation projects.

Part of the QIs that were setting-specific and for that reason not filled in by all respondents. For example, whether the primary care out-of-hours service or locum has handover forms with clinical information of patients in the terminal phase, is a useful QI for general practitioners, but not for hospitals or hospices. The QI about having a private room for the family to say goodbye to the deceased is not meant for primary care. Although they were very relevant, this kind of QIs (16) were not included in the analysis, as we limited this study on those QIs that can be used in all kind of settings.

When an international set of QIs is made, issues that are important in only a part of the countries or types of settings will be overlooked. Only QIs that were considered useful by the majority of palliative care teams that participated in a modified RAND Delphi process were included in this pilot test.⁵ This means that each country that will use the set of QIs, should consider to add country-specific QIs that are missing in this international set.

As data collection method, representatives of the services and settings filled in a questionnaire. Although we explained in the information letter that they would not be judged and that data would be used anonymously, self-reporting can result in social desirable answering. A practice visit, in which an independent assessor takes over that role, will tackle that problem.^{23,24} Yet, this is more expensive, and might be more threatening for the participating settings. Next, we used dichotomous questions (yes/no) to assess whether settings or services met our quality criteria. If these criteria will be assessed by checking documents (like medical records or protocols or websites) aggregated data enable more refined results. In that case, the QIs would consist of a numerator and a denominator. By making use of a much more expensive practice visit, this way of data collection would be possible.^{14,23,24}

6.5.2. IMPLICATIONS FOR PRACTICE

Having a set of reliable and valid QIs does not guarantee that they will be used in practice. A structured implementation program will be necessary. For that reason, in 2011 we started an EU funded FP7 project, IMPACT, which runs till 2015. In four types of settings in five countries, QIs are used to assess whether they meet the quality criteria. Based on this pretest, with the help of a consultant an improvement plan is made. One year later, the QIs are used again to measure whether the self-set objectives are met.²⁵ Results of this study can be used for wider implementation.

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6.7. REFERENCES

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CHAPTER 7



GENERAL DISCUSSION

7.1. INTRODUCTION

In 2005, the Executive Agency for Health and Consumer (EAHC) published a call for a research grant, including the identification of 'best practices in palliative care' in Europe.¹ This initiative was originally launched by the Lisbon Treaty to promote coordination among Member States in the health sector, "in particular initiatives aiming at the establishment of guidelines and indicators, the exchange of best practices, and the preparation of the necessary elements for periodic monitoring and evaluation".² The expertise centre of Pain and Palliative Medicine at the Radboud University Nijmegen Medical Center as principal investigator succeeded in obtaining this grant together with the Academic Unit of Supportive care at the University of Sheffield (UK), the Department of Radiation – Oncology and Palliative care at the University Hospitals of Leuven (Belgium), the WHO Collaborating Centre for Palliative Care Public Health Programmes at the University of Barcelona (Spain), the Department of Science and Research in Palliative Medicine at the University of Bonn (Germany), the Department of Palliative Medicine at Poznan University of Medical Sciences (Poland) and the French National Palliative Care Center Francois Xavier Bagnoud (France). The consortium members of the Europall project started to identify and construct quality indicators (QIs) that can ideally be used to identify best practices in palliative care (PC) in Europe, focusing on the organisational aspects of PC in seven European countries.

"Part 1: Organisation of palliative care" in this thesis therefore provides a synopsis of some important individual preparatory and analytical steps that were necessary to understand the organisation of PC and identify possible QIs to describe the organisation of PC. PC organisation is complex as it involves many different settings and professionals. The introduction also refers to the fact that PC is a relatively young field of medicine with a strong focus on continuous development, which in several European countries is not yet supported by structural health policies of the Ministries of Public Health.

Between 2008 and 2010, many different models for the organisation of PC were reviewed. Numerous characteristics of the organisation of PC were subsequently summarised and the international comparison of regional or national healthcare plans or laws and the organisation of volunteers seemed promising topics for future interest. This process was supported by an international glossary of terminology

composed by our research group to standardise the understanding of the terms used in the various research projects.

“Part 2, Development of quality indicators for the organisation of palliative care” concerns the development of specific QIs for the evaluation of the organisation of PC. This second part of the project was primarily initiated and motivated by the statement of the Council of Europe in 2003, namely that “the definition and adoption of indicators of good palliative care assessing all dimensions of care from the perspective of the patient should be encouraged”.³ In 2009, the Council of Europe again stressed and promoted the development of QIs for monitoring progress in patient care and the organisation of healthcare.⁴ Both statements from one of the leading European organisations strongly encouraged the development of QIs in this field of healthcare. Until then, there had been no clear definitions regarding the quality of the structure and process for the organisation of PC settings and services and how this quality should be evaluated or improved. This supported the rationale of this project to develop QIs for the assessment of the organisation of PC in Europe.

In this final chapter, I will discuss the main findings of these studies and my research in relation to PC and conclude with recommendations to further improve the quality of assessment methods for the organisation of PC in Europe.

7.2. KEY FINDINGS AND INTERPRETATION OF THE RESULTS

7.3. PART 1: ORGANISATION OF PALLIATIVE CARE (CHAPTERS 2, 3)

7.3.1. UNIFIED GLOSSARY OF TERMINOLOGY IN PALLIATIVE CARE IN EUROPE

To ensure standardisation of terms in PC across European countries, an initial objective of the Europall research group was to compile a specific glossary of terms used in palliative care (PC) (Appendix Addendum Glossary). This glossary contains pragmatic and operational definitions applicable in the context of PC development and the organisation of specific services. This glossary comprises 92 terms, covering different aspects of the organisation of PC. The development of this glossary was an important preparatory step to improve the communication and comprehension among

(1) the different team members of specific terms relating to PC in the seven participating European countries and (2) the different tasks and settings which were part of our research.

At the start of our project in 2008, no such consensus document of terms and glossary existed. Just one year later, in 2009, the European Association of Palliative Care (EAPC) published the first paper emphasising the importance of “standards and norms”.⁵ In this document, the EAPC focuses on the main terms describing PC, whereas our glossary is more comprehensive, aimed at covering all uncertainties related to our project as required for comparative research. For instance, our document contains medical terms related to PC such as controlled drugs, general PC measures or assessment scales used in PC. Furthermore, both glossary papers were developed in a different way. The EAPC’s “standards and norms” document used a consensus procedure involving board members from national associations, whereas our glossary is mainly based on a critical review of literature and in-depth consensus discussions between the research team members.⁵⁻⁷

Our definition document provided and guaranteed a common language throughout the European research project, which was very useful and facilitated transnational research. Learning from the development of our glossary, we recommend considering useful individual definitions for further integration in the standard and norms document of the EAPC in order to have a continuously updated statement document promoting transnational research and benchmarking.

7.3.2. DIFFERENCES BETWEEN LEGISLATIONS AND REGULATIONS IN PALLIATIVE CARE IN SEVEN EUROPEAN COUNTRIES

The research objective addressed in chapter 2 was to explore the existence and content of legislation and regulations relevant to palliative care (PC) in seven European countries participating in the research project Europall.

With the help of a literature study and expert interviews, we discovered a diversity of legislation and regulations relating to PC in the seven participating European countries. We were successful in ensuring that an explicit right to receive PC was mentioned in Belgian, French and German governmental laws. In addition, access to PC for patients was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on PC, although this tended to be related to national cancer plans and was not yet

commonly related to PC for patients with other than oncological diseases. Differences exist in (1) policies regarding care leave in situations where family members care for a close relative and the presence of advance directives, (2) national funding for PC activities, (3) PC training programmes, (4) specific research programmes, (5) the availability of opioids and (6) the role of volunteers.

The method we used to obtain insight into laws and legislation regarding PC in European countries is slightly different from the methods used in previous comparative studies.⁸⁻¹⁴ We asked experts committed to PC to validate and acquire data from scientific and grey sources of literature. This information on legislative and regulatory aspects was used as a starting point to gain a better overview of organisational aspects of PC in Europe, necessary for the further development of structure and process QIs. We found that PC is organised and delivered in different ways in the participating countries with regard to their legislative and regulatory aspects, which may particularly influence specific access to and the quality of PC. In view of the harmonisation of healthcare policies in European countries, agreements concerning PC policies should be on the agenda of policy makers, health institutions and scientific organisations. We therefore recommend initiating and developing further specific comparative research projects into healthcare systems to understand the differences and benchmarking for PC policies in different European countries. In this regard, we hope that the next resolution on PC for Europe by the World Health Organisation (WHO) in 2014 will support these recommendations for further comparative research.

7.3.3. ORGANISATIONAL ASPECTS OF INFORMAL WORKERS (VOLUNTEERS) IN PALLIATIVE CARE IN SEVEN EUROPEAN COUNTRIES

In chapter 3, differences and similarities in voluntary work in palliative care (PC) in seven European countries are presented with a focus on the organisational aspects of voluntary work. In all countries, volunteers are involved in PC, but their involvement across healthcare settings differs in each country. For example, the United Kingdom has a much higher relative number of volunteers per 1000 inhabitants compared to Spain which has a very low number. Volunteering is embedded in specific laws and regulations in most countries. In all participating countries, volunteers are organised at both national and regional level and training programmes are available in all countries.

So far, research on volunteering in PC has focused on the Canadian and UK perspective. Its focus is on the motivation, recruitment procedures or characteristics of volunteers.¹⁵⁻²⁶ Furthermore, various publications on volunteering in hospices or PC in Africa and India are available.²⁷⁻³¹

Organisational structures of volunteers in Europe have been described in recent years, for example by Fusco-Karman and Tinini, Gronemeyer et al., Bingley et al., and Jaspers et al.^{11,32-34} Our study partly updated and added new insights into organisational developments and also summarised collected data concerning volunteers in PC across Europe. As a result of the growing population of patients requiring PC, together with the progressive limitations of financial resources, informal caregiving adds important value and can be considered an integral part of (palliative) healthcare. Germany and the UK are possibly the best examples of the influence of volunteers, as the high number of volunteers represents a social movement influencing social attitudes towards death and dying.

With regard to volunteers in PC, the European Association of Palliative Care (EAPC) introduced a new initiative during the EAPC congress in Prague 2013 aimed at describing figures, roles, management, training and barriers for volunteers in PC.³⁵

Future challenges in this field encompass making (1) inventories of updated figures relating to volunteers across Europe, (2) the variations in training programmes, (3) identifying the differences in funding, (4) the management of volunteers in different European countries, (5) the specific difficulties they encounter in the practice of palliative care and finally, (6) the cultural differences in the involvement of volunteers in PC. All this knowledge will promote information exchange for international comparisons and provide better insight into how the provision of informal care by volunteers can be facilitated and should be organised around the patient and his family. This will consequently improve the involvement of volunteers in the member states of the EAPC and elsewhere and will enhance further research concerning specific aspects of voluntary work in PC. We recommend that best practices concerning volunteers in PC are continuously described from a European perspective, for example through a dedicated European task force.

7.4. PART 2: DEVELOPMENT OF QUALITY INDICATORS FOR THE ORGANISATION OF PALLIATIVE CARE (CHAPTERS 4, 5 AND 6)

7.4.1. STRUCTURE AND PROCESS QUALITY INDICATORS FOR THE ORGANISATION OF PALLIATIVE CARE

In chapter 4, our main research objective was to identify and develop structure and process quality indicators (QIs) to assess the organisation of palliative care (PC) in Europe. We aimed to develop a set of QIs that could be easily implemented in clinical practice in the different settings and services in all individual European countries, as a method to assess and monitor the quality of organisational aspects of PC and as an aid in quality improvement programmes.

In total, 110 QIs were identified over a framework with ten domains, applicable in different types of healthcare settings in all participating European countries. This proposed Europall set is primarily intended for internal quality improvement programmes and not for external evaluation purposes.³⁶

The developed QI Europall set consisted of both structure and process indicators, but no clinical outcome QIs. The development of the latter was not part of the Europall project as this project focused on assessing the organisational aspects of PC.

Outcome QIs merely focus on direct patient care and not directly on the organisational aspects of care, and had already been developed in other studies.³⁷⁻⁴¹

At the start of our Europall research project, only limited scientific literature on structure and process indicators in the field of PC was available. After extensive literature research, existing QIs originally relating to other types of care, such as intensive care, were therefore collected, evaluated and if appropriate, incorporated in our set of QIs.^{38,42-48} Before such QIs can be used to evaluate PC settings and services, they must undergo an extensive validation procedure. In this Europall project, this was conducted under the guidance of both clinical and methodological experts from seven European countries.⁴⁹⁻⁵¹

The Europall set of structure and process QIs was developed as a part of an Executive Agency for Health and Consumer (EAHC) international project in seven countries. Differences in culture or clinical practice of the individual countries were considered during the entire process. Additionally, in contrast to other projects working on QIs, we included specific grey literature about the organisation of PC. In the steering group meetings, we were able to benefit from the experts' detailed

knowledge of national guidelines, reports from government agencies and their comprehensive judgements on PC. This competence and additional information facilitated the research and analysis process, in which the different structure and process QIs were built. We recommend that, especially for the development of structure and process QIs, grey literature should always be part of the standardised development procedure as well as the inclusion of clinical and methodological experts for the evaluation procedure. Their knowledge and expertise of (palliative) care in the individual countries will facilitate QI implementation in normal clinical practice across Europe. As a first step for further implementation, this set of QIs was validated to test validity, reliability and feasibility for internal use in different settings all over Europe (see 7.4.2 and 7.4.3).

7.4.2. VALIDATION OF STRUCTURE AND PROCESS QUALITY INDICATORS WITH A CONSENSUS METHOD

The quality indicators (QIs) developed in the project and described in chapter 5 were evaluated in a two-round modified RAND Delphi process, a face-validation method (chapter 5). Fifty-six out of 110 QIs (51%) were considered useful and feasible. These 56 QIs cover eight domains: definition of a palliative care service, access to palliative care, infrastructure, assessment tools, personnel in palliative care services, documentation of clinical data, quality and safety, reporting clinical activity of palliative care services and education.

Concerning the framework, similar domains were present in previously published sets, e.g. infrastructure, personnel/staff, quality of life/care.^{40,52} In addition, some previously published sets used more general domains, such as structure or process.^{38,43,53}

A modified RAND Delphi process is a consensus procedure and an appropriate method for evaluating QIs.⁵⁴ To master the inclusion of multidisciplinary palliative care (PC) teams in the participating countries, the use of an online tool provided an easy solution to save time, get a high response rate and bridged geographical distances.⁵⁵

We used multidisciplinary teams as panellists to rate the QIs instead of individual experts. This is not a common procedure, although two other research groups used the same method.^{38,52,56} One advantage of this team-oriented approach is the familiarity among team members, which may have increased their comfort in the

rating activity. However, team hierarchy and differences in team size (range one to seven) may have hampered equal contribution of team members.

This was the first Delphi study to use multidisciplinary panels.^{38,52,56-58} Nevertheless, a weakness in our study was the lack of a check to ensure that the teams really represented more than one profession. All but one other study used the RAND approach and two rating rounds, which is in line with our study.⁵⁷ Only two studies focused on organisational QIs, the other on clinical QIs.^{52,58} We recommend consulting the entire multi-/interdisciplinary PC team in the validation process of QIs, as the quality of patient healthcare is assured by the cooperation between and involvement of the different disciplines in everyday practice of PC.

7.4.3. PILOTING QUALITY INDICATORS IN 25 EUROPEAN COUNTRIES

As a final step in the Europall project, a validation and feasibility study was conducted in 25 European Association of Palliative Care (EAPC) member countries using an online survey method (chapter 6). This online survey used factor and reliability analyses to test the coherence of the proposed Europall QI set.

This survey resulted in a reasonable response rate (57%) from all regions of the European continent, including participants from Northern (24%), Western (28%), Southern (20%) and Eastern Europe (12%).⁵⁹ Also outside Europe, palliative care (PC) settings from Armenia, Israel and Cyprus participated. In the context of structure and process QIs for the assessment of the organisation of PC, such an extended pilot test had never previously been performed. Of all types of participating PC services and settings, palliative care units (PCU) were most represented (27%). Of the previously developed set of 56 QIs, we only operationalised 38 into measurable items, as the other 18 were not applicable in all kinds of settings or services. These structure and process QIs were measured by yes/no questions, which is an easy but rough way to collect data. Factor and reliability analysis generated four themes: 'equipment and continuity of care', 'structured documentation of relevant aspects in the medical record', 'training and appraisal of personnel' and 'availability of controlled drugs'. Five remaining QIs could not be combined in a specific theme. No significant differences in the domains were identified between the different types of settings and services. However, this was not the primary aim of this pilot. More data is required to make sound comparisons and to test discriminative power.

Other studies evaluated the validity or feasibility of QIs.^{37,60,61} Engels et al. used a questionnaire, practice visit and an interview to validate 171 QIs across nine countries. The questionnaires were distributed to practice managers, general practitioners and patients. The practice visit was executed by a trained observer. Ultimately, 57 QIs were considered valid, whereas 53 QIs measured differences between and within countries. Claessen et al. deliberately chose PC settings, e.g. palliative day care, and half of the QIs were evaluated with a questionnaire (CQ Index PC), handed out to the patient and their relatives. For the other half of the QI set, mainly symptom QIs, numeric rating scales (NRS) were used. In their study, 33 QIs for patients and 10 QIs for relatives were rated valid. Completely different was the approach of the group of Grunfeld et al. They performed a retrospective cohort study with their QIs, using Vital Statistic files from a cancer registry.⁶¹ However, in the field of PC, feasibility testing and data reduction is rarely published.⁶² As we performed our study in 25 countries, our set of QIs can be used in an international context.^{38,43,52,53}

Our data collection used a self-reporting methodology. For that reason, we were unable to control socially desirable answering. This can be prevented by an on-site practice visit with an independent assessor. However, this was too expensive and time-intensive for the Europall project.^{60,63,64} Nevertheless, it can be recommended that immediate feedback to the professional should be given, with international standards as benchmarks. Besides, if these QIs are assessed by checking documents (such as medical records or protocols or websites), aggregated data enable more refined results. In that case, the QIs should consist of a numerator and a denominator.³⁹

As a conclusion, we were able to develop a valid, reliable and feasible set of structure and process QIs to assess the organisation of PC in different settings and practices in individual European countries. We recommend that (1) this set of Europall indicators should be further tested and fine-tuned in an implementation programme, (2) these QIs should be collected by independent and trained assessors and (3) these structure and process QIs should be further tested and related to outcome QIs in order to launch internal outcome improvement programmes in all settings all over Europe. Without this testing, implementation and evaluation programme, these QIs cannot be used for external evaluations. Currently, this set of QIs is being used within the FP7 EU-funded implementation project, IMPACT.⁶⁵ We

hope that further use and data collection will enable case-mix adjustments and national and international comparisons of the organisation of PC settings and services.

7.5. GENERAL CONCLUSIONS AND RECOMMENDATIONS

7.5.1. GENERAL CONCLUSIONS

THE EUROPALL PROJECT RESULTS: Drawing a general conclusion requires a critical review of the past and the future in relation to social needs for good healthcare. The Europall European Association of Palliative Care (EAPC) project reflects a growing interest in quality assessment and measurements in healthcare. This can be achieved by using quality indicators (QIs) as part of cyclic local, national and international improvement programmes. In this project, we managed to (1) compose a comprehensive glossary defining specific definitions relating to palliative care and enabling research on comparisons between settings and countries in Europe, (2) explore the regulations and legislation in seven European countries and their influence on the practice of palliative care (PC), (3) explore and describe the importance of volunteers in seven European countries and finally (4) develop and validate solid structure and process QIs divided into several important themes for the organisation of palliative care in Europe.

Further research and implementation programmes will be needed (1) to fine-tune specific definitions of the QIs in their descriptions of a numerator and a denominator, (2) to describe how these QIs should be used for quality improvement programmes, (3) to benchmark and improve clinical outcome for all patients and their families all over Europe and (4) to define best practices in PC.

THE EUROPALL SET OF QIS: In this Europall project, we used a stepwise, structured research method to develop a set of valid, reliable and feasible QIs which can be used in all European countries. One challenge in the development of QIs as a tool for systematic measurement of the organisation of PC was that no gold standard for the development of QIs in PC existed. We therefore decided to include best knowledge based on scientific and grey literature and the involvement of experts from all seven participating countries. Recently, a protocol to standardise the development of QIs in PC was published which mentioned similar steps to those taken in the Europall

project.³⁸ The Europall project presents methodologically sound results which will allow repeated measurement for future research. The multidisciplinary composition of our research team, with experts from both clinical practice and researchers, contributed to a productive combination of scientific quality and practical applicability. The outcome of this collective approach will facilitate information sharing concerning different perspectives.

DEFINING BEST PRACTICES: The challenge to define best practices in the organisation of PC, as described in the EAHC call is not yet finished. The aim of the Europall project was to develop a robust set of validated structure and process QIs ready to implement in the clinical practice of all European countries for internal quality improvement. The next step is to make case-mix adjustments and to set benchmarks by large samples and databases collected via systematic implementation as a first priority.⁶⁶ This will also enable the determination of discriminative power of the QIs. Finally, these structure and process QIs should be used in combination with validated clinical outcome QIs. This last step will complete the quality improvement cycle and make it possible to identify best practices of PC in Europe.³⁶

IMPLEMENTATION STRATEGIES: An important distinguishing aspect of the Europall QI set is the ability to make sub-analyses and interrelated comparisons of specific settings across Europe. The reliability of these comparisons will improve with the progressive implementation and regular evaluations of the collected data and the mutual quality improvement programmes for each national and individual setting over time. Several good examples of this process exist in other domains of clinical practice.^{67,68} Further professionalisation of PC will be enabled by demonstrating quality outcome at the level of structure, process and clinical impact for society. These QIs should be digitised and implemented in daily clinical practice and electronic medical record systems, with limited registration time of professionals in PC. Professionals do not want to spend too much time on data collection, as this distracts them from caring for the patient and his family. This process will need further consideration in the future.

COUNTRY SPECIFIC QIS: Our project included QIs in the European pilot which were rated useful in an international Delphi procedure, leaving the opportunity for further

research to make country-specific sets of QIs. As we developed an international set of QIs, quality aspects that were considered important in only one or a limited number of countries or types of settings were lost in the developmental steps, e.g. financial QIs.

This means that each country or setting which uses the set of QIs should consider adding country-specific QIs that are not included in this international set.

HOW TO MEASURE QIs: As healthcare changes over time, the set of QIs needs to be regularly updated. The Europall QIs were developed by a research group and collected in centres of excellence, identified by the chairman of the national chapters of PC of the individual European countries. The individual settings completed their questionnaires by self-evaluation in a multidisciplinary group, but socially desirable answers could not be excluded. However, as our QIs are primarily intended as an educational instrument reflecting information on the strengths and weaknesses of the organisation of PC of a setting or service, socially desirable answers would be negative for the setting or service itself and hamper its own quality improvement. Therefore, national and international scientific societies together with the Ministries of Health and patient organisations should define by whom and how QIs should be measured, reported and used for specific quality improvement programmes. From our experience, we recommended using trained and independent assessors who will visit individual settings on site all over Europe. Several important aids can be identified, such as international guidelines on how to measure QIs, a central database system, an independent task force linked to all stakeholders in palliative care and a strong connection to health economics and quality evaluations.^{2,4,38,69}

7.5.2. RECOMMENDATIONS

Observing the development of healthcare systems and health policies across Europe, international collaboration is a key issue.⁷⁰ Components affecting these developments result in patient and professional transfer between countries, distribution of new medical approaches and expectations of the society.⁷⁰

An important development for the healthcare sector is the changing demographic situation. A major challenge for the future in the healthcare sector will be dealing with on-going demographic changes resulting in ageing populations across Europe.⁷¹ A growing number of elderly people, many with one or more chronic conditions,

requires joint forces among health professionals.⁷² Thus, new models of care are needed for the growing demands at the end of life. An emerging discipline providing contributions to the care of elderly and dying patients is palliative care (PC). This is a young field still in search of its mission and relationship to curative healthcare. As expressed in the definition of PC by the World Health Organization (WHO), it is important to achieve high standards of access to PC across Europe, to ensure unified provision and equal quality of life for each citizen/ patient in the EU.

Quality of care is “that kind of care which is expected to maximise an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts”.⁷³

Therefore, coming to the end of this thesis, we formulate several recommendations based on the conclusions as presented in this book:

1. Professionals and researchers active in the field of PC should use a common and standardised comprehensive glossary and definition of terms enabling international comparisons and research projects. The EAPC should manage the ongoing updating and implementation of this glossary
2. With regard to volunteers in palliative care: best practices for volunteering should be identified in Europe and presented to national voluntary organisations and to the EAPC. The establishment of a European platform for palliative care volunteering might reduce variability in training programmes or differences in funding, taking into account cultural differences in the use of volunteering in palliative care.
3. In view of the harmonisation of healthcare policies in Europe, agreements concerning PC policies should be on the agenda of policy makers, health institutions and scientific organisations. Therefore, further specific comparative research projects to understand differences and to define benchmarks in policies for PC in different European countries should be initiated.
4. The quality of palliative care should be structurally measured by QIs. Structure and process QIs should focus on assessing the organisation of palliative care, while clinical outcome QIs should focus on the quality

of life for the patient and his proxies. Together, this constitutes a strong environment for quality improvement.

5. Special QI-guided improvement programmes should be initiated nationally and internationally. Independent task forces should guide this process and special trained assessors should visit palliative care settings to evaluate the clinical practice of palliative care in the different settings in all European countries.
6. Scientific interdisciplinary organisations of professionals should focus on quality programmes improving the outcome and quality of life for the patient and his proxies supported by adequate organisation of care.
7. Further research programmes should be launched to improve the quality of palliative care by identifying facilitators and barriers of the quality evaluation process of palliative care (compare IMPACT, 7th EU programme).
8. The framework of QIs should contribute to the improvement of patient safety. Implementing and monitoring QIs, such as 24/7 availability of PC for each patient in Europe and well-trained professionals will enhance the quality of PC.^{74,75}
9. The consequences of QI implementation programmes should be evaluated. There is a risk that QIs leading to obligatory performance of certification could cause agitation.⁷⁶
10. Finally, based on these initiatives, national guidelines, raising benchmarks and standards of care should evolve to the next level. If these steps are followed, future care will improve so that stakeholders, initially throughout the EU, can gain better understanding and supported arguments for policy decisions to benefit European patients.

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CHAPTER 8



SUMMARY

SUMMARY | SAMENVATTING | ZUSAMMENFASSUNG

SUMMARY

This thesis presents prospective evaluation methods relating to the organisation of palliative care (PC) in Europe. The scientific work is the result of a large European collaborative project built around an EU co-funded project from the Executive Agency of Health and Consumers (EAHC) on “Defining best practices in the organisation of palliative care” (Europall), executed between 2008 and 2011. Seven European countries participated: Belgium, France, Germany, the Netherlands, Poland, Spain, and the UK. The project coordination was run by the research team from Radboud University Nijmegen Medical Centre in the Netherlands.

This thesis includes qualitative and quantitative approaches to outline and evaluate the organisation of PC in Europe. The first part of the thesis contains the description of the preparatory process conducted, such as a comparative description of the organisation of PC of seven countries and a unified glossary of terms for palliative care. The focus of the whole thesis is put on part II, to evaluate and develop QIs for the organisation of PC. This included a literature search, the development of QIs during international meetings, the evaluation process of the developed QIs, and a feasibility test in a European/ international context.

The addressed research objectives were:

Part I:

- To prepare a glossary of terms to ensure identical use of terminology in Europe
- To explore the existence and implementation of legislation and regulation in palliative care in seven European countries
- To compare the organisation of informal workers (volunteers) in palliative care in seven European countries

Part II:

- To identify and develop structure and process quality indicators (sets) measuring the organisation of palliative care
- To evaluate clarity and usefulness of the identified/developed quality indicators by using a two-round modified RAND Delphi process
- To perform a feasibility test of the developed QI set in a European/ international context using an online survey method.

Chapter 1 provides a general introduction. First, the meaning and history of PC is highlighted, including facts and figures, including the multidisciplinary team approach of the organisation of PC. Differentiating between the individual components/ levels of organisation, region, setting, and domain the final section concerns QIs for PC. The section indicates what QIs are, what kind of QIs exist, and how QIs are usually developed and tested. **Chapter 1** concludes with the research objectives and an outline of the thesis.

As a starting point of our European PC study, it was considered how PC topics are subjected to legislation and regulations and how these are implemented in (national) health care plans. Therefore, **chapter 2** delivers a structured overview of the existing legislation, regulations and different health care policies regarding PC in seven European countries. Data was gathered from PC experts selected from Belgium, England, France, Germany, the Netherlands, Poland and Spain. Additionally, (grey) literature on PC health policy and regulations from the participating countries was collected to complete the inventory. Comparative analysis of country-specific information was performed afterwards. Although all included European countries have policies on PC, countries largely differ in the presence of legislation and regulations on PC as well as in the included topics. European PC policy still remains a matter of concern and development and should be further supported and implemented across Europe.

Studying the historically important role of volunteers in PC **chapter 3** summarises (1) the involvement of volunteers in PC, (2) the organisation of PC volunteering, (3) the legal regulations concerning volunteering, and (4) education and training of PC volunteering. A literature search combined with consecutive semi-structured

interviews with experts in the field of PC were performed to provide a descriptive overview of volunteer work in PC in seven European countries. It was found that volunteers were involved in PC in all countries, yet their involvement across health care settings largely differs. England has the highest number of volunteers whereas Spain mainly relies on family support. Often, volunteering is embedded in law and regulations. Exceptions are England and the Netherlands. Organisations are established on a national and on a regional level, and sustain trained volunteers.

Chapter 4 contains the first step of our systematic approach to develop QIs. To identify existing QIs, first a systematic review of the literature was performed. An update of a previous systematic review was made and extended with more databases and grey literature. Further, practitioners and experts in PC contributed to finalise the initial QI set. Covering the recommendations of the Council of Europe, 110 QIs, applicable for all settings that deliver PC, were divided into ten domains; 76 process and 34 structure QIs. In addition 24 setting-specific QIs were developed.

In accordance with the standardized process of developing QIs, **chapter 5** refers to our QI rating by expert consultation. A two-round modified RAND Delphi process was conducted in an international context to rate clarity and usefulness of the previously developed set of 110 QIs. Based on centres of excellence from seven European countries twenty multi-professional PC teams were involved as panellists to evaluate the set. Eventually, 56 valid rated QIs covered the domains ,definition of a palliative care service' (2 QIs), ,accessibility to palliative care' (16 QIs), ,specific infrastructure to deliver palliative care' (8 QIs), ,symptom assessment tools' (1 QI), ,specific personnel in palliative care services' (9 QIs), ,documentation methodology of clinical data' (14 QIs), ,evaluation of quality and safety procedures' (1 QI), ,reporting of clinical activities' (1 QI), and ,education in palliative care' (4 QI).

In **chapter 6** the final phase of the development of QIs, the validation and feasibility test, for the organisation of PC across Europe is described. As a result of the previously modified RAND Delphi process in total 38 QIs were operationalised into 38 yes/ no questions. Professionals of 107 settings and services self-completed the questionnaire across 25 EAPC countries. With the help of descriptives statistics, factor and reliability analyses, ANOVA and chi-square analysis the QIs were reduced

to four coherent subscales, being 'equipment and continuity of care', 'structured documentation of essential PC elements in the medical record', 'training and appraisal of personnel' and 'availability of controlled drugs'. No significant differences in quality criteria between the different types of settings and services were identified.

In the closing **chapter 7**, the first part of the general discussion summarises the main findings of the individual chapters of the thesis. In relation to the research objectives, preparation of a glossary, implementation of legislation and regulations in PC in seven countries, comparison of the organisation of non-professional workers (volunteers) in PC, identification and development of QI (sets) measuring the organisation of PC, evaluation of clarity and usefulness of the identified/ developed QIs, and performance of a feasibility test strength and limitations are discussed. **Chapter 7** finishes with recommendations for the clinical practice and for future research for the organisation of PC.

SAMENVATTING

In dit rapport worden prospectieve methoden voor het evalueren van palliatieve zorg (PZ) in Europa behandeld. Dit wetenschappelijke werk is het resultaat van een groot Europees samenwerkingsproject dat samenhangt met een mede door de EU gefinancierd project van het Executive Agency for Health & Consumers (EAHC) getiteld 'Defining best practices in the organisation of palliative care' (Europall), uitgevoerd tussen 2008 en 2011. Zeven Europese landen deden er aan mee: België, Frankrijk, Duitsland, Nederland, Polen, Spanje en Engeland. Het project werd gecoördineerd door het onderzoeksteam van het Radboudumc in Nijmegen.

In het rapport worden kwantitatieve en kwalitatieve benaderingen omschreven voor het schetsen en evalueren van de organisatie van PZ in Europa. Het eerste deel van het rapport bevat een beschrijving van het uitgevoerde voorbereidende werk, zoals een vergelijkende beschrijving van de organisatie van PZ in zeven landen en een volledige termenlijst voor de palliatieve zorg. De nadruk van het rapport ligt op deel II waarin kwaliteitsindicatoren (QIs) worden geëvalueerd en ontwikkeld voor de organisatie van PZ. Onderdeel hiervan zijn een literatuuronderzoek, de ontwikkeling van QIs tijdens internationale bijeenkomsten, het evaluatieproces voor de

ontwikkelde QIs en een haalbaarheidsonderzoek in een Europese/internationale context.

De onderzoeksdoelen die zijn behandeld, zijn:

Deel I:

- Samenstellen van een begrippenlijst om ervoor te zorgen dat men in Europa dezelfde terminologie hanteert
- Onderzoek doen naar de bestaande wet- en regelgeving en de uitvoering daarvan in palliatieve zorg in zeven Europese landen
- Vergelijken van de organisatie van informele werkers (vrijwilligers) in palliatieve zorg in zeven Europese landen

Deel II:

- Vaststellen en ontwikkelen van QIs voor structuur en proces (sets) waarmee de organisatie van palliatieve zorg wordt gemeten
- Beoordelen van de duidelijkheid en bruikbaarheid van de vastgestelde/ontwikkelde kwaliteitsindicatoren aan de hand van een aangepaste RAND Delphi-studie bestaande uit twee ronden
- Uitvoeren van een haalbaarheidstest van de ontwikkelde set QIs in een Europese/internationale context met behulp van een online vragenlijst.

Hoofdstuk 1 bevat een algemene introductie. Eerst worden het doel en de geschiedenis van PZ, met inbegrip van de multidisciplinaire teamaanpak van de organisatie van PZ, belicht aan de hand van feiten en cijfers. Het laatste onderdeel gaat over QIs voor PZ en maakt onderscheid tussen de diverse onderdelen/niveaus van organisatie, regio, instelling en domein. In dit onderdeel wordt omschreven wat QIs zijn, wat voor QIs er bestaan en hoe QIs gewoonlijk worden ontwikkeld en getest.

Hoofdstuk 1 wordt afgesloten met de onderzoeksdoelen en de strekking van het rapport.

Bij aanvang van ons Europese onderzoek is er gekeken wat voor wet- en regelgeving van toepassing is op onderwerpen in PZ en hoe deze onderwerpen worden behandeld in plannen voor (nationale) gezondheidszorg.

Hoofdstuk 2 bevat daarom een geordend overzicht van de bestaande wet- en regelgeving en het gezondheidszorgbeleid met betrekking tot PZ in zeven Europese landen. We kregen onze informatie van door ons uitgekozen deskundigen op het gebied van PZ uit België, Engeland, Frankrijk, Duitsland, Nederland, Polen en Spanje. Daarnaast hebben we (grijze) literatuur over PZ-beleid en -regelgeving uit de deelnemende landen verzameld om de inventarisatie volledig te maken. Vervolgens hebben we een vergelijkende analyse van landspecifieke informatie uitgevoerd. Hoewel alle deelnemende landen een beleid voor PZ hebben, zijn er grote verschillen tussen de landen wat betreft zowel het bestaan van wet- en regelgeving voor PZ als de daarin behandelde onderwerpen. Europees beleid voor PZ is nog steeds een bron van zorg. Het moet nog verder worden ontwikkeld, gesteund en ingevoerd binnen Europa.

In **hoofdstuk 3**, over onderzoek naar de historisch belangrijke rol van vrijwilligers in de PZ, wordt samengevat (1) wat de rol is van vrijwilligers in de PZ, (2) hoe vrijwilligerswerk in de PZ wordt georganiseerd, (3) wat de regelgeving is omtrent vrijwilligerswerk, en (4) hoe vrijwilligers worden onderwezen en opgeleid. Het hoofdstuk biedt een beschrijvend overzicht van vrijwilligerswerk in de PZ in zeven Europese landen. Hiervoor is een literatuuronderzoek uitgevoerd, in combinatie met opeenvolgende semi-gestructureerde interviews met deskundigen op het gebied van PZ. Een bevinding was dat in alle landen vrijwilligers betrokken zijn in PZ, maar dat er grote verschillen zijn in de mate van hun betrokkenheid in diverse zorginstellingen. Engeland heeft het hoogste aantal vrijwilligers, terwijl men in Spanje vooral afhankelijk is van mantelzorg. Er is vaak wet- en regelgeving omtrent vrijwilligerswerk. Uitzonderingen zijn Engeland en Nederland. Organisaties bestaan op nationaal en regionaal niveau en ondersteunen opgeleide vrijwilligers.

Hoofdstuk 4 vormt de eerste stap in onze systematische aanpak voor het ontwikkelen van QIs. Om bestaande QIs vast te stellen hebben we eerst systematisch literatuuronderzoek gedaan. We hebben een voorgaand systematisch overzicht bijgewerkt en aangevuld met meer databases en grijze literatuur. Ook hebben beoefenaars en deskundigen in PZ een bijdrage geleverd aan het samenstellen van de initiële set QIs. In opvolging van de aanbevelingen van de Raad van Europa hebben we 110 QIs, die van toepassing zijn op alle instellingen die PZ

verlenen, onderverdeeld in tien domeinen; 76 proces- en 34 structuurindicatoren. Bovendien hebben we 24 QIs ontwikkeld speciaal voor bepaalde instellingen.

In overeenstemming met het gestandaardiseerde proces voor het ontwikkelen van QIs verwijst **hoofdstuk 5** naar de beoordeling die we hebben uitgevoerd van de QIs door middel van het raadplegen van deskundigen. Om de duidelijkheid en bruikbaarheid van de eerder ontwikkelde set van 110 QIs te beoordelen hebben we een internationale, aangepaste Rand Delphi-studie bestaande uit twee ronden uitgevoerd. Voor het beoordelen van de set zijn twintig teams betrokken, bestaande uit professionals werkzaam in de PZ in de zeven Europese landen. 56 van de uiteindelijk als geldig beoordeelde QIs besloegen de volgende domeinen: 'definitie van palliatieve zorgverlening' (2 QIs), 'toegang tot palliatieve zorg' (16 QIs), 'specifieke infrastructuur voor het verlenen van palliatieve zorg' (8 QIs), 'meetinstrumenten voor het vaststellen van symptomen' (1 QI), 'specifiek personeel in palliatieve zorgverlening' (9 QIs), 'methodologie voor de documentatie van klinische gegevens' (14 QIs), 'evaluatie van kwaliteits- en veiligheidsprocedures' (1 QI), 'verslagleggen van klinische handelingen' (1 QI) en 'onderwijs in palliatieve zorg' (4 QIs).

In **hoofdstuk 6** wordt de laatste fase van de ontwikkeling van QIs voor de organisatie van PZ in Europa beschreven, namelijk de validatie- en haalbaarheidstest. Aan de hand van de eerdere aangepaste RAND Delphi-studie werden er voor 38 QIs 38 gesloten vragen geformuleerd. Zorgverleners uit 107 instellingen in 25 landen waar de European Association for Palliative Care (EAPC) actief is hebben de vragenlijst ingevuld. Met behulp van beschrijvende statistiek, factor- en betrouwbaarheidsanalyses, een variantieanalyse en een chikwadraattoets werden de QIs ondergebracht in vier heldere subcategorieën, te weten 'middelen en continuïteit van zorg', 'gestructureerde documentatie van essentiële elementen van PZ in de medische administratie', 'opleiding en beoordeling van personeel' en 'beschikbaarheid van medicijnen die onder wetgeving vallen'. Er werden geen significante verschillen vastgesteld in kwaliteitscriteria tussen de diverse soorten instellingen en zorgverlening.

In het eerste deel van het afsluitende **hoofdstuk 7** worden de belangrijkste bevindingen uit alle hoofdstukken van het rapport samengevat. Terugkomend op de

onderzoeksdoelen wordt er daarna ingegaan op het opstellen van een begrippenlijst, de uitvoering van wet- en regelgeving in PZ in zeven landen, een vergelijking van de organisatie van niet-professionele zorgverleners (vrijwilligers) in PZ, het vaststellen en ontwikkelen van QIs (sets) waarmee de organisatie van PZ wordt gemeten, het beoordelen van de helderheid en bruikbaarheid van de vastgestelde/ontwikkelde QIs en de functie en beperkingen van het uitvoeren van een haalbaarheidstest. **Hoofdstuk 7** wordt afgesloten met aanbevelingen voor de klinische praktijk en voor toekomstig onderzoek naar de organisatie van PZ.

ZUSAMMENFASSUNG

Diese wissenschaftliche Arbeit beschreibt die Organisation der Palliativversorgung (Palliative Care). Die Doktorarbeit basiert dem EU-geförderten Projekt "Defining best practices in Palliative Care" (Europall), mit einer Laufzeit von 2008 bis 2011. Das Konsortium bestand aus Partnern aus sieben Ländern: Belgien, Deutschland, Frankreich, den Niederlanden, Polen, Spanien und dem vereinigten Königreich. Die Projektleitung und -koordination lag bei dem Antragsteller aus den Niederlanden.

Das Projekt greift auf qualitative und quantitative Ansätze zurück, um die Organisation der Palliativversorgung zu beschreiben. Der erste Teil der Doktorarbeit präsentiert den vorbereitenden Prozess, eine vergleichende Darstellung der Organisation der Palliativversorgung in den o.g. sieben Ländern und ein Glossar mit 92 Fachtermini in Palliative Care. Der Hauptfokus der wissenschaftlichen Arbeit liegt auf dem zweiten Teil, der Entwicklung von Qualitätsindikatoren (QI) zur Evaluierung organisationaler Aspekte der palliativmedizinischen Versorgung. Dargestellt werden Methoden, Ergebnisse und kritische Diskussion der durchgeführten systematischen Literaturanalyse, der Entwicklung der QI, des Evaluierungsprozesses der entwickelten Qualitätsindikatoren sowie eine Realisierbarkeitsstudie im europäischen Kontext.

Forschungsziele:

Teil I:

- Erarbeitung eines Glossars, um den Gebrauch einer einheitlichen Terminologie sicherzustellen
- Analyse der Umsetzung von Rechtsvorschriften und Regulierungen bezüglich Palliativmedizin in den sieben Ländern
- Vergleich der Organisation nicht-professioneller Mitarbeiter (Freiwillige/ Ehrenamt) in der palliativmedizinischen und hospizlichen Versorgung in den sieben europäischen Ländern

Teil II:

- Identifikation und Entwicklung von organisationalen Qualitätsindikatoren (Struktur- und Prozessindikatoren) in der Palliative Care
- Evaluation der Formulierungsklarheit und Nützlichkeit der identifizierten Qualitätsindikatoren mit Hilfe eines modifizierten RAND Delphi Verfahrens
- Durchführung einer Realisierbarkeitsstudie der entwickelten Qualitätsindikatoren in einem europäischen Kontext mit einem internetbasierten Fragebogen

Kapitel 1 beinhaltet eine allgemeine Einführung in den Inhalt der wissenschaftlichen Arbeit. Nach der Hervorhebung des palliativmedizinischen Ansatzes, einschließlich der Präsentation von Daten und Zahlen, einer kurzen Ausführung über die Geschichte und den multidisziplinären Teamansatz, wird die Organisation der Palliativversorgung erklärt. Nach der Differenzierung der unterschiedlichen Komponenten von Organisation, Regionen, Einrichtungen und Kategorien, behandelt der abschließende Abschnitt die QI in Palliative Care. Präsentiert werden Definitionen von QI, eine Übersicht über bereits in der Literatur beschriebene Qualitätsindikatoren, Entwicklungs- und Testverfahren von QI. **Kapitel 1** endet mit den Forschungsfragen und einer Kurzdarstellung der Doktorarbeit.

Als Ansatzpunkt unserer europäischen Studie wurden Rechtsvorschriften und Regulierungen bezüglich der Palliativversorgung recherchiert und deren Implementierung in (nationalen) Gesundheitsvorhaben bzw. -systemen beschrieben.

Kapitel 2 präsentiert eine strukturierte Übersicht über die vorliegenden Rechtsvorschriften und Regulierungen sowie die unterschiedlichen Gesundheitspolitiken in Bezug auf die Palliativversorgung in den sieben europäischen Ländern. Datenmaterial wurde von palliativmedizinischen Experten aus Belgien, England, Frankreich, Deutschland, den Niederlanden, Polen und Spanien gesammelt. Um die Bestandsaufnahme zu komplementieren, wurde auch Graue Literatur zur Gesundheitspolitik und zu Rechtsvorschriften der teilnehmenden Länder zusammengetragen. Die Daten wurden einer vergleichenden Analyse unterzogen. Obwohl alle untersuchten europäischen Länder Rechtsvorschriften in der Palliativmedizin haben, unterscheidet sich die Präsenz deutlich, ebenso wie die Themen. Europäische palliativmedizinische Gesundheitspolitik ist immer noch ein Gegenstand von Bedeutung und die Entwicklung sollte weiterhin unterstützt und umgesetzt werden innerhalb Europas.

Wegen der besonderen historischen Rolle Freiwilliger/Ehrenamtlicher in der Palliativmedizin zentralisiert **Kapitel 3** (1) die Einbindung von Freiwilligen in die palliativmedizinische und hospizliche Versorgung, (2) deren Organisation, (3) Rechtsvorschriften in Bezug auf deren Einbindung und Einsatz sowie (4) eine Zusammenstellung der nationalen Vorgaben für die Befähigung Ehrenamtlicher für ihre Aufgaben in Palliative Care. Hierzu wurde eine Literaturanalyse verbunden mit halbstrukturierten Interviews mit Experten aus diesem Bereich durchgeführt. Die Ergebnisse zeigen, dass Freiwillige in allen Ländern in der Palliativmedizin eingebunden sind, trotzdem aber die Einbindung in den unterschiedlichen Einrichtungen variiert. In England wurde die größte Anzahl an Freiwilligen gefunden, hingegen in Spanien stützt sich hauptsächlich auf die familiäre Unterstützung. Oftmals sind die Freiwilligen in den Rechtsvorschriften eingeschlossen. Ausnahmen bestehen in England und den Niederlanden. Freiwilligen Organisationen sind auf regionaler, wie nationaler Ebene etabliert und unterstützen ausgebildete/fortgebildete Freiwillige.

Kapitel 4 beschreibt den ersten Schritt unseres strukturierten Ansatzes der Entwicklung von QI. Um bereits existierende QI zu ermitteln, wurde eine systematische Literaturanalyse durchgeführt. Eine Aktualisierung einer vorherigen Literaturanalyse wurde erstellt und ausgedehnt auf weitere Datenbanken und Graue Literatur. Darüber hinaus trugen Kliniker und Experten ihren Teil dazu bei, das ursprüngliche Qualitätsindikatorenset zu finalisieren. Die Vorschläge des Council of Europe einbeziehend, wurden die 110 QI in zehn Kategorien eingeteilt, wovon 76 Prozess und 34 Strukturindikatoren waren. Des Weiteren wurden 24 QI für den institutionsspezifischen Einsatz entwickelt.

Im Konsens mit dem standardisierten Prozess zur Entwicklung von QI, präsentiert **Kapitel 5** die Auswahl der QI durch die Befragung von Experten. Ein modifiziertes RAND Delphi Verfahren (zwei Runden) wurde in einem internationalen Bezugsrahmen durchgeführt, um sprachliche Klarheit und Nützlichkeit der bereits entwickelten 110 QI zu bestimmen. Zwanzig multiprofessionelle palliativmedizinische Teams aus den sieben Ländern, zusammengesetzt in Kompetenzzentren, wurden in die Evaluation einbezogen. Letztendlich wurden 56 QI anerkannt, verteilt in den Kategorien ‚Definition einer palliativmedizinischen Einrichtung‘ (2 QIs), ‚Zugang zur Palliativmedizin‘ (16 QIs), ‚Infrastruktur zum Erbringen von Palliativmedizin‘ (8 QIs), ‚Meßinstrumente‘ (1 QI), ‚Personal in der Palliativmedizin‘ (9 QIs), ‚Klinische Dokumentation‘ (14 QIs), ‚Evaluation von Qualität und Sicherheit‘ (1 QI), ‚Berichterstattung klinischer Aktivitäten‘ (1 QI), and ‚Schulung der Palliativmedizin‘ (4 QI).

In **Kapitel 6** wird die finale Phase der Entwicklung der QI für die Organisation von Palliative Care in einem europäischen Kontext, die Validierung und Realisierbarkeit, beschrieben. Die insgesamt 38 QI, welche in einem vorangegangenen modifizierten RAND Delphi Verfahren konsentiert worden waren, wurden in einem Fragebogen mit Ja/Nein Antwortmöglichkeit internationalem Fachpersonal präsentiert. Insgesamt wurde die Befragung in 107 Einrichtungen aus 25 Ländern durchgeführt. Mit Hilfe von deskriptiver Statistik, Faktor- und Reliabilitäsanalyse, ANOVA Verfahren und Chi-Test konnten die QI in vier Kategorien eingeteilt werden: ‚equipment and continuity of care‘, ‚structured documentation of essential palliative care elements in the medical record‘, ‚training and appraisal of personnel‘ and ‚availability of controlled drugs‘. Es

wurden keine signifikanten Unterschiede in der Anwendung der QI zwischen den unterschiedlichen Einrichtungstypen identifiziert.

Im schließenden **Kapitel 7**, fasst der erste Absatz der allgemeinen Diskussion die wesentlichen Ergebnisse der einzelnen Kapitel zusammen. Im Bezug auf die Forschungsziele, Erarbeitung eines Glossars, Analyse der Umsetzung von Rechtsvorschriften und Regulierungen, Vergleich der Organisation nicht-professioneller Mitarbeiter (Freiwillige/Ehrenamt), Identifikation und Entwicklung von QI (Struktur- und Prozessindikatoren), Evaluation der sprachlichen Klarheit und Nützlichkeit der identifizierten QI, Durchführung einer Realisierbarkeitsstudie der entwickelten QI in einem europäischen Kontext endet das **Kapitel 7** mit Empfehlungen für den Klinikalltag und zukünftiger Forschung im Bereich Organisation der Palliativmedizin.



APPENDICES

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CURRICULUM VITAE

Kathrin Woitha was born on April 13th, 1982 in Bochum (Germany). In 2001 she passed her A-levels at the Hellweg-Gymnasium in Bochum and continued her education with an apprenticeship at the School of Physiotherapy St. Elizabeth-Stiftung Bochum, Germany. She finished in 2004 as a public acknowledged physical therapist. Subsequently, she continued with a Bachelor degree of Science in Physiotherapy & Occupational Therapy (FH) in Osnabrück (Germany). After that she finished her Master thesis in Public Health, with the focus on Safety Promotion at the Karolinska Institute in Stockholm (Sweden).

Kathrin started to her PhD at the Department of Anesthesiology, Pain and Palliative care of the Radboud University Nijmegen Medical Centre in January 2008. Her thesis was supervised by dr. Y. Engels and promoted by prof. dr. K. Vissers (The Netherlands) and prof. dr. L. Radbruch (Germany).

She obtained further research experience at the Institute for Epidemiology, Public Medicine and Healthcare Systems Research, Hannover Medical School (Germany) where she was employed in a project financed from the Jackstädt Stiftung exploring the role of physiotherapy in palliative care (PC).

Additionally she worked in the Department of Anesthesiology, Pain and Palliative medicine, University clinic Bergmannsheil Bochum (Germany), performing a multi-centre study focusing on phantom limb pain and mirror therapy.

Recently, she is continuing with a post-doctoral position at the Universidad Navarra, as a member of the Atlantes program: Human dignity, advanced disease and palliative care at the Institute of Culture and Society.

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Book (chapters):

- Kathrin Woitha, Yvonne Engels, Jeroen Hasselaar, Kris Vissers: **The Organisation of Palliative Care in the Netherlands.** In: **Assessing Organisations to Improve Palliative Care in Europe.** Ahmedzai S, Gómez-Batiste X, Engels Y, Hasselaar J, Jaspers B, Leppert W, Menten J, Mollard JM, Vissers K [editors], Vantilt Publishers, Nijmegen, the Netherlands & Martien Frijns, Doetinchem, the Netherlands, ISBN 978-94-91024-01-6

APPENDIX ADDENDUM GLOSSARY

In: Assessing Organisations to Improve Palliative Care in Europe. Edited by Ahmedzai SH, Gomez-Batiste X, Engels Y, Hasselaar J, Jaspers B, Leppert W, Menten J, Mollard J-M, Vissers K. Nijmegen: Vantilt Publishers; 2010:91–112.

Paz S, Van Beek K, Woitha K, Ahmed N, Engels Y

CONCEPTUAL FRAMEWORK

Suggested definitions aim to be pragmatic, operational, conceived to be applied in the context of palliative care (PC) programmes' development and the organisation of services.

THEORETICAL FRAMEWORK

Important priorities to ensure the standardisation of, and uniform access to, palliative care (PC) for all cancer and non-cancer, incurably, advanced and terminally ill patients include:

- integration of PC services with the referral teams, including primary care, oncology, geriatrics, emergency, neurology and other specialties caring for chronically ill patients with PC needs;
- establishment of a specialised PC service in each major cancer, geriatric, neurology, cardiovascular, respiratory, renal and HIV/AIDS centre;
- establishment of educational programmes covering PC for medical and nursing students, junior doctors and nurses, post-graduate training, and specialists training in PC;
- support for research using appropriate methodologies to underpin the scientific basis of PC;
- establishment of quality assurance and quality improvement programmes;
- recognition of palliative medicine as a medical specialty;
- assessment of health policy implications;
- cost-effectiveness assessment.

DEFINITION OF TERMS

Glossary	
A	
Advance care directives	Also known as 'living wills' or 'advanced treatment directives'. A set of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios. They become effective in situations where the person is no longer able to make decisions.
Advance care planning	The process of discussion between an individual, their care providers, and often those close to the patient, about future care. The discussion may lead to: an advance statement (a statement of wishes and preferences); an advance decision to refuse treatment (a specific refusal of treatment(s) in a predefined potential future situation); the appointment of an advocate/surrogate. All or any of these can help inform care providers, in the event that the individual is unable to make his/her own decisions.
Adverse events	The secondary, negative, effects caused by medicine. They are recorded as the percentage of patients who experience the adverse event. For example, if 10 people out of 100 in a clinical trial take a medicine and develop a headache, then 10% of the study participants experienced this adverse event.
Advocate/surrogate	Person who will make treatment decisions for the patient if the patient becomes too incapacitated to make such decisions.
Almost-at-home-houses	Houses of this type have much in common with hospices, as far as the home-like environment and personal attendance of patients and family are concerned. The main difference is that the core staff of an almost-at-home-house consists entirely of volunteers, while professional nurses (and sometimes also doctors) work in the hospices too. For complex pain and symptom management, in the almost-at-home-houses, external professionals always have to be called in.
Anticipatory medication	Medication to anticipate the future medication needs of the patient. This way they reduce the distress caused by not having the correct medicine readily available and help prevent unnecessary hospital admissions.
Anti-decubitus mattress	A low air-loss mattress system that minimises maceration of the skin by removing excess moisture from the user/surface interface. It provides pressure relief by sequentially deflating and inflating alternate air cells on a timed interval. The replacement mattress, which offers a low air loss therapy, provides patients a comfortable pressure support suiting for each individual. The patented cell-in-cell design allows the inflation and deflation of air cells to be achieved in the shortest amount of time while providing the good pressure dispersion.
Appraisal	A method by which the job performance of an employee is evaluated. It is a chance to review, assess, debrief and, generally, develop the skills and confidence of the person being appraised.
Assessment of physical aspects of care	Assessment of the impact of the primary, and often secondary, disease on the patient's activities in daily life. Levels of pain and other distressing symptoms are assessed, with a multidisciplinary care plan designed to offer combinations of pharmacological and non-pharmacological management, alongside information and explanation.
Assessment of psychological aspects of care	Assessment of the emotional state of the patient, and what impact the illness has on his/her functioning as a person within the family or other relationship. A thorough assessment of all those affected by the person's illness, since roles, responsibilities, relationships and financial matters may act as triggers to intensify and exacerbate other symptoms.
Assessment of social aspects of care	Assessment of the social needs of a patient and their families, including a care plan to respond to these needs as effectively as possible.
Assessment of spiritual care	Assessment to understanding personal belief systems, including religion, which may support or distress the patient and those close to him/her through the disease process. These are often deeply personal areas for patients and have proved difficult to assess. However, an understanding of the spiritual being of a person can enable discussion and therapeutic work, together with the presence and practice of a chaplain (or faith leader). Spiritual care is particularly relevant in palliative care (PC) and bereavement counselling.
B	
Basic palliative care	The level of PC which should be known and provided by all health care professionals in primary or secondary care, within their duties to patients with life-limiting diseases (including knowledge about the circumstances under which specific specialized PC services or hospice services should be approached and referral of patient and/or family to these services).
Bereavement counsellor	A professional trained to help people cope with death, helping the patient and families to adjust to the inevitable changes in their lives. Bereavement counsellors meet with people immediately following a death, as well as with clients who are finding themselves unable to have close relationships or are terrified of certain situations because there was a death in their past which was never properly dealt with.
Bereavement support	The support that carers, family (including children and grandchildren) and close friends receive at the time of their grieving.
C	
Care for the carers	Activities usually undertaken to prevent burnout in staff in PC settings. Staff is perceived to be at high risk of burnout and emotional exhaustion because of the nature of palliative work, i.e. the frequent confrontation with dying and bereavement. Support meetings are one way of caring for caregivers, but they need to be accompanied by adequate resources, a supportive management structure, an extensive educational training program and attention to individual needs. Clinical supervision or peer supervision is another way.
Care home	A residential setting, where a number of older people live, that provides nursing and personal care.

Glossary	
Chair in palliative care	Chair - professorship: the position of a professor in PC.
Clinical audit	The systematic critical analysis of the quality of clinical care including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient. It is the ongoing process of information collection and review, leading to changes in practice, leading to further data collection and critical appraisal.
Collaboration	A process where two or more people or organisations work together in an intersection of common goals by sharing knowledge, learning and building consensus.
Complex palliative care system	A subcategory of highly specialised PC services that responds to a major volume of demands and complex cases and that is usually based on a teaching or university hospital. It operates closely to other hospital and community resources, is staffed with skillful professionals and has teaching and research at the heart of its activity.
Comprehensive palliative care service	A PC service should put emphasis on relief from pain and other distressing symptoms; integration of physical, psychological, and spiritual aspects of patient care; and development of a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness and in bereavement. It requires the expertise of various providers and access to a range of specialised disciplines to adequately assess and treat the complex needs of seriously ill patients and their families. A comprehensive system of services, including in-patient services, home-care services and support services should be available to cover all care needs and treatment options.
Continuity of care	The common thread linking care from one provider to another and from one health care event to another, in which information transfer is the basis. Documented information tends to focus on the medical condition, but knowledge about the patient's preferences, values, and context is equally important for bridging separate care events and ensuring that services are responsive to needs.
Controlled drugs	Prescription medicines, such as morphine, pethidine, and methadone. As these medicines are sometimes misused, they have stricter legal controls on their supply to prevent them being obtained illegally.
Cultural aspects of care	Range from the provision of a suitable diet, to the intervention of an interpreter for those who cannot communicate freely in the team's language, and to the planning of cultural aspects of death, dying and funeral procedures which will be of importance to both the patient and family.
D	
Database	An integrated collection of logically related records or files consolidated into a common pool that provides data for one or more multiple uses.
Day care centre for palliative care	Medical and paramedical services delivered to patients that are formally admitted for diagnosis, treatment or other types of health care with the intention of discharging the patient the same day. It offers a range of opportunities for assessment and review of patients' needs and enables the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.
Directory	An alphabetical list of names and addresses of persons and organisations regarding to a certain topic (e.g. PC provision).
E	
Early initiation of palliative care	Palliative care that starts at the time of diagnosis of an incurable disease. It aims to control symptoms and to maintain an optimal quality of life, and to facilitate the patient and family's adjustment to the new health situation. It is provided simultaneously with the specific treatments prescribed to control the progression of the disease in a 'working together' manner with different specialists and/or PC services.
End of life care	The specific application of PC in the last hours, days or weeks of life.
G	
General practitioner (GP)	A medical practitioner, who is the first point of contact with the health services for all non- emergency cases, provides primary care and is specialised in family medicine. A general practitioner treats acute and chronic illnesses and provides preventive care and health education to patients of all ages and both sexes. He/she has particular skills in treating people with multiple health issues and co-morbidities.
General palliative care measures	Constitute the most basic PC activity in a given health care setting; <ul style="list-style-type: none"> • are directed to patients and families who, at any point of the illness trajectory, may benefit from a PC approach, but without having specific PC needs that would require skilled interventions; • are specially relevant in 'conventional services', such as primary care, general practice, internal medicine, emergency, oncology or geriatrics that care for many chronically and terminally ill patients; • can be delivered by any health care professional who has basic training in PC; • include: a) education and training of health professionals on the basis of pain and the most frequent symptoms control; communication skills; the multidimensional evaluation of cases, and ethical reflection; b) guidelines and protocols for managing the most prevalent symptoms at the end of life; c) criteria for referring to the PC specialist; d) protocols to guarantee the continuity of care across services; e) in primary care, telephone support and carer education.
Gold Standards Framework (GFS)	A systematic evidence based approach to optimise the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting. The GFS Prognostic Indicator Guidance aids identification of adult patients with advanced disease, in the last months/year of life, in need of supportive and PC.
H	

Glossary	
Health care outcomes	The end results of particular health care practices and interventions, including the effects that people experience and the care they receive as well as changes in their ability to function, and effects on quality of life or mortality. Their definition, monitoring and understanding have become crucial to quality care improvement.
Holistic assessment in palliative care	<p>Assessment of the problems and needs of a palliative patient which includes five domains:</p> <ul style="list-style-type: none"> • Background information and assessment preferences; • Physical needs; • Social and occupational needs; • Psychological well-being; • Spiritual well-being. <p>The assessment of each domain should be 'concerns-led', focusing on items of particular concern to the patient.</p>
Hospice at home	Intensive coordinated home support for patients with complex needs who wish to stay at home with extended specialist palliative nursing, medical, social and emotional support and care in the patient's home.
Hospice	A type of specialised PC setting, which concentrates on end of life care. There are 'in-patient' and 'out-patient' hospice services. In some countries, 'in-patient hospice' may be synonymous with 'palliative care unit'.
Hospital at home	Care provided at the patient's home that is usually only available in a hospital such as observation, administration of drugs, support, nursing care, and rehabilitation.
	I
Imminent	About to occur; impending.
Impending death of a patient	The patient is dying.
Induction training	Training given to new employees. The purpose of the induction period (which may be a few hours or a few days) is to help a new employee settle down quickly into the job by becoming familiar with the people, the surroundings, the job and the business.
Informal caregiver	Someone who provides care to an ill person because of his relationship with this person. Informal care is provided mainly by family members or others who are close to the ill person, such as neighbours and friends.
Integrated delivery of palliative care	<ul style="list-style-type: none"> • A PC system which combines physicians, hospitals, and other medical services with a PC plan to provide the complete spectrum of medical care for its patients and families. In a fully integrated system, the three key elements - physicians, hospital, and health plan membership - are in balance in terms of matching medical resources with the needs of purchasers and patients; • operates in defined geographic and demographic areas, such as metropolitan, community or rural areas; • represents an established and experienced PC resource that is fully connected with the local and regional hospitals; the primary care services; local nursing homes; other long-term care facilities, as well as with other health and social resources in the community; • it relies on one or more designated professional (usually a health professional with PC expertise or a PC team) who is responsible for managing the cases, and who will guarantee the continuity of the care and follow up across the system; • criteria and pathways for referring patients from, and to, the PC team are well defined and operationalised; • within the system, patients can be temporarily transferred to other services when specific needs are to be satisfied; • case management is the approach adopted to make decisions concerning the clinical, social and financial aspects of the care and is central to the organisation and function of a PC system.
Interdisciplinary team	A team with members that work jointly but still from a disciplinary base to address a common problem. They work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified issues, expectations, needs and opportunities. Regarding PC such a team typically consists of one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists and volunteers. Other disciplines may be part of the team as well.
	K
Karnofsky performance scale (KPS)	Index for clinical estimate of a patient's physical state, performance, and prognosis after a therapeutic procedure, and for determining a patient's suitability for therapy; a score between 0 and 100 assigned by a health professional after watching a patient perform common tasks. A score of 100 means that the patient has normal physical abilities with no signs of disease. Decreasing numbers mean that the patient has less ability to perform activities of daily life.
Key worker	A dedicated person (or a group of persons) within the same team that oversee and manage the delivery of services from all agencies involved in the care and support of the patient, and ensures that the patient and/or family has access to appropriate services.
	L
Life-limiting diseases	Refers to health conditions that will cause a shorter life expectancy than the ones attributed to healthy people of the same age.
Lobby	A group of persons engaged in trying to influence legislators or other public officials in favor of a specific cause.
	M

Glossary	
Minimum data set	The valid and reliable (national) measurement of the quality of end-of-life/palliative care, these include multiple administrative data, data collected by hospice and PC providers, retrospective assessments by family members, and population-based surveys. The minimum data set for specialist PC services in the UK aims to provide good quality comprehensive data about hospice and specialist PC services. Annual data collection of aggregated patient data from each of the PC services, including in-patient care, home care, day care and hospital support, provides information which is used for strategic planning as well as local service management. This includes information about patient characteristics as well as about service uptake.
Multidimensional treatment plan	A treatment plan that takes into account several dimensions or aspects of care (physical, psychological, spiritual, social, cultural, ethical ...).
Multidisciplinary team	A team that consists of a mix of health and social care professionals. It works in parallel or sequentially from a specific disciplinary base to address a common problem. Members of a multidisciplinary team might include general practitioners, surgeons, medical or radiation oncologists, PC specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants.
National/regional palliative care plan	A strategy developed, and agreed upon, by policymakers, health care managers, health care professionals, and patients, the aims and principles of which are to achieve coverage, equity, and quality in terms of effectiveness, efficiency and users' and professionals' satisfaction in the provision of PC. A national/regional PC plan includes the assessment of end of life care needs; clearly and timely defined aims and objectives; the implementation of specific services to respond to identified needs, and according to available resources and to the cultural and social background of the population to be cared for; education and training; promotion of opioids availability; specific legislation and financing; the elaboration of standards, and systematic evaluation of the outcomes.
National palliative care association	Umbrella organisation for all those who are involved in providing, commissioning and using hospice and PC services (for each country).
Numeric Rating Scale (NRS)	A numeric (0-10) scale for measurement of pain intensity by self-report, the scale requires patients to rate their pain on a scale of 0 (no pain) to 10 (worst pain). 0
Occupational therapist	Person legally qualified by education and training to engage in the practice of occupational therapy, who actively engages people in purposeful activities to promote, regain or maintain health and wellbeing, using occupations as therapy and enabling individuals to engage in occupations. Occupational therapists work with children and adults of all ages, whose difficulties may be congenital or the result of an accident, illness, ageing or lifestyle. P
Palliative care approach	The approach that aims to promote physical, psychosocial and spiritual well-being of patients and their families, and is a vital and integral part of all clinical practice whatever the illness or its stage.
Palliative care crisis	Any unexpected change near the end-of-life. The precipitating events can be physical related, e.g. acute dyspnoea, acute delirium, acute pain or massive hemorrhage; psychological related e.g. suicide attempt; social related e.g. acute loss of family or caregiver such as caregiver fatigue/caregiver illness; and spiritual-related, e.g. existential distress.
Palliative care hospital support team	Describes a specialist PC team made up of at least one physician and one nurse that provides professional advice and support within a general hospital, including in-house training. The patients' care-as long as he/she is an in-patient remains the primary responsibility of the physician at the respective ward.
Palliative care model	A theoretical representation of the way in which PC is delivered in a given social context. It serves to explain the different aspects of the reality of PC provision, and the labels and terms used to describe this reality. PC models and the taxonomy associated with them are inherent tools to goal-directed activities.
Palliative care network	A coordinated, integrated or liaised system between PC services and other health and social care services within a specific demographic context, usually a district or sector, including both intramural and extramural services.
Palliative care out-patient clinic	A service for ambulatory palliative patients (so not meant for hospitalised patients) which is considered an important service in the continuum of PC. It may be a stand-alone service or incorporated into another clinic, such as an oncology, neurology, infectious disease, pain clinic, etc. An out-patient PC clinic can offer a range of services, from ongoing symptom management to follow-up for patients discharged from in-patient services. Almost by definition, patients seen in the out-patient clinic are seen earlier in the course of their illness, and may be receiving both palliative and curative/restorative therapy. It permits efficiency and flexibility in the assessment and management of symptom control problems; psychosocial support, information and counseling; continuity of care and contact with the medical system; triage of patients to other specialty services offered by the institution or community; development of liaisons with home care services; bereavement services; access to care providers and professional advice by telephone.
Palliative care programme	Describes a group of PC resources developed within a given health care region or sector that operates in a coordinated manner with other health and social care services. PC programmes mostly respond to local demographic and epidemiological needs. Funding sources may vary greatly. When funded by the local, regional or national government, their public access is guaranteed.

Glossary	
Palliative care resource	<p>Generic term that comprises any specific PC facility, such as a support team, an out-patient clinic, a unit, operating within any health care setting. Each PC resource can be categorised according to the activity it develops. For instance:</p> <ul style="list-style-type: none"> • out-patient care; • in-patient care (in specifically allocated beds or not); • home care; • supportive care [based on the definition]; • expert advice in the hospital; • expert advice in the community; • telephone support to other health professionals and to informal carers; • day care; • around the clock duties (24 hrs/day); • on-call duties (7 days/week); • teaching/training/education; • research; • audit.
Palliative care service	<p>A specialised form of interdisciplinary health care that is designed to enhance comfort and improve the quality of a patient's life as opposed to achieving a cure. It emphasises care that alleviates the physical, emotional, social, and spiritual discomforts of an individual in the last phases of life. Its treatment goals are pain control, symptom management, quality of life enhancements, and spiritual and emotional comfort for the patient and family. Among other intents, PC services aim to</p> <ul style="list-style-type: none"> • respect and support patient preferences; • improve pain and symptom control; • restore some measure of choice and control to patients and families at a time when choice and control seem to slip away; • prevent inappropriate emergency department and in-patient admissions; • increase patient and family satisfaction with care; • increase the number of patients benefiting from end-of-life care services; • increase the number of families and relatives benefiting from bereavement support services; • increase clinician knowledge of end-of-life care services; demonstrate cost-effectiveness.
Palliative care support team	<p>Describes a specialist PC team made up of at least one physician and one nurse that provides professional advice and support to professional caregivers in a certain region (as well in hospitals, at home, or in other settings).</p>
Palliative care team	<p>A group of knowledgeable and skilled professionals who develop specific PC activities in any health care setting.</p>
Palliative care unit	<p>A health care unit with in-patient beds, designated to provide high quality specialised PC for patients (and their family) with more complex physical, psychosocial and/or spiritual needs. These units work in close cooperation with hospital-based and community-based services, e.g. the regional PC network. Frequently, they are located on the grounds of, adjacent to, or are part of, a general hospital setting, a cancer institute, a nursing home or other type of long-term care facility. There also are other understandings about what a palliative care unit (PCU) comprises. For instance, in Poland, the term PCU comprises different types of palliative care organisations; i.e. home care (hospice at home), out-patient clinic, in-patient unit.</p>
Palliative care	<p>According to the World Health Organisation (2006), PC is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. PC:</p> <ul style="list-style-type: none"> • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten or postpone death; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patients illness and in their own bereavement; • uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; • will enhance quality of life, and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. In the opinion of the European School of Oncology (Ahmedzai et al, 2004), PC is 'the personcentred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or relatives (including close friends and informal carers)'.
Palliative home care support team	<p>A specialised PC team that visits patients at home and advises the primary care team and informal carers on management; has been conceived as the resource that would fulfill patients' wish of having their care undertaken in their own home and also as one of the most cost-effective resources for providing this type of care in the community. It may develop different activities according to the needs it has to respond to. Some of these teams mostly focus on advising other services and see a patient only in very critical situations, or to conduct the initial needs assessment. In Germany, for instance, there are: a) 'palliative' home care services, with main focus on palliative medical and nursing services; b) 'hospice' home care services, with main focus on counseling and psychosocial support of patients and their families. A similar model also applies to Poland while in The Netherlands PC can be a 'basic' or 'specialised' service.</p>

Glossary	
Palliative Performance Scale (PPS)	A scale of five observer-rated domains correlated to the Karnofsky Performance Scale (100-0). It is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients. It has been found useful for purposes of identifying and tracking potential care needs of PC patients, particularly as these needs change with disease progression. Large validation studies are still needed, as is analysis of how the PPS does, or does not, correlate with other available prognostic tools and commonly used instruments.
Palliative sedation	An intervention with the intention to relieve intolerable suffering, and in which a sedating drug for symptom control is used. The successful outcome is the alleviation of distress. The use of heavy sedation (which leads to the patient becoming unconscious) may sometimes be necessary to achieve identified therapeutic goals; however, the level of sedation must be reviewed on a regular basis and in general used only temporarily.
Patient's complaints procedure	This procedure applies to complaints about the policies, procedures, or actions regarding the care the patient received (or did not receive) by a certain organisation.
Patient's preferences	What a patient wants. This can be patient's preference of place of care; patient's preference of care or advance directives; patient's preference of daily living; patient's preference for bowel and bladder excretion.
Patient-centred care	An approach to care that consciously adopts a patient's perspective. This perspective can be characterised around dimensions such as respect for patient's values, preferences, and expressed needs in regard to coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, transition and continuity.
Primary care out of hours	Before or after stated hours during which primary care practice is fully staffed.
Primary care	The medical care received on first contact with the medical system (before being referred elsewhere) provided by general practitioners, allied health professionals and nurses.
Professional caregiver	A person who has obtained a degree in a professional field. He/she is an expert and has specialised knowledge in the field in which they are practicing professionally.
Q	
Quality assessment	A systematic strategy for identifying needs; defining expected outputs and outcomes; applying indicators, standards and performance improvement strategies; measuring the impact of the intervention; agreeing on ways for monitoring change and improving care and satisfaction; adapting practice and treatment guidelines, and encouraging and strengthening team work. A frequently used quality assessment approach in PC is the simple 'design (or planning) – monitoring – improvement'. It guarantees a more consistent and economically efficient process of care as well as less risk of errors and organisational liability.
Quality indicator	A measurable element of practice performance for which there is evidence or consensus that it can be used to assess quality and hence changes in the quality of care provided. Good quality indicators (QIs) should be valid, reliable, feasible, acceptable and sensitive to change. On the basis of such indicators, tools can be developed to measure the quality of care being provided or the quality of practice management.
R	
Resuscitation wishes	The wish that in the case of a cardiac or respiratory arrest the patient is or is not resuscitated with an emergency medical procedure. In some countries DNR (Do Not Resuscitate) documents are widespread. This is a binding legal document that states that resuscitation should not be attempted if a person suffers cardiac or respiratory arrest. Such an order may be instituted on the basis of an advance directive from a person, or from someone entitled to make decisions on their behalf, such as a patient's advocate/surrogate.
S	
Specialised palliative care	The standard of PC provided at expert level, by professionals working in trained multi-professional teams, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialist members of the primary or secondary care teams (including knowledge about the circumstances under which other specialised services or hospices services should be approached and referral of patient and/or family to these services).
Specialist palliative care service	A specialised PC resource that operates in any given health care setting, and comprises a) hospital PC teams; b) palliative home care teams; c) out-patient clinics; d) PCU; e) hospice care; <ul style="list-style-type: none"> • is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care; • may complement and enhance disease-modifying therapy or may become the total focus of care. The degree of the PC service intervention is determined by the nature and the complexity of patients' and carers' needs, and by where in the disease progression the intervention is required; • is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of the caring process related to PC, and who are able to provide timely interventions that require experienced professionals; • guarantees the follow up and the continuity of the care, including bereavement support; • frequently provides training and research opportunities to interested professionals; • provides: <ul style="list-style-type: none"> • direct care to referred patients with complex needs; • consultation based services to patients being cared for by primary care providers; • support and education for services providing end of life care.

Glossary	
Specialist palliative care	The level of PC that requires the true designation of PC as a specialty in the country's medical curriculum [then called palliative medicine] and specialist training.
Specific palliative care measures	Constitute the most basic specialist resource in PC usually made up of two professionals, a PC physician and a nurse, or a psychologist or a social worker; <ul style="list-style-type: none"> • are applicable to health care services caring for patients and families who would benefit from specialist PC inputs at some point in the illness trajectory. The complexity of their demands is such that it requires the intervention of a skilled, PC specialist; • are specially relevant in general hospitals, cancer institutes, specialised hospitals, nursing homes, and the community; • include: a) PC support teams in hospitals; b) PC support nurses in the community; c) day care centres; d) telephone line for specialist advice; e) bereavement support teams.
Spiritual/religious caregiver	A person that provides spiritual and religious support to all patients/residents, families, and staff who request these services by connecting them to pastoral and volunteer spiritual caregivers from their own religious communities. Spiritual/religious caregivers offer spiritual care to those who have no religious affiliation and require assistance with the meaning of suffering, illness, healing and recovery.
Supportive care	The care of cancer and other chronically ill patients from the time of diagnosis, or even pre-diagnosis, throughout both curative and palliative treatments. It is aimed at enhancing treatment tolerance and outcomes by means of diminishing or controlling anticipated side effects caused by treatment of a disease, psychological, social, and spiritual problems related to the disease or its treatment.
Syringe driver	A small, portable battery-driver infusion pump, used to give medication subcutaneously via a syringe usually over 24 hours. It can be used when other routes (e.g. oral, buccal, rectal, trans-dermal) are unsuitable.
T	
Team Climate Inventory (TCI)	Team climate is a variable possessed by an organisation that can be described, measured, and manipulated to enhance the effectiveness of the organisation. In line with this approach, a questionnaire to measure climate (the Team Climate Inventory; TCI) has been developed and received preliminary validation in primary care teams. The idea that climate is 'shared' can be examined using statistical procedures to determine agreement and consensus.
Transdisciplinary work	Members work using a shared conceptual framework, drawing together disciplinary-specific theories, concepts and approaches to address a common problem.
Transfer summary	A brief description of the patient's course of treatment or service that also contains recommendations for further treatment and/or service when the patient is transferred to another setting/ward.
Tumor, Nodes and Metastases (TNM)	A system for staging malignant neoplastic disease.
V	
Validity	The extent to which a variable or intervention measures what is supposed to be measured or accomplishes what is supposed to be accomplished.
Visual Analogue Scale (VAS)	An assessment tool consisting of a 10 cm line with 0 on one end, representing no pain or other symptom at all (depending on the symptom it is used for), and 10 on the other, representing the worst pain or other symptom ever experienced, which a patient marks to indicate the severity of his or her symptom. VAS is also available for the measurement of feelings (states of the self and incorporate moods and sensations).

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APPENDIX CHAPTER 3

Appendix A: Manual

Part A: General

1. Please shortly describe your national health system, as it is relevant to palliative care. Describe the level of political decision making (national or regional).
2. Is there a system for comprehensive patient palliative care needs assessment? If yes, please describe. (if you can say something about family needs assessment too, please add) (Clinical level, not public health!)

Part B: Organization of Care

3. What kind of laws regarding palliative care do exist? (plus year established) (Please specify: regional or national; name and summary of content. We do not mean laws about volunteers etc, although it might be linked to palliative care; laws about euthanasia etc can be mentioned if they also mention palliative care)
4. Is there a national and/or regional health policy regarding palliative care in your country? If yes, describe it (development, budget, aims). Describe the implementation of the plan, regarding the organisation of services! Is there a national / regional palliative care association / federation/ organisation in your country? Please describe! How is palliative care financed? Please describe, also relevant budgets: Public /private / voluntary. Is it dedicated for palliative care? Differences between care settings?
5. Are there barriers or incentives to provide or receive palliative care? Please describe (e.g. attitudes, costs, availability of services, professionals, drugs, medical resources, lack of knowledge, financial implications for doctors, poor communication with patient)
6. Are volunteers involved in palliative care? If yes, is care dependent of the presence of volunteers? Does it depend on the setting? Do volunteer networks exist? Are they specifically trained for palliative care? How?
7. Where do patients prefer to die? (percentage that prefers to die at home)
8. How many patients die at home? (percentage; what sort of patients; if available also percentages of other settings)

9. How many identified palliative care beds per 100.000 inhabitants are present?
10. What kind of palliative care structures / models do exist? For explanation of the services, see 'definitions of terms'

Part C: Research

11. Is there a structured national research programme?
12. Are there other than national research programmes (e.g. universities, master thesis, PhD etc, please specify)
13. Is research in palliative care funded by the government? How much? (yearly)
14. Is there non-governmental research funding?

Part D: Education

15. How many chairs for palliative medicine do you have in your country?
16. How many chairs for palliative nursing do you have in your country?
17. Is there a distinct medical specialization in palliative medicine?
18. Is there a distinct nursing specialization in palliative care?

Appendix B: Key words entered for the database and grey literature search

Keywords				
"palliative care"	AND	Name of the		
"hospice"		[country]		
"terminal care"		[region]		
"bereavement"		[city]		
"end of life"				
"palliative care"	AND	Name of the	AND	"organization"
"hospice"		[country]		"programme"
"terminal care"		[region]		"model"
"bereavement"		[city]		"service"
"end of life"				"resources"
				"home"
				"community"
				"funding"
				"research"
				"education"
				"training"

Appendix C: Sources from database and grey literature

Country	Literature
Belgium	D'Hulster Ronny et al. Vrijwilligerswerking in de palliatieve hulpverlening. Kapellen: Pelckmans, 1997.
	"Baerten H, Clicteur B, Helaers P et al. De onzichtbare kracht- vrijwilligers in de palliatieve thuiszorg. Studie van de FPZV. Available at: http://mailsystem.palliatief.be/accounts/15/attachments/Publicaties/vrijwilligers_ptz_tvanierselea.doc ; accessed August 2008."
	"Van Iersel Trudie. Palliatieve zorg in Vlaanderen, feiten en cijfers. Tijdschrift Federatie palliatieve zorg Vlaanderen, oktober 2005."
United Kingdom	"Moreno MM, Harris M, Gorgojo L, Clark D, Normand C, Centeno C. Palliative Care in the European Union. Policy Department Economic and Scientific Policy. A report for the European Parliament. This study was requested by the European Parliament's Committee on the Environment, Public Health and Food Safety. May 2008."
	"Ward D. Hospice and Palliative Care Directory United Kingdom and Ireland 2008. Compiled by Hospice Information Editor Daniel Ward 2008 Help the Hospices (The directory is produced by Hospice Information-a joint venture between Help the Hospices and St Christopher's Hospice-and is based on information gathered through an annual survey conducted between August 2007 and February 2008)."
	Ward D. Hospice and Palliative Care Directory United Kingdom and Ireland 2009-2010.
France	Law 99-477 of June the 9th, 1999: right of access to palliative care.
Germany	Andersson B, Ohlén J. Being a hospice volunteer. Palliat Med. 2005 Dec;19(8):602-9.
	Raß R. Curriculum für die Koordination ambulanter Hospizdienste. Bonn: Pallia Med, 2003.
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	Mueller M, Heinemann W. Handreichung fuer Multiplikatoren – zur Befaehtigung und Ermutigung ehrenamtlich Mitarbeitender in Hospiz(dienst)en. Pallia Med: Bonn, 2005.
	Rest F. Sterbebeistand – Sterbebegleitung – Sterbegeleit. 5. Auflage. Stuttgart: Kohlhammer, 2005
	Bluemke D, Hartwig C, Fuchs-Enzminger H, Neumann U, Otto P, Rieffel A. Qualitätsanforderung zur Vorbereitung Ehrenamtlicher in der Hospizarbeit. Hrsg. Bundesarbeitsgemeinschaft Hospiz e.V. Niederzier, 2005.
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Wissert M, Popelka D: Qualitaet und Qualitaetsentwicklung ehrenamtlicher ambulanter Hospizarbeit. Ein Projekt der BAG Hospiz im Rahmen des Gesamtprojekts: „Netzwerk zur Qualitaetssicherung in der Hospizarbeit“. In: Bundesarbeitsgemeinschaft Hospiz e.V. (Hg.): Hospiz schafft Wissen. Dokumentation der Fachtagung der Bundesarbeitsgemeinschaft Hospiz e.V. vom 9. November 2003. Wuppertal: der hospiz verlag, 2004, pp 81-94.	

Country	Literature
Spain	Majado, B. et al. Desarrollo de un plan de voluntariado de Cuidados Paliativos. Med Pal (Madrid) 2008; 15:2; 82-88
	Lacasta, Ma. et al. Formación del voluntariado en cuidados paliativos. Med Pal (Madrid) 2000; 7:1; 6-9
	Montesinos F, et al. Formación y satisfacción del voluntariado de cuidados paliativos. Psicología Vol. 5, Núm. 2-3, 2008, pp. 401-408. Asociación Española Contra el Cáncer, Madrid.
	Dávila, M.C., et al. Análisis de las tasas de abandono en una muestra de voluntarios y causas más frecuentes. Psicología Social y Problemas Sociales. Vol. 5. (pp.205-212). Madrid: Biblioteca Nueva. (2005).

Country	Organisation	URL
Belgium	Fédération Wallonne des Soins Palliatifs. La revue des soins palliatifs en Wallonie	http://www.SoinsPalliatifs.be
	PANAL	http://www.panal.be/nl/page/startpagina.html
France	Enquête CABA de la SFAP et la CNAMTS extract.	www.sfap.org/pdf/VII-I9c-pdf.pdf
	Fédération JALMALV	http://www.jalmalv.fr/
	Fondation du Bénévolat	http://www.benevolat-info.fr/index_accueil.php
Germany	Deutscher Hospiz- und Palliativverband e.V.	www.hospiz.net ; accessed 12 January 2010.
The Netherlands	Associatie van zelfstandige high-care hospices	www.hospices-highcare.nl/
	Nederlandse Instituut voor onderzoek van de gezondheidszorg	www.nivel.nl
	Ruide Kruis	www.rodekruis.nl/campagne/3fm/
	Buddy Netwerk	www.buddynetwerk.nl/website/
Poland	VPTZ	http://www.vptz.nl/asp/page_netwerk.asp
	Available at:	www.woluntariat.hospicja.pl , last access 8th May 2010.
Spain	CUDECA	http://www.cudeca.org/
	Caritas Spain	http://www.caritas.es/
	Guiaongs.org.	http://guiaongs.org/
	ONCE	http://www.once.es/new
	Plataforma del voluntariado en Espana	http://www.plataformavoluntariado.org/
	Red Cross Spain	http://www.cruzroja.es/preportada/tv/index.html
	Spanish League against Cancer	https://www.todocancer.com/ESP/
	Voluntario.net.	http://voluntariado.net/
AECC	http://www.uicc.org/	

Appendix D: National experts per country

Country	National experts
Belgium	
JC	Coordinator palliative network PANAL
RvN	Head nurse of the Palliative Care Unit Sint Pieter, University Hospital Leuven
TVI	Research coordinator Flemish Palliative Care Federation
MD	Specialist nurse hospital support team UZ Leuven
BS	Administrator, Service Research, Development & Quality of the National Institute for Health and Disability Insurance
JM	Coordinator Palliative Support Team, University Hospital Leuven
AD	Coordinator palliative care unit, University Hospital Brugmann, Brussels
United Kingdom	
LS	Director National Council for Palliative Care
AE	Minimum Data Sets Project Manager
MH	UK Information Manager, Help the Hospices
JB	Director of Practice Development
LW	Academic Palliative and Supportive Care Studies Group (APSCSG)
DO	Consultant in Palliative Medicine
Germany	
MM	M.A., ALPHA Rhineland
The Netherlands	
WJ	Coordinator Network Palliative Care Amsterdam
RK	Director IKMN
CD	Board member of the Dutch Association of cancer organisations (NFK)
ST	Director Medical Oncology University Utrecht
AR	Director AGORA
HB	Director VPTZ
CG	IKO
Spain	
XGB	Senior consultant in palliative care

APPENDIX CHAPTER 4

Appendix A: Search strategies for databases

Database	Search strategy
Medline	((("Palliative Care"[MeSH] OR ((palliative[ti] OR terminal[ti] OR hospice[ti]) AND care[ti]) OR "Terminal Care"[MeSH:noexp] OR "Life Support Care"[MeSH] OR "Advance Care Planning"[MeSH] OR "Resuscitation Orders"[MeSH] OR "Withholding Treatment"[MeSH] OR "Hospice Care"[MeSH] OR "Hospices"[MeSH] OR "Terminally Ill"[MeSH]))) AND (("Quality Indicators, Health Care"[MeSH])) OR (((("Palliative Care"[MeSH] OR ((palliative[ti] OR terminal[ti] OR hospice[ti]) AND care[ti]) OR "Terminal Care"[MeSH:noexp] OR "Life Support Care"[MeSH] OR "Advance Care Planning"[MeSH] OR "Resuscitation Orders"[MeSH] OR "Withholding Treatment"[MeSH] OR "Hospice Care"[MeSH] OR "Hospices"[MeSH] OR "Terminally Ill"[MeSH]))) AND (("quality measure" OR "quality measures" OR "quality criterion" OR "quality criteria" OR "quality assessment" OR ((Quality[ti] OR performance[ti] OR satisf*[ti]) AND (indicator*[tw] OR criteri*[tw] OR assess*[ti] OR measur*[ti] OR scale[ti] OR validat*[tw]))) NOT (letter[pt] OR editorial[pt] OR comment[pt] OR case reports[pt]))
Scopus	See Medline
PsycINFO 18.05.2009	((palliative care or terminal care or hospice care or advance care or life support care) and (quality indicators or measure or quality measures or assessment) and (organisation or organization))
Social Medicine 26.05.2009	"Title=(palliative care' or 'end of life care' or 'hospice care' or hospice or 'terminal care') And Title=('quality measure?' or 'quality assessment' or 'quality criteri?' or indicator?)" in Dates (After 2006)
CINAHL 18.05.2009	((("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND ("quality indicator*" OR " clinical indicator*" OR "clinical measure*" OR "quality measure*" OR assessment) AND organi?ation) -"intensive -care -unit" -"symptom -assessment"
Cochrane Database	See Medline
Embase 15.05.2009	(exp Palliative Therapy/ OR ((palliative.ti. OR terminal.ti. OR hospice.ti.) AND care.ti.) OR Terminal Care/ OR Life Support Care.mp. OR Advance Care Planning.mp. OR Resuscitation/ OR Withholding Treatment.mp. OR exp Hospice Care/ OR exp Hospice/ OR exp Terminally ill patient/) AND (clinical indicator/ or performance measurement system/ OR quality measure OR quality measures OR quality criterion OR quality criteria OR quality assessment OR ((Quality.ti. OR performance.ti. OR satisf*.ti.) AND (indicator*.mp. OR criteri*.ti. OR assess*.ti. OR measur*.ti. OR scale.ti. OR validat*.mp.)))
SIGLE	((palliative care OR terminal care OR hospice care OR advance care OR life support care) AND (quality indicators OR measure OR quality measures OR assessment) AND (organisation) "palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "end of life care" and (indicators OR measure OR assessment OR audit)
ASCO	See Medline
Wonca	See Medline
Google Scholar	((palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "end of life care") AND (indicators OR "quality measure" OR audit) 5620 results vanaf 2007 ("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "end of life care") AND (indicators OR "quality measure") 3 780 results vanaf 2007 ("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "end of life care") AND (indicators OR "quality measure" OR audit) AND (organization OR organisation) (("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND (quality indicators OR measure OR quality measures OR assessment) AND (organization OR organization)) NOT "intensive care unit" 3810 vanaf 2007 (("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND ("quality indicators" OR indicator OR measure OR "quality measures" OR assessment) AND (organization OR organization))-"intensive -care -unit" 4320 vanaf 2007 (("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND ("quality indicator" OR " clinical indicator" OR "clinical measure" OR "quality measures" OR assessment) AND (organization OR organization)) -"intensive -care -unit" 3 750 sinds 2007 (("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND ("quality indicator" OR " clinical indicator" OR "clinical measure" OR "quality measures" OR assessment) AND (organization OR organization)) -"intensive -care -unit" -"symptom -assessment" 3 540 hits (("palliative care" OR "terminal care" OR "hospice care" OR "advance care" OR "life support care" OR "end of life care") AND ("quality indicator" OR " clinical indicator" OR "clinical measure" OR "quality measures" OR assessment) AND (organization OR organization)) -"intensive -care -unit" - "symptom assessment"

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Appendix C: Indicator set for the organisation of palliative care

No	QI	Type	Application	Status	Database / Hand search	Grey literature
Definition of a palliative care service						
1	All the services below are part of a comprehensive palliative care service: Palliative day care, Palliative home care support team, Hospice beds, Palliative hospital support team, Inpatient palliative care hospital beds, Palliative care outpatient clinic, Bereavement support	Structure indicator	All settings	New developed		
2	All the services below are part of a comprehensive palliative care service: Palliative day care	Structure indicator	All settings	New developed		
3	All the services below are part of a comprehensive palliative care service: Palliative home care support team	Structure indicator	All settings	New developed		
4	All the services below are part of a comprehensive palliative care service: Hospice beds	Structure indicator	All settings	New developed		
5	All the services below are part of a comprehensive palliative care service: Palliative hospital support team	Structure indicator	All settings	New developed		
6	All the services below are part of a comprehensive palliative care service: Inpatient palliative care hospital beds (e.g. palliative care unit)	Structure indicator	All settings	New developed		
7	All the services below are part of a comprehensive palliative care service: Palliative care outpatient clinic	Structure indicator	All settings	New developed		
8	All the services below are part of a comprehensive palliative care service: Bereavement support	Structure indicator	All settings	New developed		
Access to palliative care						
A: Access and availability (All settings)						
9	A palliative care team is available at the request of the treating professional/team in all of the following settings: Day care, at home, Hospital, Hospice, Nursing home, Outpatient clinic, Day care	Process indicator	All settings	New developed		
10	A palliative care team is available at the request of the treating professional/team in all of the following settings: Day care (excluding palliative day care)	Process indicator	All settings	New developed		
11	A palliative care team is available at the request of the treating professional/team in all of the following settings: At home (or home replacing institution s.a mental institution, prison)	Process indicator	All settings	New developed		
12	A palliative care team is available at the request of the treating professional/team in all of the following settings: Hospital	Process indicator	All settings	New developed		
13	A palliative care team is available at the request of the treating professional/team in all of the following settings: Hospice	Process indicator	All settings	New developed		
14	A palliative care team is available at the request of the treating professional/team in all of the following settings: Care home	Process indicator	All settings	New developed		
15	A palliative care team is available at the request of the treating professional/team in all of the following settings: Outpatient clinic (excluding palliative care outpatient clinic)	Process indicator	All settings	New developed		
16	For every professional/team specialised palliative care advice is available 24 hours a day, 7 days a week	Process indicator	All settings	Changed	²⁻⁴	1
17	Patients in need of palliative care and their families have access to palliative care facilities: Throughout the entire duration of their disease	Process indicator	All settings	Changed	⁶	1
18	Patients in need of palliative care and their families have access to palliative care facilities: With no extra financial consequences for the patient	Process indicator	All settings	Changed	⁷	
19	Patients receiving palliative care have access to diagnostic investigations (e.g. X-rays, blood samples) regardless of their setting	Process indicator	All settings	Changed	⁸	
Primary care (Home, Nursing home)						
20	Palliative care is available for the patient and their family by: Phone	Process indicator	Primary care indicator	Changed	²	1
21	Palliative care is available for the patient and their family by: Visiting the patient	Process indicator	Primary care indicator	Changed	²	1
22	Palliative care is available for the patient and their family by: Bringing the patient to the service	Process indicator	Primary care indicator	Changed	²	1
23	For a palliative patient in a crisis, the following can be arranged within 24 hours: Admission	Process indicator	Primary care indicator	Changed	⁹	1

No	QI	Type	Application	Status	Database / Hand search	Grey literature
24	For a palliative patient in a crisis , the following can be arranged within 24 hours: An urgent discharge to patients home	Process indicator	Primary care indicator	Changed	⁹	1
25	For a palliative patient in a crisis , the following can be arranged within 24 hours: Transfer to another setting of care	Process indicator	Primary care indicator	Changed	⁹	1
B. Out of hours (All settings)						
Staff						
26	A member of a palliative care team is available 24 hours a day, 7 days a week: For palliative care consultation by phone	Process indicator	All settings	Changed	^{2,3,10}	1
27	A member of a palliative care team is available 24 hours a day, 7 days a week: To provide bedside care in a crisis	Process indicator	All settings	Changed	^{2,3,10}	1
Drugs						
28	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Opioids and other controlled drugs	Structure indicator	Primary care indicator	Combined/ Changed	^{11,12,13,14}	1
29	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Anticipatory medication for the dying patient	Structure indicator	Primary care indicator	Combined/ Changed	¹¹	1
30	The following treatments are available for a palliative patient 24 hours a day, 7 days a week: Syringe drivers	Structure indicator	Primary care indicator	Combined/ Changed	¹¹	1
C. Continuity of care (All settings)						
31	There is a procedure for exchange of clinical information across caregivers, disciplines and settings	Process indicator	All settings	Changed	⁷	
32	Before discharge/ transfer/ admission there is information transfer to the caregivers in the next setting regarding care and treatment	Process indicator	All settings	Changed		
33	There is a professional caregiver per individual palliative patient nominated as responsible 'key worker' who coordinates care	Process indicator	All settings	Combined/ Changed	¹⁵	1
34	The responsible 'key worker' pays special attention to continuity of care within and across settings	Process indicator	All settings	Combined/ Changed	¹⁵	1
Inpatient setting (Hospital, Palliative care unit, Hospice)						
35	General practitioners (GP's) are routinely called when a patient is being discharged home or transferred to another setting	Process indicator	Inpatient setting indicator	Changed	^{3,9,17}	
36	The discharge/ transfer letter of palliative care patients contains a multidimensional diagnosis, prognosis and treatment plan (see indicator 48 Clinical record)	Structure indicator	Inpatient setting indicator	Changed	¹⁸	
Primary care						
37	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	Structure indicator	Primary care indicator	Changed		
Infrastructure						
A. All settings						
Infrastructure						
38	Specialist equipment (e.g. anti decubitus mattresses, aspiration material, stoma care, oxygen delivery, special drug administration pumps, hospital beds, etc) is available for the nursing care of palliative care patients in each specific setting	Structure indicator	All settings	Changed		1
39	There is a dedicated room where multidisciplinary team meetings within one setting takes place	Structure indicator	All settings	New developed	¹⁹	
40	There are dedicated facilities for multidisciplinary communications across settings: A dedicated room for meetings	Structure indicator	All settings	Changed	²⁰	
41	There are dedicated facilities for multidisciplinary communications across settings: Facilities for video or telephone conferences	Structure indicator	All settings	Changed	²⁰	
Information about care						
42	There is an up to date directory of local caregivers and organisations that can have a role in palliative care	Structure indicator	All settings	New developed	¹⁷	
43	There are dedicated information about the palliative care service: A website	Structure indicator	All settings	Changed	⁶	
44	There are dedicated information about the palliative care service: Leaflets or brochures	Structure indicator	All settings	Changed	⁷	
45	Patient information should be available in relevant foreign languages	Structure indicator	All settings	Changed	³	

No	QI	Type	Application	Status	Database / Hand search	Grey literature
46	Appropriately trained translators should be available if professional caregivers and patient or family members do not speak the same language	Process indicator	All settings	Changed	³	
47	There is a computerised medical record , to which all professional caregivers involved in the care of palliative care patients have access: Within one setting	Process indicator	All settings	Combined	⁶	
It systems						
48	There is a computerised medical record , to which all professional caregivers involved in the care of palliative care patients have access: Across different settings	Process indicator	All settings	Combined	⁶	
B. Inpatient setting (Hospital, Palliative care unit, Hospice, Nursing home)						
49	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)	Structure indicator	Inpatient setting indicator	Changed	¹²	
50	Dying patients are able to have a single bedroom if they want to	Process indicator	Inpatient setting indicator	New developed		
51	There are facilities for a relative to stay overnight	Structure indicator	Inpatient setting indicator	New developed		
52	Family members and friends are able to visit the dying patient without restrictions of visiting hours	Process indicator	Inpatient setting indicator	Changed	¹²	
53	There is a private place (e.g. dedicated room) for saying goodbye to the deceased	Structure indicator	Inpatient setting indicator	New developed	¹⁹	
C. Home care						
54	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	Process indicator	Home care indicator	Changed	¹⁹	
Assessment tools						
55	There is a holistic assessment of palliative care needs of patients and their family caregivers (e.g. SPARC)	Process indicator	All settings	Changed	^{9,21-26}	
56	There is an assessment of pain and other symptoms using a validated instrument	Process indicator	All settings	Changed	²⁷⁻³⁶	¹
Personnel palliative care services						
A. Staff						
57	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Physician	Structure indicator	All settings	Changed	⁸	³⁸
58	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines:Nurse	Structure indicator	All settings	Changed	⁸	³⁸
59	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines:Spiritual/ religious caregiver	Structure indicator	All settings	Changed	⁸	³⁸
60	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Psychologist/ Psychiatrist	Structure indicator	All settings	Changed	⁸	³⁸
61	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Social worker	Structure indicator	All settings	Changed	^{8,39,40}	³⁸
62	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Physiotherapist	Structure indicator	All settings	Changed	⁸	³⁸
63	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Occupational therapist	Structure indicator	All settings	Changed	⁸	³⁸
64	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Dietitian	Structure indicator	All settings	Changed	⁸	³⁸
65	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Bereavement counselor	Structure indicator	All settings	Changed	⁸	³⁸
66	The multidisciplinary team that provides palliative care consists of at least one of the following disciplines: Pharmacist	Structure indicator	All settings	Changed	⁸	³⁸
67	New staff receives a standardised induction training	Process indicator	All settings	Changed		¹
68	All team members have certified (accredited?) training in palliative care, appropriate to their discipline	Process indicator	All settings	Changed	⁴²	

No	QI	Type	Application	Status	Database / Hand search	Grey literature
69	All volunteers have training in palliative care.	Process indicator	All settings	Combined/ Changed		13
C. Support Systems						
70	All team members have an annual appraisal	Process indicator	All settings	Changed		41
71	All team members who professionally deal with loss have access to a program for care for the carers	Process indicator	All settings	Changed	23,24,43-45	
72	Satisfaction with working in the team is assessed (e.g. Team Climate Inventory)	Process indicator	All settings	Changed	17,18,46,47	48
D. Organisation of care						
73	Palliative care services work in conjunction with the referring professional/ team	Process indicator	Inpatient setting indicator	New developed		
74	There is a regular interdisciplinary/ multi-professional meeting to discuss palliative care patients: daily meetings to discuss day-to-day management of palliative care patients	Process indicator	All settings	Combined/ Changed	44	
75	There is a regular interdisciplinary/ multi-professional meeting to discuss palliative care patients: weekly (inter- and multidisciplinary) meeting to review palliative care patients referrals and care plans	Process indicator	All settings	Combined/ Changed	18,44,49,50	
E. Information sharing						
76	All relevant team members are informed about patients who have died	Process indicator	Inpatient setting indicator	Changed		41
Documentation of clinical data						
A: Clinical record (All settings)						
77	For patients receiving palliative care a structured palliative care clinical record is used	Process indicator	All settings	Changed	7	
78	The palliative care clinical record contains evidence of documentation of the following items: Clinical summary	Process indicator	All settings	Changed	5	1
79	The palliative care clinical record contains evidence of documentation of the following items: Physical aspects of care	Process indicator	All settings	Changed	6	1
80	The palliative care clinical record contains evidence of documentation of the following items: Psychological and psychiatric aspects of care	Process indicator	All settings	Changed	5,12,39,53-55	1
81	The palliative care clinical record contains evidence of documentation of the following items: Social aspects of care	Process indicator	All settings	Changed	5,12,22,56,57	1
82	The palliative care clinical record contains evidence of documentation of the following items: Spiritual, religious, existential aspects of care	Process indicator	All settings	Changed	5,19,22	1
83	The palliative care clinical record contains evidence of documentation of the following items: Cultural aspects of care	Process indicator	All settings	Changed	5	1
84	The palliative care clinical record contains evidence of documentation of the following items: Care of imminently dying patient	Process indicator	All settings	Changed	5	1
85	The palliative care clinical record contains evidence of documentation of the following items: Ethical, legal aspects of care	Process indicator	All settings	Changed	5,12,19,58	1
86	The palliative care clinical record contains evidence of documentation of the following items: Multidimensional treatment plan	Process indicator	All settings	Changed	5,18,59,60	1
87	The palliative care clinical record contains evidence of documentation of the following items: Follow up assessment	Process indicator	All settings	Changed	5,16,61	1
B. Timley documentation						
Inpatient setting (Hospital, Palliative care unit, Hospice, Nursing home)						
88	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	Process indicator	Inpatient setting indicator	Changed	12,18,46,62	
89	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	Process indicator	Inpatient setting indicator	Changed	18	

No	QI	Type	Application	Status	Database / Hand search	Grey literature
90	There is documentation about the discussion of patient preferences within 48 hours of admission	Process indicator	Inpatient setting indicator	Changed	³⁶	
91	A discharge/ transfer summary is available in the medical record within 48 hours after discharge/ transfer	Process indicator	Inpatient setting indicator	Changed	³⁶	
All settings						
92	There is documentation of pain assessment at 4 hour intervals	Process indicator	All settings	Changed	^{12,19,50,63}	
93	The discussion of patient's preferences is reviewed on a regular basis (in parallel with disease progression) or on request of the patient	Process indicator	All settings	Changed	⁶⁴	
94	There is documentation that within 24 hours after patient transfer, the responsible physician in the receiving setting has visited the patient	Process indicator	All settings	Changed	¹³	
95	There is documentation that within 24 hours after patient transfer, the new palliative care team in the receiving setting has visited the patient	Process indicator	All settings	Changed	³	
Quality and safety issues						
A: Quality policies						
96	The palliative care service has a quality improvement program	Process indicator	All settings	Changed	^{3,17,66}	
97	There is documentation whether targets set for quality improvement have been met	Process indicator	All settings	Changed	³	
98	Clinical audit are part of the quality improvement program	Process indicator	All settings	Changed	⁴	⁴⁸
99	The setting uses a program about early initiation of palliative care (e.g. the Gold Standards Framework)	Process indicator	All settings	Changed		¹
B. Adverse events						
100	There is a register for adverse events	Process indicator	All settings	Changed	⁵	⁴⁸
101	There is a documented procedure to analyse and follow up adverse events	Process indicator	All settings	Changed		⁴⁸
C: Complaint procedure						
102	There is a patient complaints procedure	Process indicator	All settings	Changed		⁴¹
Reporting clinical activity of palliative care services						
103	The palliative care service uses a database for recording clinical activity	Process indicator	All settings	Changed	⁶⁸	⁶⁹
104	The following is part of the database: Diagnosis, Date of diagnosis, Date of referral, Date of admission to the palliative care service, Date of death, Place of death, Preferred place of death	Process indicator	All settings	Changed	^{2,42,49-51,70-72}	¹
105	From the database the service is able to derive: Time from diagnosis to referral to palliative care, Time from referral to initiation of palliative care, Time from initiation of palliative care to death, Frequency of unplanned consultations with the out-of-hours service for palliative care patients who are at home, Frequency of unplanned hospital admissions of palliative care patients, Percentage of non-oncological patients receiving palliative care	Process indicator	All settings	New developed	⁷³	
106	Based on the database, an annual report is made about the service	Process indicator	All settings	Changed	¹⁷	¹
Research						
107	There is evidence that the palliative care service is involved in research in palliative care (e.g. authorship of publications, research grants)	Process indicator	All settings	Changed	⁷⁷	
Education						
108	All health and social care students have standardised learning objectives for basic training in palliative care	Process indicator	All settings	Changed	^{14,42,78,79}	¹
109	All health and social care professionals have standardised learning objectives for continuing basic training in palliative care	Process indicator	All settings	New developed	^{14,78,79}	³⁸
110	There is a program for specialised training in palliative care for professionals working in a service that provides specialised palliative care	Process indicator	All settings	New developed		³⁸

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