Reflecting the Positive diversities of European priorities for research & measurement in end-of-life care

PRISMA
Symposium 2011

Research, practice, science & innovation in end-of-life care

Held under the Patronage of Her Royal Highness Princess Mathilde of Belgium, and under the Auspices of the European Association for Palliative Care, EAPC Onlus
European populations are ageing with increasing numbers of people living longer. Chronic conditions are leading causes of mortality across the world, and by 2020 their contribution is expected to rise to 73% of all deaths and 60% of the global burden of disease. PRISMA was designed to harmonise end-of-life care research and best practice across Europe through targeting measurement, involving positive cultural diversity, and being influenced by European citizens’ priorities and preferences. PRISMA is delivering timely and high-quality scientific evidence to inform end-of-life policy at national and European levels, including Africa. The PRISMA Symposium 2011 offers a forum for policy makers, research funders and experts from the fields of palliative and end-of-life care to share the findings and outputs from PRISMA and to drive forward better care for European and African citizens at the end of life.

PRISMA was a major three-year coordinating action project funded by the European Union under the Seventh Framework Programme (FP7). The PRISMA consortium comprises nine European and African countries, and eleven partner organisations that specialise in end-of-life care. Since its inception in 2008, PRISMA has delivered an integrated programme coordinating research priorities and practice regarding end-of-life care across Europe and Africa through sharing examples of good practice; coordinating research; delivering research outputs; and identifying key priorities for end-of-life care. The core activity of PRISMA is to generate new knowledge to ensure that policy, funding and care activities are influenced by the clinical and public priorities of Europe. PRISMA has established bodies of knowledge and networks of experts to serve those who are responsible for directing end-of-life care.

We are delighted to welcome you to the PRISMA Symposium 2011, held under the patronage of Her Royal Highness Princess Mathilde of Belgium, and under the auspices of the European Association for Palliative Care, EAPC Onlus. The symposium aims to shape end-of-life care policy across Europe and enable foresight to inform coordinated action regarding the direction and funding of end-of-life research. It also aims to address the health objectives of European citizens through understanding priorities of European service users and providers; improving measurement; establishing European research collaborations that involve world-leading individuals and centres focussed on end-of-life care.

www.prismafp7.eu
Programme

09.00-10.25
FORUM ONE

What is the end-of-life care experience in Europe? Priorities, barriers & opportunities for end-of-life care research in Europe

Chair & welcome:
Professor Irene J Higginson
PRISMA Scientific Director

09.00-09.25
Opening address:
Meeting the challenge of end-of-life care in Europe: Research, practice, science & innovation
Dr Maria-José Vidal-Ragout
Acting Head of Unit, Medical Research Unit, Directorate of Health, Directorate General Research and Innovation, European Commission

09.25-09.45
Europe in action: End-of-life care in the midst of an ageing population
Mr Tom Hudson
President, European Cancer Patient Coalition

09.45-10.05
The European model: Recommendations & strategies for end-of-life care
Dr Agis Tsouros
Head, Centre for Urban Health, WHO EURO Region Office

10.05-10.15
An overview of PRISMA reflecting public priorities & harmonising research & practice across Europe
Dr Richard Harding
PRISMA Principal Investigator, King’s College London, Cicely Saunders Institute

10.15-10.25
Opening of representatives’ stands & launch of measurement resources
Professor Irene J Higginson
PRISMA Scientific Director, King’s College London, Cicely Saunders Institute

List of stands
- European Cancer Patient Coalition
- European Palliative Care Research Centre at the Norwegian University of Science and Technology, Trondheim (NTNU) & the European Palliative Care Research Collaborative (EPCRC)
- EMGO+ Institute for Health and Care Research, Center of Expertise in Palliative Care (CEPC) and EURO IMPACT
- OPCARE9
- PRISMA
- The Palliative care Outcome Scale (POS)
- The Cicely Saunders Institute & King’s College London, a WHO Collaborating Centre for Palliative Care and Older People

10.25-10.45
Refreshments
10.45-13.00

**FORUM TWO**

**Best science for better end-of-life policy, research & care for European citizens: Measurement & palliative care research, culture & priorities**

**Chair:**
Professor Sheila Payne
Incoming Chair of the European Association For Palliative Care

10.45-12.15

**PRISMA results: Research priorities, culture & measurement**

**Presentations & discussion**

- Dr Marjolein Gysels
  PRISMA lead on culture, Spain
- Barbara Gomes
  PRISMA lead on public priorities & preferences, UK
- Professor Stein Kaasa
  PRISMA lead on clinical research priorities, Norway
- Dr Claudia Bausewein
  PRISMA lead on measurement tools, Germany
- Professor Pedro Lopes Ferreira
  PRISMA lead on measurement resources, Portugal
- Professor Luc Deliens
  PRISMA lead on measurement in long-term care facilities, The Netherlands

12.15-13.00

**Roundtable discussion**

The Honourable Senator Sharon Carstairs P.C.
The Senate of Canada (Manitoba)

Professor David Currow
Discipline of Palliative & Supportive Services, Flinders University, Chief Cancer Officer & CEO, Cancer Institute NSW, Australia

Dr Richard Harding
PRISMA Principal Investigator, King’s College London, Cicely Saunders Institute

Professor Irene J Higginson
PRISMA Scientific Director, King’s College London, Cicely Saunders Institute

Mr Tom Hudson
President, European Cancer Patient Coalition

Dr Kathleen Foley
Attending Neurologist in the Pain & Palliative Care Service, Memorial Sloan-Kettering Cancer Center, WHO Expert Consultant

Professor Dr Bart Van den Eynden
General Practitioner, Consultant Palliative Care, University of Antwerp

Dr Maria-José Vidal-Ragout
Acting Head of Unit, Medical Research Unit, Directorate of Health, Directorate General Research and Innovation, European Commission

13.00-14.00

**Lunch**

14.00-17.00

**FORUM THREE**

**Foreseeing & responding to a public health priority: Determining future directions & priorities for end-of-life research in Europe**

**Chair:**
Dr Richard Harding
PRISMA Principal Investigator, King’s College London

14.00-14.30

**North America: Canada’s model of integrated research, legislation, clinical care & policy**

The Honourable Senator Sharon Carstairs P.C.
The Senate of Canada (Manitoba)

14.30-15.00

**Palliative care in Australasia: Maximising learning from the Australian model**

Professor David Currow
Discipline of Palliative & Supportive Services, Flinders University, Chief Cancer Officer & CEO, Cancer Institute NSW, Australia

15.00-15.30

**Discussion: Reflections on national & European policy & research**

Discussion involving all delegates

15.30-16.00

**Closing remarks: Maximising opportunities within Europe**

Professor Irene J Higginson
PRISMA Scientific Director, King’s College London

16.00-17.00

**Reception**
PRISMA was a major European commission funded project focused on end-of-life care to help Europe respond to the need for quality end-of-life care through coordinating practice and research efforts. PRISMA comprised eight work packages or work streams (WPs):

- **WP1: Culture** (Lead: Dr Marjolein Gysels)
- **WP2: Public priorities and preferences** (Lead: Barbara Gomes)
- **WP3: Clinical research priorities** (Lead: Professor Stein Kaasa)
- **WP4: Measurement tools, specifically the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS)** (Lead: Dr Claudia Bausewein)
- **WP5: Symptom measurement and the Palliative care Outcome Scale Symptom Card (POS-S)** (Lead: Professor Pedro Lopes Ferreira)
- **WP6: Long-term care facilities and measurement** (Lead: Professor Luc Deliens)
- **WP7: Management, integration and dissemination** (Lead: Dr Richard Harding)
- **WP8: PRISMA Symposium 2011** (Leads: Dr Barbara Daveson and Dr Noel Derycke).

PRISMA was funded as a collaborative action project, which meant that the project aimed to bring together clinicians, researchers, academics, policy makers, service-users and others to improve end-of-life care in Europe. To support this aim, a number of related, high-quality research projects were conducted by PRISMA.

Since its inception in 2008, PRISMA drew together participants from over 36 countries across Europe, and including an African partner. PRISMA’s lead partner (King’s College London, a WHO collaborating centre for palliative care and older people) was also involved in palliative care capacity-building events hosted by the WHO European regional office, involving discussions with representatives from Albania, Slovakia, Slovenia, Latvia, Montenegro and Turkey. Service-user consultation formed part of PRISMA and links were established with the European Cancer Patient Coalition.

PRISMA’s African partner allowed for comparisons outside of Europe, and work with national initiatives from Australia aided PRISMA’s innovations in outcome measurement. PRISMA’s European Union-level events have helped bridge the gap between practice, policy and research, culminating in the launching of our findings and resources at the PRISMA symposium 2011.

**Contract number:** Health-F2-2008-201655
PRISMA’s findings

PRISMA has produced a set of original and substantive findings to improve outcome measurement in palliative and end-of-life care across Europe for all European citizens. PRISMA’s findings relate to six key areas: culture, public priorities and preferences, clinical research priorities, measurement tools especially in relation to the POS and STAS, symptom measurement and the POS-S, and long-term care facilities and measurement.

Culture (WP1)
In order to develop collaboration on culture and end-of-life care across different countries in Europe, this work package explored and mapped cultural differences in definitions and priorities for end-of-life care in and across eight European countries (the UK, Germany, Norway, Belgium, the Netherlands, Spain, Italy and Portugal). The evidence on culture and end-of-life care was also examined through a literature review for eight European countries. Efforts for future directions in achieving culturally appropriate quality standards for end-of-life care were coordinated. An expert network of the most prominent experts on culture and end-of-life care was constructed to progress this work. This network was realised through international expert workshops and meetings. In addition, an accompanying survey was conducted to clarify definitions of end-of-life care; end-of-life care in policy and practice; country-specific priorities; and culturally specific approaches to end-of-life.

In total, 168 responses to PRISMA’s survey were received, demonstrating great interest in the field. However, there was scope for expertise in work on cultural issues in end-of-life care to be developed further. In addition, there was little consensus regarding terminology and definitions about end-of-life practice across the countries, reflecting a diversity of ideas and experiences within end-of-life care.

An international workshop, held as a two-day event (Vic, Catalonia) drew together 30 experts who identified the following priorities for cross-cultural research: (1) clarifying ideas of culture and cultural competence; (2) defining end-of-life in a context of social and cultural diversity, experiences of receiving and giving end-of-life care, and care practices in different settings; and (3) developing appropriate methods and outcome measurement that address diversity. Presentations by international experts and a debate regarding the current issues in culture and end-of-life care with an audience of 250 national and international delegates took place on day two of the workshop.

The literature review involved a review of 868 sources. Country reports for the eight countries were produced based on the evidence on culture and end-of-life care. In summary, in the UK context, ‘culture’, or ‘cultural diversity’ has come to be interpreted in terms of minority ethnic groups, while in the rest of Europe, interest in cultural issues was rather directed towards each countries’ ‘own’ cultural traditions and practices. These new findings establish a strong and robust platform for future research in the area of culture and end-of-life care.

Public priorities and preferences (WP2)
This work package examined existing evidence on public preferences and priorities for end of life cancer care; designed, commissioned and disseminated a cross-national opinion poll of public preferences and priorities for end of life care in seven European countries; and promoted cross-national reflection amongst palliative and end-of-life care researchers to ensure end-of-life cancer care research and measurement addressed diversities as well as commonalities in public views across Europe. In addition, a street survey in Nairobi (Kenya) was conducted with 201 people to determine African preferences and priorities for end-of-life care. New knowledge regarding priorities and preferences of European and African citizens for end-of-life cancer care has resulted.

PRISMA’s survey was administered over the telephone to 9,344 people (66% women) aged 16 or over (mean age 51) in seven European countries: Germany, England, the Netherlands, Belgium (Flanders), Portugal, Spain and Italy. The survey allowed for an investigation of people’s experiences of illness, death and dying and facilitating conditions (such as age, gender and religion) and how these affected preferences and priorities. During the survey, preferences and priorities of members of the general public were elicited as if they were confronted with a serious disease, such as cancer for example, and had less than one year to live.

An overwhelming majority thought that improving the quality of life for the time they had left would be more important than extending life, although many identified both these goals as equally important.

Opinions varied across countries as to whether keeping a positive attitude (Spain, Italy, the Netherlands and Germany), having pain and discomfort relieved (England, Portugal and again Spain) or making sure relatives and friends were not distressed (Belgium) were the most important priorities. People for whom keeping a positive attitude was the top priority were more likely to want to die at home. Having practical matters resolved was not seen as the most important priority in any of the countries.

A comprehensive and detailed set
of these findings will be published, along with findings from Africa. Information regarding the publications will be available via www.PRISMAfp7.eu.

Regional reports within each of the countries will also be available via PRISMA’s website. Local reports for commissioners and the public will be provided to help plan and improve future care.

This is the first survey to demonstrate key commonalities but also cross-national variation in European citizens’ preferences and priorities for end-of-life care. This is a seminal contribution to advancing palliative and end-of-life care in Europe and Africa.

Clinical research priorities (WP3)
The clinical research priorities work package studied and compared how research involving end-of-life cancer care has been conducted across Europe, identifying and developing a research agenda based upon clinical priorities for end-of-life care. This was achieved through a survey and an international workshop. The survey findings allowed for mapping and a description of how research in end-of-life care in Europe has been conducted, and the identification of priorities and barriers. During the international workshop an exploration of the results and issues revealed by the survey was completed, in order to (1) identify clinical priorities for end-of-life cancer care research within Europe, and to propose a future research agenda, (2) identify barriers to end-of-life care research, along with possibilities and solutions to overcome barriers and improve the research.

Invitations for participation in the survey were distributed to 36 European countries; 127 responses were received. Eighty-five percent of the scientific team leaders were physicians. The most frequently reported active research areas were pain, assessment and measurement tools, and last days of life and quality of death. The following areas were ranked as the most important research priorities: last days of life and quality of death, pain, fatigue (tiredness) and cachexia (general physical wasting and malnutrition), and assessment and measurement tools. The most important research barriers were lack of funding, lack of time, and insufficient knowledge and expertise. Most research groups in end-of-life care were small. In contrast, the few large groups identified (14%) had almost half of the reported publications, and more than half of the current PhD students.

Thirty participants (representing 25 European countries) selected from those who responded to the survey attended the international workshop; most were physicians. Consensus was reached on the following priorities for research in end-of-life cancer care in Europe: distressing symptoms; issues related to care of the dying; and policy and organization of palliative care services. The experts emphasized that how research is carried out is important. A need for common tools for assessment and measurement of symptoms and outcomes was also highlighted, along with a need for a common classification system to be able to compare results across studies. Symptom research should focus on pain, fatigue, cachexia, delirium (confusion) and breathlessness. Lack of consensus on common definitions, outcomes, and methodology was identified as a substantial research barrier. Other barriers were related to capacity and funding, environment and culture, and knowledge transfer and dissemination. It was agreed that these areas were interrelated and should not be addressed in isolation.

Measurement tools, especially the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) (WP4)
The objectives of the measurement work package were to: identify and describe the ways in which measurement tools have been used in end-of-life care in European countries; coordinate exchange of experiences in those who have used the identified tools in end-of-life care; and develop resources and support for those who use POS and STAS in end-of-life cancer care. This was achieved through a web-based survey sent to approximately 2,000 European citizens after being reviewed by experts and piloted in seven European countries. An international workshop to build consensus regarding the future use and development of outcome measurement in Europe and Africa was also conducted.

The first page of PRISMA’s online survey (which gave more specific information about the survey) received 1,592 unique site visitors (1,291 in Europe and 301 in Africa). The overall participation rate was 42% (663/1,592), and the overall completion rate 59% (392/663). The majority of respondents were female (63.4%), and the mean age was 46 years (SD 9). Of those respondents from Europe, 68.1% had experiences with outcome measures in palliative care. This was 73.3% for African respondents.

Non-users reported time constraints, burden, lack of training and guidance as main reasons for not using outcome measures. In clinical care / audit, assessment of patients’ situation, monitoring changes and evaluation of services were the main reasons to use outcome measurement. Choice of outcome measurement for research was influenced by validity of the instrument in palliative care and comparability with international literature. POS was one of the most frequently used tools in both Europe and Africa. Overall findings indicated that professionals need more support for the use and implementation of outcome measures in clinical practice and research through training and guidance.

Outcome measurement in palliative care and the work package’s survey findings were then discussed in an international workshop (Berlin, Germany). Thirty-two professionals from 15 countries across Europe, Africa and North America and eight different professional backgrounds were involved in the workshop. Barriers for the use of outcome measures were identified, including patients’ frail health status, the lack of time in clinical care and the lack of staff training as well as clinicians’ reluctance to use outcome measures in palliative care. The translation of existing measures into different languages, patients’ cultural diversity, and the role of nurses in tool development were identified as priority areas. An international taskforce on outcome measurement has been established as a result of this work to sustain PRISMA’s achievements.

Symptom measurement and the Palliative care Outcome Scale Booklet and Symptom Card (POS-S) (WPS)
A major output of work package five was the POS-S (Palliative care Outcome Scale-Symptom) booklet and symptom card for health professionals and researchers. The benefit obtained by the use of POS-S, an instrument designed to measure the symptoms experienced
by cancer patients at the end of their lives, was achieved through sharing and pooling experiences regarding implementation of POS-S in Portugal. The value of POS-S as an outcome measure in end-of-life care research was also determined. The practicality and impact of POS-S in a cancer setting with a view to shape best practice was addressed, and researchers examined ways of working together with POS-S, especially as POS was already in use in Europe and Africa.

The original version of POS-S was translated and culturally adapted into Portuguese. This process was followed by a cognitive debriefing with 10 patients and a feasibility study with another set of 30 patients receiving palliative care. Extensive contacts were established with the main palliative care Portuguese institutions (public and private) in order to create a national network of POS users.

The new version of the POS-S booklet and symptom card were then presented and refined at an international workshop for symptom measurement (Porto, Portugal). Forty clinicians, researchers and academics (from Germany, the UK, Portugal and Australia) participated in this workshop, and four topics were addressed: (1) the experience of validation and application of the POS-S in hospital-based palliative care units in Portugal; (2) the value of POS-S as an outcome measure in end-of-life care research; (3) the usefulness, practicality and impact of POS-S in cancer clinical practice, in terms of shaping best practice; and (4) exploration of future collaborations between researchers using POS-S. The workshop participants discussed, debated and suggested modifications to the POS-S booklet and symptom card. Based on these conclusions and feedback from wide consultation, a second version of the booklet and card was developed and published. This final POS-S booklet and symptom card were produced initially in English and have been translated into several other languages, including Dutch, Italian, German and Spanish. See http://www.csi.kcl.ac.uk/pos-s.html for the English version and http://www4.fe.uc.pt/booklet/pt/ for the Portuguese version. A database of POS-S users from across Europe was established as a result of this work.

Long-term care facilities and measurement (WP6)

The long-term care facilities and measurement work package explored what constituted quality care for those with cancer at the end of life in long-term care facilities (including in nursing homes), and built capacity by developing a collaboration that focused on end-of-life cancer care in long-term care facilities across Europe. Experiences in measuring quality in end-of-life nursing home care using POS and other tools were examined, and the aim of collating an inventory of tools was explored. Best practice in measuring quality for residents with and without capacity was investigated along with the performance of POS, STAS and other tools.

Several methods were used to build an expert research network to identify good practice in measuring palliative care in long-term care facilities and to develop a future research agenda. First, knowledgeable European researchers and eligible datasets on palliative care from patients residing in long-term care facilities across Europe were identified, primarily by searching the literature and through a web-based survey. PRISMA identified two different (but overlapping) groups of researchers for two different purposes: one group of researchers who had data available on outcome measures relevant for end-of-life care in long-term care facilities in Europe were identified, and another group of (prominent) researchers who were working on end-of-life care in long-term care facilities to develop a research agenda and to build a sustainable collaboration. A workshop was organised for the first group of researchers in order to share experiences in measurement and to explore possibilities for comparative secondary data analyses. A second workshop was organised for the other group of researchers to develop a long-lasting collaboration and future research agenda.

PRISMA found little research in Europe on patient outcome data collected from palliative care patients residing in long-term care facilities. However, a great number of researchers from different European countries have been identified as people working on and interested in palliative care research in long-term care settings. The European studies on palliative care outcomes collected by use of measurement instruments with residents of long-term care facilities greatly differed with regard to study design, study population and outcome variables. Consequently, it was not possible to perform comparative secondary data analyses with patient outcome data from different European countries, or to identify best practice in measurement within long-term care settings. These findings highlighted the importance of developing a future research agenda and to facilitate the development of a research network.

A number of priority topics for future research have been established based on the viewpoint of researchers from PRISMA’s network, including: adequate research methods and well-developed and tested measurement instrument(s) (such as POS); advance care planning; communication; and organisational aspects of palliative care in long-term care facilities.

Integration and triangulation of PRISMA’s international, multidisciplinary and interprofessional data offers important new evidence from which to develop and enhance the policy environment and to improve the end-of-life care for European and African citizens.
End-of-life care measurement in Europe

For patients and families in health care, extensive assessments are often made to help diagnose problems, to determine needs and monitor response to treatments. In cancer treatments, this often involves extensive computer technology, scanning, monitoring bloods, monitoring tumour markers, x-rays or other scans and monitoring blood results. However, these types of tests miss the important effects of the illness on the person and their family, the symptoms, the psychological, social and spiritual needs, and how these are responding to care and treatment. To provide truly holistic care, these assessments are needed.

The Palliative care Outcome Scale (POS) is a well-established measure developed over 10 years ago to assess and monitor outcomes for patients with advanced illness. It was initially validated in a wide range of hospital and community settings, including hospital inpatient services, inpatient and community hospices, community hospitals and homecare. It has been used by specialist palliative care services and by general services including renal medicine, general practice, respiratory medicine and other settings. It has been tested in different translated formats and in different cultures, and is now available in numerous European languages as well as for many other parts of the world.

A specific programme focused on the development of a culturally suitable version of POS for Africa that is also available: the APCA African POS. Most importantly for palliative care, POS is extremely brief. Testing with patients found that they could complete POS in around 5 minutes, which is very important for patients who are quite ill or disabled. There are also validated forms of POS for completion by family members (caregivers), and by health professionals.

As a result of PRISMA, POS has been improved and refined. PRISMA’s collaborative efforts have resulted in POS being seen now as providing a small core measure but with additional bolt-on assessments for different circumstances, or settings, or health care conditions. Some POS items, which in the past may have resulted in missing data, have been reviewed and refined to form a comprehensive set of stronger items. A new format with a POS-S and POS-S booklet, which is handy to carry in the pocket, is available.

The PRISMA online survey regarding views and experiences of outcome measurement in palliative and end-of-life care (WP4) informed us that clinicians and researchers don’t need or want new tools. They need guidance and training in existing tools. PRISMA’s outcome measurement guidance booklet contains guidance in how to use POS and other measures, what to look for when assessing minimally clinical important differences, and how to collect and interpret POS data. Importantly, as PRISMA identified that a lack of access to tools was an obstacle primarily for nurses working in palliative care, PRISMA’s guidance plus the POS-S booklet and symptom card (which also includes guidance) have been made freely available to all.

POS, we have learned, can be used in a number of ways, just the way a chest x-ray or CT scan can serve a number of purposes. An initial POS score can serve to screen for problems, including pain and other symptoms, such as breathlessness, depression, psychosocial needs including anxiety, information needs, practical and quality of health care needs, and the needs of the family (just the way a scan or blood test can screen for cancer). POS can also be used to monitor progress in response to treatment and has been demonstrated in work across Europe and Africa to be useful in assessing the impact of care, in evaluating care, in measuring outcomes, and in identifying continuing unmet needs that require further treatment. POS is useful in training new staff as it highlights the important areas of palliative care that need to be addressed, and in identifying those patients in most need of palliative care, as it identifies the complexity of symptoms and problems.

PRISMA’s survey and PRISMA’s collaborations have helped improve POS and POS training materials. Consensus regarding areas for future innovations for this robust and sensitive tool has been agreed through PRISMA. POS is a preferred outcome measure for palliative and end-of-life care clinicians and researchers within Europe and Africa.

PRISMA & service users

Service user involvement was one of PRISMA’s key performance indicators. This assisted with maximising feasibility, acceptability and relevance of PRISMA’s proposed future work in end-of-life cancer care. Each work package led a patient and family user involvement session, and in each participating PRISMA country, the findings and recommendations were discussed with patients and families. Discussions with the European Cancer Patient Coalition were conducted regarding the outcomes to ensure PRISMA’s relevance to service users. PRISMA anticipates that service user collaboration will form an integral part of future work.
New PRISMA resources

PRISMA has produced a number of freely available and high-quality resources, based on expert opinion and science, including a PRISMA website to aid dissemination, a cultural blog regarding end-of-life care, an outcome measurement guidance booklet for clinicians and early stage researchers, and a POS-S booklet and symptom card.

The PRISMA website (www.PRISMAfp7.eu), launched in June 2008, has assisted communication across the PRISMA consortium and with external stakeholders. Presentations from PRISMA’s events, PRISMA news, and links to information websites (for example, the Europa website) are available on this website. The framework for the PRISMA website grew throughout the duration of the project, and interactivity expanded to enable service-user input. All PRISMA partner organisations are linked to PRISMA’s website, and PRISMA has featured on associated websites [e.g., the European Association for Palliative Care and the official website of the European Association for Palliative Care and the national charity Help the Hospices].

A culture and end-of-life care blog site, launched in 2009 (http://cultureeol.wordpress.com) provides a user-friendly space for the exploration of cultural issues in end-of-life care in Europe. The blog involved five threads of discussion separated into five different pages: (1) front page, (2) about, (3) join the debate-forum, (4) resources, and (5) experience. The link to the blog was circulated to those who responded to PRISMA’s culture questionnaire respondents, and has also been used by others external to this group.

PRISMA’s new guidance for professionals in the use of outcome measures in palliative and end-of-life care provides a general introduction on outcome measurement and the need for measurement in palliative care. Information on the characteristics that make a good measure and how to choose a measure for clinical care or research is included. As implementation of outcome measures was identified as problematic in palliative care, change management guidance and information on organisational culture was also produced to enable successful implementation of outcome measurement in palliative and end-of-life care contexts. Information about useful resources in journal articles, books and websites have been included. This guidance booklet has been recognised by the European Association for Palliative Care and the national charity Help the Hospices. In the UK, Help the Hospices has supported the printing and distribution of this resource to all UK hospices, ensuring this guidance is used by clinicians with patients and their families. This dissemination activity has provided a good example of dissemination on a national level, and will be used as a dissemination model in other countries. PRISMA’s outcome measurement booklet will be used as a platform to develop training resources such as courses, workshops or online teaching material for the use of outcome measures in end-of-life care.

The POS / POS-S booklet and symptom card produced by PRISMA contains an explanation about the POS-S explaining its use and properties and an easy-to-use card for healthcare professionals with the POS one side and the POS-S on the other. The POS / POS-S booklet and symptom card produced by PRISMA has been very well-received by healthcare professionals across Europe.

To date, this resource has been translated into: English, Portuguese, German, Italian, Dutch and Spanish. Translation into other languages is being explored. This development is another example of how PRISMA has produced high-quality resources to aid outcome measurement in end-of-life care across Europe.

Sustainable collaboration

In addition to the PRISMA consortium (43 members from across Europe and Africa), five sustainable collaborations have been established to further coordinate research across Europe and Africa.

PRISMA’s network of prominent experts regarding culture and end-of-life care was constructed through international expert workshops and meetings to progress work in this field. In addition to the European Association for Palliative Care, an international taskforce regarding outcome measurement has been established for professionals who work with patients with advanced diseases at the end of their lives. Collaborations between those who contributed to the identification of clinical research priorities have been sustained. Similarly, the long-term care facilities contributors have, in combination with the European Association for Palliative Care taskforce, continued to collaborate and develop protocols for future research. This collaboration has optimised efforts for future research regarding end-of-life cancer care in long-term care facilities through establishing a network of researchers in long-term care facilities in Europe, based on systematic and rigorous identification of experts. Databases of POS and POS-S collaborators have been consolidated.
## Current research priorities

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<th>Work Package 1</th>
<th>Culture</th>
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<td>How are the concepts of culture and cultural competence to be understood to enable the delivery of end-of-life care which is culturally appropriate?</td>
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<td>What are the concepts central to or pervading end-of-life care in diverse cultural contexts?</td>
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<td>What are the experiences of receiving and giving end-of-life care in diverse cultural contexts?</td>
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<td>Which domains should be covered by a best standard core set of outcome measures and which outcome measures should be used in combination for assessment in clinical care and clinical decision making?</td>
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<td>Outcome measures that have been identified above should be refined with regard to cultural diversity, translations into other languages and other populations.</td>
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<tr>
<th>Work Package 2</th>
<th>Public preferences and priorities</th>
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<tr>
<td>Development/evaluation of new European models of care to support people’s preferences to die at home, but models that are responsive to variations and specific context within each country.</td>
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<tr>
<td>Development/evaluation of public education interventions on pain and care options at the end of life.</td>
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<tr>
<td>Who dies in care homes and how? A mixed methods study using ethnographic methods should be conducted.</td>
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<tr>
<td>Effective treatments for breathlessness must be developed.</td>
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<tr>
<td>Mental health promoting interventions for patients at the end of life.</td>
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<tr>
<td>Which interventions meet preferences for African populations?</td>
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<thead>
<tr>
<th>Work Package 3</th>
<th>Clinical research priorities</th>
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<tbody>
<tr>
<td>How can end-of-life care research groupings be optimised in skills and resources?</td>
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<tr>
<td>What are the optimum tools and methods for collaborative research? Can consensus be achieved?</td>
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<tr>
<td>What are clinical priorities for populations at different stages of disease progression?</td>
<td></td>
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<tr>
<td>How can prevalence data on patients’ problems be robustly translated into intervention studies?</td>
<td></td>
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<tr>
<td>What are the non-medical clinical research priorities, and how do these compare with the medical priorities?</td>
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<table>
<thead>
<tr>
<th>Work Package 4</th>
<th>Measurement tools, especially the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the most effective way to train professionals in outcome measurement in palliative care and what resources would be most useful?</td>
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<tr>
<td>Which domains should be covered by a best standard core set of outcome measures and which outcome measures should be used in combination for assessment in clinical care and clinical decision making?</td>
<td></td>
</tr>
<tr>
<td>Which domains should be covered by a best standard core set of outcome measures and which outcome measures should be used in combination for assessment in research?</td>
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<tr>
<td>Outcome measures that have been identified above should be refined with regard to cultural diversity, translations into other languages and other populations.</td>
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<tr>
<th>Work Package 5</th>
<th>Symptom measurement and the Palliative care Outcome Scale Booklet and Symptom Card (POS-S)</th>
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<tbody>
<tr>
<td>What are the effects of using the POS / POS-S booklet &amp; symptom card work in daily clinical practice?</td>
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<tr>
<td>Looking at different instruments to monitor the health status/quality of life of palliative patients, what are the relative advantages and disadvantages of using one or another measure? Would a mix of measures be better than only one?</td>
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<tr>
<td>What is the minimum dataset of indicators to be measured in palliative care units?</td>
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<tr>
<td>How can electronic capture of palliative care indicators by practitioners and patients be implemented?</td>
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<th>Work Package 6</th>
<th>Long-term care facilities and measurement</th>
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<tbody>
<tr>
<td>How are advance directives defined, used and implemented in different countries?</td>
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<tr>
<td>How often and how do different countries involve patients with dementia, their proxies and different caregivers in advance care planning?</td>
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<tr>
<td>What is the content, quality and effect of communication concerning critical choices and decisions on residents, family and staff?</td>
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<tr>
<td>What kind of interventions are there to promote dignity? What kind of measurement instruments are needed to evaluate the effects of an intervention? How to involve patients in an intervention study?</td>
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<tr>
<td>What is an adequate instrument to evaluate pain/symptom(s) in unconscious patients at the end of life?</td>
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<tr>
<td>Is there an organisational model of service delivery for palliative care in long-term care settings (how comparable is this with the international standardised classification(s) of long-term care)?</td>
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</table>
Implications for policy

1 We recognise that palliative and end-of-life care for European citizens is currently suboptimal and epidemiological data clearly demonstrate the need for an increase in policy funding and research focus.

2 In order to provide effective palliative and end-of-life care for Europe’s ageing population, evidence through high-quality research is urgently required.

3 PRISMA has exemplified the need for international collaboration and leadership to drive forward appropriate demonstrably effective care at the European regional level.

4 The policy environment must enable the identification, provision and measurement of end-of-life care that reflects multiple understandings and needs of a diverse European population. Service user collaboration is essential for this.

5 Policy must facilitate care at the end of life based on evidence of public preference and priority. PRISMA findings demonstrate a preference for death at home, and good communication, management of multidimensional problems (e.g., the physical and psychological), and the valuing of quality and quantity of life.

6 In order to demonstrate the effectiveness and appropriateness of end-of-life care provision, outcomes must be measured and reported at the patient and family level.

7 The measurement of patient and family self-reported outcomes requires highest principles of scientific rigour, and tools must be selected to reflect priorities and to enhance cross-national collaboration and comparisons. PRISMA has developed guidance on choice of tools and has improved a commonly used measure in palliative and end-of-life care (i.e., POS).

8 Numerous outcome measures are currently available; already established tools should be used rather than inventing new tools. Those investigated in the project (POS and STAS) are widely used in a variety of settings and countries and they are validated. Clinicians and researchers must be supported in the selection, application, and interpretation of measures and of implementing findings to enhance care. PRISMA offers guidance on tool selection and implementation. A further policy focus on integral support to ensure integration in daily practice is required with corresponding national and regional coordination and infrastructure. Regional funding specific to the field of end-of-life care is important.

9 Routine measurement of patient and family outcomes in Europe and Africa using appropriate and well-validated tools is required (i.e., tools that reflect the multidimensional aspects of this population and that are validated within end-of-life care and sensitive to the citizens they are being used with).

10 Expertise exists in the science and measurement of end-of-life care experience and established centres of excellence should lead both the scientific development and clinical application of measurement to enhance the measurement and quality of end-of-life care for all European citizens.

PRISMA publications

PRISMA is committed to sharing the scientific findings with a wide range of audiences. A list of articles published so far, including those currently accepted for publication, is included below. PRISMA anticipates additional PRISMA publications in high-ranking journals. Information regarding new publications will be available via PRISMA’s website.

Albers G, Harding R, Pasman RW, Omwuteaka-Phillipsen BD, Hall S, Toscani F, Ribbe MW, Deliens L, on behalf of PRISMA.
What is the methodological rigour of palliative care research in long-term care facilities in Europe? A systematic review.

Daveson BA, Bechinger-English D, Bausewein C, Simon ST, Harding R, Higginson IJ, Gomes B on behalf of PRISMA.
Constructing understandings of end-of-life care in Europe: a qualitative study involving cognitive interviewing with implications for cross-national surveys.

Sigurdardottir KR, Haugen DF, van der Rijt CC, Siggren P, Harding R, Higginson IJ, Kaasa S; PRISMA.
Clinical priorities, barriers and solutions in end-of-life care research across Europe. Report from a workshop.

Harding R, Higginson IJ; PRISMA.
PRISMA: a pan-European coordinating action to advance the science in end-of-life cancer care.

Kaasa S, Higginson IJ.
Palliative care in cancer: how to improve clinical research.

Sigurdardottir KR, Haugen DF, Bausewein C, Higginson IJ, Harding R, Rosland JH, Kaasa S, on behalf of project PRISMA.
A pan-European survey of research in end-of-life cancer care.
Support Care Cancer. 2010 Nov 30. [Epub ahead of print].
Biographies

Speakers, discussants & chairs

Professor Irene J Higginson
PRISMA Scientific Director, Professor of Palliative Care and Policy, King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation

Professor Irene J Higginson qualified in medicine from Nottingham University and has worked in wide-ranging medical and university positions, including radiotherapy and oncology, in-patient and home hospice care, the Department of Health (England), and various universities. Her last post was as Senior Lecturer/Consultant at the London School of Hygiene and Tropical Medicine and Director of Research and Development at Kensington & Chelsea and Westminster Health Authority. She has been at King’s College London as Professor and Head of Department since October 1996. Her research interests and publications in the following areas: quality of life and outcome measurement, evaluation of palliative care particularly of new services and interventions, epidemiology, clinical audit, effectiveness, psychosocial factors and care, symptom assessment, cachexia/anorexia, and elderly care. The Department of Palliative Care, Policy and Rehabilitation, a WHO Collaborating Centre for Palliative Care and Older People, based at the Cicely Saunders Institute, is the first purpose-built institute for research into palliative care offering palliative care courses and other resources relevant to palliative care. She has led and collaborated on numerous studies involving measurement and was the creator of the Palliative care Outcome Scale. Author of many seminal works in palliative and end-of-life care, she was awarded an OBE for her services to medicine.

Dr Maria-José Vidal-Ragout
Acting Head of Unit, Medical Research Unit, Directorate of Health, Directorate General Research and Innovation, European Commission

Dr Maria-José Vidal-Ragout is Acting Head of the Medical Research Unit from the Directorate of Health, Directorate General Research and Innovation, European Commission. The objective of health research under Framework Programme Seven is to improve the health of European citizens and boost the competitiveness of health-related industries and businesses, as well as address global health issues. With a budget of 6.1bn euros over the duration of the Framework Programme Seven, health research is a major priority for the European Union.

Mr Tom Hudson
President, European Cancer Patient Coalition

Mr Robert LT Hudson (Tom) is currently President of the European Cancer Patient Coalition (ECPC) and member of its founding group, Chairman of Europa Uomo, the European Prostate Cancer Coalition, acting Chairman of the World Wide Prostate Cancer Coalition and board member of Men Against Cancer, and the Irish Prostate Cancer Patients’ Support Group. Tom entered industry in 1950, specialising in personnel management, marketing and general management in a career that lasted 35 years, then was head-hunted and appointed CEO of the Irish Cancer Society, (1985-1997) during this period he was actively involved in the first Europe Against Cancer Programme and subsequently became President of the Association of European Cancer Leagues from 1993 to 1997. The International Union against Cancer (UICC) invited Tom to take over the Chairmanship of the COPES programme (1998-2004) and he was elected to the UICC council (1998 to 2006). Past roles include Vice President of The European Network for Smoking Prevention and a founding member and board member of ASH Ireland (10 years).

Dr Agis Tsouros
Head, Centre for Urban Health, World Health Organization, Regional Office for Europe, Copenhagen

Dr Agis Tsouros has a degree in medicine (University of Athens) and a Master’s certificate and a Ph.D. in public health (University of Nottingham). He is an accredited public health specialist and Fellow of the Faculty of Public Health (UK). He is a visiting professor in the Department of Epidemiology and Public Health at University College London (UCL). Since he joined the WHO Regional Office for Europe in 1998 he has had leadership responsibility for several areas including urban health policies and healthy cities;
healthy ageing, palliative care, public health functions and infrastructures, non-communicable diseases and risk factors, environmental health and health policies at national and sub-national levels. At the WHO Regional Office for Europe he has led the Healthy Cities Network, involving hundreds of local governments from across the Region in long-term, cutting-edge public health work. At present he heads the Policy and Cross-Cutting programmes & Regional Director’s Special Projects Unit. The Unit is responsible for the development of the new European Policy for Health – Health 2020. He heads the Centre for Urban Health and Governance.

### Dr Richard Harding
PRISMA Principal Investigator, Reader in Palliative Care, King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation

Dr Richard Harding is Reader (Associate Professor) in palliative care at the Cicely Saunders Institute at King’s College London. He has an academic background in social science and care management, and he is Principal Investigator on a large number of studies focusing on intervention development and testing, family caregiver outcomes, non-cancer including HIV and heart failure, cancer (particularly home care and information giving), and leads a large programme of global health research in sub-Saharan Africa. He has been given a number of national and international personal and competitive awards to conduct health-oriented study and research. Dr Harding sits on the Board of the International Association for Hospice Palliative Care, and holds a number of journal editorial positions. He is the Principal Investigator (coordinator) for PRISMA, and has a strong interest in international collaboration for multidimensional patient-centred outcome measurement, having worked on palliative outcome measure development and validation in Europe, Latin America, Asia and sub-Saharan Africa.

### Professor Sheila Payne
Incoming Chair of the EAPC, Director, International Observatory on End of Life Care, Lancaster University

Professor Sheila Payne is the Help the Hospices Chair in Hospice Studies and Director of the International Observatory on End of Life Care. Sheila has a health psychologist, with a background in nursing and over 20 years experience in academia. She is the Deputy Head of the Division of Health Research. Based in the International Observatory on End-of-Life Care, Sheila’s post (the first of its kind in the UK and supported since 2006 for five years by the national charity Help the Hospices) leads important new research to help improve lives of many thousands of patients and families that depend on hospice care. She also directs the NCRI funded Cancer Experiences Collaborative for 6 years from 2006, and since 2007 has been Vice President of the European Association for Palliative Care. Sheila has a long track record in palliative care research and scholarship. Her research agenda focuses on palliative care, end-of-life care and bereavement support. Sheila has supported over 20 PhD students and has been published widely in academic and professional journals. She has published 12 books and edited the “Health Psychology” book series produced by the Open University press.

### Barbara Gomes
Cicely Saunders International PhD Research Training Fellow, King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation

Barbara completed her first degree in Psychology and Health at the University of Porto and an MSc in Palliative Care at King’s College London with distinction. Having gained experience in research she worked for one year in a palliative care unit in Portugal, before relocating to London. Together with Professor Irene J Higginson, Barbara leads a long-term project supported by Cicely Saunders International aiming to understand where people die and to discover ways of empowering patients to die in the place of their choice, with quality care, dignity and with support for their families. She coordinates a population-based survey with around 600 bereaved relatives of cancer patients in London – the QUALycare study – examining variations in the quality of care, costs, preferences and outcomes for patients and families. She is also leading a pan-European survey with around 10,000 members of the general public on their preferences and

### Dr Marjolein Gysels
Associate Research Professor, Barcelona Centre for International Health Research (CRESIB)

Marjolein Gysels completed an MA at the University of Ghent in Belgium and received a PhD in anthropology at the University of Amsterdam in 1996. She has carried out research in D.R. Congo on Swahili and oral literature. She worked for the TANESA project on AIDS in Tanzania on female infertility, and for the Medical Research Council (UK) Programme on AIDS in Uganda on commercial sex work. At King’s College London, she collaborated on the Project to Improve Management of Terminal Illness (PROMOTE), and she wrote the systematic reviews for the Research Evidence Manual which has been published as part of the NICE Guidance for supportive and palliative care for those affected by cancer. Currently she is senior research fellow conducting a programme of research on breathlessness funded by The Cicely Saunders Foundation. This encompasses research projects on the experience of breathlessness in patients with different conditions, at different phases in their illness and in different settings. Marjolein leads PRISMA’s work package that is focussed on culture.
Claudia was Vice President of the German Association for Palliative Medicine and was co-editor of the German Journal of Palliative Medicine from 2000 to 2009. Claudia’s current work focuses on breathlessness, outcome measurement and palliative care in non-cancer patients as well as on research methodologies. She is leading the work on outcome measurement (WP4) in the European Commission funded PRISMA.

Professor Stein Kaasa
Professor of Palliative Medicine, Faculty of Medicine, NTNU, Director of the Cancer Department Trondheim University Hospital, Director of the European Palliative Care Research Centre, National Cancer Director Norwegian Directorate of Health

Stein Kaasa has extensive experience in leading national and international multidisciplinary collaboration. He also has extensive administrative / leader experience through the establishment of the Palliative Medicine Unit in Trondheim 13 years ago and he is still the leader of the program both clinically and scientifically. He has been the leader of the Department of Cancer Research and Molecular Medicine and President of the European Association for Palliative Care (EAPC) and is the incoming chair of the EAPC Research Network. He is also the leader of the European Palliative Care Research Collaborative (EPCRC). He is leading PRISMA’s clinical research priorities work package.

Professor Pedro Lopes Ferreira
Associate Professor of Health Economics at the Faculty of Economics of the University of Coimbra

Pedro Lopes Ferreira has been the Associate Professor of Health Economics at the Faculty of Economics of the University of Coimbra since 1986; Director of the Centre since 1997; coordinator of the Masters programme in Health Management and Health Economics since 1995; and of the Postgraduate course on Health Organisations Economics and Management since 2006. He is a founding member and current coordinator of the Portuguese Observatory on Health Systems, created in 2000.

Dr Claudia Bausewein
Senior Clinical Research Fellow & Saunders Scholar, King’s College London, Cicely Saunders Institute, Department of Palliative Care and Policy

Claudia qualified in medicine at Munich University in 1992. Her medical background is internal medicine although she has been involved in palliative care in Germany for more than 20 years. From 2001 to 2007 she worked as a Consultant in Palliative Medicine at the Interdisciplinary Centre for Palliative Medicine at Munich University. From 2004 to 2010, Claudia was Vice President of the German Association for Palliative Medicine and was co-editor of the German Journal of Palliative Medicine from 2000 to 2009. Claudia’s current work focuses on breathlessness, outcome measurement and palliative care in non-cancer patients as well as on research methodologies. She is leading the work on outcome measurement (WP4) in the European Commission funded PRISMA.

Professor Luc Deliens
Professor of Public Health & Palliative Care, Director of the End-of-Life Care Research Group of Ghent University & Vrije Universiteit Brussel, in Belgium, and member of the Palliative Care Centre of Expertise, at the VU University Medical Centre in Amsterdam, the Netherlands

Luc Deliens has received several scientific awards for his research, and published over 300 journal articles, book chapters and reports. In 2009, he became the first member of the Royal Academy of Medicine of Belgium to represent palliative care and end-of-life care in the Academy. He is currently supervising 25 PhD students and leading on-going local, national and international studies. His present research includes studies on care setting transitions, prevention of hospitalisation at the end of life, early diagnosis of palliative care needs in general practice, palliative care in nursing homes, advance care planning, end-of-life communication, palliative care quality indicators, euthanasia and other medical end-of-life decisions as well as the attitudes of the public towards palliative care and euthanasia. Internationally, he is coordinating EURO IMPACT (the European Intersectorial and Multi-disciplinary Palliative Care Research Training), a Marie Curie Initial Training Network; the EURO SENTIMELC study on end-of-life care trajectories; the international place of death study (IPod study); and the UNBIASED study on palliative sedation in the UK, the Netherlands and Belgium.

Senator Sharon Carstairs, P.C., Senator (Manitoba), Canada

The Honourable Sharon Carstairs, P.C. has been a tireless champion for hospice palliative care in Canada since 1994, as a Senator and as federal Cabinet Minister. Originally from Halifax, Nova Scotia, Senator Carstairs obtained a Bachelor of Arts in Political Science and History (Dalhousie University), and a Masters of Arts in Teaching at (Smith College, Northampton, Massachusetts). She has taught in Massachusetts, Alberta and Manitoba in the public, private and Catholic school systems. In 1986 she moved to public life, and was elected to the Legislative Assembly in Manitoba. In 1988, she led the Liberal Party in Manitoba to a monumental election gain and became the first woman to lead the Official Opposition in a Canadian Legislative Assembly. She remained a provincial Member of the Legislative Assembly until her appointment to the Senate in 1994.
From 1997 to 1999 Senator Carstairs served as the first woman to be Deputy Leader of the Government in the Senate. She served as Federal Cabinet Minister from 2001 to 2003 as Leader of the Government in the Senate and Minister with Special Responsibility for Palliative Care. Senator Carstairs has also been an advocate for women and children and a defender of human rights. She has served as a founder and President of the Prairieaction Foundation, a non-profit organisation dedicated to the elimination of family violence and violence against women. She is currently the Chair of the Human Rights Committee of the IPU. Senator Carstairs has served as a member and as Chair of various Senate Committees, including two Committees that examined the issues of hospice palliative care and she served as Chair of the Special Senate Committee on Ageing. She has released two special reports on palliative care in Canada, one in 2005 and the most recent one in June 2010 on the state of palliative care in Canada, titled Raising the Bar.

Professor David Currow

Discipline of Palliative and Supportive Services, Flinders University, Chief Cancer Officer & CEO, Cancer Institute NSW, Australia

Professor David Currow is Chief Cancer Officer and CEO of the Cancer Institute NSW (Australia). Prior to this he was the foundation Chief Executive Officer of Cancer Australia, the Australian Government’s national cancer control agency. Former roles include foundation Director of the Nepean Cancer Care Centre, Sydney and Area Director of Palliative Services Wentworth Area Health Service, Sydney. He has published widely in palliative care journals and the general medical literature. Among other projects, he is co-chief investigator on an anthology of evidence for palliative care practice and service delivery www.caresearch.com.au, and leads a national collaborative the Australian Palliative Care Clinical Studies Collaborative (PaCCSC) running phase III studies for symptom-control medications at a level that allows changes in registration and subsequent subsidy applications. Other research interests include the symptomatic management of dyspnoea, improving population based planning for people with life-limiting illnesses and improving the evidence base around which clinical decisions are made in palliative care. He continues to hold the appointment of Professor of Palliative and Supportive Services at Flinders University in Adelaide, and grants from the National Health and Medical Research Council, the National Institutes of Health (USA) and the Cancer Council Australia. He continues on the Board of the International Association of Hospice and Palliative Care and has been on the American Society of Clinical Oncology taskforce on palliative care education. He is a former president of both the Clinical Oncological Society of Australia and Palliative Care Australia, a senior associate editor of the Journal of Palliative Medicine.

Dr Kathleen M. Foley

Neurologist in the Pain & Palliative Care Service at Memorial Sloan-Kettering Cancer Center, New York City & Professor of Neurology, Neuroscience, and Clinical Pharmacology at Weill Medical College, Cornell University

Formally the Director of the WHO Collaborating Center for Cancer Pain Research and Education at Memorial Sloan-Kettering Cancer Center, Dr Kathleen M. Foley holds the Chair of the Society of Memorial Sloan-Kettering Cancer Center in Pain Research. She was elected to the Institute of Medicine of the National Academy of Sciences for her national and international efforts in the treatment of patients with cancer pain. Dr Foley is currently the Medical Director of the International Palliative Care Initiative of the Open Society Foundation working to advance palliative care globally. Dr Foley chaired three expert committees that resulted in the publication of the three WHO monographs on Cancer Pain and Palliative Care: “Cancer Pain Relief” (1996), “Cancer Pain Relief and Palliative Care” (1990), and “Cancer Pain and Palliative Care in Children” (1996).

Professor Dr Bart Van den Eynden

General Practitioner, Consultant Palliative Care, University of Antwerp

Professor Bart Van den Eynden graduated as a medical doctor (University of Antwerp), and this was later followed by a MSc Anthropology (University of Leuven), and a PhD about ‘Quality of Life in Palliative Care’. He specialised as general practitioner and as palliative care consultant. He works clinically as a general practitioner and as Medical Director of the Centre for Palliative Care in Antwerp. At the University of Antwerp as professor palliative medicine within the Department of Primary and Interdisciplinary Health Care, he is responsible for education and research concerning palliative medicine and care. He is also the coordinator for the Postgraduate Interuniversity Course in Palliative Medicine. He has published many scientific articles about palliative and chronic care. His main interests are quality of care, education, care ethics, spirituality and the development of primary palliative care. An important project, by order of the Flemish Government, is the development of a primary palliative care pathway for nearing end of life. He is member of many scientific organisations and boards concerning palliative care. One of these is the International Primary Palliative Care Research Group.
### Work packages

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<th>WP</th>
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<tr>
<td>1</td>
<td>Cultural difference in end-of-life care</td>
<td>Dr Marjolein Gysels</td>
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<tr>
<td>2</td>
<td>Public priorities &amp; preferences for end-of-life care</td>
<td>Barbara Gomes</td>
</tr>
<tr>
<td>3</td>
<td>Clinical research priorities in end-of-life care</td>
<td>Prof Stein Kaasa</td>
</tr>
<tr>
<td>4</td>
<td>Best practice &amp; resources for the use of end-of-life life care quality indicators</td>
<td>Dr Claudia Bausewein</td>
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<tr>
<td>5</td>
<td>Best practice in symptom measurement</td>
<td>Prof Pedro Lopes Ferreira</td>
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<tr>
<td>6</td>
<td>Best practice in long-term care facilities</td>
<td>Prof Luc Deliens</td>
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<tr>
<td>7</td>
<td>Management</td>
<td>Dr Richard Harding</td>
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<tr>
<td>8</td>
<td>Final conference</td>
<td>Dr Barbara Daveson &amp; Dr Noël Derycke</td>
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### Beneficiaries

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<td>Deutsche Gesellschaft fur Palliativmedizin (DGP)</td>
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<td>Hospital Santa Maria (HSM)</td>
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<td>African Palliative Care Association (APCA)</td>
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<td>Istituto di Ricerca in Medicina Palliavta (IRMP)</td>
<td>ONLUS</td>
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<td>11</td>
<td>Federatie Palliatieve Zorg Vlaanderen (FPZV)</td>
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PRISMA Symposium Committee

Dr Claudia Bausewein
Cicely Saunders International Senior Clinical Research Fellow, King’s College London, Cicely Saunders Institute

Dr Barbara Daveson
PRISMA Symposium Lead, PRISMA Project Manager and Research Fellow, King’s College London, Cicely Saunders Institute

Professor Luc Deliens
Professor of Public Health & Palliative Care EMGO Institute for Health and Care Research, VU Medisch Centrum Amsterdam

Dr Noël Derycke
PRISMA Symposium Lead, Professor of Public Health and Palliative Care, Universiteit Antwerpen

Dr Richard Harding
PRISMA Principal Investigator, Reader in Palliative Care, King’s College London, Cicely Saunders Institute

Professor Irene J Higginson
PRISMA Scientific Coordinator, Head of Department, Palliative Care, Policy and Rehabilitation, King’s College London, Cicely Saunders Institute

Professor Stein Kaasa
Professor of Palliative Medicine, Faculty of Medicine, NTNU, Director of the Cancer Department, Trondheim University Hospital; Director of the European Palliative Care Research Centre, National Cancer Director, Norwegian Directorate of Health

Professor Lukas Radbruch
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