OPCARE9
A European collaboration to optimise research for the care of cancer patients in the last days of life

March 2008 – 2011

Executive Report
OPCARE9 - A European collaboration to optimise research for the care of cancer patients in the last days of life. 2012

Marie Curie Palliative Care Institute Liverpool
Liverpool Cancer Research Centre
University of Liverpool
200 London Road
Liverpool L3 9TA
United Kingdom

Web: www.opcare9.eu
Foreword

OPCARE9 was a three year International Collaboration (2008 - 2011) of nine partner countries with the aim of optimising research for the care of cancer patients in the last days of life. Funded by a European Union 7th Framework Co-ordination and Support Action Grant OPCARE9 systematically investigated current practice across a range of healthcare environments and diverse cultures. The main focus of this work was to bring together clinicians and researchers working within the field of end of life care in a variety of countries across Europe (and beyond) to systematically collate and evaluate the existing evidence base. This included evaluating a variety of sources, incorporating research studies and expert opinion regarding clinical approaches, to develop a European consensus to underpin the delivery of quality care in the last days of life. There were seven workpackages (WP). This report overviews the work of the OPCARE9 collaboration together with its key findings. Further dissemination will be achieved through national and international conferences, and peer reviewed journals.

Over the past three years I have been privileged to work with an enthusiastic and dynamic group of committed experts who have dedicated their time and energy to focus on how we can make a real difference to care of the dying. Working across countries, cultures and languages has its challenges but also its rewards in its richness of the variety of experiences and expertise that can be shared and developed. In particular I want to acknowledge the contributions of Mrs Andrea Boeddeker, volunteer coordinator from Germany, who sadly died during the finalisation of the project.

One of the most significant outcomes of the programme is the ability of individuals from different disciplines and academic backgrounds to work cohesively and constructively together. This has led not only to the successful completion of OPCARE9 but to joint international research projects and collaborations. The OPCARE9 collaboration has enabled a significant step forward to be made in improving care of the dying in Europe and on a global basis.

John E Ellershaw MA FRCP
OPCARE9 Project Coordinator
Professor of Palliative Medicine, University of Liverpool UK
Director, Marie Curie Palliative Care Institute Liverpool, University of Liverpool, UK.
## Contents

**Introduction** - A European collaboration to optimise research for the care of cancer patients in the last days of life  
5 – 7

1. **Signs & Symptoms of Approaching Death**  
   1.1 Results  
   1.2 Conclusion  
   8 – 9

2. **End of Life Decisions**  
   2.1 Results  
   2.2 Conclusion  
   10 – 11

3. **Complementary Comfort Care**  
   3.1 Results  
   3.2 Conclusion  
   12 – 13

4. **Psychological and Psychosocial Support**  
   4.1 Results  
   4.2 Conclusion  
   14 – 15

5. **Voluntary Service**  
   5.1 Results  
   5.2 Conclusion  
   16 – 17

6. **Cross Cutting Themes in OPCARE9: Quality Indicators**  
   6.1 Results  
   6.2 Conclusion  
   18 – 19

7. **Project Management, Communication & Dissemination in OPCARE9**  
   7.1 Management & Leadership  
   7.2 Scientific Project Assistant Group  
   7.3 Workpackage leaders and teams  
   7.4 Conclusions  
   20 – 21

8. **Evaluation of Collaborative Working in OPCARE9**  
   8.1 Results  
   8.2 Conclusion  
   22 – 23

9. **The Liverpool Care Pathway for the Dying Patient (LCP) International Programme**  
   9.1 Outcomes  
   9.2 Conclusions  
   24 – 25

10. **Outcomes and Developments of OPCARE9**  
    10.1 Conclusions  
    26 – 28

11. **OPCARE9 Members**  
    29 – 30
Introduction

Changing health and demographic profiles across Europe and beyond highlight the emergence of a longer lived and increasingly aged population. Projections indicate that across Europe the mean age at the time of death will rise from 78.5 years to an estimated 84.1 years by 2050, and that the proportion of the population over the age of 60 will rise from a current 22% (161 million) to 37% (256 million).\(^1\)\(^2\)\(^3\) Old age brings with it an increased risk of chronic disease such as cancer, respiratory disease and heart failure. Cancer makes a considerable contribution to the global disease burden; it is estimated that 1.3 million Europeans will die from Cancer in 2012.\(^4\) Accordingly, these projections highlight an emerging burden of need, likely to be exacerbated by an increasing demographic imbalance, placing healthcare systems across Europe under considerable strain.

OPCARE9 was a 3 year EU FP7 Co-ordination & Support Action grant funded collaborative project to optimise the care of cancer patients in the last days of life. The project was managed within an international collaborative framework, across Europe and beyond, integrating knowledge from a range of healthcare environments and cultures (Table 1). Its structure comprised of a multi-professional interdisciplinary team to ensure maximal integration across the project and optimal success. Its partners, “beneficiaries” were:

<table>
<thead>
<tr>
<th>Organisation / Country</th>
<th>Lead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marie Curie Palliative Care Institute - University of Liverpool, UK.</td>
<td>Professor John Ellershaw</td>
</tr>
<tr>
<td>National Cancer Research Institute - Genoa, Italy.</td>
<td>Dr Massimo Costantini</td>
</tr>
<tr>
<td>Cologne University - Cologne, Germany.</td>
<td>Professor Raymond Voltz</td>
</tr>
<tr>
<td>Erasmus MC, University Medical Centre Rotterdam - The Netherlands.</td>
<td>Dr Lia van Zuylen &amp; Dr Agnes van der Heide</td>
</tr>
<tr>
<td>University Hospital for Respiratory and Allergic Diseases - Golnik, Slovenia.</td>
<td>Dr Urska Lunder</td>
</tr>
<tr>
<td>Stockholms Sjukhem Foundation – Stockholm, Sweden.</td>
<td>Professor Carl Johan Fürst</td>
</tr>
<tr>
<td>Cantonal Hospital - St Gallen, Switzerland.</td>
<td>Dr Steffen Eychmüller</td>
</tr>
<tr>
<td>Pallium Latinoamerica (NGO) - Buenos Aires, Argentina.</td>
<td>Professor Gustavo De Simone</td>
</tr>
<tr>
<td>Arohanui Hospice - Palmerston, New Zealand.</td>
<td>Dr Jean Clark &amp; Dr Simon Allan</td>
</tr>
</tbody>
</table>

Aims

The aim of OPCARE9 was to reach consensus positions, based on current practice and available research evidence, on the optimum care to be delivered in the last days of life to cancer patients and to identify gaps in the knowledge base within five primary themes.

- **Work Package 1**  Signs & Symptoms of Approaching Death
- **Work Package 2**  End of Life Decisions
- **Work Package 3**  Complementary Comfort Care
- **Work Package 4**  Psychological & Psychosocial Support
- **Work Package 5**  Voluntary Service

Deliverables for each work package were identified at the beginning of the project, leading to the development of innovative research methodologies and protocols to address identified gaps in knowledge through future international collaboration.

---

\(^1\) Carone G and Costello D. Can Europe Afford to Grow Old. Finance and Development 2006.
\[^{3}\]  United Nations, Department of Economic and Social Affairs. [http://esa.un.org/wpp/unpp/p2k0data.asp](http://esa.un.org/wpp/unpp/p2k0data.asp)
Methods

Each theme, structured as a primary work package (WP), was facilitated by a specific named beneficiary, with an identified work package lead (WPL). Work package leads were supported by a Scientific Project Assistant (SPA), who assisted in the structuring of the scientific tasks and methodological processes required. Each work package had representation from all of the nine partner countries via their work package membership (WPM).

Two established methodologies were engaged in the primary work packages:
- Systematic Review: employing explicit procedures to review both published and unpublished (grey) literature
- Delphi Method: using a panel of identified experts, the Delphi method is an iterative process used to develop consensus positions or collective judgments in relation to an explicit question(s).

To assist with the Delphi studies, each country lead facilitated the development of a National Reference Group, comprised of multi-professional and multidisciplinary experts in palliative care.

Two executive work packages, administered by the coordinating team in Liverpool (UK), were established in addition to the primary work packages. These were: to ensure that project deliverables were achieved; to capture and disseminate the experience gained from undertaking a large scale collaborative project; and to assist in the further development of the Liverpool Care Pathway for the Dying Patient\(^5\) (LCP) at an international level.

- **Work Package 6**
  - Project Management, Communication and Dissemination
- **Work Package 7a**
  - Evaluation of Collaborative Working
- **Work Package 7b**
  - Liverpool Care Pathway for the Dying Patient (LCP) International Programme

In addition to the primary and executive work packages three cross cutting themes were examined to supplement projected findings within each work package and to contribute to the development of future research methodologies (Figure 1). The Cross Cutting Themes were:

- **Needs Assessment**: An assessment of the disease demographics and service provision for cancer patients, families, volunteers and healthcare professionals.
- **Quality Indicators**: Identification of “Quality Indicators” against which to measure future care in the last days of life
- **Tools & Technologies**: Identification of “Technologies” with which to improve the delivery of care in the final days of life

![Figure 1 – Cross Cutting Themes: Core Elements for Work Package Consideration](image)

\(^5\) The LCP is a continuous quality improvement programme that translates the excellent model of hospice care for the dying into other health care settings and develops outcome measures using an integrated care pathway for the last hours or days of life. Ellershaw J & Wilkinson S (eds). Care of the dying: a pathway to excellence. 2nd rev ed. Oxford: Oxford University Press, 2011.
Procedure
OPCARE9 was structured around a series of seven 3-day international colloquiums, hosted by one of the European partners. These international meetings, occurring at six monthly intervals, enabled OPCARE9 members to both develop and drive the essential activities required to meet specific work package deliverables. These meetings enabled work package members to report back initial findings, debate and refine understanding and work towards consensus. A wide range of professions were represented at each Colloquium, from clinical areas including medicine, nursing, pharmacy and psychology, and other related areas such as epidemiology, educational science, sociology, social work, public health research, ethics, law, health service, health innovation and management.

Critical Friends
External experts in the fields associated with each Work Package were invited to participate as a “Critical Friend” in the penultimate colloquium (Table 2). Defined as a “trusted” person, external to the project, who provides a constructively critical perspective of work undertaken, the critical friends offered support and critical examination of the emergent findings.6

Table 2: Critical Friends of the OPCARE9 Project

<table>
<thead>
<tr>
<th>Critical Focus</th>
<th>Critical Friend</th>
</tr>
</thead>
<tbody>
<tr>
<td>WP1 Signs &amp; Symptoms of Approaching Death</td>
<td>Dr Paddy Stone - Macmillan Reader in Palliative Medicine, St George’s University of London, UK.</td>
</tr>
<tr>
<td>WP2 End of Life Decisions</td>
<td>Professor Luc Deliens - Professor of Public Health and Palliative Care, Head of the End-of-life Care Research Group – EMGO Institute, University of Amsterdam. Director of the End-of-Life Care Research Group, Vrije Universiteit Brussels, Belgium.</td>
</tr>
<tr>
<td>WP3 Complementary Comfort Care</td>
<td>Dr Julia Downing - Deputy Executive Director, African Palliative Care Association.</td>
</tr>
<tr>
<td>WP4 Psychological &amp; Psychosocial Support</td>
<td>Professor Gary Rodin - Head, Department of Psychosocial Oncology and Palliative Care Princess Margaret Hospital, University Health Network Professor of Psychiatry, University of Toronto, Canada.</td>
</tr>
<tr>
<td>WP5 Voluntary Service</td>
<td>Professor Allan Kellehear - Professor of Sociology, Department of Social and Policy Sciences, University of Bath, UK.</td>
</tr>
<tr>
<td>WP7b – Liverpool Care Pathway</td>
<td>Dr Kris Vanhaecht - Secretary General of the European Pathway Association.</td>
</tr>
<tr>
<td>OPCARE9</td>
<td>Professor Susan Block - Professor, Department of Psychiatry, Harvard Medical School; Professor, Department of Medicine, Harvard Medical School; Professor, Medical Oncology, Dana-Farber Cancer Institute, USA.</td>
</tr>
</tbody>
</table>

1. Signs and Symptoms of Approaching Death

Achieving best care of the dying should be recognised as a core clinical proficiency and an integral part of comprehensive cancer care, as basic as diagnosis and treatment. Current pathways, such as the Liverpool Care Pathway for the Dying Patient\(^7\) (LCP), provide a framework that can support the clinicians in the process of identifying the beginning of the dying phase. However, the supportive evidence base requires development. Such information is imperative for practice, as failure to recognise and respond to the dying phase (diagnosing dying) can lead to sub-optimal care.

Conducted in collaboration between the Centre for Palliative Care, Cantonal Hospital St. Gallen in Switzerland and the Regional Palliative Care Network at the National Cancer Research Institute, Genoa in Italy, the aim of this work package was to identify whether a consensus exists on what are the most useful signs and symptoms of approaching death.

Initial review identified that no common definition of the dying phase can be found. For the purpose of this project, a timely definition – “the last days” (up to seven days) of life have been chosen as a working definition for Delphi and Review.

After deliberation, two questions guided and informed the focus of the work package:

1. Which phenomena are considered to identify that somebody is in the last days of life?
2. Are these phenomena predictive for having only a few more days to live?

1.1 Results

Phenomena such as laboratory values (low albumin, LDH concentration), performance status (distinct daily activities, mobility), oliguria, oedema and number of metastatic sites were identified by the systematic literature review. In addition, a list of 37 tools/ instruments has been collated that have been studied and tested for:

- Predicting survival in patients with terminal cancer in combination with medical data
- Validity to predict mortality risk
- Psychosocial outcomes and survival

A total of 21 phenomena for predicting the entering of the last days of life were generated (Table 3)

<table>
<thead>
<tr>
<th>Phenomenon</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Death rattle</td>
<td>Breathing</td>
</tr>
<tr>
<td>2 Organ failure</td>
<td>General deterioration</td>
</tr>
<tr>
<td>3 Irreversible deterioration of consciousness</td>
<td>Consciousness – cognition</td>
</tr>
<tr>
<td>4 Rapid degradation of general condition</td>
<td>General deterioration</td>
</tr>
<tr>
<td>5 Comatose</td>
<td>Consciousness – cognition</td>
</tr>
<tr>
<td>6 No fluid or food intake</td>
<td>Intake of fluid, food, other</td>
</tr>
<tr>
<td>7 Changed breathing rhythm</td>
<td>Breathing</td>
</tr>
<tr>
<td>8 Changes in breathing patterns</td>
<td>Breathing</td>
</tr>
<tr>
<td>9 Intuition of professionals, gut feeling</td>
<td>Non observations, expressed opinions, other</td>
</tr>
<tr>
<td>10 Conscious level deteriorating and slowing</td>
<td>Consciousness – cognition</td>
</tr>
<tr>
<td>11 Marble-like skin</td>
<td>Skin</td>
</tr>
<tr>
<td>12 Peripheral shut-down</td>
<td>General deterioration</td>
</tr>
<tr>
<td>13 Pale around nose and mouth</td>
<td>Skin</td>
</tr>
<tr>
<td>14 Cannot drink</td>
<td>Intake of fluid, food, other</td>
</tr>
<tr>
<td>15 Cold extremity</td>
<td>Skin</td>
</tr>
<tr>
<td>16 Swallowing impossible</td>
<td>Intake of fluid, food, other</td>
</tr>
<tr>
<td>17 Irreversible status</td>
<td>Non observations, expressed opinions, other</td>
</tr>
<tr>
<td>18 Semi-comatose</td>
<td>Consciousness – cognition</td>
</tr>
<tr>
<td>19 Restlessness</td>
<td>Emotional state</td>
</tr>
<tr>
<td>20 Cyanosis</td>
<td>Skin</td>
</tr>
<tr>
<td>21 Changes in breathing</td>
<td>Breathing</td>
</tr>
</tbody>
</table>

From Delphi consolutions, dying can be diagnosed (based on expert opinion) by assessing:

- Changes in breathing: change in breathing patterns
- General deterioration
- Lowering of consciousness
- Caregivers' clinical judgment
- Lowered oral intake

As yet, no single tool or technology has been developed and tested for the specific purpose of diagnosing dying or predicting the entering of the last days of life.

1.2 Conclusion

Although health care professionals often fail to recognize the dying phase, the results of this work package suggest that some consensus exists on phenomena which may help remedy this challenge.

A three cycle Delphi process enabled the compilation of a list of signs and symptoms (phenomena) being clinically relevant to recognize and identify the last days of life. Categories such as changes in breathing, general deterioration, lowering of consciousness, caregivers' clinical judgment and lowered oral intake are considered to be most meaningful.

The results from the systematic literature review show that various signs and symptoms of approaching death have been investigated, some of which seem to be helpful in identifying imminent death. Nevertheless, there is evidence that health care professionals fail to recognize the dying phase. However, no single tool or technology has been developed and tested for the specific purpose of diagnosing dying or predicting the entering of the last days of life.

This project has accessed the best available evidence as a basis for further development and research. It is hoped that a proposed research protocol on developing a new tool to “diagnose the dying phase” will close an important gap, and feed back into current best practice in end of life care; e.g. the Liverpool Care Pathway for the Dying Patient Pathway (LCP). Furthermore, a better understanding of multiple phenomena of the last days of life may help to reduce fears and myths within the broad public. Such development is needed to avoid “medicalisation” of dying and death – a major challenge in our ageing societies.
2. End of Life Decisions

End of life care often requires difficult ethical decisions by the patients, their families and the clinical teams. Numerous challenges exist, such as the use of deep sedation to control symptoms, withholding and/or withdrawing treatment such as artificial hydration and feeding, ventilation and dialysis, and discussions and decisions around resuscitation in the event of cardiac arrest. Robust research evidence concerning the effects of withdrawing/withholding treatments is relatively scarce and at best, inconclusive. Here, as in all aspects of care at the end of life, cultural diversity (both within and between participating countries) impacts on such decisions and the opportunity to share and debate current knowledge with colleagues across Europe (and beyond) is invaluable.

Led by the Dutch team from the Erasmus MC, University Medical Centre in Rotterdam, the aim of this Work Package was to assess current practices around end of life decision making in the beneficiary countries, to establish the available evidence that can support end of life decision making, and to identify difficult issues in end of life decision making for which more evidence-based guidance might be useful.

An inventory was made, with the support of the national reference groups from the beneficiary countries, of the end of life decisions that were considered most important.

- withdrawing and/or withholding of medical treatment
- symptom management
- place of death
- information & communication
- social/relational issues

Based on the inventory, decisions regarding the use of artificial nutrition (AN), artificial hydration (AH), and sedatives were chosen to serve as templates for further study in end of life decision making.

2.1 Results

From the scientific literature, five studies reported on the effects of AH: two found positive effects (less chronic nausea, less physical dehydration signs), two found negative effects (increased incidence of ascites, increased need for intestinal drainage) and four found no effects on terminal delirium, thirst, chronic nausea and fluid overload. No study reported on the sole effect of AN. Although providing AN or AH to cancer patients who are in the last week of life is a frequent practice, the effects on comfort, symptoms and length of survival seem limited.

The Delphi study established the commonest issues related to end of life decisions, and the most frequently mentioned issues related to;

- medical aspects, such as futility of treatment and side effects
- how to address patients’ wishes
- how to address relatives’ wishes.

The second Delphi established what issues were most important in assisting with end of life decisions;

- Optimal strategies for communication with patients and relatives about needs and wishes
- Appropriate indications for using sedatives in the last days of life
- The effects of (de)hydration on patient comfort and quality of life.

Overall, this Delphi showed palliative care experts from different professions in different countries to encounter similar issues in end of life decision making. Adequate communication about these issues is universally experienced as a challenge, which might benefit from increased knowledge. This shared experience enables and emphasizes the need for more international research.

A review of the existence of, and support for, national protocols in end of life decision making was also undertaken to highlight differences and similarities (Table 4). All identified guidelines were produced through expert opinion, with only the Dutch guidelines integrating some evidence from research studies.
Table 4: Availability of National Protocols and Guidelines on End of life Decision Making

<table>
<thead>
<tr>
<th>National protocol</th>
<th>AR</th>
<th>UK</th>
<th>DE</th>
<th>IT</th>
<th>NL</th>
<th>NZ</th>
<th>SI</th>
<th>SE</th>
<th>CH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative sedation</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Artificial Nutrition &amp; Hydration</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Withholding/ withdrawing treatment</td>
<td>YesYes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

Further work highlighting the similarities and differences between the beneficiary countries with respect to patients’ legal right to refuse medical treatment, the legal status of advance directives and prohibition of euthanasia, legal regulations for assisted suicide and suicide, was also conducted; results will be published in the academic press (www.liv.ac.uk/opcare9/publications.htm).

2.2 Conclusions

A systematic appraisal of the current literature showed that the evidence on the effects of artificial nutrition and hydration in the last week of life on comfort, symptoms and length of survival is limited. This is reflected in the limited number of protocols on artificial nutrition and hydration in place amongst the OPCARE9 beneficiaries. Expert consensus identified that communication on end of life care, indications for sedatives and effects of (de)hydration are topics that can benefit from future research; the results of which will contribute to better care for dying patients and their families.

Overall, the results of WP2 in OPCARE9 serve well to prioritize future research on end of life decision making. It both accounts for and expands beyond the medical perspective, providing a platform for integrating the health care professions to optimise care for the dying within Europe and beyond.

There is a common base of interest in issues around end of life decision making and a shared perception of current gaps in knowledge despite cultural diversity within the EU and beyond. This consensus should both empower and encourage international co-operation to improve the quality of the evidence base, thus providing the means to improve care at this critical life-point.
3. **Complementary Comfort Care**

As patients enter the last days of life it is important that health care professionals adopt practices to promote patient comfort. This is in accordance with the World Health Organisation’s suggestion of focus on communication, psychological, social and spiritual care as well as measures to promote the physical comfort of patients through non-invasive, non-technological therapies; such as regular mouth care, bowel care, skin care, and appropriate pain and symptom management (both pharmacological and non-pharmacological).<sup>8</sup> Although the evidence base for clinical care is developing, it is widely acknowledged that more research is needed to investigate symptoms that occur at the end of life. Accordingly, the aim of this work package was to generate an understanding of the most prevalent symptoms, including both the severity and the degree to which they are problematic to patients.

Led by the Swedish and Slovenian teams, three areas of investigation were undertaken:
- Pharmacological interventions
  - Discussion within the Work Package indicated that the practical and/or legal availability of relevant drugs and widespread implementation of good practice was a more salient issue than a review of literature on drugs for symptom control during the last days of life.
- Non-pharmacological care-giving activities (NPCA)
  - Recognition of the limited systematic data on NPCA in the last days of life, led to a “free-listing” approach to explore the variation of practice in non-pharmacological care, to obtain guidance for future research.
- Spiritual care
  - a systematically structured literature search, supplemented with expert commentaries on the findings generated.

3.1 **Results**

Pharmacological Interventions:

The first round of the Delphi sought to identify drugs seen as essential in the last days of life, and then to identify drugs and therapies seen as difficult to withdraw. The most common first choice drug per symptom was:

- **Anxiety:** midazolam
- **Dyspnoea/breathlessness:** morphine
- **Nausea and vomiting:** metoclopramide
- **Pain:** morphine
- **Respiratory tract secretions:** hyoscine
- **Terminal restlessness and agitation:** midazolam (38%), haloperidol (38%).

Participants reported 334 drugs and therapies as difficult to withdraw, with 86% of responses concerning drugs for particular diagnoses (e.g. heart failure, Chronic Obstructive Pulmonary Disease) and therapies patients or family often perceive to be necessary (e.g. oxygen and artificial hydration/nutrition).

The second Delphi round had the primary aim of forming consensus around a maximum 5 essential drugs from the list generated in the first Delphi and to explore further difficulties of withdrawing drugs.

- There was a high degree of consensus, with physicians regarding morphine, haloperidol and midazolam as essential. There was no clear consensus about drugs for respiratory tract secretions. Based on this Delphi, an essential drug list for broad use in non-specialised palliative care settings should consist of morphine, haloperidol, midazolam and an anticholinergic drug.
- A number of types of drug were perceived as difficult to withdraw due to a lack of evidence around the potential effects. In the main, these included antiepileptics, corticosteroids, drugs for use in diabetes and antithrombotics.

---

Non-pharmacological care-giving activities (NCPA):

The free-listing exercise identified a total of 985 NCPA. An underlying feature in many NPCA is the effort to provide personalized and compassionate care through ‘maintaining connections to the individual’s everyday life’. A substantial portion of NPCA addressed bodily care and contact with patients and family members, with refraining from bodily care also described as a purposeful care-giving activity. Several forms of communication were described; information and advice was at one end of a continuum, and communicating through non-verbal presence and bodily contact at the other. Rituals surrounding death and dying included not only spiritual/religious issues, but also more subtle existential, legal and professional rituals. Analysis indicated that many NPCA were aimed at creating an aesthetic, safe and pleasing environment for the dying person and his/her family.

Spiritual/existential support:

Fourteen review articles were identified, with five excluded as irrelevant in context. Although no article focused specifically on the last days of life, major themes identified included:
- Dignity - including what is important to the person as an individual, in relationships with others, and provision of ‘dignity-conserving care.’
- Existential loneliness - including interventions addressing this.
- Integrated care - how spiritual/existential care can be provided through attending to a dying person’s body.

Tools and technologies:

Tools and Technologies (T&Ts) are means to facilitate comfort of the dying patient. Although often defined and understood as mechanical devices and standardized measurement tools, this view is too limited for relevance in comfort care of the dying. In actuality, technologies used in the last days of life for comfort were primarily “low-tech” and readily available e.g. pillows, blankets, sheets, sound, light and aromas. Therapeutic use of staff providing care also is described as one of the foremost ‘tools’ (also called ‘soft technologies’) for comfort care as death becomes imminent.

3.2 Conclusions

There is a high level of consensus about appropriate pharmacological care for common symptoms in the last days of life among physicians in specialized palliative care. However all the recommended drugs are not presently available in all countries and care settings. Further, there are specific knowledge gaps in regard to drug withdrawal in the last days of life and these point to an important area for new, basic research and applied research. The consensus on essential drugs for symptom treatment in the last days of life can provide a means of exerting pressure toward constructive change in local, regional, and national drug policies, as well as a basis for minimum standards of care.

A wide variety of refined and seamlessly integrated care-giving activities addressing fundamental and comfort needs of dying persons in the last days of life have been identified. However, the lack of a consistent common language to describe NPCAs hinders development of knowledge.

Limited research-based literature was identified which directly addressed spiritual/existential issues in the last days of life, through the search strategies used here. There is a notable lack of conceptual clarity in the existing literature on spiritual/existential care, which suggests a need for a conceptual analysis from different stakeholder perspectives.

Whilst it is now possible to ameliorate many types of symptom distress, consensus is still lacking about the knowledge-base and skill-set needed to recognize, assess and compassionately address existential and spiritual aspects of the dying experience. An area notably lacking in most literature and of particular interest for future research is the relationship between bodily care and spiritual/existential comfort. Increasing knowledge in this area has already contributed to constructive suggestions on the revisions to the Liverpool Care Pathway for the Dying Patient (LCP).
4. Psychological and Psychosocial Support

Psychological and psychosocial support (PPS) is an essential element of the “total” care philosophy, contributing to addressing the patient as a whole and enhancing the quality of life of patients, their families and caretakers. However, the opportunity for in-depth psychological and psychosocial assessments and interventions is often limited in the last days of life. Although interventions exist that may prove to be of benefit, there is however, still a lack of knowledge regarding the psychosocial needs of patients, relatives and their carers in the dying phase.

Led by the German team from the University of Cologne, the primary aim of this work package was to establish what constitutes appropriate supportive communication with patients in the final days of life and identifying appropriate methods for engagement.

The main tasks in providing psychosocial support were identified as to:
- support expressing and handling emotions, working on relationships,
- assist in reaching acceptance or reconciliation,
- assist in addressing existential issues and saying goodbye.

4.1 Results

Consensus on the definitions of “specialised psychological support” “social support” and “psychological support” was established (Table 5).

<table>
<thead>
<tr>
<th>Table 5: Descriptors for Psychological and Psychosocial Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
</tr>
<tr>
<td>Specialised Psychological support</td>
</tr>
<tr>
<td>Psychological support / care</td>
</tr>
<tr>
<td>Social support</td>
</tr>
</tbody>
</table>

Key tasks and issues for PPS were consensually agreed and conditions for delivery (Table 6).

<table>
<thead>
<tr>
<th>Table 6: Key Tasks and Conditions for Delivery of Psychological and Psychosocial Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tasks</strong></td>
</tr>
<tr>
<td>- to discover and support the personal resources</td>
</tr>
<tr>
<td>- take care of individual needs / live and die in manner of their choice</td>
</tr>
<tr>
<td>- explicitly ask for patients’ and relatives’ needs &amp; wishes.</td>
</tr>
<tr>
<td>- to generate a calm environment</td>
</tr>
<tr>
<td>- to help in the process of grief</td>
</tr>
<tr>
<td>- to bear patients’ and relatives’ emotions</td>
</tr>
<tr>
<td>- to develop a relationship with patients and relatives</td>
</tr>
<tr>
<td>- to address unfinished business</td>
</tr>
<tr>
<td>- to help making ones’ peace.</td>
</tr>
<tr>
<td><strong>Issues</strong></td>
</tr>
<tr>
<td>- to give patients and relatives room to express feelings and thoughts</td>
</tr>
<tr>
<td>- that it respects and meets the individual way of patients and relatives</td>
</tr>
<tr>
<td>- give patients the chance to experience positive emotions</td>
</tr>
<tr>
<td>- that it is needs-oriented.</td>
</tr>
<tr>
<td><strong>Health Professionals.</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
An integrated analysis of the undertaken Delphi studies and the integrated findings from the systematic review highlighted the key challenges in communication when striving to provide psychological and psychosocial support (Table 7).

| Objectives to be addressed by palliative care teams | - Hospital to ensure a supportive environment, encouraging calmness, peace, awareness and acceptance of death  
- encouraging creation of legacies, involving the dying individuals in the future plans of those they consider most important to them  
- offering framework to manifest spiritual beliefs  
- providing individualized information for relatives  
- discussing treatment decisions, possible complications, the final days, relatives’ needs after death  
- discussing preferences regarding place of death  
- exploring fears / myths, existential issues. |
| Phenomena that professionals in palliative care should be aware of | - the most sought information by relatives was that explaining the patient’s condition, course of illness, symptoms and treatment, alternatives and available resources  
- perception of staff as “gate-keepers”  
- different rating of symptoms between relatives and patient with implications for action  
- coping strategies across families can be very different. |

Interestingly, there appeared to be culturally distinct variances in the professional groups primarily responsible for those PPS. For example, in Argentina social workers were in charge of much of the PPS care, whereas in Germany psychologists were most often mentioned reflecting the composition of experts with their professional background in these countries.

4.2 Conclusion

Psychological and psychosocial support is an important issue for all persons involved in the dying phase and needs to be oriented according to the individual dying trajectory. Accordingly, all health professionals and volunteers caring for dying patients should be able to provide basic PPS, and this necessitates that training (at all levels) requires a detailed and considered approach.

The philosophy of total care, that every staff member should be able to provide basic PPS, requires a flexible understanding of multi-professional collaboration and necessarily dedicated time for team reflection (e.g. supervision). Future research requires a set of validated measurement tools for PPS to enable cross-cultural comparison. To date, there is a lack of evaluated interventions and studies are necessary to determine which approaches are suited to particular professional and clinical groupings.
5. Voluntary Service

Palliative care services have developed very differently across Europe and the world. In several countries the volunteer movement has been at the forefront of the establishment and delivery of palliative care. However, there is little available data to illustrate the number, quality and impact of volunteer services integrated into the care of cancer patients in the last days of life.

Led by a team from the Marie Curie Palliative Care Institute Liverpool – UK, and supported by the team from Pallium Latinoamerica - Argentina, the aim of this work package was to explore, share and compare the current volunteer provision beyond the organizational models that can be categorised as supporting, supplementing or supplementing services, for each beneficiary country.

There were numerous challenges to overcome in attempting to meet the Work Package objectives. For example, engaging the strict scientific methods of the wider OPCARE9 project in an attempt to study volunteerism would have excluded a large body of evidence not ordinarily available to orthodox approaches. Learning to accommodate the scientific methodologies without losing the unique sense of volunteerism led to innovative and creative approaches to data collection. For investigation purposes, volunteer expertise was conceptually examined two ways; academic assessments of volunteerism; exploration of the volunteers themselves (a first on international and multi-lingual basis) in naming their expertise.

Establishing a “baseline” of volunteering roles and activities across OPCARE9 proved challenging due to the further conceptual variations of volunteerism inherent in each country. General volunteering has a large value and is strongly engaged across the globe. For example, we found that volunteers in the UK are strongly involved in structural and fundraising, and comparatively rarely involved in direct patient care at the very end of life. This contrasts starkly with volunteer work in Germany, Italy and the Netherlands. The differences between direct and indirect voluntary patient care is one example of the need for greater clarification of the terminology and paradigms used in international contexts to chart the terrain.

The value of volunteering in palliative care appears to have a separate niche, dependant on many variables – for example;

- reimbursement: governmentally subsidized, charity based or none
- structural: direct patient care; i.e. engaging in practice to support the clinical teams vs engaging in providing care, such as fundraising, office duties, board membership, etc..
- direct patient care:
  - in the patients home
  - in a variety of institutions in different roles

Further depth is uncovered in the “grey” literature, conveying (in native languages) the current “heart and soul” of the volunteering movement. A categorized overview is available at www.opcare9.eu

5.1 Results

A systematically structured review of the scientific literature (English language) shows that the field of volunteering is too widely different and dispersed to establish a useful “core” sense of volunteering in palliative care; other than the enormous value volunteering contributes, which all accessed studies agreed upon. Several key themes emerged (Table 8).

OPCARE9 – Executive Report 16
Table 8: Emergent themes from the systematically structured literature review

<table>
<thead>
<tr>
<th>Key Themes in Volunteerism for End of Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Importance of shifts in interpretative cadres &amp; advancement of volunteerism</td>
</tr>
<tr>
<td>- Service &amp; Organisational aspects of volunteering: role and emergent quality indicators</td>
</tr>
<tr>
<td>- Provision and effects of volunteering</td>
</tr>
<tr>
<td>- Education and Qualification for volunteers</td>
</tr>
<tr>
<td>- Methodological aspects of Education and Supervision</td>
</tr>
<tr>
<td>- Emerging research (Canada, the Netherlands and the United States)</td>
</tr>
</tbody>
</table>

Where the systematically structured review covered mostly scientific literature in the English language, a "Thematic Review" was written to demonstrate the advancement of volunteerism in the non-English speaking countries and publications. The research reviewed, provides the first English translations of peer-reviewed magazines in the other seven native languages of the OPCARE9 countries. A modified Delphi process engaged the opinions of volunteers active in end of life care from the beneficiary countries. Subsequent interviews provided a unique lens into roles, values and identities within the world of volunteering of the OPCARE9 countries, summarized by volunteers themselves as being “the non-professional experts”.

Despite large numbers of volunteers engaging in the support of patients across Europe (and beyond), very few measuring instruments have been developed to assess the impact. Only three studies were identified that attempted to examine the effect and impact of volunteers. Further, only two tools for direct use in the hospice setting were found: the Volunteering Impact Assessment Toolkit and a psycho-social assessment of volunteer intervention developed by Wissert and Popelka. In the face of the contribution of volunteers, the lack of study is very surprising. For example, in Germany the support of volunteers was calculated as equaling a fiscal contribution of some €95 million per year, and in a 2006 pilot survey of independent hospices in the UK, Help the Hospices calculated the total volunteer value as equivalent to a to a £112 million contribution.

5.2 Conclusion

The Public Health oriented approach, which aims to empower the community and its citizens, shows signs of taking hold in engaging active support for patients and families at the end of life. In Germany some 80,000 volunteers (trained over the last 20 years) have developed into a strong force to support care of the dying, developing important strategies which both supplement and surpass existing community structures. Further examples are evident in the organisation of volunteers in Italy, the UK and the Netherlands, where we found a curriculum expressly focusing on care of the dying. These developments provide the platform for establishing collaborations to compare, develop and evaluate a methodology and curriculum of excellence for volunteerism in end of life care.

Strengthening an infrastructure to enable patients to die a supported dignified death should be irrespective of place of death. OPCARE9 has opened the doors to a research and development strategy to establish a core-curriculum of excellence. With the international collaboration evolving from OPCARE9 in place, further coordinated and supported development can now both be realistically anticipated and engaged.

---

6. Cross Cutting Themes in OPCARE9: Quality Indicators

The Needs Assessment and Tools & Technologies work streams from the Cross Cutting Themes have been used where appropriate, to support the findings within the primary work packages. However, the developed Quality Indicator theme was of such weight that it was pursued as an interest within its own right. Although there is a general consensus on the domains that contribute to the quality of end of life care, it is proposed that a lack of collected and consistent data on quality has been one of the most important barriers to improve end of life care. Collecting this information requires robust, commonly accepted and potentially routinely used quality indicators (QI).

Led by Prof Dr Christoph Ostgathe and the Scientific Project Assistants, the aim of this work stream was to identify and evaluate a set of QI that can be used, at international level, to measure and assess the quality of end of life care. Quality indicators are explicitly defined and measurable items referring to the outcome, process and structure of care. These describe the outcome, process and structure of care that is required for a particular patient or clinical circumstance. Quality indicators are usually described with a numerator, a denominator and a performance standard (here referred to as a ‘pure’ quality indicator) measuring the frequency with which an event occurred, but also inferring judgment about the quality of care provided: the Donabedian model. ¹⁵ Many publications on QI focus on palliative care in general, but rarely focusing specifically on the last days of life.

6.1 Results

From the literature review, 33 Quality indicators were defined as pure QI related to the end of life. The national guidelines of Switzerland, the Netherlands, Sweden and Italy were reviewed, identifying 28 quality indicators of which only one was identified as pure.

A multidisciplinary Delphi was conducted, surveying respondents to rate the level of ‘good descriptor’ and the level of the QI being ‘applicable’ for the last days of life. These results shown in Table 9 and Table 10 highlight the top 5 QI in each section.

Table 9: Top Five QI Rated as a Good Descriptor of Quality of Care at the End of Life.

<table>
<thead>
<tr>
<th>Descriptor of Quality Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structure</strong></td>
</tr>
<tr>
<td>Presence of dedicated room space for meetings on ICU between clinicians and families</td>
</tr>
<tr>
<td>More than 90% of all families served by home palliative care services should have received a home visit on the days following patients death to provide support during the mourning process</td>
</tr>
<tr>
<td>Fewer than 4% of patients who died from cancer have had more than one Emergency Room visit in the last 30 days</td>
</tr>
<tr>
<td>Fewer than 10% of patients who died from cancer received chemotherapy in the last 14 days of life</td>
</tr>
<tr>
<td>More than 65% of all patients who died from cancer are cared for by a palliative network at home or in a hospice</td>
</tr>
<tr>
<td>More than 90% of all families served by home palliative care services should have received a home visit on the day of the patients death</td>
</tr>
<tr>
<td><strong>Process</strong></td>
</tr>
<tr>
<td>Family insight is achieved in at least 75% of all patients during the last week of life</td>
</tr>
<tr>
<td>Pain control is achieved in at least 75% of all patients during the last week of life</td>
</tr>
<tr>
<td>Communication from professional to patient and family is successfully engaged in at least 75% of all patients during the final week of life</td>
</tr>
<tr>
<td>The global score for gastrointestinal symptoms does not increase over the initial score during the final week of life in at least 75% of the patients</td>
</tr>
<tr>
<td>Communication between professionals is successfully engaged in at least 75% of all patients during the last week of life</td>
</tr>
</tbody>
</table>

### Table 10: Top Five QI Rated as Being Applicable at the End of Life.

<table>
<thead>
<tr>
<th>Structure</th>
<th>Applicability at the End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Process</strong></td>
<td></td>
</tr>
<tr>
<td>Presence of dedicated room space for meetings on ICU between clinicians and families</td>
<td></td>
</tr>
<tr>
<td>More than 90% of all families served by home palliative care services should have received a home visit on the days following patients death to provide support during the mourning process</td>
<td></td>
</tr>
<tr>
<td>More than 65% of all patients who died from cancer are cared for by a palliative network at home or in a hospice</td>
<td></td>
</tr>
<tr>
<td>More than 90% of all families served by home palliative care services should have received a home visit on the day of the patients death</td>
<td></td>
</tr>
<tr>
<td>Fewer than 10% of patients who died from cancer received chemotherapy in the last 14 days of life</td>
<td></td>
</tr>
<tr>
<td>At least 95% of all patients who receive home palliative care should be enabled to stay at home until death</td>
<td></td>
</tr>
<tr>
<td>Pain control is achieved in at least 75% of all patients during the last week of life</td>
<td></td>
</tr>
<tr>
<td>The global score for pain does not increase over the initial score during the final week of life in at least 75% of the patients</td>
<td></td>
</tr>
<tr>
<td>The global score for gastrointestinal symptoms does not increase over the initial score during the final week of life in at least 75% of the patients</td>
<td></td>
</tr>
<tr>
<td>Communication from professional to patient and family is successfully engaged in 75% of all patients during the final week of life.</td>
<td></td>
</tr>
<tr>
<td>The global score for breathing difficulties does not increase over the initial score during the final week of life in at least 75% of the patients</td>
<td></td>
</tr>
</tbody>
</table>

In total 34 existing QI were assessed for their usefulness in measuring quality of care at the end of life. A high consensus on several good descriptions of QI on the level of structure, process and outcome was reached. The consensus on the applicability of the QI was rather low; especially of outcome QI. This may be related to the challenges that can accompany the dying process. However, despite all efforts in identifying relevant QI, those identified from the literature review did not clearly state whether they specifically apply to the last days of life. Additionally, the high number of ideas for additional QI in the free text entries (N=65) suggests the need for QI that specifically apply to the particular needs for the last days of life.

The additional QI generated reflect the multidisciplinary input of the experts involved. However, the generated QI do not (as expected) fit within the normal definition for inclusion as a QI; including a numerator, denominator and performance standard. It is a challenge to define good QI, which are truly applicable to the end of life. This is something to consider when developing a set of QI that are valid for end of life and applicable in different European and International contexts.

#### 6.2 Conclusions

As yet, no definitive set of QI specifically for end of life cancer care exist.\(^{16}\) Both existing and newly generated QI need to be developed, tested and implemented focussing clearly on the dying patients, their families / relatives as well as their caretakers. The OPCARE9 collaboration with the cross cutting QI task force, that has been successfully built up during the last three years, can be a major resource to develop and carry out studies on QI in end of life care, to evaluate their reliability, validity and effectiveness in quality improvement strategies and to facilitate the transfer of knowledge between settings and countries.

---

\(^{16}\) It is noted that Claessen and colleagues have recently published (in 2011) work conducted in the Netherlands on a rigorously developed set of QI for Palliative Care. However, the OPCARE9 focus is specifically on the care of cancer patients in the last days of life, rather than a broader assessment of palliative care.
7. Project Management, Communication and Dissemination in OPCARE9

The design and structure of project management and the way in which the work packages were explored was a unique undertaking, given the complex nature of such a multi-national and inter-disciplinary project environment (Figure 2). WP6 executed, managed and monitored the project according to scientific plan and budget and also continually supported the development of robust plans for continued collaboration beyond the project end. Together with the formal and independent developmental evaluation of the project (WP7a) which comprised the ‘workings’ of the collaborative group and sub groupings provided feedback throughout the project regarding performance against the stated aims. This involved a range of qualitative approaches to the collection of data ranging from observation of colloquiums, interviews with group members (individual/focus) and surveys of opinion. Many factors were explored which could potentially have facilitated or hindered progress towards the stated aims, including workload, relationships, styles of working, reaching consensus, the perceived impact of cultural differences and other issues as they arose throughout the life of the project. The approach within this work package was therefore responsive to emergent findings throughout the life of the project.

Figure 2 - Underpinning Structures and Organisation of the Collaboration

7.1 Management and Leadership

Project Steering Group (PSG) was the final decision-making body for the collaboration, with input on project management, including technical, financial, budgetary control and task scheduling matters. Regular review and monitoring was undertaken for all work package tasks, progress towards objectives, quality assurance and any arising ethical or intellectual challenges. With the support of the Project Management Team (PMT), action plans were produced and decisions communicated to the wider project membership and the EU as appropriate.

7.2 Scientific Project Assistant Group (SPAG), provided support for the Work Package Leads in the executing of the tasks required to conduct the systematic review and Delphi process. Equally, the SPAG provided a support network for the assistants working in each of the primary Work Packages, with the subsidiary aim of providing a further mechanism for project wide collaboration. On a rotational basis, one member represented the SPAG group at PSG meetings, establishing an effective bi-directional communication format.

OPCARE9 – Executive Report
7.3 Work package leaders and teams

The project was divided into work-packages, with coordination, implementation and reporting of activities in each work-package being the responsibility of those beneficiaries directly involved. One beneficiary acted as the leader of the work-package. A representative of that institution was responsible for the completion of the task concerned, with the support of the SPAG, including communication between beneficiaries involved in the task, monitoring the progress of the work package, and reporting the results to the PSG. Work package leaders assumed responsibility for the scheduling of activities for that work package and for submitting progress reports (written and oral) to the Project Management Team/Project Steering Group at the project steering group meetings.

In the early part of the project, work within each WP focused mainly on ‘scoping’ and defining terms using two methodologies - Delphi and reviews of the literature (broad scope). This initially broadened the scope of each of the WPs by enabling the inclusion of information from the literature and the views of experts from within the 9 countries. This information allowed the identification of consensus in understanding as well as highlighting diversity between different countries and cultures. On the surface these 5 areas may appear to be distinct entities, but they are necessarily interconnected in the challenge of optimising care.

**Figure 3: Work Package Integration**

Refinement of the appropriate focus of each WP was then promoted through feedback and debate involving the whole project group at the early Colloquiums. This process reinforced the need for clarity in the definition of terms and of the specific questions that each WP sought answers to from within the published and unpublished literature, and by further consultation with experts in the field.

7.4 Conclusions

The work undertaken was a true collaboration since all beneficiaries were involved in all work packages and in the 3 day colloquiums to debate and share and develop the knowledge gathered from each work package. This involvement in all elements of the work ensured that the existing cultural diversity between the beneficiaries was fully represented and that the outcomes of this work were relevant to a wide cross section of clinicians, researchers, teachers and learners, policy makers, service delivery providers and most importantly cancer patients and their relatives across Europe and beyond.
8. Evaluation of Collaborative Working in OPCARE9

Collaborative networks, such as OPCARE9, provide a promising mechanism to share information, tap into new knowledge sets and potentially lead to increased opportunities for creating new and innovative approaches that may not be possible from one organisation alone. However, the ability to coordinate the various elements of a collaborative network into a collective ‘whole’ presents key leadership challenges and is critical to success; research shows that 50-60% of collaboratives fail in the first 12 months of establishment.\(^\text{17}\)

The range of key characteristics\(^\text{18}\) required to support effective collaborative and partnership working are defined as;

- **Characteristic 1** - Recognise and accept the need for partnership/collaboration
- **Characteristic 2** - Develop clarity and realism of purpose
- **Characteristic 3** - Ensure commitment and ownership
- **Characteristic 4** - Develop and maintain trust
- **Characteristic 5** - Create clear and robust partnership/collaborative arrangements
- **Characteristic 6** - Monitor, measure and learn

The infrastructure established to support the operationalisation of the OPCARE9 project were structured to embrace the principles of collaborative working. Accordingly, it was imperative that the OPCARE9 project developed a system to examine and evaluate the quality of the collaborative working undertaken. To ensure an objective analysis, an independent consultancy agency, Organisation Development Services (ODS) was contracted to provide a two phase evaluation of the OPCARE9 project. The aim of the evaluation was to:

- assess the effectiveness of the collaborative working by exploring and analysing the attitudes and perceptions of a range of stakeholder groups; i.e. OPCARE9 members,
- provide a report that will inform future collaborative working venture.

8.1 Results

**Collaborative Leadership**: Characteristics 3 and 4 were perceived to have been achieved by the OPCARE9 collaborative. Additionally, there was some evidence that OPCARE9 has fulfilled the requirements of characteristic 6. Some of the key learning within this domain includes:

- A clear, well-articulated vision and tangible objectives are critically important to successful collaborative working
- An adaptable inclusive, democratic leadership style and approach at different levels within a collaborative is essential to ensuring the interdependent work programmes are successfully delivered
- Leadership ‘style’ requires consideration from the outset – with different styles being adopted at different stages during the lifetime of a collaborative network
- Being more directive at the outset of projects of this scale is desired, encouraging groups to take on more responsibility and accountability over time
- Understanding the nature of human relationships, group dynamics, different cultural influences and experiences takes time
- Positive interpersonal relationships are key to successful working.

**Achievement of objectives and outcomes**: Characteristics 1, 2 and 3 were perceived to have been achieved by the OPCARE9 collaborative. Additionally, there was some evidence that OPCARE9 has fulfilled all the requirements of characteristic 6. Some of the key learning within this domain includes:

- Attention needs to be paid to defining aims and objectives for each component part of the collaborative; there has been a positive shift in the degree of clarity at Work Package level during the life cycle of the OPCARE9 project

---


- Collaborative working was viewed as providing greater benefits than working alone
- OPCARE9 has unique characteristics e.g. scale, size, complexity and subject matter
- There was a high degree of collaborative working demonstrated across OPCARE9 through the sharing of progress, knowledge and resources to ensure objectives were achieved
- The importance of monitoring, measuring and learning was understood and applied successfully across the project. However, there were some areas where this was more successful than others; for example, there were some initial challenges in establishing the focus and process for Cross Cutting Themes.

**Structure and working arrangements:** Characteristics 3 and 5 were perceived to have been achieved by the OPCARE9 collaborative. Additionally, there is some evidence that OPCARE9 has fulfilled all the requirements of characteristic 6. Some of the key learning within this domain includes:

- Programme management structure and a co-ordination role is essential for delivery of results
- Working with English as the main language across an international collaborative requires consideration by all parties i.e. understanding the meaning and intent behind phrases; this is also the case for members with English as a first language
- Over reliance on virtual or electronic communication in this project were challenging. Face to face communication was perceived as more effective
- High levels of commitment and trust were demonstrated across the Collaborative. Nevertheless, there were occasions where it was expressed that the clarity and transparency in the decision making processes could be improved
- SPAG acting as a vertical and horizontal communication conduit was key to ensuring members of OPCARE9 were kept informed and could contribute effectively; this was perceived as enhancing the leadership function.

**Sustainability and legacy:** Six criteria for successful collaborative working were drawn from the literature. The findings in this section demonstrate that OPCARE9 has integrated these essential ingredients in to the existing Collaborative and has a future vision for building on the learning and success from this process to create future opportunities for creating greater quality and value in the field of palliative care

### 8.2 Conclusions

Analysis of the aggregated “Key Characteristic” data across the four domains presented, suggests that OPCARE9 was functioning successfully and effectively as an integrated collaborative (Table 11).

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recognise and accept the need for collaboration</td>
<td>Strong</td>
</tr>
<tr>
<td>2</td>
<td>Develop clarity and realism of purpose</td>
<td>Strong</td>
</tr>
<tr>
<td>3</td>
<td>Ensure commitment and ownership</td>
<td>Strong</td>
</tr>
<tr>
<td>4</td>
<td>Develop and maintain trust</td>
<td>Strong</td>
</tr>
<tr>
<td>5</td>
<td>Create clear and robust collaborative arrangements</td>
<td>Strong</td>
</tr>
<tr>
<td>6</td>
<td>Monitor, measure and learn</td>
<td>Medium</td>
</tr>
</tbody>
</table>

The final report from ODS identifies that “OPCAR9 has demonstrated significant success given its size, scale and complexity. Indeed, in organisational development terms and when contrasted with equivalent findings in the literature, OPCARE9 is viewed as ahead of ‘predictable’ development for a network of this nature.” It is clear that OPCARE9 has been successful in establishing a Collaborative that has delivered upon its original brief and provides an excellent example of a successful collaborative network with strong foundations for sustainability.

---

19 Strong = clear evidence & examples; Medium = partial evidence – areas for development; Weak = Little or no evidence
9. The Liverpool Care Pathway for the Dying Patient (LCP) International Programme

The LCP programme is a Continuous Quality Improvement Programme (CQIP) using an Integrated Care pathway (ICP) that can transform care of the dying. Integrated Care Pathways (ICP) are a clear means to determine best practice for a well defined group of patients during a well defined period. The Liverpool Care Pathway for the Dying Patient (LCP) is an example of an ICP that can determine best evidence based practice for those in the last hours or days of life. It is appropriate to suggest that, although the LCP is a generic document, it should be implemented and supported by specialist palliative care services.

Since 2000 the LCP Central Team at the Marie Curie Palliative Care Institute Liverpool, UK (MCPCIL), has been working alongside palliative care and oncology leads across 10 countries around the world regarding the development, implementation and dissemination of the LCP Programme. This has led over time to mutual learning of how best to integrate the LCP programme in other countries. OPCARE9 benefited from the learning within the international LCP context and in turn, the OPCARE9 programme has enabled the key leads in International LCP development to work together towards the development of a robust LCP International programme.

Key objectives included:
- Establish an International Reference Group for the LCP
- Incorporate recommendations of the Work Packages into the LCP framework
- Development of a robust process for international spread and dissemination of the LCP
- Share research methodologies relating to the LCP
- Development of a robust evaluation framework for the LCP
- Identify research questions related to the LCP framework and identify suitable research methodologies to address these.

9.1 Outcomes

The best quality of care in the last hours or days of life is a basic human right that transcends cultural beliefs and boundaries. The LCP serves to encompass the four key domains of care i.e. physical, psychological, social, and spiritual which are intrinsic in care of the dying. Individual patient preferences and belief systems can then be reflected and documented accordingly. The LCP can support the cultural norms that exist within an individual country.

The levels of integration and collaboration of LCP activity has been outlined within 3 levels (Table 12).

<table>
<thead>
<tr>
<th>Level 1 State / Country</th>
<th>When any organisation / institution within a state or a country is registered with LCP Central Team at MCPCIL. This activity is driven by each organisation independently and is not coordinated by a designated state or country lead.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 2 State / Country</td>
<td>When any organisation / institution across a state or a country is registered with LCP Central Team at MCPCIL and there is a recognised LCP Lead who coordinates the LCP activity across a region or a geographical location.</td>
</tr>
<tr>
<td>Level 3 State / Country</td>
<td>When any organisation / institution within a state or a country is registered with LCP Central Team at MCPCIL and has achieved national endorsement and funding within that state or country’s healthcare system, to implement, disseminate and sustain the LCP Programme across the state or country. There will be a state / country nominated lead and a recognised LCP office with a full legally binding agreement with the LCP Central Team.</td>
</tr>
</tbody>
</table>
9.2 Conclusions

International LCP meetings have attracted a multiprofessional audience since 2004 as an opportunity for shared learning, networking and the potential for service innovation. The OPCARE9 programme incorporated a work package to develop a more robust innovation and research agenda across the international LCP community and led to the inaugural LCP International Reference Group meeting held in London in December 2011. International and multidisciplinary collaboration regarding the LCP Programme has culminated in a designated international chapter in the core LCP text book:


The international programme now developing, driven by the reference group will enable the collaborative progress of emerging research methodologies related to the LCP that respond to and inform the International OPCARE Research Collaborative (IORC) agenda.
10. Outcomes and Developments of OPCARE9

OPCARE9 has addressed focused questions in the care of the dying and highlighted significant gaps in terms of research, education and clinical guidance. The gaps and unmet needs identified during the three-year OPCARE9 project have been discussed with various professionals from different countries and background. Such discussion highlighted that policy makers from all over Europe – and potentially from all over the world – must pay greater attention to this last phase of life to serve their communities well. Accordingly, the “Liverpool Declaration” (Figure 4) was created and an international policy summit was held on this topic during the project’s final conference in Liverpool, March 2011

**Figure 4: The OPCARE9 Liverpool Declaration**

1. Every person has the right to live in societies where death and dying are acknowledged as part of life. We commit ourselves to improving societal and public health approaches to meet this goal.

2. Every person has the right to die receiving optimal care with respect to their wishes. We commit ourselves to improving awareness to meet this goal.

3. Every person has the right to access adequate palliative and hospice care in all settings. We commit ourselves to implementing care of the dying in all curricula for healthcare professionals and volunteers.

4. Every person has the right to this care given by professionals and volunteers who are appropriately trained. We commit ourselves to implementing care of the dying in all curricula for healthcare professionals and volunteers.

5. Every person has the right to continuous improvement of palliative and hospice care through transfer of research results into practice. We commit ourselves to improving conditions for research for care of the dying and implementation of research results.

6. Every person has the right to equitable access to high quality end of life care across all countries. We commit ourselves to the setting of international standards and evaluating their ongoing implementation.

The results of the OPCARE9 project indicate that scope of the current knowledge base within each of the themes examined lacks depth and breadth. Accordingly, there is the need for coordinated high quality research on which to base the delivery of care in the last days of life. OPCARE9 has provided consensus positions on optimum care and developed innovative research protocols to address identified knowledge gaps and needs. The Coordination and Support Action funding scheme, has provided the basis for future local, national and international collaborative research to improve and expedite the equitable delivery of care for cancer patients and their families, in the last days of life.

The recommendations from the work packages are also incorporated into the international development of the Liverpool Care Pathway for the Dying Patient (LCP) and an International Reference Group for the global development of the LCP has been constructed. The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life, and has been recognised as promoting “best practice” in the care of the dying and is established in over 20 countries worldwide.

A parallel evaluation, to examine the challenges involved and the successes achieved in inter-professional and international collaborative working, identified that the OPCARE9 group were operating at a level far in advance of their projected development. It suggests that future collaborative projects emanating from the OPCARE9 collaborative will develop from a strong structural and organisational footing. Indeed, prior to completion of OPCARE9, two of the developed research protocols had already received major funding, one international collaborative project had begun and several international review papers had been published in high impact journals.

In order to realize the potential generated by OPCARE9, the collaborative network has restructured as the International OPCARE Research Collaborative (IORC). The IORC will seek to potentiate the development of local and national research projects examining care of the dying, and will serve as a platform to elevate suitable studies for international collaboration (Figure 5).
The IORC will also look to support the development of collaborative working that develops from the established networks both with and beyond the OPCARE9 project. In addition, the IORC will play a facilitative role in linking developments with the International LCP Reference Group and the activities of the IORC, making sure that engaged research will produce appropriate outcomes to improve practice and change policy, and reciprocally that the research agenda is driven by appropriate need.

Within the IORC, a clear focus on care of the dying has emerged. However, what has also been apparent in the assessment of the available evidence is that to fully understand and engage with care of the dying, an appreciation of the factors that shape the dying phase is crucial. Therefore, although the focus of the IORC is to develop evidence to improve practice in the dying phase, this may require engaging with the wider illness trajectory to ascertain the interplay of key determinates (Figure 6).

**Figure 6 – IORC Focus for developing the evidence base in end of life care.**
10.1 Conclusions

There is one indisputable commonality for humankind; that we will all die. Yet, as evidenced in the outputs of OPCARE9, little attention is given to the care of the dying throughout international health care systems. Public information, health care education, research and societal debate all demonstrate the lack of knowledge, skills and attitude towards this topic compared to the significance and impact of dying on each person’s life. Changing demographics and the increasing number of people requiring appropriate end of life care has highlighted “care of the dying” as a key issue for clinicians, politicians and society.

The design of the future collaborative working grounded in the learning emerging from the developments within OPCARE9 are the two major initiatives; the International OPCARE Research Collaborative (IORC) and the LCP International Reference Group. These groups commit themselves to sustain the political debate, undertake collaborative research, and make a difference to care of the dying in Europe and on a global basis.

OPCARE9 Public Website

The OPCARE9 public website can be accessed at the following address www.opcare9.eu
**OPCARE9 MEMBERS**

**Project Steering Group (PSG)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution and Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor John Ellershaw</td>
<td>Marie Curie Palliative Care Institute, UK</td>
</tr>
<tr>
<td>Dr Massimo Costantini</td>
<td>National Cancer Research Institute, Genoa, Italy</td>
</tr>
<tr>
<td>Professor Raymond Voltz</td>
<td>Cologne University, Germany</td>
</tr>
<tr>
<td>Dr Lia van Zuylen /</td>
<td>Erasmus MC, University Medical Centre, The Netherlands</td>
</tr>
<tr>
<td>Dr Agnes van der Heide</td>
<td>Rotterdam, Netherlands</td>
</tr>
<tr>
<td>Dr Urška Lunder</td>
<td>University Hospital for Respiratory &amp; Allergic Diseases, Golnik, Slovenia</td>
</tr>
<tr>
<td>Professor Carl Johan Fürst</td>
<td>Stockholms Sjukhem Foundation &amp; Karolinska Institutet, Sweden</td>
</tr>
<tr>
<td>Dr Steffen Eychmüller</td>
<td>Center for Palliative Care, Kantonsspital St Gallen, Switzerland</td>
</tr>
<tr>
<td>Professor Gustavo De Simone</td>
<td>Pallium Latinoamerica (NGO), Argentina</td>
</tr>
<tr>
<td>Dr Jean Clark</td>
<td>Arohanui Hospice, New Zealand</td>
</tr>
<tr>
<td>Dr Simon Allan</td>
<td></td>
</tr>
</tbody>
</table>

**Project Management Team (PMT)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution and Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor John Ellershaw</td>
<td>MCPCIL, University of Liverpool, UK</td>
</tr>
<tr>
<td>Dr Stephen Mason</td>
<td>MCPCIL, University of Liverpool, UK</td>
</tr>
<tr>
<td>Jane Dowson</td>
<td>MCPCIL, University of Liverpool, UK</td>
</tr>
<tr>
<td>Maureen Gambles</td>
<td>MCPCIL, University of Liverpool, UK</td>
</tr>
<tr>
<td>Sian Edwards</td>
<td>MCPCIL, University of Liverpool, UK</td>
</tr>
</tbody>
</table>

**OPCARE9 Participants**

**UK**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution and Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Ami Nwosu</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Dr Andrew Dickman</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Colin Bragg</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Deborah Murphy</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Dr Jan Ablett</td>
<td>Royal Liverpool &amp; Broadgreen University Hospitals NHS Trust</td>
</tr>
<tr>
<td>Dr Richard Latten</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Dr Ruthmarijke Smeding</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Dr Sarah Fradsham</td>
<td>MCPCIL, University of Liverpool</td>
</tr>
<tr>
<td>Simon Chapman</td>
<td>National Council for Palliative Care (NCPC)</td>
</tr>
</tbody>
</table>

**GERMANY**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution and Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrea Boeddeker</td>
<td>University Hospital of Cologne</td>
</tr>
<tr>
<td>Professor Christoph Ostgathe</td>
<td>University of Erlangen</td>
</tr>
<tr>
<td>Dr Johannes Buekki</td>
<td>University of Erlangen</td>
</tr>
<tr>
<td>Dr Maren Galushko</td>
<td>University Hospital of Cologne</td>
</tr>
<tr>
<td>Nicole Nolden</td>
<td>University Hospital of Cologne</td>
</tr>
<tr>
<td>Dr Ovidiu Popa-Velea</td>
<td>University Hospital of Cologne</td>
</tr>
<tr>
<td>Vanessa Romotzky</td>
<td>University Hospital of Cologne</td>
</tr>
</tbody>
</table>
THE NETHERLANDS
Dr Judith Rietjens
Natasja Rajmakers
Dr Siebe Swart
Erasmus MC, University Medical Center
Erasmus MC, University Medical Center
Erasmus MC, University Medical Center

ITALY
Dr Augusto Caraceni
Giorgia Gollo
Dr Guido Miccinesi
Monica Beccaro
Silvia Di Leo
Fondazione Ircss Istituto Nazionale Dei Tumori
National Cancer Research Institute, Genoa
Prevention and Research Institute – ISPO, Florence
National Cancer Research Institute, Genoa
National Cancer Research Institute, Genoa

SWEDEN
Prof Birgit Rasmussen
Dr Carina Lundh Hagelin
Prof Carol Tishelman
Dr Gunilla Lundquist
Dr Olav Lindqvist
Sylvia Sauter
Umeå University
Stockholms Sjukhem Foundation & Karolinska Institutet
Stockholms Sjukhem Foundation & Karolinska Institutet
Umeå University
Stockholms Sjukhem Foundation & Karolinska Institutet
Stockholms Sjukhem Foundation & Karolinska Institutet

SLOVENIA
Dr Anja Simonic
Branka Cerv
Dr Majda Pahor
Dr Tina Jeric
University Clinic of Respiratory & Allergic Diseases, Golnik
Oncology Institute Ljubljana
University of Ljubljana
University Clinic of Respiratory & Allergic Diseases, Golnik

SWITZERLAND
Barbara Grossenbacher
Franzisca Domeisen
Stefanie Schuler
Center for Palliative Care, Kantonsspital St Gallen
Center for Palliative Care, Kantonsspital St Gallen
Center for Palliative Care, Kantonsspital St Gallen

ARGENTINA
Margarita Jorge
Maria Laura Daud
Dr Vilma Tripodoro
Pallium Latinoamerica (NGO)
Pallium Latinoamerica (NGO)
Pallium Latinoamerica (NGO)

Critical Friends

Professor Susan Block
Dr Paddy Stone
Professor Luc Deliens
Dr Julia Downing
Professor Gary Rodin
Professor Allan Kellehear
Dr Kris Vanhaeckt
Harvard Medical School / Dana-Farber
St George’s Healthcare NHS Trust
EMGO Institute, University of Amsterdam
African Palliative Care Association
Princess Margaret Hospital / University of Toronto
University of Bath
European Pathway Association
Cancer Institute
UK
Belgium
Africa / UK
Canada
UK
Belgium