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OPCARE9

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

Grant Agreement number: Health-F2-2008- 202112

Final Report

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PROJECT REPORT

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I, as scientific representative of the coordinator (Professor John Ellershaw) of this project and in line with the obligations as stated in Article II.2.3 of the Grant Agreement declare that:

- The attached periodic report represents an accurate description of the work carried out in this project for this reporting period;
- The project (tick as appropriate):
 - has fully achieved its objectives and technical goals for the period;
has achieved most of its objectives and technical goals for the period with relatively minor deviations
 - has failed to achieve critical objectives and/or is not at all on schedule.
- The public website is up to date, if applicable.
- To my best knowledge, the financial statements which are being submitted as part of this report are in line with the actual work carried out and are consistent with the report on the resources used for the project (section 6) and if applicable with the certificate on financial statement.
- All beneficiaries, in particular non-profit public bodies, secondary and higher education establishments, research organisations and SMEs, have declared to have verified their legal status. Any changes have been reported under section 5 (Project Management) in accordance with Article II.3.f of the Grant Agreement.

Name of scientific representative of the Coordinator : Professor John Ellershaw

Date: 23 / 05 / 2011

Signature of scientific representative of the Coordinator.



Acknowledgements

The challenges in coordinating, conducting and delivering upon a large international collaborative product such as OPCARE9 are as complex as they are numerous. However, the spirit of camaraderie and co-operation, combined with sense of purpose, made participation in the project many things: inspiring, frustrating, enlightening and entertaining to say the least. Accordingly, a debt of gratitude is owed to all those that participated in the project, whether in the organisation of colloquiums, the planning of the final conference or the production of the work package objectives – the drive and enthusiasm of the OPCARE9 group is evident in both the quality of the results and their continued quest to improve the care of cancer patients in the last days and hours of life. Special thanks must also go to the key members of Project Management Team (Sian Edwards, Jane Dowson, Maureen Gambles and Stephen Mason) in both the production of the Final Report, and ensuring the project was delivered on time.

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Executive Summary

Changing health and demographic profiles across Europe and beyond highlight the emergence of a longer lived and increasingly aged population.¹ Accordingly, the pressure on health care services to meet the need of this ageing population, particularly in end of life care, is a pressing challenge for clinicians and policy makers alike.

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 day of life. The project was structured using both an inter-professional and international collaborative framework. The beneficiaries were:

- *Marie Curie Palliative Care Institute, University of Liverpool – UK; Cologne University – Germany; Erasmus MC, University Medical Centre Rotterdam – Netherlands; National Cancer Research Institute, Genoa – Italy; Stockholms Sjukhem Foundation – Sweden; University Hospital for Respiratory and Allergic Diseases, Golnik – Slovenia; Cantonal Hospital St Gallen – Switzerland; Pallium Latinoamerica (NGO) – Argentina; Arohanui Hospice – New Zealand.*

OPCARE9 sought to systematically investigate current practice and evaluate the evidence base across a range of healthcare environments and diverse cultures, using 5 key themes:

- *Signs & Symptoms of Approaching Death; End of Life Decisions; Complementary Comfort Care; Psychological & Psychosocial support; and Voluntary Service.*

Results 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 recommendations from the workpackages are also incorporated into the developing Liverpool Care Pathway for the Dying Patient (LCP) framework, 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.²

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 and suggests that future collaborative projects emanating from the OPCARE9 collaborative will develop from a strong structural and organisational footing.³

The two major initiatives in design of the future collaborative working, grounded in the learning emerging from the developments within OPCARE9, are;

- The International OPCARE Research Collaborative (IORC)
- The International Liverpool Care Pathway - Reference group (ILCPRG).

These groups commit themselves to sustain the political debate, undertake collaborative research, and make a difference to care of the dying in Europe and beyond. The ambition is to build on the local and national research projects emanating from OPCARE9, developing a European (and beyond) wide cohort study - “Dying in Europe”.

¹ Murray CJL and Lopez AD. Alternative projections of mortality and disability by causes 1990–2020. Global burden of disease study Lancet, 1997, 349:1498–1504 in W.H.O 2004

² The LCP has been recognised as promoting “best practice” in the care of the dying by the Department of Health in the UK and is established in over 20 countries worldwide.

³ Prior to completion of OPCARE9, two of the developed protocols had already received major funding, one international collaborative project had begun and several international review papers had been published in high impact journals.

1. OPCARE9: Introduction

OPCARE9 was a European collaborative project to optimise research for the care of cancer patients in the last day of life. It was a 3 year EU FP7 Co-ordination & Support Action grant. Through systematically investigating current practice across a range of healthcare environments and diverse cultures, it shares the existing knowledge base and identifies knowledge gaps to reach consensus positions on optimum care and develop innovative research protocols to address identified needs. The project does this within an international collaborative framework, across Europe and beyond, integrating knowledge from a range of healthcare environments and cultures (Table 1.1). Collaborations, such as OPCARE9, are an efficient way of organising people and resources to provide mechanisms to share information, tap new knowledge sets and increase opportunity for creating new approaches that may not be possible from working alone.

Table 1.1 OPCARE9 Beneficiaries

	Beneficiary	Country
1	Marie Curie Palliative Care Institute, University of Liverpool ⁴	UK
2	Cologne University	Germany
3	Erasmus MC, University Medical Centre Rotterdam	Netherlands
4	National Cancer Research Institute, Genoa	Italy
5	Stockholms Sjukhem Foundation	Sweden
6	University Hospital for Respiratory and Allergic Diseases, Golnik	Slovenia
7	Cantonal Hospital St Gallen	Switzerland
8	Pallium Latinoamerica (NGO)	Argentina
9	Arohanui Hospice	New Zealand

The project consolidates and further develops an established collaboration around a specific programme to improve care in the last days of life - the Liverpool Care Pathway for the Dying Patient (LCP). Accordingly, OPCARE9 provided a rich and dynamic interface for health care providers, educators and researchers within the field of palliative care and beyond.

The OPCARE9 collaborative was represented by researchers from clinical areas including medicine, nursing, pharmacy, psychology, education and other related areas such as epidemiology, sociology, social work, health research, ethics and law. This multinational and multi-professional project team worked in collaboration to integrate knowledge from a wide range of healthcare environments, addressing cultural diversity whilst also seeking to avoid the duplication of resource and effort.

This report will highlight the structure, organisation and outputs of the OPCARE9 project.⁵ The introductory chapter will outline the background to the project and detail the organisational approach taken to deliver on the identified objectives. Following this, summaries of the 5 primary Work Packages, and 2 executive Work Packages, will be presented.⁶ A final discussion will contextualise the findings from the project and consider opportunities to build on the outputs and established collaborative networks that have been generated by OPCARE9.

⁴ Project Coordinator

⁵ Brief references have been footnoted for guidance where appropriate - A full reference list is available for each workpackage in accompanying publications, or from the central project co-ordinating team at the Marie Curie Palliative Care Institute, Liverpool.

⁶ Details on the process and outcomes of each Work Package can be found in the attached appendices.

1.1 Background

The need for a coordinated approach to the structuring and development of end of life care services for cancer patients is perhaps most evident in the rapidly changing population demographics. For example, projections indicate that across Europe, median age will rise from 75.1 years to an estimated 81.2 years by 2050, and that the proportion of the population over the age of 65 will rise from a current 16.3% (119, 134) to 27.8% (189,118).⁷ These projections highlight an emerging burden of need, likely be exacerbated by an increasing demographic imbalance, placing healthcare systems across Europe under considerable strain.

Old age brings with it an increased risk of chronic disease such as cancer, respiratory disease and heart failure. Despite advances in treatment, the increasingly elderly population will require a wider range of integrated specialist interventions due to increased incidence of chronic co-morbidity in their final years, months and days.⁸ Cancer already makes a considerable contribution to the global disease burden and in 2002, 45% of all worldwide cancer deaths occurred in people aged 65 or older.⁹ The need for the development and implementation of health care policies and strategies focussed on end-of-life care for an ever increasing elderly population, including a growing number of elderly cancer patients, is starkly apparent.

There is a pressing requirement for palliative care, and care specific to the final days of life, to be enhanced and made available in all care settings before the weight of these needs become “unmanageable.” Crucially for health care planners it should be noted that “if appropriate measures are implemented in time, population ageing does not inevitably lead to significantly higher health care expenditure.”¹⁰ Accordingly, the WHO has expressed concern at the relative neglect in the stratified development of palliative care services paralleled by a concomitant “lack of awareness and knowledge of the scale of the problem. The slow pace of development is a concern for all as research indicates that cancer patients continue to experience “pain, physical suffering, helplessness, loneliness and marginalization” needlessly, due to “underassessment and under-treatment of their problems and lack of access to palliative care.”¹¹ Thus understanding the needs and challenges faced by cancer patients and their families in the last days of life has the potential to drive the improvement of care for a sizeable proportion of our population.

1.2 Objectives

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 5 primary themes.

- **Signs & Symptoms of Approaching Death**
- **End of Life Decisions**
- **Complementary Comfort Care**
- **Psychological & Psychosocial support**
- **Voluntary Service**

Subsequently, it was envisaged that the project would result in the development of innovative research methodologies and protocols to address identified gaps in knowledge through future international collaboration

⁷ Murray CJL and Lopez AD. Alternative projections of mortality and disability by causes 1990–2020. Global burden of disease study Lancet, 1997, 349:1498–1504 in W.H.O 2004

⁸ Mathers CD, Loncar D. Projections of Global Mortality and Burden of Disease from 2002 to 2030. PLoS Med 2006;3(11): e442.

⁹ Ferlay, J., Shin, H.-R., Bray, F., Forman, D., Mathers, C. and Parkin, D. M. (2010), Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. International Journal of Cancer 2010: 127; 2893–2917.

¹⁰ Smith TJ and Cassell JB. Cost and non-clinical outcomes of palliative care. Journal of Pain and Symptom Management. 2009 Jul;38(1):32-44

¹¹ World Health Organization (WHO) (2004). *Better palliative care for older people*. Washington, DC.

1.3 The Process

Conducting robust research with patients in the last days of their lives and their families is fraught with moral, ethical, methodological and practical challenges. Consequently, there is little evidence on which to base appropriate organization and service delivery. Understanding the needs of patients, informal carers, volunteers and health care professionals is vital as sub-optimal care in the last days of life can lead to poor symptom control for patients, reduced job satisfaction for staff, poor adjustment to bereavement and formal complaints from bereaved relatives.

Undertaking a review, systematically and collaboratively, with research active institutions across the EU (and beyond) has ensured a comprehensive and robust approach to the care of cancer patients in the last days of life and avoided unnecessary duplication of effort and resource.

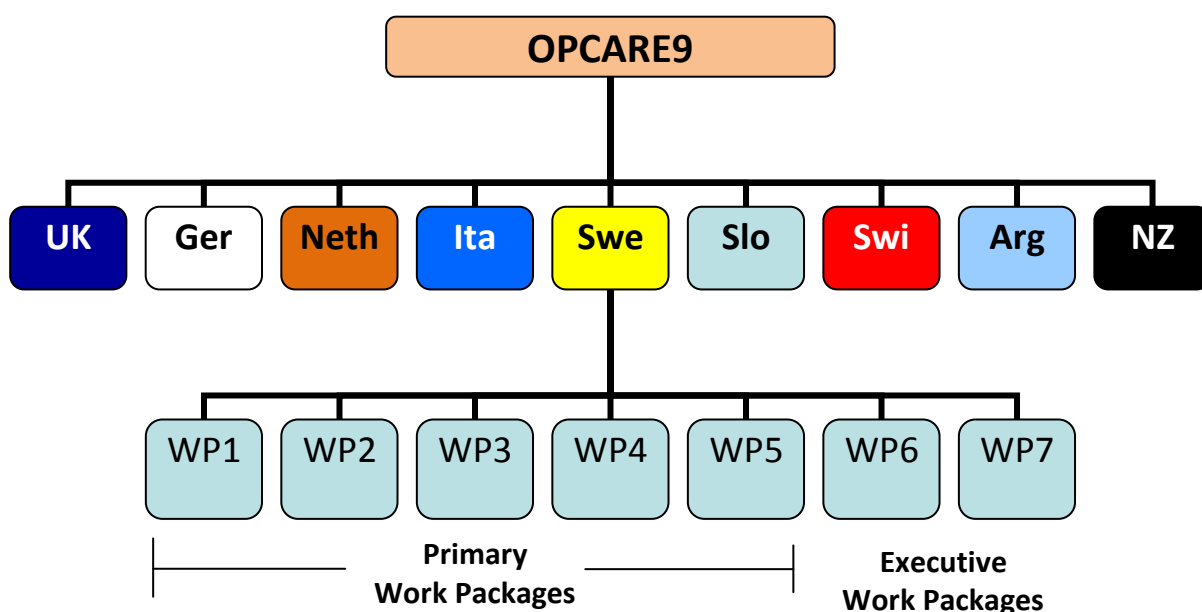
1.4 Primary Work Packages

The project explores and shares existing knowledge and practice in 5 primary Work Packages¹² commensurate with the identified themes:

- **WP1 Signs & Symptoms of Approaching Death**
- **WP2 End of Life Decisions**
- **WP3 Complementary Comfort Care**
- **WP4 Psychological & Psychosocial support to patients, families, caretakers**
- **WP5 Voluntary Service**

Each primary Work Package was facilitated by a specific host nation, with an identified Work Package lead (WL). Work Package leads were supported by a Scientific Project Assistant (SPA), who assisted in the structuring of the scientific tasks and methodological processes that required attention from the Work Package members. Each Work Package had representation from all of the nine partner countries: the Work Package members (Appendix1).

Figure 1.1 Integrative Structure of OPCARE9



¹² The international membership of the individual Work Packages is presented in Appendix 1

1.5 Methodology

Two established methodologies were used to address the project objectives in the 5 primary Work Packages:

- Systematic Review: Using both published and unpublished (grey) literature, extensive systematic reviews were conducted across all primary Work Packages to find, evaluate and synthesize the results of relevant research. This process was undertaken to identify what can reliably be said on a subject, according to the established evidence. Systematic reviews employ explicit procedures to ensure that the exercise is transparent, can be replicated and minimise selection bias. Typically these include;
 - A clearly formulated question
 - Clear inclusion/ exclusion criteria
 - A systematic and explicit search strategy to identify, select and critically appraise relevant research
 - Systematic and explicit methods to code and analyse the data of included studies
 - Meta-analysis (where possible) to summarize the results of studies
- 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). It involves structured sequence of questionnaire/group interview, feedback and review that is repeated until consensus or theoretical saturation is achieved. This technique is particularly suited to areas where research evidence is lacking in clarity or equivocal in nature. Although consensus methods do not normally require ethical approval, it was recognised that each country has its own particular governance, therefore all countries were required to obtain approval where necessary.

Each country organised a National Reference Group; a multidisciplinary and multi-professional group comprised of 'Experts' external to the current collaboration and known leaders in the field, representing all professions. The National Reference groups provided guidance on key developmental tasks within each Work Package, participated in the Delphi studies and provided access to grey literature for the systematic reviews.

1.6 Executive Work Packages

Two executive Work Packages, administered by the coordinating team in Liverpool, were established in addition to the primary Work Packages to ensure that targeted outcomes are delivered, the lessons of establishing a collaborative project are captured for wider dissemination and future learning, and to develop the potential of the Liverpool Care Pathway at an international level:

- **WP6 Management, Communication & Dissemination**
- **WP7a Evaluation**
- **WP7b Liverpool Care Pathway International**

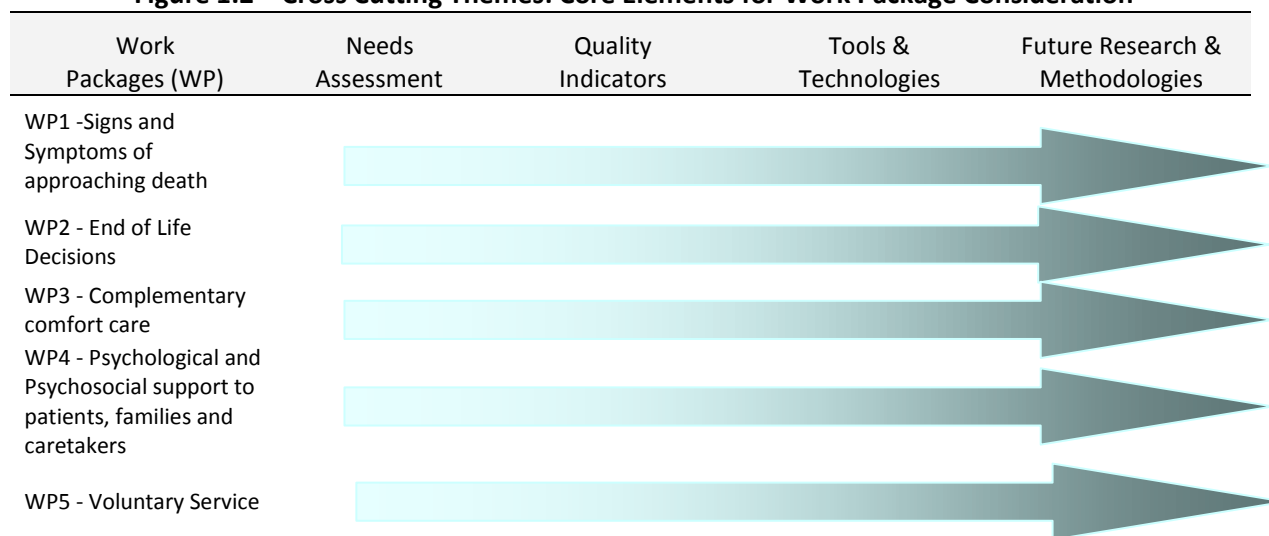
1.7 Cross Cutting Themes

In addition to the primary and executive Work Packages, three cross cutting themes were identified to supplement projected findings (Figure 1.1). These are:

- Needs: An assessment of the disease demographics and service provision for cancer patients, families, volunteers and healthcare professionals.
 - o This variation of a "needs assessment" assesses "bigger picture" illustrating the demographic forces shaping the future provision of services required to care for cancer patients in the last days of life, highlighting the pressing need throughout Europe and beyond for well organised, appropriate and universally available palliative care. This document has been used to provide a contextual background for the Work Packages in addressing their specific objectives.

- Quality Indicators: Identification of “Quality Indicators” against which to measure future care in the last days of life
 - o Quality indicators are explicitly defined and measurable items referring to the outcome, process and structure of care. The aim was to identify and evaluate a set of QI that can be used, at international level, to measure and assess quality of end-of life care.
- Tools & Technologies: Identification of “Technologies” with which to improve the delivery of care in the final days and hours of life
 - o Devices, tools (e.g. psychometric scales) or formal approaches that can be used to facilitate the delivery and/ or measurement of, end of life decision making in the last days of life. Tools and Technologies specific to each Work Package are presented within each Work Package summary.

Figure 1.2 – Cross Cutting Themes: Core Elements for Work Package Consideration



1.8 Management

The OPCARE9 project was conducted over a 3-year work programme, March 2008 - February 2011 and in order to achieve its stated objectives, both considered management principles and an appropriate organisational structure were applied. Details of the constituent members of each group are detailed in Table 1.2 and Terms of reference for PSG & SPAFG are provided in the Appendix (Appendix 2):

Table 1.2: Constituent Group Membership: OPCARE9

OPCARE9 Group	Membership
Project Steering Group	Work Package Leads, Country Leads, SPAG representative, members of the Project Management Team
Scientific Project Assistant Group	Scientific Project Assistants
Project Management Team	Project Co-ordinator, Project Managers, Financial Consultant and Project Administrative Assistant

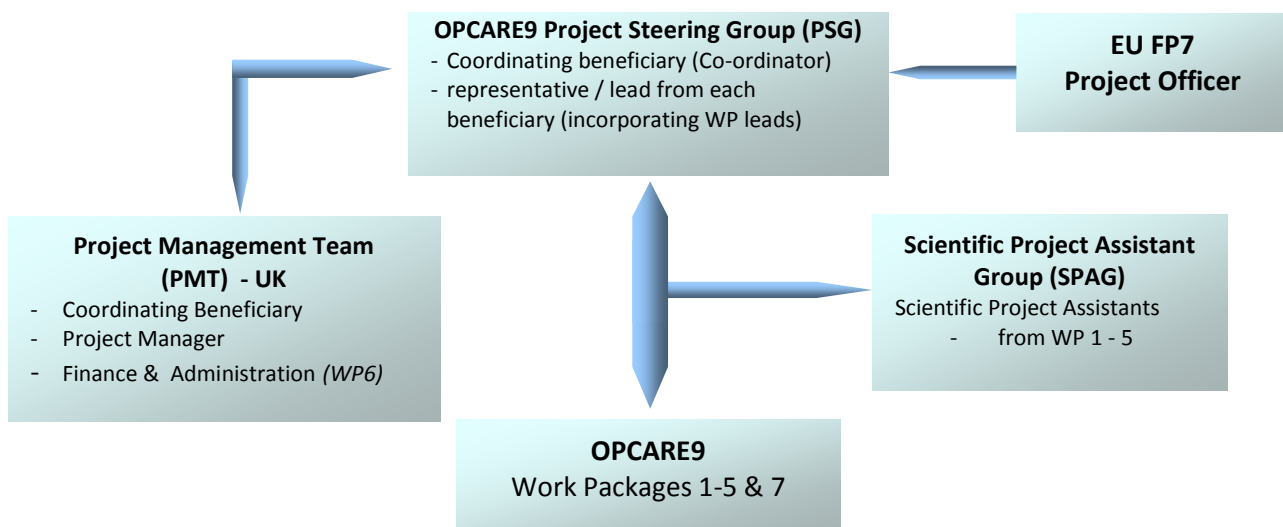
- a. The Project Steering group (PSG), has ensured that the project aims and objectives have been appropriately monitored and met. The PSG has been supported in this task by the Project Management Team (PMT) and the Scientific Project Assistant Group (SPAG). The PSG is the final decision-making body for the consortium and has had input on all matters relating to project management, including technical, personnel, financial, budgetary control and task scheduling matters. The PSG developed appropriate documentation in order to enhance the functionality and operationalisation of the project (Appendix 3). These include;

- i. Consortium Agreement
 - ii. A Colloquium Planning Document
 - iii. Guidelines for publication procedure
 - iv. Dissemination templates
 - v. Corporate Documentation
 - vi. VOCAL electronic communication platform.
- b. The 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.
- c. A Project Management Team (PMT) facilitated budgetary and operational guidance and reporting for the OPCARE9 project at an executive level.

1.9 Work Package Management

The coordination, implementation and reporting of activities in each Work Package was the responsibility of the identified Work Package Lead (or nominated deputy). The lead assumed responsibility for the liaison and communication between Work Package members, monitoring progress and reporting the results to the Project Management Team (PMT) and Project Steering Group (PSG). The lead had overall responsibility for the scheduling of activities within their Work Package and for submitting progress reports (written and oral) to the PMT ahead of the meetings of the PSG that occurred during colloquia.

Figure 1.2 OPCARE9: Organisational Structure



Guided by specific Work Package Leads, Scientific Project Assistant's (SPA's) executed the running of the project (for and via) by the Work Package members, and also assisted in facilitating within and between Work Package communications. An overview of the work undertaken throughout the life of the project is presented in the Appendix (Appendix 4).

1.10 Colloquiums and Critical Friends

The OPCARE9 project was structured around a series of seven international colloquiums, hosted by one of the European partners. These international meetings (Table 1.3), occurring at six monthly intervals, enabled OPCARE9 members to both develop and drive the essential activities required to meet specific Work Package deliverables (Appendix 5). A dissemination record emanating from the OPCARE 9 project is presented in Appendix 6

Table 1.3 – OPCARE9 Colloquiums

Month	Activity
	Colloquium 1 – March 2008, UK
1	<ul style="list-style-type: none"> • Overview of the project: proposed methodologies, systems for management (including reporting responsibilities, formats and expected timings, mechanisms for future communication) • WP7 – Systematic observation of the colloquium and interview with key stakeholders; 1st meeting of the LCP Development Group • Discuss and agree action plan and meeting schedules for interim meetings of the Work Packages
	Colloquium 2 – October 2008 Sweden
6	<ul style="list-style-type: none"> • Each Work Package presents 6 month progress report to collaboration • Collaboration to discuss/debate findings & amend/agree action plan/approach in line with findings (including findings of development evaluation of the collaboration - WP7) • WP6 to present draft Website • WP7 to undertake a systematic observation of the colloquium and interviews with key stakeholders and to feed back emergent findings from the evaluation to improve the functioning of the collaboration (e.g. factors that may enhance or inhibit optimal collaboration and realisation of the project aims) • 2nd meeting of LCP Development Group to discuss progress to date
	Colloquium 3 – March 2009 Switzerland
12	<ul style="list-style-type: none"> • Each Work Package presents 6 month progress report to collaboration • Collaboration to discuss/debate findings • WP7 to undertake a systematic observation of the colloquium, interviews and to feedback emergent findings • 3rd meeting of LCP Development Group to discuss progress to date
	Colloquium 4 – September 2009 Germany
18	<ul style="list-style-type: none"> • Each Work Package presents 6 month progress report to collaboration • (WP1 – 5 = results of systematic review and Delphi) • Collaboration to discuss/debate findings • WP7 to undertake a systematic observation of the colloquium, interviews and to feedback emergent findings • 4th meeting of LCP Development Group to discuss progress to date
	Colloquium 5 – Feb/march 2010 Italy
24	<ul style="list-style-type: none"> • Each Work Package to present 6 month progress report to collaboration • (WP1 – 5 = summary of needs assessment/technologies/QI) • Collaboration to discuss/debate findings • WP7 to undertake a systematic observation of the colloquium, interviews and to feedback emergent findings • 5th meeting of LCP Development Group to discuss progress to date
	Colloquium 6 and Workshop of Experts – September 2010 The Netherlands
30	<ul style="list-style-type: none"> • Each Work Package presents 6 month progress report to collaboration • (WP1 – 5 = outline protocols; WP6 – Website summary of evaluated technologies/QI across WPs) • Collaboration to discuss/debate findings • Workshop with Critical Friends to debate/refine Work Package findings and protocols for future research • WP7 to undertake a systematic observation of the colloquium, interviews and to feedback emergent findings • 6th meeting of LCP Development Group to discuss progress to date
	Colloquium 7 and International Conference, March 2011, UK
36	<ul style="list-style-type: none"> • Each Work Package presents Final Reports to collaboration and Collaboration to discuss/debate findings & feedback comments • WPs 1-5 and 7 present findings to the one day International Conference

Additional face to face Project Steering Group meetings were held in December 2009, July 2010 and January 2011 (Amsterdam), including meeting convened during the European Association of Palliative Care Congress in Vienna (2009) and Glasgow (2010). Individual Work Packages used available opportunities, both within and between colloquia, to hold

development meetings using face to face or tele/web conferencing platforms. A secure interactive web-platform (VOCAL), hosted by the University of Liverpool, was developed to support communication both within and across the project. This contained essential project documentation, templates and discussion papers, ensuring equitable access for all.

External experts (Table 1.4) in the fields associated with each Work Package were invited to participate as a “Critical Friend” in the penultimate colloquium to offer support and critical examination of the emergent findings (Appendix 7).¹³

Table 1.4 - Critical Friends of the OPCARE9 Project

Work Package	Critical Friend
WP1 Signs & Symptoms of approaching death	Dr Paddy Stone - Postgraduate Teaching Coordinator, Palliative Care Theme Lead Reader/Honorary Consultant in Palliative Medicine
WP2 End of Life Decisions	Professor Luc Deliens - Professor of Public Health and Palliative Care, Head of the End-of-life Care Research Group – EMGO Institute, University of Amsterdam.
WP3 Complementary Comfort Care	Dr Julia Downing - Deputy Executive Director, African Palliative Care Association.
WP4 Psychological & Psychosocial support	Professor Gary Rodin - Head, Department of Psychosocial Oncology and Palliative Care Princess Margaret Hospital, University Health Network Professor of Psychiatry, University of Toronto
WP5 Voluntary Service	Professor Allan Kellehaer - Professor of Sociology, Department of Social and Policy Sciences, University of Bath
WP7a – Liverpool Care Pathway	Dr Kris Vanhaecht - Secretary General of the European Pathway Association.
OPCARE9	Professor Susan Block - Professor, Department of Psychiatry, Harvard Medical School; Professor, Department of Medicine, Harvard Medical School; Professor, Medical Oncology, Dana-Farber Cancer Institute

In addition to the clinical and academic experts, patient representatives were invited to ensure that the widest perspective on the process and outcomes of OPCARE9 were engaged. The patient representatives were:

- Rob Bruntink - a freelance journalist who has written extensively on the challenges in palliative and end of life care
- Angela Poort – from the Client Advisory Board for University Hospitals (CRAZ), which monitors and promotes the quality aspects of care given to patients and represents the common interests of patients and carers across hospitals in the Netherlands.

¹³ A critical friend has been defined as “a trusted person who asks provocative questions, provides data to be examined through another lens, and offers critiques of a person’s work as a friend. A critical friend takes the time to fully understand the context of the work presented and the outcomes that the person or group is working toward. The friend is an advocate for the success of that work”

2. OPCARE9: Work Package 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. Patients during the dying phase should be supported properly, integrating technical expertise with a humanistic and ethical orientation. “Diagnosing dying” is regarded as a core competency during this process. Current pathways, such as the Liverpool Care Pathway for the dying patient (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.

Limited research has been conducted to determine whether a core set of signs and symptoms are routinely seen in patients as they enter the last days of their lives. Such information is imperative for practice, as failure to recognise and respond to the dying phase (diagnosing dying) can lead to sub-optimal care.¹⁴ Accordingly, there is a need to identify whether a consensus (based on current practice and available research evidence) on what are the most useful signs and symptoms of approaching death exist. This will assist in facilitating the initiation of appropriate care delivered in the final days of life. Further, where evidence is lacking, innovative research studies need to be developed to clarify the situation.

Accordingly, the following objectives of this Work Package were:

- To identify and collate a list of signs and symptoms that are associated with approaching death
- To systematically evaluate the available evidence for these signs and symptoms
- To develop protocols for future research to enhance the existing evidence base for signs and symptoms
- To identify tools and technologies currently available to screen and predict approaching death
- To systematically evaluate the evidence for each tool and/ or technology in order to provide a useful resource for clinical and/ or research use
- To develop protocols for future research to enhance the existing evidence base for prognostic indicators in care of the dying
- To review the current criteria for diagnosing dying on the LCP and make recommendations regarding modification and development of the pathway

2.1 Organization and collaboration: Work Package 1

Work Package 1 (WP1) has been 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 Work Package lead (Dr Steffen Eychmüller) and SPAG members (Franziska Domeisen, Stefanie Schuler) prepared and structured all WP activities. Tasks and responsibilities were stratified in regard of the “triplet” methodology:

- a. Team A: Delphi process
- b. Team B: Systematic literature review
- c. Team C: Review of non- scientific literature

Country representatives from each OPCARE9 country actively supported and advised the Work Package 1 team throughout the project processes.

¹⁴ Butler LD, Koopman C, Cordova MJ, Garlan RW, DiMiceli S, & Spiegel D. Psychological distress and pain significantly increase before death in metastatic breast cancer patients. *Psychosom.Med* 2003; 65; 416.

2.2 Challenges: Definition of the dying phase

Results from the project indicate that no common definition of the dying phase can be found. This is true neither for the literature nor for the expert opinion as captured by the Delphi process.

There might be two directions to work on in the future: a timely definition of the dying phase, or the definition of this phase by needs – needs by patients and carers. 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 WP:

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?

2.3 Methodology

An extensive search strategy was engaged, combining three different methods:

1. A systematic literature review (SLR)
 - i) signs and symptoms of approaching death
 - ii) tools and technologies
2. A three cycle Delphi survey asking professional experts and non-professionals accessed by the OPCARE9 collaboration
3. A systematic search strategy to screen available information from non-scientific literature (public library, internet fora, google)

2.4 Results - 1. Systematic literature review

From an initial 5602 hits in step 1, the systematic process employed resulted in 12 articles being included for final analysis. In addition, two separate lists of tools/ instruments and technology were generated, one for assessing signs and symptoms of approaching death and another to accurately predict dying.

2.5 Results – 2i. Delphi

As a result of the Delphi process three different lists of phenomena or more specifically of “signs and symptoms of approaching death” were generated:

- A broad list of phenomena, observations or perceptions which seem to be important to identify that somebody is dying (n=194)
- A reduced list of important phenomena and “signs and symptoms” respectively highlighting the recognition of the last days of life (n=59)
- A final list of ranked phenomena and “signs and symptoms” respectively relevant to predict that someone will die within the next few hours/days (n=21) (See table 2.1).

In terms of categories, 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

Table 2.1 : Ranked phenomena for predicting the entering of the last days of life

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

2.6 Comparison of outcomes systematic literature review and Delphi

Compared to the list resulting from the Delphi survey, phenomena such as laboratory values (low albumin, LDH concentration), performance status (distinct daily activities, mobility), oliguria, oedema and number of metastatic sites were only identified by the systematic literature review. Pain and fever are phenomena identified by exclusively by Delphi 1.

2.6.1 Results - 2ii. Tools/technologies assessing the dying phase & accurately predicting dying

A list of 37 tools/ instruments has been collated. Several tools identified, such as the Karnofsky Performance Scale; Euro-QoL (EQ-5D: 5 items), MDS (Minimum Data Set), QLQ-C30 (Quality of life questionnaire), Profile of mood states (POMS), Impact of event scale (IES), Centre for epidemiologic studies-depression (CES-D), Positive states of mind (PSOM), 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

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.

2.6.2 Results. 3 - Review of non-scientific literature

Non-scientific literature was reviewed, accessed via a variety of strategies: e.g. Local and City Libraries, Popular Literature, Journals/ Magazines, Internet Bookshops. Search engine (google.ch/.de/.com). The non-scientific literature contained phenomena related to communication patterns not identified by either the Delphi or Systematic review. This indicates a potentially important difference in the “known” phenomena predicting death and dying between the professional views and the lay literature. The perspective of lay carers is rarely systematically assessed and not included into scientific reviews on end of life issues.

2.7 Development of future research protocol

The aim of a future study is to construct and test a tool to estimate the sensitivity and specificity of a set of criteria/ dimensions in recognizing imminent death (defined as 7 days in a population of terminal cancer patients) in different settings of care (home care, hospital, hospice and nursing home).

Research Question/ main hypotheses are:

- Which clinical phenomena identified by prior research are predictive for the dying phase, and is it possible to compose a diagnostic test based on such phenomena?
- There are a number of clinically relevant phenomena specific for the dying phase which needs to be assessed regularly (“day by day”) by an inter-professional care team.
- A diagnostic test for entering the dying phase (last 7 days of life) can be developed and will identify the dying phase more accurately than other prognostic tools already available.

2.8 Critical Friend

Dr Paddy Stone provided many erudite challenges for the Work Package team to consider, and an engaging discussion has helped refine the thinking around the development of potential research protocols. Dr Stone commented:

- *“Having undertaken a thorough and systematic review of the literature and a Delphi process the WP1 team have produced a draft research proposal to develop a new tool to “diagnose dying”. The proposal appears to be well conceived and will address an important issue for palliative care clinical practice.”*

2.9 Conclusion

Although health care professionals often fail to recognize the entering of 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/ hours 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 systematic literature review show that various signs and symptoms of approaching death have been investigated. Some of those seem to be helpful in identifying imminent death. Nevertheless, there is evidence that health care professionals fail to recognize the entering of the dying phase.¹⁵ Results from non scientific-literature search suggest a possibly important difference in the phenomena predicting death and dying. Perspectives by lay carers and family should be actively included into further research.

Prognostic tests such as the Palliative Prognostic Score (Pap Score) and Palliative Prognostic Index (PPI) have been developed to accurately predict survival in terminally ill cancer patients and have been validated widely, but they are not specific to the imminent diagnosis of dying. In addition, none of these tests seem to be based on a broad literature review, taking into account that “dying” is not solely a medical problem. 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.¹⁶

¹⁵ Brandt HE, Deliens L, Ooms ME, van der Steen JT, Van der, WG & Ribbe, MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. Arch.Intern.Med. 2005; 165; 314.

¹⁶ Lau F, Cloutier-Fisher D, Kuziemyky C, Black F, Downing M, Borycki E, & Ho F. A systematic review of prognostic tools for estimating survival time in palliative care. J Palliat.Care 2007; 23; 93-112.

Defining the dying phase, not only by time but also by needs, will remain an ongoing and important task that must be linked directly to the needs and views of the population rather than professionals only. Based on the current review there is little evidence that phenomena in the dying phase differ between cancer and non- cancer so far, but future research is needed to strengthen this view.

2.10 Potential Impact

This project has accessed the best available evidence as a basis for further development and research. It is hoped that the 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 (LCP). Furthermore, a better understanding of multiple phenomena at the very end 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 aging societies.

2.11 Observations – Support & Collaboration

The Work Package team consider the impact of this European (and beyond) collaboration project as both exceptional and vital for “capacity building” in end of life research in Switzerland. This is in relation to the research capacity and competency within our centre for palliative care, but also in regard of national and international collaboration. In addition, the project has helped to dramatically enhance the basis for future research projects and collaborations within and around our centre and national reference group. This is especially true for services, such as ours, that has a clear focus on clinical care (biggest palliative care service in Switzerland) but a far less developed academic background.

Project Deliverables

D 1.1	Month 37	Final report Signs and Symptoms of approaching death: Final report
D 1.2	Month 37	A minimum of one article for publication Eychmüller S, Domeisen F, Latten R, Walker J and Costantini M on behalf of OPCARE9 <i>“Diagnosing dying”: Signs and symptoms of approaching death in cancer patients. A systematic literature review.</i> Domeisen F, Eychmüller S, Grossenbacher-Gschwend B, Schuler S, Latten L, Laura Daud M, Clark J, Peternelj A, Lindqvist O, van der Heide A, Costantini M and Ostgathe C, on behalf of OPCARE9. <i>Phenomena of approaching death in cancer patients – generating consensus by Delphi technique.</i>
D 1.3	Month 37	A minimum of two presentations for future national/international conferences Eychmüller S, Domeisen F. <i>Presentation of Community Palliative Care research protocol</i> at Annual Meeting of the International Primary Palliative Care Research Group in Lisbon (EAPC) in May 2011. Eychmüller S, Domeisen F. <i>Diagnosing dying – challenging the Liverpool Care Pathway.</i> Abstract submitted to DGHO, Annual congress in Basel (CH). September/ October 2011 Eychmüller S, Domeisen F. <i>Diagnosing dying – challenging the Liverpool Care Pathway.</i> Abstract submitted to Palliative.ch, Annual congress of Swiss Palliative care association in Biel (CH). November 2011
D 1.4	Month 37	A minimum of one protocol for future research to enhance the evidence base for end of life decisions Protocol title: “Diagnosing dying” – development of a tool for identifying the last days of life Authors: Eychmüller S, Costantini M and Domeisen F.

3. OPCARE9: Work Package 2 - End of Life Decisions

End of life care often requires difficult ethical decisions by the patients, their families and the clinical team. Numerous challenges exist, such as the use of deep sedation to control symptoms, withholding and/or withdrawing life sustaining treatments 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.

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. Accordingly, the Work Package objectives were;

- To collect and collate information regarding the key end of life decisions undertaken within beneficiary countries
- To explore cultural and legal differences and similarities within the beneficiary countries
- To identify and evaluate existing evidence regarding the effects of such end of life decisions on patients, carers and health care professionals
- To identify tools/technologies currently available to support the making of such decisions
- To systematically evaluate the current evidence base for such tools/technologies
- To identify and evaluate any current quality indicators for the making of such decisions
- To develop protocols for future research to enhance the evidence base for end of life decision making
- To review the LCP in relation to end of life decision making and make recommendations for its modification and development

3.1 Organization and collaboration

Work Package 2 has been led from the Dutch team from the Erasmus Medical Centre in Rotterdam. The Work Package leads (Dr Lia Van Zuylen and Dr Agnes van der Heide) and Scientific Project Assistant (Natasja Raijmakers, MSc) prepared and structured all WP activities. Country representatives from each OPCARE9 country were regularly consulted for advice and agreement, and also provided the entrance for the Delphi study to the national reference groups.

3.2 Challenges: Defining “end-of-life” decisions.

The first step for the Work Package was to find a common definition of what constitutes an end-of-life decision, to establish a shared base for this international collaboration. Through consultation, discussion and refinement, the Work Package members agreed on the following definition:

- A decision involving a person who is in the last days of life that has (may have) a significant impact on the quality, place and/or time of dying.

The definition is limited to persons who are in the last days of life as this is the focus of the OPCARE9 project. Subsequently, an inventory was made with the support of the national reference groups from the beneficiary countries of the end-of-life decisions that they considered most important.

3.3 International Inventory

The most frequently mentioned topics could be categorized in five groups:

- 1) withdrawing and/or withholding of medical treatment
- 2) symptom management
- 3) place of death
- 4) information & communication
- 5) social/relational issues

In the category withdrawing/withholding of treatment, artificial nutrition (AN) and artificial hydration (AH) were the most frequently mentioned topics, followed by stopping anti-cancer treatment. In the category symptom management, using sedatives was most frequently mentioned. Based on the inventory, decisions regarding the use of artificial nutrition, artificial hydration, and sedatives were chosen to serve as templates for further studying end-of-life decision making.

3.4 Methodology

The methods used to address objectives of the Work Package include:

- Literature review: systematic review
- Expert consultation: Delphi.

The inventory of end-of-life decisions was used to determine the focus for a systematic literature review and of a Delphi study. The focus of the systematic literature review consisted of decision making on whether or not to provide artificial nutrition (AN) and hydration (AH) at the end of life.¹⁷ Specific questions addressed were:

- 1) how and how often are AN and AH provided in the last week of life of cancer patients
- 2) what is the effect of AN and AH during the last week of life on symptoms, comfort and quality of life of cancer patients
- 3) does providing or not providing AN and AH hasten death or prolong life?

The focus of the Delphi was extended to include artificial nutrition and hydration and the use of sedatives at the end of life.

Besides the systematic literature review and the Delphi process, we also made an international inventory of legal frameworks and tools & technologies, i.e. protocols and guidelines, related to end-of-life decision making. All results were used to assess current practices and levels of knowledge and to define important, internationally relevant research questions and protocols.

3.5 Results – Systematic review

From an initial 2198 articles identified from the electronic databases, the systematic selection process yielded 15 papers for inclusion in the review. Reported percentages of patients receiving AN or AH in the last week of life varied from 3% to 53% and from 12% to 88%, respectively. Five studies reported on the effects of AH: two found positive effects (less chronic nausea, less physical dehydration signs), two found negative effects (more ascites, more intestinal drainage) and four found also no effects on terminal delirium, thirst, chronic nausea and fluid overload. No study reported on the sole effect of AN.

Providing AN or AH to cancer patients who are in the last week of life is a frequent practice. However, the effects on comfort, symptoms and length of survival seem limited. Further research will contribute to better understanding of this important topic in end-of-life care.¹⁸

¹⁷ The use of sedatives was not included, because evidence on this topic was already reviewed by other Work Packages.

¹⁸ Results have been published: Raijmakers NJH, van Zuylen L, Costantini M et al., *Annals of Oncology*, 2011

3.6 Results - Delphi

Two rounds of Delphi were conducted. The first round established the commonest issues related to end-of-life decisions, and the most frequently mentioned issues related to;

- 1) medical aspects, such as futility of treatment and side effects
- 2) how to address patients' wishes
- 3) how to address relatives' wishes.

Other issues were related to; decision making, professional caregivers wishes, ethical issues, (such as autonomy of patient, hastening death), practical issues (such as insurance problems, cultural issues (such as the role of nutrition in a specific culture) and legal issues, (such as capacity of patient to decide when in low consciousness state).

The second round of the Delphi aimed to establish what further knowledge is required to end-of-life decision making. In total 55 experts responded (response rate 61%), identifying that the most important issues in need for more knowledge were:

- 1) Optimal strategies for communication with patient and relatives about needs and wishes
- 2) Appropriate indications for using sedatives in the last days of life
- 3) how to improve multidisciplinary medical decision making
- 4) effects of (de)hydration on patient comfort and quality of life.

Communication with terminally ill patients and relatives on end-of-life decision making is a challenging issue that could benefit from future research. Additionally, more evidence is needed on indications for and effects of providing or withholding specific medical treatments during the dying phase, such as artificial hydration or sedatives. These results serve well to prioritize future research for optimizing the care of the dying.

3.7 Tools & technologies: for end-of-life decision making

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 3.1). All guidelines were the result of expert opinion. Only the Dutch guidelines integrated some evidence from research studies.

Table 3.1 - Availability of national protocols and guidelines on end-of-life decision making

National protocol	ARG	UK	GER	IT	NI	NZ	Slov	Swe	CH
Palliative sedation	No	No	Yes	Yes	Yes	No	No	Yes	No
Artificial Nutrition & Hydration	No	Yes	No	Yes ¹⁹	Yes	No	No	No	No
Withholding/ withdrawing treatment	Yes	Yes	Yes	Yes	No	No	No	Yes	No

3.8 Inventory of laws & legal frameworks

Differences and similarities between the beneficiary countries regarding legal regulations concerning patients' legal right to refuse medical treatment, the legal status of advance directives and prohibition of euthanasia, assisted suicide and suicide are highlighted in the full report.

¹⁹ Guideline on artificial nutrition and hydration in patients with a persistent vegetative state

3.9 Development of Future Research protocols

Communication: Based on the work conducted, several research questions have been generated in line with the themes indicated by the international experts. Subsequent to discussion within the Work Package and with the critical friend, it was identified that as communication is an issue important for all (patients, relatives, professional caregivers, volunteers) and this should be the focus for development as it is likely to make a difference in the care for the dying. It is the intention to study different perspectives on, awareness of, and communication about the role of food and fluids at the end of life.

Liverpool Care Pathway: End-of-life decision making is one of the key elements in the Liverpool Care Pathway (LCP) for the dying patient. In the LCP (version 12) detailed prompts focus on assessment of whether artificial nutrition and hydration are indicated or not. It remains to be established that such detailed attention is applicable in other countries, because cross-national and cross-cultural perspectives on appropriate and ethically sound end-of-life decision making may vary.

3.10 Critical Friend

Professor Deliens commented on the validity of the potential outputs of Work Package 2, and the focus of the OPACRE9 project, opining:

- *“OPCARE9 used an interesting and efficient method to produce similar and complementary outcomes of the different WPs... .. Different protocols have been discussed... ..I am convinced that the topics indeed need further and more in-depth research.”*
- *“OPCARE9 is focusing on the last days of life. This choice can be defended from a point of feasibility and focus in future research. However this choice yields also some limitations. Improvement of end of life care has not only to be initiated by looking for barriers and facilitators within the last days of life, but very often the seeds for good (or for poor) end of life care have been developed up-stream in the disease trajectory and within the care givers patient and relatives interactions.”*

3.11 Conclusions

International and multidisciplinary consensus has established core themes in end-of-life decisions as:

- withholding or withdrawing of medical treatment
- symptom management
- communication
- place of death
- relational issues,

This shared interest is an important basis for international collaboration.

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, interdisciplinary team decision making and effects of (de)hydration are topics that can benefit from future research; the results of which will contribute to better care for many (all) dying patients and their relatives.

Overall, the results of WP 2 in OPCARE9 serve well to prioritize future research on end-of-life decision making. It both accounts for and expands beyond the medical perspective, and provides a platform for integrating the health care professions to optimize care for the dying within Europe and beyond.

3.12 Potential impact

There is a common base of interest in issues around end-of-life decision making and a shared feeling of current gaps in knowledge despite cultural variety within the EU and beyond. This consensus should empower international cooperation to improve the quality of the evidence base, thus providing the means to improve care.

3.13 Observations – Support and Collaboration

The collaboration between the different countries and professions in this Work Package has been very successful. Over the 3 year project, contact during the colloquia proved to be very helpful in overcoming numerous challenges in communication and design.

This collaboration has led to a site visit of the Arohanui Hospice, Palmerston North, New Zealand, by the Scientific Project Assistant (Natasja Raijmakers). The aim was to plan and check the feasibility of further research, which was successful.

This site visit of the SPA has resulted in:

- a) an oral presentation about the OPCARE9 collaboration at the 19th NZ Hospice Conference in Wellington, New Zealand,
- b) an oral presentation about the progress of OPCARE9 at the Arohanui Hospice, Palmerston North, New Zealand,
- c) attending the national research meeting palliative care NZ,
- d) a paper in the national LCP newsletter of New Zealand.

In addition, three bi-lateral collaborations, between the Netherlands and New Zealand, Italy, and the UK have been designed to develop applied research studies that will address the questions generated by this Work Package:

- New Zealand: WP2-members from New Zealand and the Netherlands are planning to conduct a qualitative, comparative participant- observational study in a hospice in New Zealand and a hospice in the Netherlands.
- Italy: WP2-members from Italy and the Netherlands have decided to collaborate on data from a trial that assessed the effects of using the LCP in Italy.
- United Kingdom: WP2-members from the UK and the Netherlands have collaborated on a systematic literature review on the opinions and attitudes of patients, family and professional caregivers towards artificial nutrition and hydration in the last week of life.

Project Deliverables

D2.1 Month 37 **Final report**

End of Life Decisions: Final Report

D2.2 Month 37 **A minimum of one article for publication**

Raijmakers NJ, van Zuylen L, Costantini M, Caraceni A, Clark J, Lundquist G, Voltz R, Ellershaw JE, van der Heide A; on behalf of OPCARE9. *Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects*. Annals of Oncology. 2011 Jan 3 (e-pub)

Raijmakers NJ, van der Heide A, Rietjens J, Swart S, van Zuylen L. *OPCARE9: Collaboration in Europe for better care in the dying phase*. Dutch-Flemish Journal of Palliative Care. 2011 (11) 1

Raijmakers NJ, Fradsham S., van Zuylen L, Mayland C, Ellershaw J, van der Heide A. *Artificial hydration at the end of life. A systematic literature review of opinions and attitudes towards its provision and effects*. Current Opinion in Supportive & Palliative Care. Invited paper for April 2011

Raijmakers NJ, van Zuylen L, Costantini M, Caraceni A, Clark J, Lundquist G, Voltz R, Ellershaw JE, van der Heide A; on behalf of OPCARE9. *End of Life Decision Making: Similar or different? An international modified Delphi study*. Submitted to Palliative Medicine, May 2011

D2.3 Month 37 **A minimum of two presentations for future national/international conferences**

Van Zuylen L, Raijmakers NJ, van der Heide A. End of Life Decisions. 7th -10th May 2009. European Association for Palliative Care (EAPC), Vienna, Austria

Van der Heide, Raijmakers NJ, van Zuylen L. OPCARE9 project. 10th -12th July 2009. National Research Meeting Palliative Care (AGORA), Bunnik, the Netherlands

Raijmakers NJ, van Zuylen L, van der Heide A. Important end-of-life decisions in the last days of life. International and multidisciplinary consensus. 14th – 16th April 2010. European Oncology Nursing Society (EONS). The Hague, the Netherlands

Raijmakers NJ, van Zuylen L, van der Heide A. Considerations in end of life decision making. 9th -11th November 2010. 19th Hospice New Zealand Palliative Care Conference. Wellington, New Zealand.

D2.4 Month 37 **A minimum of one protocol for future research to enhance the evidence base for end of life decisions**

Protocol title: Communication on food and fluids at the end of life. A qualitative approach

Authors: Raijmakers, NJ, van Zuylen L, Clark J, Allan S, Caraceni A, Costantini M, De Simone G, Rasmussen B and van der Heide A.

4. OPCARE9: Work Package 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 suggesting a 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).²⁰ 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, an understanding of the most prevalent systems, including both the severity and the degree to which they are problematic to patients is required.

The objectives of this Work Package were;

- To identify and systematically evaluate the evidence base for appropriate comfort measures in the last days and hours of life including:
 - Symptom control
 - Nursing interventions
 - Spiritual care
- To determine European consensus on the optimum management of symptoms at the end of life, including:
 - Pain
 - Terminal agitation
 - Respiratory tract secretions
 - Dyspnoea
 - Nausea and vomiting
- To determine European consensus on nursing interventions for care of the dying.
- To identify and evaluate current tools/technologies available to support
 - The measurement of symptom burden
 - The delivery of high quality complementary comfort care
- To develop protocols for future research to enhance the existing evidence base
- To review the LCP in relation to complementary comfort care and make recommendations for its modification and development
- To recommend European quality indicators in care of the dying

4.1 Organization and collaboration

Work Package 3 has been led by the Swedish and Slovenian teams involved in OPCARE9. Due to the scope of the Work Package objectives, three areas of investigation were operationalised;

- Pharmacological interventions
- Non-pharmacological care-giving activities
- Spiritual care.

Although delineated for investigation, pharmacological, non-pharmacological and spiritual care is viewed as integrally linked in the provision of “total care” for “total pain.”

The Work Package Lead (Prof Carl Johan Fürst) and Scientific Project Assistants (Dr Carina Lundh Hagelin & Dr Olav Lindqvist) prepared and structured all WP activities for pharmacological and non-pharmacological care. Dr Urska Lunder facilitated Work Package activities relating to Spiritual care. Representatives from each OPCARE9 country formed the core membership of this Work Package.

²⁰ WHO. Palliative Care for Older People. Copenhagen, WHO Europe, 2004.

4.2 Challenges

Discussion within the Work Package, examining relevant knowledge and potential knowledge gaps, 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.

For 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.

4.3 Methodology

Following a survey of current drug use in 26 palliative care units, a two-stage Delphi method was employed: Stage 1) for building consensus on the use of necessary drugs, and Stage 2) to explore experts’ views on drugs that are difficult to withdraw during the last days of life. The results provided a basis for a strategic literature review.

The free-listing exercise sought to identify the variety of non-pharmacological care-giving activities (NPCA) carried out by different professionals during the last days of a patient’s life. Data was recorded by asking staff in each country to think and document practice activities over a 4 week period. Based on these NPCA’s, a strategic review of literature about supportive environments for the dying was performed and senior researchers were invited to generate research questions.

The concepts existential and spiritual care lack generally-accepted and consistent descriptions. Keeping this in mind, a literature search was performed for review articles regarding the existential and spiritual dimensions of care during the last days of life. Article summaries were then sent to a diverse sample of relevant experts in the OPCARE9 countries, who were asked to brainstorm new research questions to complement the extant literature.

4.4 RESULTS

The results are presented below.

4.4.1 Pharmacological Interventions.

The first round of the Delphi sought to: 1) identify drugs seen as essential in the last days of life, and 2) 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%).

The 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 drugs) and therapies perceived as potentially not medically necessary, but difficult to withdraw when patients or family perceive these 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.

A literature review was conducted to examine existing knowledge on the pharmacological and physiological effects of drug withdrawal in the last days of life focusing on antiepileptics, corticosteroids, drugs used in diabetes, and antithrombotics.

4.4.2 Non-pharmacological care-giving activities:

The free-listing exercise identified a total of 985 NCPA's. An underlying feature in many NPCA is the effort to provide personalized and compassionate care through 'maintaining connections to the individual's everyday life'. Even refraining from action was described as a purposeful part of care provision. Analysis also indicated that many NCPA's were aimed at creating an aesthetic, safe and pleasing environment for the dying person and his/her family. The descriptions of NPCAs often appeared to seamlessly address bodily, spiritual, existential, psychological and social dimensions, and were often carried out in an integrated manner.

A literature review was conducted entitled "*Supportive Environments in Palliative Care*", guided by the question: What is known about the impact of sensory environment on patients' sense of well-being in palliative care?

4.4.3 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 and in relationships with others, what they value, 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.

4.5 Tools and technologies

Tools and Technologies (T&Ts) are means to facilitate comfort of the dying patient. A secondary analysis of the NPCA data from 16 settings in the nine OPCARE9 countries was performed, with the following examples of T&Ts used in one or more settings:

- 1) *Mechanical devices*: catheters; subcutaneous- or venous accesses; syringe-drivers; bed rails, etc. Other non-mechanical T&Ts used include: blankets; towels; perfume; light; music; pillows, etc.
- 2) *Measurement and Assessment*: fever thermometer; anamnesis of needs for the terminal phase. Other assessments described were of skin integrity; signs of discomfort through assessing body movements and facial expressions, etc.
- 3) *Care pathways*: Liverpool Care of the Dying Pathway
- 4) *Other systematic approaches*: written information; registration of death; systematic use of communication as evidence of conscious application of a palliative philosophy.

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.

4.6 Development of future research protocols

Three research protocols have been developed.

4.6.1 Pharmacological Interventions:

Based on the work results of the survey and two-stage Delphi, numerous areas for research development have been identified. Accordingly, a core research proposal has been developed to address the challenges outlined: *“Withdrawal of drugs in the last week of life in cancer and palliative care”*.

4.6.2 Non-pharmacological care-giving activities:

As with Pharmacological interventions, numerous (over 150) research questions were generated. Based on these data a trans-disciplinary research project for sensory environment has been developed, with a feasibility study now underway: *“Experiencing sensory environment at the end of life”*.

4.6.3 Spiritual/existential support:

Summaries of the reviewed articles were distributed to representatives of all OPCARE9 countries for discussion and dissemination to a sample of multi-disciplinary experts in the field from each respective country, to generate new research questions. From Sixty-two returned research questions, an overarching research proposal was formulated - *“Exploring spiritual/existential care in the last days of life as experienced by patients, family members and staff in different settings and cultures”*.

4.7 Critical Friend

Critical discussion with Dr Julia Downing provided some challenges to the Work Package on conceptual and organisation aspects. For example, it was suggested that developed protocols could have wider international participation by utilising the networks nurtured through the OPCARE9 project. Accordingly, Dr Downing emphasised that “it is important to see this bigger picture and where the specific research sits” in order to promote improved care on a global axis.

4.8 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 points to an important area for new, basic research and applied research.

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.

4.9 Potential Impact

The consensus found in regard to appropriate pharmacological care for common symptoms, there is a potential to develop recommendations for standard care of patients with cancer approaching death. However, the lack of accessibility to different drugs in some countries and settings is an important factor, highlighting potential inequities. Nevertheless, 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.

While palliative care can now 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.

Crucially, the three aspects examined in this Work Package have a complementary rather than hierarchical relationship in the provision of comfort care for the dying person and his/her family.

4.10 Observations – Support and Collaboration

Although OPCARE9 is focussed on cancer, the importance of disseminating knowledge from cancer-related end-of-life care to care-giving situations involving dying patients with similar needs is paramount, e.g. care in long-term residential facilities. In such settings, knowledge and professional resources are not as extensive as in specialized palliative care facilities. The importance of staff with competence in both non-pharmacological and pharmacological end-of-life care has become evident from the results generated from this Work Package.

Another key implication of the OPCARE9 collaborative is the development of a well-functioning network of professionals, without prior collaboration, within Sweden. This group is able to unify northern rural areas and the urban capital region, despite large distances, and will continue to work together in the future. One practical outcome of this new collaboration is a cluster randomized controlled trial investigating use of LCP in residential care homes in northern Sweden. Our group can function as a platform for further international collaboration to continue to optimize research for the care of patients with cancer in the last days of life.

Project Deliverables

D3.1 Month 37 **Final report**

Complementary Comfort Care

D3.2 Month 37 **A minimum of one article for publication**

Lindqvist O, Tishelman C, Clark J, Daud LM, Dickman A, Domeisen F, Fürst CJ, Galushko M, Lunder U, Lundh Hagelin C, Lundquist G, Miccinesi G, Sauter S, Rasmussen BH, on behalf of OPCARE9. *Complexity in caring for the dying: An international inventory of non-pharmacological care-giving activities in the last days of life*. (Submitted for publication)

Lindqvist O, Tishelman C, Clark J, Daud LM, Dickman A, Domeisen F, Fürst CJ, Galushko M, Lunder U, Lundh Hagelin C, Lundquist G, Miccinesi G, Sauter S, Rasmussen BH, on behalf of OPCARE9. *Four essential drugs needed for quality care of the dying - An international expert consensus* (manuscript)

Lindqvist O, Tishelman C, Clark J, Daud LM, Dickman A, Domeisen F, Fürst CJ, Galushko M, Lunder U, Lundh Hagelin C, Lundquist G, Miccinesi G, Sauter S, Rasmussen BH, on behalf of OPCARE9. *Supportive Environments in Palliative Care* (manuscript)

D3.3 Month 37 **A minimum of two presentations for future national/international conferences**

Tishelman C. *OPCARE9: International interdisciplinary collaboration to improve end-of-life cancer care*. 7th – 11th March 2010. 16th International Conference on Cancer Nursing, Atlanta USA.

Lindqvist O. *Non-pharmacological care-giving activities: an international inventory of what is done in the last days of a patient's life*. 7th – 11th March 2010. 16th International Conference on Cancer Nursing, Atlanta USA.

Fürst CJ, Lindqvist O, Lund-Hagelin C, Lundquist G, Rasmussen B, Sauter S, Tishelman C. *OPCARE9. Första Nationella konferensen i palliativ vård* April 12th – 13th, 2010, Stockholm Sweden.

D3.4 Month 37 **A minimum of one protocol for future research to enhance the evidence base for complementary comfort care**

Protocol title: Experiencing sensory environment at the end of life

Protocol title: Withdrawal of drugs in the last week of life in cancer and palliative care – Towards more appropriate use of drugs in the last days of life

Protocol title: Exploring spiritual / existential care in the last days of life as experienced by patients, family members and staff in different cultures

4. OPCARE9: Work Package 4 - Psychological and psychosocial support for patients, families and caretakers

Psychological and psychosocial support (PPS) is an essential element of the “total” care philosophy, contributing to addressing the patient as a whole and enhancing 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. Nevertheless, interventions exist that may prove to be of benefit.

Psychological support is not only offered by psychologists, but by a range of professions. Endeavours to improve these aspects of palliative care have been undertaken in recent years. However, there is still lack of knowledge regarding the psychosocial needs of patients, relatives and their caretakers in the dying phase.²¹

The aim of this Work Package was to facilitate debate on what constitutes appropriate supportive communication with patients in the final days of life. It aimed to establish both the research base and expert consensus regarding methods for engaging in such communication to provide guidance on appropriate ways to identify patients’ and families’ psychological and psychosocial needs. It also sought to develop innovative research protocols to further understanding in this area.

Accordingly, the Work Package objectives were:

- To identify and systematically evaluate the evidence base for the prevalence of psychological and psychosocial issues for:
 - Patients in the final days and hours of life
 - Those of their families and caretakers
- To identify and systematically evaluate current evidence regarding appropriate communication in the dying phase around issues such as recognition of dying with:
 - Patients
 - Families and caretakers
- To explore cultural differences, similarities and existing approaches to the identification of need and delivery of care
- To identify and systematically evaluate current tools/technologies to support
 - The measurement of psychological and psychosocial support needs for patients, families and caretakers
 - The delivery of high quality psychological and psychosocial support for patients, families and caretakers
- To identify and systematically evaluate any existing Quality Indicators for the measurement of need or delivery of care
- To develop protocols for future research to enhance the existing evidence base
- To review the LCP in relation to psychological and psychosocial support and make recommendations for its modification and development
- To recommend European quality indicators in care of the dying

5.1 Organization and collaboration

Work Package 4 has been led by the German team from the University of Cologne. The Work Package Lead Prof Raymond Voltz, with the support of Prof Christophe Ostgathe and the Scientific Project Assistants (Maren Galushko, Dr Ovidiu Popa-Velea and Vanessa Romotzky) prepared and structured all WP activities. Country representatives from each of the OPCARE9 beneficiaries participated in the core Work Package activities.

²¹ Jünger S, Payne SA, Constantini A, Kalus C, Werth Jr JL. (2010). The EAPC Task Force on Education for Psychologist in Palliative Care, European Journal of Palliative Care 2010. 17: 2; 84-87

The aim of this WP was to use experts' view and evidence out of the literature to explore psychological and psychosocial support (PPS) for cancer patients in the last days of life and their relatives. Systematic review (SR) and Delphi methods were used to address the following research questions:

- 1) What is the perspective of experts on psychosocial, psychological and social support in the last days of life?
- 2) What topics and areas have been addressed in research so far in psychosocial, psychological and social support in the last days of life?

5.2 Methodology

Delphi: Three Delphi rounds on PPS were conducted with experts (i.e. experienced professionals working in the field of palliative care).

- Delphi 1 - explored the definition of PPS, persons who can deliver PPS and who should receive PPS in the last days of life.
- Delphi 2 - explored the needs of patients, relatives, staff and volunteers for different levels of support and aimed to identify the most important tasks for health professionals and volunteers in giving PPS. Additionally, consensus was sought on the provided working definitions (Table 5.1)
- Delphi 3 - addressed the responsibility of delivering PPS tasks in different countries, appropriate communication, measurements of distress and interventions, important issues for social support and future research.

Table 5.1 - Descriptors for Psychological and Psychosocial Care

Category	Support
Specialised Psychological support	support / care that can only be delivered by specially trained mental health professionals (psycho-oncologists, psychotherapists, psychiatrists, etc.) - including therapeutic interventions such as cognitive behavioural therapy, systemic therapy, psychoanalytical interventions, etc.
Psychosocial support / care	support that all health professionals (including specialists) should be able to deliver, including: being present; listening; giving room for the expression of strong emotions as well as providing contact to care / nursing teams; referring to hospices / specialists / chaplains, etc.
Psychological support / care	support that can be delivered by health professionals with advanced training, including: using psychological techniques as patient-centred communication, problem solving, relaxation etc.
Social support	support that can be given by social workers (or national equivalent) including: organizing further care; counselling in financial and legal issues, etc.
Relatives (family & friends)	support given by family and friends, including: being present; listening; giving room for the expression of strong emotions, etc.

Systematic review: The aim of the systematic review (SR) was to identify and document the focus of research studies investigating PPS for cancer patients and their caretakers in the patients' dying phase.

5.3 Results

5.3.1 Delphi Survey:

Delphi 1 - The main tasks identified by the experts were to:

- support expressing and handling emotions, working on relationships
- reaching acceptance or reconciliation
- addressing existential issues and saying goodbye.

It was also assumed by the majority of experts that every palliative care team member and volunteer should be trained in providing basic PPS. For complex situations they considered specialised mental health professionals with additional training in palliative care to be important. This service should be part of every specialised palliative care team.

Delphi 2 - Consensus on the definitions of “specialised psychological support” “social support” and “psychological support” was established. Additionally, key tasks and issues for PPS were consensually agreed and conditions for delivery (Table 5.2)

Table 5.2 Key Tasks and Conditions for Delivery of Psychological and Psychosocial Care

Tasks	<ul style="list-style-type: none"> - to discover and support the personal resources - take care of individual needs / live and die in manner of their choice - explicitly ask for patients’ and relatives’ needs & wishes. - to generate a calm environment - to help in the process of grief - to bear patients’ and relatives’ emotions - to develop a relationship with patients and relatives - to address unfinished business - to help making ones’ peace with the life lived 	Patients	<ul style="list-style-type: none"> - social support should be offered to all patients in the last days of life as part of routine care.
		Relatives	<ul style="list-style-type: none"> - social support should be offered to every relative as part of routine care. - Every relative does not need specialised psychological support.
		Health Professionals	<ul style="list-style-type: none"> - all HP and volunteers interacting with patients and their relatives should participate in regular continuous discussions within the team (without an external supervisor). - specialists for psychological and social support should also have an advanced training in PC to deliver psychosocial support for patients. - doctors, nurses, social workers and chaplains need additional training to be able to offer psychological support for patients in the last days of life and their relatives. - specialized psychological and social support should only be given by specialists. - Health professionals and volunteers interacting with patients and relatives need psychological support.
Issues	<ul style="list-style-type: none"> - to give patients and relatives room to express feelings and thoughts - that it respects and meets the individual way of patients and relatives - give patients the chance to experience positive emotions - that it is needs-oriented 		

Delphi 3 - Documented consensus on key issues for support of patients and their relatives in the last days of life (table 5.3)

Table 5.3 – Social Support Tasks

Social Support	<ul style="list-style-type: none"> - Emotional support for patients - Responding immediately to acute needs - Assure coordination and continuity of care - Organisation of care according to patients’ wishes - Emotional support for relatives - Activating resources of patients and relatives - Assessing acute needs - Assessing patients’ preferences for place of care and death - Prevention of complicated grief - Support in maintaining relationships between patients and relatives - Provide access to information about available services - Help in family conflicts - Organisation of transition of care (changing place of care)
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Additionally, Delphi 3 integrated the findings from Delphi’s 1&2, with the finding from the systematic review to examine communication issues and cultural nuances in PPS (Table 5.4)

Table 5.4 – Communication challenges in end of life care

Objectives to be addressed by palliative care teams	<ul style="list-style-type: none"> - hospital ensuring a supportive environment encouraging calmness and 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	<ul style="list-style-type: none"> - most wanted information by relatives refers to 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

Equally, Delphi 3 and the Systematic Review highlighted cultural variances in the delivery of PPS. For example, there appeared to be distinct professional groups primarily responsible for those PPS; in Argentina social workers were in charge of much of the PPS care, whereas in Germany psychologists, and in Romania²² physicians were most often mentioned reflecting the composition of experts with their professional background in these countries

5.3.2 Systematic review

The majority of studies (27 = 59%) focused on patients, whereas the remainder 19 (41%) focused on relatives and/ or hospital caretakers. 30 studies (65%) used a qualitative methodology, whereas 14 (30%) had a quantitative methodology and two (4%) a mixed method approach.

²² Although Romania was not a partner country, Dr Ovidiu Popa- Velea (SPA for WP4) was based in Romania and thus able to contribute this perspective

The research questions (RQs) of the studies yielded were themed accordingly:

- i. Characteristics of dying and death - Dying process; Good death / quality of death; Consequences; Coping strategies
- ii. Symptoms, concerns, needs - Desire for hastened Death; Spiritual; Not Specified
- iii. Interventions
- iv. Bereavement
- v. Euthanasia
- vi. Communication

The largest category of Research Questions referred to the characteristics of dying and death studies (n=26), whereas the category least represented related to issues of euthanasia (n=3).

5.4 Tools and technologies

Delphi consensus identified the “clinical interview” as the best way to assess patients’ or relatives’ psychosocial distress in different settings;

- in specialized psychological care for **patients** (71,4%),
- in specialized psychological care for **relatives** (70,6%)
- in general routine care **for patients / for relatives** (each 63,9%).

A broad scope of interventions (technologies - supportive, cognitive-behavioural, systemic, analytical and art or music therapies) were mentioned. They seemed to correlate with the professional background. More specialized forms of support (e.g. systemic or analytical) were mentioned by psychologists and physicians. A list of the tools and their focus (clinical/research; last days of life; national validation) is presented in the full report.

5.5 Development of Future Research Protocols

The findings of the systematic review suggested some important points to be considered in designing new protocols, such as:

1. the balance between qualitative and quantitative research methodologies, both having strengths, as well as flaws.
2. the high ethical demands of a research protocol targeted on dying patients and their relatives.

In Delphi 3, participants were asked to rank importance on issues to be addressed in future research. In accordance with the results, the proposal aims to evaluate the effects of attachment styles in the outcome of varied interventions to promote well-being and ameliorate distress for families attending patients with palliative care needs.

5.6 Critical Friend

Following lively and informative discussion with Professor Gary Rodin, it was agreed that new research might begin most efficiently by developing novel studies that build on established research programmes in different countries. Crucially, it was articulated that interventions that take place earlier in the course may have a profound impact in the last days of life. It was also appreciated that research findings needed to be considered within a national and cultural context, which may affect study results.

5.7 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.²³ 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 multiprofessional 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 groupings.

5.8 Potential Impact

It was proposed that the qualification of staff was very important in the delivery of psychological and psychosocial support; the relationship between receiver and provider as being a key issue. Accordingly, the majority of experts considered every palliative care team member and volunteer to be trained at an appropriate level, suggesting also that all specialised palliative care teams should be able to provide general support, whilst having access to specialised PPS. Therefore, it is essential for all institutions aiming to provide high quality palliative care to take into account also the needs of staff for additional training, coordination, supervision and self-care. This includes improving the possibilities of reflection and coping with stressful care situations.

5.9 Observations – Support and Collaboration

The professional background of the respondents seemed to be associated with particular issues for psychological and psychosocial support, including interventions. As psychological distress is multi-factorial, different professions, by virtue of their differing training and experience address different factors contributing to the overall distress. However, this is a strength of multidisciplinary teams.

Most of the studies in the systematic review had a qualitative design. This illustrates that research at the end of life needs a careful approach, for which qualitative design may be most suited. In contrast, quantitative methodology was seldom used, perhaps because of the ethical and clinical difficulties these designs may imply.

²³ Rodin, G. (2008). New findings in psychosocial oncology research, *Journal of Psychosomatic Research* 2008:65; 511-512.

Project Deliverables

D 4.1 Month 37 **Final report**

Psychological and social support for patients, families and caretakers: Final Report

D 4.2 Month 37 **A minimum of one article for publication**

Popa-Velea O, Galushko M, Romotzky V, Simonič A, Ostgathe C, Voltz R on behalf of OPCARE9. *Psychological and psychosocial support for cancer patients and their relatives in the last days of life: What are the current research topics?*

Popa-Velea O, Simonič A, Ablett J, Galushko M, Romotzky V, Ostgathe C, Voltz R on behalf of OPCARE9. *Communication issues in the literature regarding psychological and psychosocial support for cancer patients and their relatives in the last days of life.*

D 4.3 Month 37 **A minimum of two presentations for future national/international conferences**

Romotzky V, Galushko M, Popa-Velea O, Ostgathe C, Ellershaw J, Voltz R. *The Dying phase: How is psychological and psychosocial support understood by palliative care experts across Europe? 9th – 11th 2010.* 8th congress of the German Association of Palliative Medicine (DGP) . Dresden, Germany.

Galushko M, Romotzky V, Popa-Velea O, Ostgathe C, Ellershaw J, Voltz R. *The dying phase: who is in need of and who can deliver psychological and psychosocial support - the perspective of palliative care experts in Europe.* 9th – 11th 2010. 8th conference of the German Association of Palliative Medicine (DGP) . Dresden, Germany.

Romotzky V, Galushko M, Popa-Velea O, Ostgathe C, Ellershaw J, Voltz R. *The dying phase: European experts' views on important communication issues in the last days of life.* European Association of Palliative Care (EAPC). 19th -21st May 2011. Lisbon, Portugal.

D 4.4 Month 37 **A minimum of one protocol for future research to enhance the evidence base for end of life decisions**

Protocol title: Psychosocial support for relatives of dying patients

Authors: Voltz R, Ostgathe C, Galushko M, Popa-Velea O, Romotzky V, Ablett J, Clark J, Di Leo S, Jorge M, Pahor M, Simonic A, Swart S, Tishelman C

6. OPCARE9: Work Package 5 – Voluntary Service

The model of care championed by the modern hospice and palliative care movement seeks to improve quality of life (and death) by promoting appropriate physical, psychosocial and spiritual care of dying patients and their families. Palliative care services have developed very differently across Europe (and beyond) and in several countries (for example Germany, Italy, the Netherlands and the UK) the volunteer movement has been at the forefront of the delivery of such care. In other countries, however, there is little available data to illustrate the quality and number of volunteer services integrated into the care of severely ill and dying cancer patients. Through the systematic identification and scrutiny of current research findings and assessment of expert opinion, this collaboration has facilitated exploration, sharing and comparison of current volunteer provision in supporting, supplanting or supplementing services in each beneficiary country. It has facilitated examination of education and training needs, and identified where possible, curricula of excellence in this area. It has also allowed the identification of existing technologies and quality indicators and facilitated the development of new ones for the appropriate assessment of such services. Where current evidence is lacking, this collaboration has developed innovative research proposals.

Accordingly, the objectives of this Work Package were:

- To explore, share and compare current provision in each of the beneficiary countries
- To provide insights into the various roles undertaken by volunteers in different countries– i.e. support, supplanting and supplementing services (Payne, 1998), in relation to the dying patient and their families
- To identify current education and training provision to determine future need and establish curricula excellence in this area.
- To Identify appropriate models for the delivery of high quality volunteer services now and in the future
- To develop protocols for future research to enhance the existing evidence base

6.1 Organization and collaboration

Work Package 5 has been led by Dr Ruthmarijke Smeding (Marie Curie Palliative Care Institute Liverpool, UK). The Work Package lead was assisted by the Scientific Project Assistants Colin Bragg (MCPCIL, UK)²⁴ and Margarita Jorge (Pallium Latinoamerica, Argentina), who assisted in the preparation and structuring of all WP activities. Representatives from each OPCARE9 country formed the core Work Package membership.

6.2 Challenges:

There were numerous challenges to overcome, both conceptual and organisational, in attempting to meet the Work Package objectives. Membership of the Work Package was very fluid over the 3 years of OPCARE9, and there were varying levels of connectedness to “volunteering” across the multidisciplinary Work Package members.

Establishing a “baseline” of volunteering roles and activities across OPCARE9 proved challenging due to the conceptual variations of volunteerism inherent in each country. The differences between direct and indirect patient care emerged from the onset. For example, we found that British volunteers are strongly involved in charity and fundraising, and rarely involved in direct patient care at the very end of life. This is in contrast to examples from Germany, Italy and the Netherlands. Multi-disciplinarity depicts the domain of volunteerism for Hospice & Palliative Care in general and accordingly it has been researched from many different disciplinary perspectives: in the systematized review, eight different disciplines were

²⁴ From Oct 2008 – Jul 2010

represented by primary authors alone. As a result, a need for clarification of terminology and paradigms to chart the terrain has been identified, reflecting the already known disparate state of the palliative care across Europe (and beyond).

Statistics and overviews are managed in a variety of categorizations, and although various organizations initially agreed to participate in (e.g. baseline surveys) answers to the questions generated were often not provided. As a group, WP5 agreed to stop this part of the data gathering process, though incomplete, as of the 1st of December 2009, acknowledging that information was either not provided, incomplete, or not available in the required format.

6.3 Methodology

Inductive formats were engaged, pulling together what was known in the group, before venturing out into uncharted terrain. A collated first baseline led to an initial survey of “volunteering” in the OPCARE9 countries, via 5 structured questions, posed to both volunteers and professionals. Subsequently, appropriate “Grey Literature” was collated.

Using strict “Systematic Review” and Delphi methodologies proved a challenge for Work Package 5. For example, engaging a traditional protocol for systematic review would have resulted in the exclusion of data from 7 of the 9 OPCARE9 countries. Similarly, a Delphi designed for the medical-academic world was projected to be of little value. Accordingly, as it was evidenced that as “Volunteerism” lives in native languages, a “thematic” review of the literature was generated (combining 32 articles in 8 native languages), to portray the state of the art, supplemented by a modified Delphi.

6.4 Results: Baseline Survey, Initial Survey and Grey Literature

General volunteering has a large value and is strongly engaged in all participating countries. However, the value of volunteering for Palliative Care appears to have a separate niche and depends on many variables – for example, where:

- reimbursement or financial streams range from governmentally subsidized, to, charity based (coordinators and health care insurance) to none, meaning self-raising, or providing funds
- palliative care volunteering is considered mainly for home situations, with exceptions that seem more to do with individuals and/or particular organizations allowing such in their institutions than with policies.
- direct patient care provided by volunteers in institutions was found in well developed, though structurally rather different formats, in Italy, Germany, the Netherlands and in Switzerland.

Analysis from the data initial survey shows the breadth, variety and the opening of dialogue between countries on volunteerism. More depth is uncovered in the “Grey Literature”, listing the current heart and soul of the volunteering movement. This information was collated and will be made centrally available on the public OPCARE9 website.

6.5 Systematic and Thematic Review.

The systematic review of the English scientific literature yielded 180 articles. Following the application selection and exclusion criteria, 42 articles remained for analysis. Exhausting the review criteria to find work in their own countries, Work Package 5 members found on a handpicked basis an additional 31 articles, in eight native languages, addressing the stipulated foci, which will be addressed in a separate article. Although a “core” sense was absent, key themes were yielded (Table 6.1).

Table 6.1 Key Themes in Volunteerism for End of Life Care

Key Themes in Volunteerism for End of Life Care
<ul style="list-style-type: none"> • Importance of shifts in interpretative cadres & advancement of volunteerism • Service & Organisational aspects of volunteering: role and emergent quality indicators • Provision and effects of volunteering • Education and Qualification for volunteers • Methodological aspects of Education and Supervision • Emerging research (Canada, the Netherlands and the United States)

The second part of the methodologically prescribed OPCARE9 project engaged a modified Delphi process to address the issues highlighted in the systematic review: to identify core issues, to benefit from such a process.

6.6 Delphi: Volunteers as non-professional experts

Academics with expert knowledge in volunteering for end of life care vary over a variety of disciplines, countries, and experience. Accordingly, this made consulting with internationally identified experts in a conventional Delphi practicably impossible. Therefore, the modified Delphi engaged the opinions of volunteers active in end of life care. Volunteers from eight of the beneficiary countries (it was not practicable for a volunteer to attend from New Zealand), participated in a panel discussion based on questions resulting from the English language systematic review. The interview has provided a unique lens into the world of volunteering of the OPCARE9 countries. Key finding from the panel discussion: volunteers viewed their contribution as that of “non-professional experts”.

6.7 Tools and Technologies

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. The four identified are: Claxton-Oldfield (2009)²⁵, Luykx and Schols (2009)²⁶ and the Volunteering Impact Assessment Toolkit (Institute for Volunteering Research, 2004)²⁷ and a psycho-social assessment of volunteer intervention (Wissert and Popelka, 2004).²⁸

6.8 Critical Friend

Feedback from Professor Allan Kellehear commended the Work Package team on the breadth and depth of the work undertaken, particularly in tying together a disparate body of knowledge. A number of potential papers for publication were identified from the collated material, and suggestions to encourage a de-medicalisation of the original search strategy and the incorporation of a more social and community development-based view of lay participation in palliative care services, were well received by the Work Package group.

²⁵ Claxton-Oldfield S, Gosselin N, Schmidt-Chamberlain K and Claxton-Oldfield J. (2010) A Survey of Family Members' Satisfaction With the Services Provided by Hospice Palliative Care Volunteers. *Am J Hosp Palliat Care* 2010; 27 (3),191-96.

²⁶ Luykx K.G, and Schols, JMGA. (2009) Volunteers in Palliative Care Make a Difference. *Journal of Palliative Care* 2009; 25, 30-39.

²⁷ Institute for Volunteering Research (2004) Volunteering Impact Assessment Toolkit. Institute of Volunteering Research, London/UK. www.voluntering.org.uk

²⁸ Wissert M, Popelka D. „Professionelle Qualität in der ehrenamtlichen Sterbebegleitung“ (Professional Quality for Volunteering to Accompany the Dying” in M. Wissert and D. Popelka (Ed) *Hospiz schafft Wissen*“ (Hospiz creates knowledge), Documentation of the Federal Working Group Hospiz Working Conference, 9th of November, 2003. Wuppertal/Germany, Der hospiz verlag.

6.9 Development of Future Research Protocol

From the findings of the systematic and thematic reviews, and complemented by outputs from the modified Delphi, three protocols for future research are in development.

- A proposal for a 2 year project with international collaboration, to engage volunteer support for dying patients and their families in the primary care setting in Liverpool has been developed and successfully secured £240,000 of funding from the Dimbleby Marie Curie Cancer Care Research Fund. Following validation of the newly to develop educational model, based on international experiences from Italy, Germany, the Netherlands, Canada and the UK, opportunities will exist to expand the intervention in both national and international contexts.
- A proposal has been developed to examine and document the activities of Palliative Care volunteers in supporting patients and their families in the last days and hours of life across all health care settings in Cologne, Germany. This project would be part of a hypothesis generating process, for further development of research protocols and follows directly a report in Argentina, from prospective research undertaken to chart the contributions of volunteers.
- A proposal to investigate the determinate factors that prompt individuals to volunteer in palliative care: based within Liguria, Italy.

6.10 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, and the Netherlands, where we found a curriculum expressively 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.

6.11 Potential Impact

A recent article for the German Hospice and Palliative Care Association (DHPV), calculated the fiscal contribution of volunteers as some 95 million Euros per year. Similarly, in a 2006 pilot survey of independent hospices in the UK, Help the Hospices calculated a £12 million pounds contribution, an equivalent of the NHS contributions in those days. Accordingly, the contribution of volunteers is not to be underplayed.

Strengthening an infra-structure to enable patients to die a supported dignified death should be irrespective of place of death. The submitted research proposals from Germany, Italy and the UK support a development strategy for volunteering, as do existing Italian and Dutch curricula. Accordingly, OPCARE9 has opened the doors to a research and development strategy to establish a core-curriculum of excellence. With our international collaboration in place, further coordinated and supported development can now be realistically anticipated.

6.12 Observations – Support and Collaboration

This Work Package has not been without its challenges. “Volunteers” as a subject, demonstrated an “otherness” in OPCARE9, which required adjustments in the (mainly) medically oriented structures and processes. Given the complexity of the task, the members of WP5 in a variety of formats have been a remarkable and supportive group, journeying on a

sometimes very challenging path. The loss of the dedicated Scientific Project Assistant provided a major challenge that was addressed by member of the Work Package and the wider OPCARE9 supportive structures. Particular thanks must be extended to the support offered from Germany, Switzerland and Argentina, the latter taking on an extra role in providing a new SPA - Margarita Jorge. With each challenge, the group has sought to address issues where possible, and engage in lateral thinking to provide solutions to unanswered questions. In this, the group’s efforts parallel that of the early hospice pioneers – the quest to improve the care given to patients and their families at the end of life.

Project Deliverables

D5.1 Month 37 Final report

Volunteerism and care of the dying. Final Report for OPCARE9

D5.2 Month 37 A minimum of one article for publication

Smeding RM, Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J, Popa Velea O, Mason S, and Ellershaw JE on behalf of OPCARE9. *Care, roles, education & training for volunteers in End of Life Care: a systematic Review*. For submission to Social Science and Medicine.

Popa Velea O, Smedding RM, Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J, Mason S, and Ellershaw JE on behalf of OPCARE9. *Edgewalking I + II: Volunteers and Volunteering in the last days of life: a baseline and a survey*.

Smeding, Rm, Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J, Popa Velea O, Mason S, and Ellershaw JE on behalf of OPCARE9. *Edgewalking III: Systematic Review of the English Literature on volunteers and volunteerism*.

Smeding, Rm Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J, Popa Velea O, Mason S, and Ellershaw JE on behalf of OPCARE9. *Edgewalking IV: A Thematic Review of the Literature on volunteers and volunteering in eight native languages*.

D5.3 Month 37 A minimum of two presentations for future national/international conferences

Smeding RM, Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J, Mason S, and Ellershaw JE on behalf of OPCARE9. *Edgewalking: Volunteers' Comments on the Questions of the Systematic Review for OPCARE9, WP5 (Volunteers)*. EAPC Lisbon 2011

Smeding, Rm, Bragg C, Jorge M, Schuller S, Boeddekker A, Gollo G, Reijtens J, Simonic A, Sauter S, Domiesen F, Clark J and Ellershaw JE on behalf of OPCARE9. *Volunteers at the end of life: Progress report OPCARE9, WP5*. EAPC Vienna 2009

D5.4 Month 37 A minimum of one protocol for future research to enhance the evidence base for voluntary service

Protocol Title - A Living Community Presence—an innovative approach for volunteers to support the care of patients and their families in the last hours and days of Life

Authors - Smeding R, Mason S, Voltz R, Salmon P and Ellershaw JE

7. OPCARE9: Quality Indicators

There is a general consensus on the domains that contribute to the quality of end-of-life care. However, the 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).

The aim of this project 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. To identify published and available QI, a literature search was performed, with selected QI assessed through an international panel of experts in the OPCARE9 community.

7.1 Development & Process

The QI assessment went beyond the boundaries of individual Work Packages (WP) and it was appropriate to make it a combined project for all WPs within OPCARE. Accordingly a “QI task force” was formed, consisting of:

- Scientific Project Assistants
- Representatives of PSG: Prof Dr John Ellershaw (and Maureen Gambles)
- QI-expert and coordinator: Prof Dr Christoph Ostgathe
- Four representatives of New Zealand, Italy, Argentina and Slovenia (countries without representation in SPAG)

Definition of Quality Indicator

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. Many publications on QI focus on palliative care in general, but rarely focusing specifically on the last days of life.

Identifying Quality Indicators

All quality indicators detected in the literature and national guidelines which may address the last days of life were identified. Then a survey among the OPCARE9 community was performed on the quality and applicability of the identified quality indicators. It was decided to address only ‘pure’ QI, which are referring to the last days of life and/or first days after death.

For these procedures we conducted the following steps:

- Update of Pasman’s²⁹ review including a search for end-of-life
- Selection of articles according to defined criteria
- Data extraction of selected articles
- Search for QI in national guidelines and documentation
- Dividing the results into three categories:
 - ‘Pure’ QI = QI with numerator, denominator and cut-off point
 - Measurement tools without numerator/ denominator
 - Areas/ issues of potential importance for QI-development

²⁹ Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009;38:145-56

7.2 Results

7.2.1 Literature Search, Assessment and Outcomes

From the literature review, 282 applicable references were detected. Following the application of selection criteria nine papers were included, and assessed by a data extraction tool. The systematic review performed by Pasman et al. included a total of 108 appropriate quality indicators. 33 were defined as pure QI, related to the end of life.

7.2.2 Search in National Guidelines for Quality indicators

The national guidelines of Switzerland, the Netherlands, Sweden and Italy have been reviewed. Out of these national guidelines 28 quality indicators have been detected. One of them was a “pure quality indicator” - those defined as having a numerator, denominator and performance standard.

7.2.3 Overview Identified Quality Indicators

Table 7.1 Number of QI identified in all beneficiary countries of OPCARE9

Source	QI for last days of life	Pure QI
National Guidelines (CH, Swe, NI & I)	28	1
Pubmed Literature search	282	-
Pasman article	108	33
Complete	418	34

7.3 Quantitative results

A Delphi was conducted, surveying the OPCARE9 members. In total, 41 out of 71 experts responded (58%). They had different professional backgrounds: 34% physicians, 17% nurses, 12% psychologists, 12% researchers, 7% social workers, 2% spiritual workers and 15% others. In total 66% were involved directly in patient care, with a mean experience of 11.3 years in practice, and 34% in QI development, with a mean experience of 5.2 years practice. All countries were represented.

The respondents rated the level of ‘good descriptor’ and the level of the QI being ‘applicable’ for the last days of life. These results are shown in table 7.2 and 7.3, highlighting the top 5 QI in each section, including the percentage of experts agreeing with the QI to be a good descriptor and/or applicable.

Table 7.2 Top five QI rated as a good descriptor of quality of care at the end of life.

	Descriptor of Quality Care	Valid N	% agree
<i>Structure</i>	Presence of dedicated room space for meetings on ICU between clinicians and families	38	89.5
	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	36	97.2
<i>Process</i>	Fewer than 4% of patients who died from cancer have had more than one ER visit in the last 30 days	35	82.9
	Fewer than 10% of patients who died from cancer received chemotherapy in the last 14 days of life	36	80.6
	More than 65% of all pts who died from cancer are cared for by a palliative network at home or in a hospice	36	77.8
	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	36	77.8
	The score for family insight is 0-1 ³⁰ in at least 75% of all patients during the last week of life	37	91.9
<i>Outcome</i>	The score for pain control is 0-1 in at least 75% of all patients during the last week of life	36	88.9
	The score for communication from professional to patient and family is 0-1 in at least 75% of all patients during the final week of life	36	88.9
	The global score for constipation does not increase over the initial score during the final week of life in at least 75% of the patients	32	87.5
	The score for communication between professionals is 0-1 in at least 75% of all patients during the last week of life	37	86.5

7.4 Qualitative Results

The open question presented in the survey which sought to identify other QI yielded 46 suggestions for Quality of Care, and 19 suggestions for Applicability at the end of life (range 1-5). The answers were formulated in a general manner and did not describe QI according to the definition used in the questionnaire ('pure' QI). Ten responses were omitted from analysis as they were incomplete or unclear.

There were no clear differences between suggestions written as: good in describing the Quality of Care vs. Applicable in order to assess Quality of Care. Some new QI areas, not included in the questionnaire, were proposed. For example, suggestions of *Structure* indicators were:

- aspects of training and education of staff delivering the care
- access and availability of service and support.

Suggestions of *Process* indicators included:

- interdisciplinary team meetings in a timely manner
- if the patient can make own decisions; and use of applicable pathways.

For *Outcome* indicators, aspects not asked for in the QI questionnaire included:

- patient and family wishes fulfilled
- the proportion of patients who died in their preferred place was suggested.

³⁰ Where 0 indicates that there is no activity related to the outcome, and 1 indicates successful activity

Additionally, support of volunteers for patients and families / relatives, irrespective of place of care, was mentioned as a possible QI.

Table 7.3 Top five QI rated as being applicable at the end of life.

	Applicability at the End of Life	Valid N	% agree
<i>Structure</i>	Presence of dedicated room space for meetings on ICU between clinicians and families	38	92.1
	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	37	91,9
<i>Process</i>	More than 65% of all pts who died from cancer are cared for by a palliative network at home or in a hospice	36	88.9
	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	36	88.9
	Fewer than 10% of patients who died from cancer received chemotherapy in the last 14 days of life	36	88.9
	At least 95% of all patients who receive home palliative care should be enabled to stay at home until death	38	86.8
	The score for pain control is 0-1 in at least 75% of all patients during the last week of life	36	83.3
<i>Outcome</i>	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	33	81.8
	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	32	81.3
	The score for communication from professional to patient and family is 0-1 in at least 75% of all patients during the final week of life.	35	80
	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	34	79.4

7.5 Discussion

In total 34 existing QI were assessed for their usefulness in measuring quality of care in the last week 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 involved 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.

7.6 Conclusions

As yet, no definitive set of QI for end of life care for cancer patients exists. 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 European (and beyond) quality improvement strategies and to facilitate the transfer of knowledge between settings and countries.

7.7 Potential Impact of Conclusion

A European (and beyond) study on QI for the care of the dying cancer patient has to be initiated.

Additional Project Deliverables

D4.1 Month 37 **Final report**

Quality Indicators

4.2 Month 37 **One article for publication**

Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa Velea O, Romotzky V, Schuler S, Ellershaw J and Ostgathe C on behalf of OPCARE9. *Quality indicators for care in the last week of life: Experts' views on how well they describe good care and their applicability in the last week of life.*

D4.3 Month 37 **Presentation for future national/international conferences**

Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa Velea O, Romotzky V, Schuler S, Ellershaw J and Ostgathe C on behalf of OPCARE9. *Quality indicators for care in the last week of life: Experts' views on how well they describe good care and their applicability in the last week of life.*
Oral presentation @ European Association of Palliative Care (EAPC) Meeting, Lisboa, Portugal, May 2011

8. WP6 Management, Dissemination and Communication

8.1 Project Steering Group (PSG)

The Project Steering Group (PSG) has been the final decision-making body for the consortium and has had input on all matters relating to project management, including technical, personnel, financial, budgetary control and task scheduling matters.

The PSG met regularly during the project, both during Colloquia and in additional face to face PSG meetings held in December 2009, July 2010 and January 2011 (Amsterdam), meetings during the European Association of Palliative Care Congress (Vienna 2009 and Glasgow 2010), as well as regular intranet discussions, SKYPE, email and blog with respect to feedback and ongoing discussions at required times. Each beneficiary has demonstrated their commitment, time and effort into effectively operating as a PSG for the current timeframe of this project. As the project developed, more strategic thinking around sustainability and legacy into the future, as well as scheduled planning for future key research themes, emerged.

The PSG has ensured that the project aims and objectives for the reporting period have been appropriately monitored and met and have been supported in this task by the Project Management Team (PMT) and the Scientific Project Assistant Group (SPAG) – see below. No changes have been made to the Consortium in the reporting period and there are no problems to report.

The PSG has developed appropriate documentation in order to enhance the functionality and operationalisation and of the project (Appendix 3). These include:

- A Colloquium Planning Document to provide important planning information and reference material to beneficiaries who have the responsibility of organising one of the 7 Colloquia in their country. This document is reviewed by the organising party after each Colloquium and amended in support of improved planning for future Colloquia. This was a live document, continuously updated and was of enormous benefit to hosts and can be used to guide future collaborative meetings.
- Guidelines for publication procedure. These guidelines (which form part of the Consortium Agreement) were developed and refreshed to support the process of writing and submitting publications with respect to OPCARE9 collaborations. The format that emerged included guidance on writing committees and appropriate authorship and relates to all publications, whether in peer reviewed journals or abstracts for posters or oral presentations.
- Dissemination templates. To support the recording of dissemination activities a template was developed to help identification of specific dissemination for each WP and Beneficiary. Using this template, all personnel have been able to view and track progress across the project as the life cycle of Opcare9 has progressed thus far and into the future. This also enables potential duplicates of activity to be identified at an early stage and further promoted joint presentation of specific work at major events across Europe and the international arena.
- Corporate Documentation. Further corporate documentation has been developed, including letterhead template and finalised “core slides” for all personnel to be used in presenting the outputs of OPCARE9.
- VOCAL Platform. A highly sophisticated, multi dimensional and fully interactive intranet has been developed by Liverpool in order to engage all project personnel with continual and up to the minute information and discursive opportunity. All WPs had individual sites within the main site and there is an opportunity for all to locate and review documentation which was pertinent to the project’s cross-cutting themes. Workspaces and documents appropriate to each Project Colloquium allowed project personnel to remain informed about progress across the project in advance of the upcoming Colloquia and discussions and

blogs were a regular occurrence, thus moving project ideas and methodologies forward as quickly as possible to as wide an audience as possible. This truly reflected the collective and collaborative nature of this project. The VOCAL platform will continue to be used and accessed by members as plans for future collaborative working are realized.

8.2 Project Management Team (PMT)

The Project Management Team (PMT) has met regularly (monthly) during the reporting period in support of the work of the PSG. Specifically, the PMT have:

- Overseen the day to day project management and administration of the project and ongoing reporting of progress to the PSG
- Acted as point of contact for beneficiaries in communications with the EU, leading and collating reporting to the EU including the submission of audit reports and cost claims and the ongoing progress and development of the project
- Monitored and managed budgetary matters, including the receipt and distribution of income, financial control and guidance on eligibility of costs, responding in a timely manner to beneficiaries on all matters
- Presented contractual options and obligations which all beneficiaries and critical friends were made aware of in executing the project
- Developed internal electronic systems to enable timely collection and collation of data through templates and databases
- Established and maintained communication and reporting mechanisms across the project including the production and distribution of monthly updates (circulated via our Intranet site as well as via PSG members to appropriate colleagues in each beneficiary country) to support wider communication of successes and challenges across the project.
- Supported the organisation of all Colloquia in conjunction with host countries.
- Supported the monitoring of progress, identification of problems or key areas requiring further action, and provided assistance in resolving problems
- Archived project documentation (including progress reports, minutes, documentation developed by the PSG)
- Monitored the progress against the action points that have arisen from the PSG meeting(s) in all seven Colloquiums.

8.3 Scientific Project Assistant Group - SPAG

A major development of note was the establishment of the Scientific Project Assistant Group (SPAG) during Year 1. At least one Scientific Project Assistant was appointed in WPs 1 -5 primarily to undertake and support the systematic review and Delphi process within each WP. However, it was recognised that extending their role to encompass a project wide focus would have a potentially positive impact on both the project and the development of the young researcher's expertise. The SPAG was therefore established to provide 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. An identified SPA also represented the group at PSG meetings in an effort to support effective communication between these essential groups.

The SPAG group offered a channel for fast, effective and regular contact throughout the OPCARE9 collaborative as they became responsible for the majority of the project correspondence on a day-to-day basis as time went by. The group facilitated the flow of information between the Project Management Team, Project Steering Group and Work Package Groups; moreover, it provided a direct connection across all areas of the project, from project management to individual members and extended National Reference Groups. Joint

PSG and SPAG meetings were held at each Colloquium to facilitate the project's progress and also served as a developmental activity for junior researchers in contributing to the strategic direction and thinking of the PSG.

The SPAG group communicated regularly via a dedicated VOCAL forum as well as by telephone and email. They also met at least once a month via Web-conference in which they collaborated as a group on key issues, support and learn from each other and discussed project wide issues in order to avoid the duplication of work and resources.

The SPAG group played an important role in highlighting future research opportunities and also potential congresses or journals for future dissemination of OPCARE9 work. In the final year, the SPAG took a leading role in the development of a further working group, in cooperation with the individual WP's, to define and identify Quality Indicators, with the aim to address this cross cutting theme in a broad and systematic manner.

8.4 Work Package Meetings

These intra and inter colloquium scheduled meetings provided a forum for the WP groups to meet to discuss, develop and agree action plans and progress work together. The opportunity to meet face to face was valued by all and is particularly important in light of the fact that all beneficiaries are represented within all WP's. The majority of interaction outside of the Colloquiums was undertaken mainly using the highly interactive and functional intranet facility which had been developed by PMT. This was used extensively by all project personnel for joint working, blogging and responding to discussion items as well as reviewing and updating documentation. In addition to face to face work within WP's, these meetings also offered the opportunity for all project personnel to engage in parallel workshop activity on specific themes, such as the LCP and cross cutting themes. Project Steering Group (PSG) continued to meet to manage the process and progress of the project during Colloquia.

8.5 Development of Website and intranet facility

An 'outward facing' website www.opcare9.eu went live during the second reporting period and continues to be updated with useful information about ongoing activities to interested parties. Hits have increased and reached a peak prior to the Liverpool Final Conference. Visitor statistics were collected regularly in order to monitor interest and make improvements to pages.

An intranet facility "VOCAL" (see earlier description of this platform) was developed by PMT during the reporting period and underwent several updates to improve interactivity and functionality. At the time of writing, membership of the VOCAL site has reached 80 active members contributing regularly to online project discussions and furthering project outcomes.

Appendix 3 contains selected information and statistics from both sites.

Project Deliverables

D6.1 Month 17	Consortium agreement
D6.2 Month 12	Fully functioning website
D6.3 Month 12	List of: peer reviewed journals; appropriate conferences (national and international); and potential sources of research funding
D6.4 Month 18	Mid term review/evaluation reports
D6.5a Month 12	Annual Cost Report
D6.5b Month 24	Annual Cost Report
D6.7a Month 1	Steering Group Minutes (1st project group colloquium)
D6.7b Month 7	Steering Group Minutes (2nd project group colloquium)
D6.7c Month 13	Steering Group Minutes (3rd project group colloquium)
D6.7d Month 19	Steering Group Minutes (4rd project group colloquium)
D6.7e Month 25	Steering Group Minutes (5th project group colloquium)
D6.7f Month 31	Steering Group Minutes (6th project group colloquium)
D6.7g Month 37	Steering Group Minutes (Final project group colloquium)
D6.8 Month 37	International workshop of experts
D6.9 Month 37	Database of agreed technologies and Quality Indicators
D6.10 Month 37	International Conference
D6.11 Month 37	Plan for continuation of collaboration
D6.12 Month 37	Final Report Progress against milestones and Dissemination & Exploitation

9. OPCARE9: Work Package 7a - Evaluation of Collaborative Working

OPCARE9 was a European Collaboration established to optimise research for the care of cancer patients in the last days of life. OPCARE9 was a complex collaboration that brought together experts from different countries, organisations and cultures.

Collaborative networks have increasingly become identified as a legitimate way of organising people and resources to deliver diverse and high quality benefits to consumers, communities and wider economies. The relational power of collaborative networks, with their emphasis on trust, reciprocity and mutuality, provides the mechanism to bring together resources and knowledge from dispersed and even competitive groups or organisations into a collective venture.³¹ Collaborative networks also provide a promising mechanism to share information, tap into new knowledge sets and potentially lead to increase opportunity 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 a key leadership challenge and is critical to success; research shows that 50-60% of collaboratives fail in the first 12 months of establishment³².

9.1 Key Characteristics of Effective Collaborative and Partnership Working

A review of the management literature identifies key characteristics required to support effective collaborative and partnership working as;³³

- 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 aimed to embrace the principles of collaborative working as outlined above. These principles imply the need for both considered leadership and management in order to maximise the benefits from work of this nature, size and complexity.

Accordingly, it was imperative that the OPCARE9 project developed a system to examine and evaluate the quality of the collaborative working undertaken in order to provide data to highlight incumbent challenges and support successful practice. 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:

- a. 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
- b. Provide a report that will inform future collaborative working ventures

9.2 Methodology

Phase 1: Phase one of the evaluation was conducted between in months 14-16 of the 36 month project, using structured questionnaires to collect quantitative and qualitative data.

Phase 2: The findings from the first phase were used to inform the design of evaluation approach for the second phase. The framework designed explored the following domains:

- a. Collaborative leadership

³¹ Agranoff R. "Inside Collaborative Networks: Ten Lessons for Public Managers". Public Administration Review, Special Issue, 2006.

³² Kelly, M. et al. Managing alliance relationships: Key challenges in the early stages of collaboration. R&D Management 32; 2002.

³³ Hudson B. Hardy B. et al. In Pursuit of Inter-Agency Collaboration in the Public Sector: What is the contribution of theory and research? Public Management. 1999; 1: 235-260.

- b. Achievement of objectives and outcomes
- c. Structure and working arrangements
- d. Sustainability and legacy

Phase two was conducted between in months 28-31 of the project, using a combination of semi-structured telephone interviews, structured questionnaires and semi-structured group interviews.

9.3 Results

The results report on evidence of the “Key Characteristics” as these emerged within the four domains: Collaborative Leadership; Achievement of Objectives and Outcomes; Structure and Working Arrangements; and Sustainability and Legacy.

9.3.1 Collaborative Leadership

In regards of Collaborative leadership, OPCARE9 was perceived to have achieved two of the six characteristics (characteristic 3 and 4). Additionally, there was some evidence that OPCARE9 has fulfilled the requirements of characteristic 6.

- *Characteristic 3* - Ensuring commitment and ownership – PSG and SPAG were identified as critical in providing motivation, engagement and commitment. PSG played a key role in the earlier stages in creating the conditions for collaborative working for OPCARE9. SPAG enhanced this further by providing a key intermediate role between the strategic requirements and the day to day delivery.
- *Characteristic 4* - Developing and maintaining trust – building on pre-existing relationships, ensuring leaders were accessible and the adoption of a ‘democratic’ and engaging style of leadership throughout the OPCARE9 project is evident in the fielded data. For example;
 - o *“Every person in every country can contribute their own piece of knowledge and experience. If it is organised in a different way, in a hierarchical way, it would not have worked. This openness is good. We have 5 Work Packages but all the time had openness feeling. Even if you are not a leader or a professor you could still contribute. You were important and felt so everyone could get their own place in the collaboration” – Work Package Member*
- *Characteristic 6* – Monitoring, measuring and learning - There was some variance in perception from members in OPCARE9 about the level of monitoring, measuring and learning. Overall OPCARE9 members perceived that the majority of Work Packages were on target to deliver Work Package objectives. It was suggested that in the early days there was less focus on process management, which for some OPCARE9 members presented challenges as there was a sense of ‘lack of direction’. It was acknowledge that this was a ‘normal’ stage in any team, group or collectives’ development. For some OPCARE9 members it seems that the ‘telling’ step was less overt. This highlights the important role that leaders play in building trust and new ways of working together and not assuming that the wider collaborative are comfortable with ambiguity or emergent development.

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. This could be supported by using a framework such as Blanchard and Hersey (1988) situational leadership model to instigate dialogue and understanding of expectations and requirements

- 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.

9.3.2 Achievement of objectives and outcomes

In regards of Achievement of Objectives and Outcomes, OPCARE9 is perceived to have achieved three of the six characteristics (characteristic 1, 2 and 3). Additionally, there was some evidence that OPCARE9 has fulfilled all the requirements of characteristic 6.

Characteristic 1 - Recognise and accept the need for collaboration – members cited tangible benefits at a personal level, within their professional sphere of expertise and ultimately to wider society. This was underpinned by the diversity of membership, speed of access to data and the opportunities created through multi-disciplinary working. The ‘uniqueness’ of the collaborative provided challenges: these were overcome due to the experience, commitment and passion of the OPCARE9 members.

Characteristic 2 – Develop clarity and realism of purpose – The clarity of vision evidenced in phase one of the evaluation highlights that OPCARE9 members could identify the wider benefits of international collaboration.

Characteristic 3 - Ensuring commitment and ownership – PSG and SPAG were identified as critical in providing motivation, engagement and commitment. PSG played a key role in the earlier stages in creating the conditions for OPCARE9 and SPAG enhanced this further by providing a key intermediate role between the strategic requirements and the day to day delivery.

Characteristic 6 – Monitoring, measuring and learning – There is stronger supporting evidence in this section that OPCARE9 has systems and processes in place to monitor, measure and learn. There was a high degree of confidence that the OPCARE9 collaborative would achieve its goals and increased clarity at Work Package level about objectives and timeframes for delivery. A culture of learning is evident within OPCARE9. Work Package 5 offers OPCARE9 the opportunity to review and learn when an aspect of a complex project is not working at the same pace or is experiencing challenges delivering agreed objectives.

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 and complexity and nature of 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.

9.3.3 Structure and working arrangements

The findings in this section demonstrate that OPCARE9 is perceived to have achieved two of the six characteristics through the collaborative leadership approach (characteristic 3 and 5). Additionally, there is some evidence that OPCARE9 has fulfilled all the requirements of characteristic 6.

Characteristic 3 - Ensuring commitment and ownership – All OPCARE9 members articulated high levels of commitment. Participants in the evaluation process contributed significant amounts of personal time to the project.

Characteristic 5 – Create clear and robust collaborative arrangements – For many OPCARE9 members this was their first experience of working on a project of this size, scale and

complexity. It was difficult for some to assess if different working arrangements would have improved the effectiveness of OPCARE9. Overall, working arrangements were viewed positively. Communication was challenging, however members worked hard to overcome difficulties of interpretation and meaning.

Characteristic 6 – Monitoring, measuring and learning – There is evidence in previous sections of this report that highlight some degree of success in putting place mechanisms for monitoring and measuring. Cross cutting themes appear to have not have had the same level of attention i.e. defining aims, objectives and responsibilities

The key learning within this domain includes:

- Having a programme management structure and co-ordination role are 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 (references to e-mail and VOCAL being problematic). 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 communication conduit (vertical and horizontal) was key to ensuring members of OPCARE9 were kept informed and could contribute effectively. This was perceived as enhancing the leadership function
- Working on cross cutting themes was challenging and would have benefitted from conceptual clarity at an early stage

9.3.4 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

9.4 Overall Analysis: Accordingly, analysis of the aggregated “Key “Characteristic” data across the four domains presented, suggests that OPCARE9 was functioning both successfully and effectively as an integrated collaborative (Table 9.1)

Table 9.1 - Strength of Evidence of Successful Collaborative Working

Criteria	Description	Strength of evidence ³⁴
1	Recognise and accept the need for collaboration	Strong
2	Develop clarity and realism of purpose	Strong
3	Ensure commitment and ownership	Strong
4	Develop and maintain trust	Strong
5	Create clear and robust collaborative arrangements	Strong
6	Monitor, measure and learn	Medium

³⁴ Strong = clear evidence and examples; Medium = partial evidence – areas for development; Weak = Little or no evidence

9.5 Conclusions

OPCARE9 has been successful in establishing a Collaborative that is delivering its original scope and brief. The project provides an excellent example of a successful collaborative network with strong foundations for sustainability. There is sufficient evidence from the evaluative process to demonstrate that OPCARE9 fulfils success criteria when compared with a number of studies from management, leadership and business literature.

9.6 Observations – Support and Collaboration

OPCARE9 has demonstrated significant success given its size, scale and complexity. Indeed, in organisational development terms OPCARE9 is ahead of ‘predictable’ development for a network of this nature, based on the findings in the academic literature. For example, ventures of this nature have been identified as taking up to 5 years to function at the integrated level on which OPCARE9 is operating.³⁵ This can be attributed to the factors described within this report, such as the leadership approach, project infrastructure, the passion, commitment and attitude of its members who throughout this evaluative process have demonstrated high degrees of maturity, authenticity and a compelling desire to make a real difference in their field of expertise and people that they care for.

Overall, there has been an enormous amount of enthusiasm about the approach and work of the Collaborative. The dedication and commitment to the project was overwhelmingly demonstrable by all involved in the evaluation process.

Project Deliverables	
D7.3 Month 37	Final evaluation report Fowler-Johnson S, Mason, S, Dowson J, Gambles M and Ellershaw J. <i>The collaborative working of OPCARE9: an evaluation of a European project to optimise research for the care of cancer patients in the last days of life.</i>
D7.4 Month 37	A minimum of one draft publication (peer reviewed journal) and 2 conference presentations on the learning of the programme relating to the principles underlying effective collaborative, co-ordination and support programmes Article Mason S, Dowson J, Gambles M, Fowler-Johnson, S and Ellershaw JE. <i>European collaborative working to optimise care of cancer patients in the last days of life: an evaluation of OPCARE9.</i> To be submitted to European Journal of Palliative Care Presentations Mason S, Dowson J, Gambles M, Fowler-Johnson, S and Ellershaw JE. <i>Evaluation of European collaborative working to optimise research for the care of cancer patients at the end of life.</i> European Association of Palliative Care Conference – Lisbon 2011 Gambles, Dowson J, Fowler-Johnson, S and Ellershaw JE. <i>OPCARE9: International interdisciplinary collaboration to improve end-of-life cancer care.</i> Ellershaw JE. European Association of Palliative Care Conference – Vienna 2009

³⁵ Kanter R. Collaborative Advantage: the art of alliances. Harvard Business Review 1994: **72** (4); 96-108. Kelly, M. et. al. Managing alliance relationships: Key challenges in the early stages of collaboration. R&D Management 2002 :**32** (1); 11-22. Mandell and Keast. A new look at leadership in collaborative networks: Process catalysts. In: Raffel, J; Leisink, A. and Middlebrooks, A. (eds.) Public Sector Leadership. Cheltenham, Glos & Northampton, Mass.: Edward Elgar Publishing Inc, 2009.

10 OPCARE9: Work Package 7b - 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 within an environment. The implementation of the programme will create a change situation. Recognition of the fundamental aspects of a change management programme is pivotal to success to empower, enable and engage those with whom you work. The service improvement model used at the Marie Curie Palliative Care Institute Liverpool (MCPCIL) is a 4 phased approach to change management.

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. In the UK with its established specialty of palliative medicine it is absolutely reasonable to suggest that although the LCP is a generic document it should be implemented and supported by specialist palliative care.

Since 2000 the LCP Central Team at the Marie Curie Palliative Care Institute Liverpool (MCPCIL) has been working with a number of palliative care and oncology leads in several countries around the world regarding the development, implementation, and dissemination of the LCP programme. As described above, there was on the one hand the UK with its well established palliative care approach, and on the other hand, many countries where palliative care was in its infancy with new structures for palliative care integration being developed within their healthcare systems. This has led over time to a mutual learning of how best to integrate the LCP programme in other countries. Based on evaluation of this learning an LCP International Programme has developed.

To maintain the integrity of the LCP programme it is important to collaborate with colleagues within English and non English speaking countries. Learning in support of a continuous quality improvement process, and the development of the research and innovation agenda for care of the dying will be enhanced if it is agreed that the goals on the model LCP remain the same.

10.1 Organisation and Collaboration

It has been demonstrated that the LCP is transferable for use in other languages and within very different cultural contexts. Since 2004 an annual LCP international meeting has attracted attendance across 20 countries. Doctors, nurses, social workers, psychologists, researchers, and other professionals come together to share experiences of the LCP programme and the LCP model itself. The OPCARE9 Project has enabled the key leads in International LCP development to work together towards the development of a robust LCP International programme.

10.2 Key objectives included;

- Establishing an International Reference Group for the LCP
- Incorporating recommendations of the Work Packages into the LCP framework
- Development of a robust process for international spread and dissemination of the LCP
- Sharing research methodologies relating to the LCP
- Development of a robust evaluation framework for the LCP
- Identifying research questions related to the LCP framework and identifying suitable research methodologies to address these

10.3 Critical Friend

Feedback from Kris Vanhaecht commended the LCP as a unique example of a model pathway. He outlined the four levels of pathway products. The model pathway which is not organisational specific but sits at an international / national or state level, the operational pathway that includes local personalised prompts as part of the local governance framework and the assigned pathway which is used at the bedside that becomes the completed pathway that can be audited to measure the quality of care delivery. The fact that the LCP is used in different types of organisations, on different continents within different cultures, professional, competencies, and interests; inspires other clinicians and other networking associations to translate this knowledge transfer into other clinical areas. The patient and relative/carer information that sits within this pathway based on the model and operational pathway should be a pertinent by product to support the design and development of other pathways within palliative care.

10.4 Conclusions

International and multidisciplinary collaboration regarding the LCP Programme has culminated in a designated international chapter in the core LCP text book:

Ellershaw J. & Wilkinson S. (2011) *Care of the dying: a pathway to excellence*. 2nd rev ed. Oxford: Oxford University Press

Each of the OPCARE9 collaborators contributed their International perspective. The LCP International Reference Group has been formulated with Terms of reference and membership agreed and a set of Work Packages over the coming year to rive up the quality agenda regarding care in the last hours or days of life using the conduit of the LCP Programme. The first formal meeting of the Group will be held in conjunction with the International LCP Conference in London in December 2011.

10.5 Potential Impact

10.51 Work Package 1 - Signs & Symptoms of approaching death

It is hoped that the 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. This is likely to assist in the education programme of the Liverpool Care Pathway, providing evidence based guidance to clinicians to assist clinical decision making regarding the engagement of the pathway.

10.52 Work Package 2 - End of Life Decisions

End-of-life decision making is one of the key elements in the Liverpool Care Pathway (LCP) for the dying patient. In the LCP (version 11) the prompts of one of the goals focuses on assessment of whether artificial nutrition and hydration are indicated or not. The systematic literature review and Delphi study of Work Package 2 have proven that evidence for decision making about nutrition and hydration is currently insufficient. Nutrition and hydration in the last phase of life are sensitive topics that can raise emotional debates, as evidenced in recent media coverage in the United Kingdom. As a response to these debates, the latest UK version of the LCP (version 12) has been adapted. More detailed considerations have been included concerning artificial hydration and nutrition. It remains to be proven that such detailed attention for this topic is also feasible in other countries, because cross-national and cross-cultural perspectives on appropriate and ethically sound end-of-life decision making may vary.

10.53 Work Package 3 - Complementary Comfort Care

As part of the thinking emanating from Work Package activity, suggestions for the forthcoming revision of LCP have been collated. A selected group of practitioners were asked to consider the “non pharmacological care activities” list in terms of possible amendments or additions to the goals as presently formulated in the LCP. Comments included;

- A new goal under the heading “care after death” could be added about closure in contact with the family (e.g. bidding farewell to the deceased, follow-up bereavement support).
- The LCP should / could be more oriented to patients/family perspectives, i.e. active participation and resources should support patient/family sense of agency and control.
- A new LCP goal, based on the review of the NPCA list: “Maintaining connections to the individual’s everyday life”.

10.54 Work Package 4 - Psychological & Psychosocial support

The Liverpool Care Pathway (LCP) can promote a greater openness around death and dying, potentially contributing to a deeper and more meaningful clinical relationship, a better recognising of dying and a better teamwork around all carers. A number of LCP goals correspond well with some of the research themes identified in workpackage 4; such as communication (goals 3.1 and 3.2), symptoms/concerns/needs (goal q) and interventions (goal p).

The Delphi results showed that the LCP is a well-known intervention and evaluated as an tool that is useful in the dying phase. Consequently, it is possible to conceive LCP as a good international reference point for professionals engaged in care to meet the psychological and psychosocial goals, irrespective of their different expertise. It could show who is engaged, in different countries, in realizing certain goals of care and it could equally facilitate communication across countries and professions about how to deliver better care. The use of LCP in different countries has the potential to contribute to a deeper understanding of cross-cultural differences in multiprofessional teamwork.

10.55 Work Package 5 - Voluntary Service

The UK research proposal is directly related to the Liverpool Care Pathway. An LCP-volunteer group (LCP-v), trained via an international curriculum focusing on the last days and hours of life, will pilot a next step for the LCP, namely to provide, if so wanted, a bridge between the community and the place of dying: in this case, a 1100 bed university hospital. LCP-v, aims at bringing the soul of hospice to the “unit of care” no matter where the patient is dying, overcoming the duality “institute” vs. “community” by combining organizational and community “languages” to accompany those on their last journey, in order to create circumstances that allow for as good a death as possible within the given context.

10.6 Observation Support and Collaboration

The Work Package collaboration has demonstrated that 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.

Level 1 State / Country	When any organisation / institution within a state or a country is registered with LCP Central Team at Marie Curie Palliative Care Institute Liverpool (MCPCIL). This activity is driven by each organisation independently and is not coordinated by a designated state or country lead.
Level 2 State / Country	When any organisation / institution across a state or a country is registered with LCP Central Team at Marie Curie Palliative Care Institute Liverpool (MCPCIL) and there is a recognised LCP Lead who coordinates the LCP activity across a region or a geographical location.
Level 3 State / Country	When any organisation / institution within a state or a country is registered with LCP Central Team at Marie Curie Palliative Care Institute Liverpool (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.

Project Deliverables

D7.1 Month 37 International Evaluation and Dissemination Plan for the LCP

Actions Undertaken

- Establishing of an international reference group for the LCP (IR-LCP)
- Terms of Reference Established
- IR-LCP populated
- Annual International Meeting and Conference scheduled
- Incorporation recommendations of the Work Packages into the LCP Programme
- Development of robust process for international spread and dissemination of the LCP
- IR-LCP Established as focal point for sharing research methodologies relating to the LCP
- Development of a robust evaluation framework for the LCP
- Identification of research questions related to the LCP Programme and identifying suitable research methodologies to address these

D7.2 Month 37 Reports re recommendations for further development of the LCP

Murphy D, Bolger M and Ellershaw JE. *Work Package 7b - Liverpool Care Pathway for the Dying Patient (LCP) International Programme*

Ellershaw J. & Wilkinson S. (2011) *Care of the dying: a pathway to excellence*. 2nd rev ed. Oxford: Oxford University Press

11. OPCARE9 - Conclusions and Future Developments

As evidenced in the Work Package reports, the scope of the current knowledge base within each of the themes examined lacks depth and breadth. Evident is the need for co-ordinated high quality research on which to base the delivery of care in the last days of life. The established collaboration provided a supportive forum for debate and critical challenge to promote best practice. The Coordination and Support Actions 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.

11.1 OPCARE9 Conference 2011: Optimising Care of the Dying in the 21st Century

At the end of the three year programme, an international conference was held in Liverpool to disseminate the findings from the individual Work Packages and celebrate the successes of the collaborative venture. Clinicians, researchers, policy makers, patients and carers were invited to engage and reflect on the achievements and future challenges inherent in optimising palliative care. In parallel with the conference, a policy summit was hosted, which offered an opportunity to review the continued development of international palliative care, and to prepare strategies to provide an environment in which future collaborative research would be realised to improve the evidence base for clinicians caring for dying patients and their families.

Some reflections from conference attendees, speakers and chairs included:

"As a patient / carer I am very positive that OPCARE9 has the right approach in ensuring that the LCP, embedded in international research is the pathway of choice for all terminally ill patients, no matter what country they are unfortunate to receive that dreadful news. It is reassuring to know that out of the conference policy summit meeting there is an agreed strategy which includes patient / carer involvement in the measurement of that care."

Sharon Bird

Patient & Carer Representative

Liverpool, North Cheshire & Wirral Cancer Locality Group.

"It was an excellent day and I felt privileged to be invited."

Barbara Burkey

Vice chair of the Patient/Healthcare Professional Partnership Group.

Member of the End of Life and Palliative Care Clinical Network Group

User Representative & Taskforce Member: Merseyside and Cheshire Cancer Network

"The work of OPCARE9 has placed emphasis on how different countries and cultures provide care for the dying and how a collaborative approach to research can bring benefits to patients here in the UK and beyond. We need to continue to work between nations"

Professor Sir Mike Richards

National Clinical Director of Cancer & End of Life Care, Department of Health, England.

"The research collaboratives that have been established, with so much effort and so much energy, have to be kept going... ...I'm quite happy to hear of the research proposals being constructed from the results of the OPCARE9 meeting. The exchange between the countries, between the cultures is really important to get down to the basics of what's behind palliative care."

Professor Lukas Radbruch

President of the European Association of Palliative Care (EAPC)

11.2 Conclusions: Collaboration and Support

Key aspects of international collaborative working have been learned from participation in this project. This forms the basis for the continued work and development of the group beyond OPCARE9. For example, prior to the start of the collaboration, a management structure was engaged to lead this project. Although based on considered principles, and on experience from participants involved in previous European Union Framework collaborative projects³⁶, it was not anticipated that the structure would perform as designed, rather that a process of learning, adjustment and assimilation would emerge.

Working internationally, 2 aspects were anticipated:

1. A structure only works when the people working in it, can own it.
2. The structure needs to integrate and synchronise existing high power leadership in the nine beneficiary countries - that means different concepts, styles and contexts.

We were aware that it would take time, careful listening, flexibility and continuous reflections, to optimise the functioning of the new structure employed. The confidence of the group to work in this way was further developed with the invitation of a Critical Friend, Professor Susan Block, to review and examine the functioning and output the collaborative during the 4th colloquium in Germany. Following this successful experiment, the colloquium expanded to the invitation to employ critical friends for each workpackage to attend the penultimate colloquium and provide specific contextual feedback on progress and outputs generated.³⁷

The levels of reflection, as these emerged during the 6th Colloquium, demonstrated both a sense of group and subject-maturity. Where challenged one day, the group reflected and by the next day demonstrated that it was competent to receive and work with such criticism, following the generated path with confidence, where the scientific dialogue involves discussion that either adjusts it's course along the lines of the criticism provided, or strengthens its position from the ability to support the criticism on deeper levels, staying with the original design.

I had the privilege of participating in the Cologne and Rotterdam meetings as a critical friend. I found the level of engagement, enthusiasm, commitment, and effort at both meetings to be extremely high. The role of a critical friend is a privileged perspective as one is both an insider and an outsider. I felt that, in my role, I was able to see the strengths and weaknesses of the project from both perspectives. It was challenging at the first meeting to get a sense of the goals, objectives, processes, and desired outcomes of the project, as well as what was expected of me. It was much clearer at the second visit. By the second meeting, I had a greater sense of where the project was going and what the project asked of me. I hope my contributions were useful to the group; I also felt that I learned a great deal from my participation in the project.

Professor Susan Block – Harvard Medical School

In addition to the testing of OPCARE9 by the critical friends, both as a functioning collaborative and in its scientific endeavours, two further developments emerged as key in the success of the collaboration.

The first consideration relates to the genesis of the structural organisation of the project. The design of the project methodology was set up by the team at the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in the UK. This design, functioning as an invitational format, was based in MCPCIL's experience of that time, in working cooperatively and collaboratively,

³⁶ EU 5th Framework Programme – Promoting the Development and Integration of Palliative Care Mobile Support Teams in the Hospital

³⁷ see table 1.4, p.13 for a list of critical friends

including working with different cultures. This initial and invitational design was consequently used in a facilitated manner, that is, the collective membership, was invited to sculpt a format that would fit the whole group. This “invitational facilitation” was used continuously, sculpting and shaping a process, in which all would be encompassed. Systematic reflections, both in the PSG and as MCPCIL co operational leadership, were used, to continue facilitating, until a fitting and workable format emerged. It is this aspect of a successful creation, by way of adjustment to international collaboration and cooperation that we would like to own as an OPCARE9 PSG team. We anticipate that there is far more to be learned in this context, yet over the years, this was a continuous and major learning process, in which we now can, in shared ownership of newly created structures, move forward together. The process has allowed for an open format that is adjustable. This “gain” can be viewed as a professional trust that has created an operational basis from which we seek to research “care of the dying” in Europe and beyond.

The second consideration, evident upon reflection, related to the consolidation of established international relationships. There has been great benefit in working with an international group of colleagues, already established as leaders in their field, whom we already knew through the emerging International Liverpool Care Pathway network. This network had previously been steered and led by the MCPCIL, as the owners and designers of the LCP. The MCPCIL team was already engaged in a leadership position for the implementation of the complex intervention (the LCP) in both a national (British) and an International perspective (the LCP is currently used in 21 different countries). This process is one of continual development, and meshed seamlessly with the key aims of OPCARE9: realised as a discrete executive Work Package 7b. Accordingly, the OPCARE9 project has provided further impetus into the development of the international development of the LCP, in the formation of an International LCP Reference Group, and this opportunity for reciprocal development has immeasurably strengthened both elements: OPCARE9 & International LCP.

11.3 Conclusions: OPCARE9 Scientific Project Assistants Group (SPAG)

Early in the OPCARE9 project, it became evident that, besides the Project Steering Group (PSG), an interconnection on the operational level was needed in the project. For this reason, a group of young researchers from the five primary Work Packages was established in October 2008; the Scientific Project Assistants Group (SPAG). The objectives of SPAG were to consolidate and standardize research methodologies throughout the project, support and learn from each other, act as a channel for fast and easy contact and to avoid a duplication of work. The SPAG has over the years had different compositions, but most of the time the SPAG has consisted of 3 senior lecturers and 6 junior researchers with different levels of experience and professions (social scientist, physician, nurse and social worker). Besides the face to face meeting at OPCARE9 colloquiums, additional communication tools have been used, such as e-mail, a dedicated web-based forum for sharing documents and discussions (VOCAL), and monthly web meetings. Topics discussed have focused on methodological issues and progress actions across the collaborative, as well as a collaboration activity of quality indicators and communication with PSG. To ensure the connection between management and the operational level, a rotating SPAG member has acted as a group representative towards the PSG.

The SPAG had an active, ongoing creative and inspiring learning process during the OPCARE9 that has resulted in international collaborative network of young researchers that have been vital for the success of the project. Collaborating, debating and discussing research projects with researchers and clinicians of different levels, and to learn to argue for this has been vital for these young researchers during the project. Hence, empowerment of young professionals

should be considered by every extensive collaborative as a possibility for establishment of a new generation of researchers.

11.4 Conclusions: OPCARE9 International Policy summit: “Rethinking dying in Europe and beyond– a roadmap for change”

OPCARE9 has addressed focused questions in the care of the dying and highlighted enormous gaps in terms of research, education and clinical guidance. The gaps and unmet needs identified during the 3 years OPCARE9 project have been repeatedly discussed with various professionals from different countries and background. Such discussion finally led to the insight that policy makers from all over Europe – and potentially from all over the world – must pay great attention to this last phase of life to serve their communities well. Accordingly, the “Liverpool declaration” was created and a policy summit was held on this topic during the project’s final conference in Liverpool in March 2011.

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 improving healthcare structures to meet this goal.*
 - 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*
-

During this summit, various domains of most needed activities, both national and international have been identified. Professor Sir Mike Richards from the UK as chair of this summit summarized a list of future actions. These points of future action based on the Liverpool declaration can only move forward this widely neglected area of need, if discussed, evaluated and adapted on a regular basis. Therefore the International OPCARE Research Collaboration (IORC) and the International Liverpool Care Pathway - Reference Group (IR-LCP) as the two major collaborations coming out of OPCARE9, commit themselves to sustain this political debate.

Following the policy summit, it was recommend that a bi-annual international conference should be convened in Liverpool, inviting clinicians, educators, researchers and policy makers to

demonstrate their will to improve the care of the dying in Europe and beyond. It is proposed that a further policy summit will be conducted to progress the agenda.

11.5 Future Developments: International OPCARE Research Collaborative

Growing together into a democratic structure for OPCARE9 is based in a concerted effort and a mutual commitment for growth, understanding and continuous exchange of all involved. Accordingly, what has emerged from OPCARE9 is a strong collaborative and coordinated network of research active clinical and educational groups, all with a key aim of generating the evidence which will inform practice and improve the care of dying patients across the partner countries and beyond.

I think that OPCARE9 is primarily a great opportunity to create an international platform for international and multidisciplinary collaboration on end-of-life care research and palliative care. The researchers... ..are at the forefront of the end-of-life care research community in Europe and an interesting mixed group of people from different backgrounds and disciplines. The fruitful interaction between different professions groups (physicians, nurses, psychologists and social researchers) and between researchers from Canada and the US during the meetings will contribute to capacity building in Europe and beyond. It will facilitate future collaborations in concrete research projects. OPCARE9 has also identified important end-of-life issues to be studied in the near future. Hence, it has contributed to the development of a research agenda for the years to come. Although it is a complicated project because it is not about research itself, it facilitated enormously the development of joint international collaboration and research.

Professor Luc Deliens- University of Amsterdam

In order to realize the potential generated by OPCARE9, the collaborative network has restructured as The International OPCARE Research Collaborative (IORC). Accordingly, terms of reference for membership of IORC have been drafted (Table 11.1).

Table 11.1 IORC Terms of Reference

International OPCARE Research Collaborative - Terms of Reference
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The IORC – is responsible for:

- Developing the research protocols collated as part of the OPCARE9 EU 7th Framework Coordination and Support Action Programme.
- Ensuring the effective communication between members of the Collaborative.
- Responding to the research agenda as set by the International OPCARE9 Research Collaborative Steering Group (IORC- SG).
- Collating reports and action plans and reporting to the IORC-SG and provide detailed research protocols for optimising care of the dying into the future within an international framework.
- Horizon scanning to develop future collaborative research programmes to attract ongoing funding / resources within the agreed research portfolio as set by the IORC-SG.

Membership

- Key Researchers and Country Leads from the OPCARE9 EU 7th Framework Coordination & Support Action Programme.

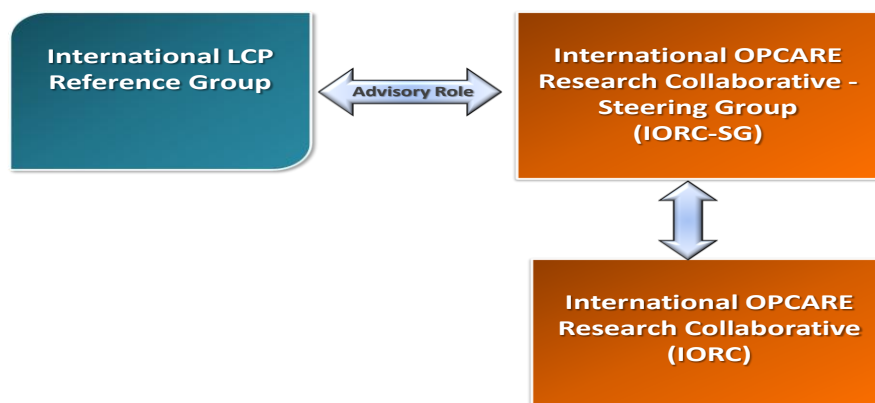
As with OPCARE9, a Steering Group (IORC-SG) has been constructed to coordinate and monitor the development of the IORC. Accordingly, the IORC will seek to potentiate the development of local and national research projects examining care of the dying, and will serve as a platform to elevate suitable studies for international collaboration. This structure is illustrated in figure 11.1.

Figure 11.1 - IORC development of local, national and international research development



The IORC emerges as a collaborative structure to potentiate the research protocols that have emerged from the OPCARE9 project. Further, 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-SG 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 reciprocally that the research agenda is driven by appropriate need.

Figure 11.2 Integration of the IORC and LCP International Reference Group



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Consideration as to the necessary support structure necessary has already been given, and development in terms of design guidance and core management activities have already been drafted. For example, a developed research protocol may seek to engage in research at a local/national level - for example, Work Package 2 “Communication amongst clinicians regarding end of life care decisions in the last 48 hours of life”. The developed protocol, can be used to apply for funding in line with the local/national implementation. However, the potential exists for IORC to provide a collaborative exchange to examine whether the methodology is amenable to application in a partner country, and develop data to establish internationally comparative data. Equally, developed protocols may be designed with an existing international collaborative framework, and IORC will be able to identify interest and source the collaboration required.

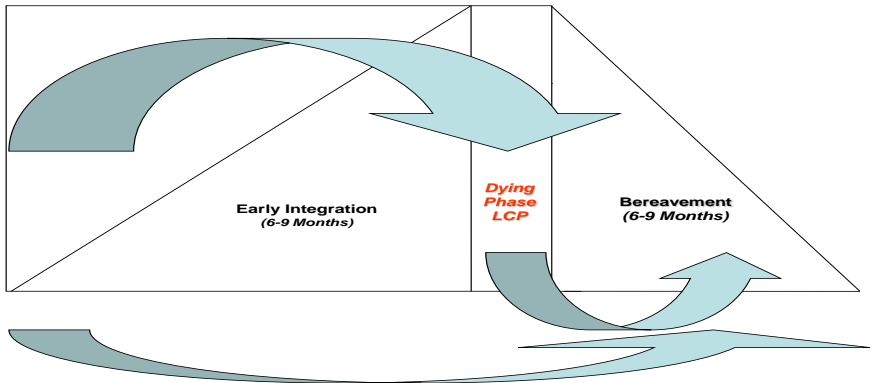
A timetable of meetings has been established to sustain the momentum of establishing the IORC from the outputs of OPCARE9 (Table 11.2).

Table 11.2 – Schedule for International OPCARE Research Collaborative

Mar 2011	May 2011	Nov 2011	Mar 2012	Oct 2012
OPCARE 9 Conference	EAPC Lisbon	International LCP Conference (UK)	IORC Meetings - IORC - IORC-SG	International LCP Conference
Launch of IORC	Meetings; IORC IORC- SG	Meetings; IORC IORC- SG		Meetings; IORC IORC- SG

In reference to the potential developments of research championed by 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 11.3). For example, the protocol emanating from Work Package 4 seeks to establish the effect of attachment style in promoting well being and ameliorating distress. However, it will be important to understand whether attachment style (e.g. in relation the interaction of patients with clinicians) is a malleable concept and whether it is altered over the illness trajectory. Such would be an important finding, particularly in terms of the influence in guiding potential interventions.

Figure 11.3 – IORC Focus for developing the evidence base in end of life care.



11.6 International Cohort Study

A key factor in facilitating the development of the OPCARE9 collaborative was the shared use and belief in the Liverpool Care Pathway for the Dying Patient (LCP) as a tool to drive up quality for care of the dying and provide a method for ensuring an equitable base standard of support. Equally, the LCP provides an opportunity to be the fulcrum of a large international cohort study to both explore the complexity and diversity of care of the dying and undertake intervention studies in care of the dying in Europe and beyond.

The LCP guides and enables healthcare professional to focus on care in the last hours or days of life. This provides high quality care tailored to the patient's individual needs, when their death is expected. Key goals of care are regularly assessed and formally documented (4 hourly) on a standardised pro-forma. The opportunity exists to use the LCP as a platform to develop additional "recording modules" that could facilitate the appropriate collection of research data that goes beyond the core LCP documentation of the goals of care for example; evaluating the quality of care received as perceived by the patient, the family and both formal and informal carers. The LCP is currently used in over 2,500 practice sites across Europe and beyond, providing a feasible and established infrastructure for such an ambitious, but crucial study. Nevertheless, the complexity of engaging on an international project on this scale is not insignificant. However, the experience and relationships developed within OPCARE9 place the group in a unique position to begin fielding the data that will articulate and shape the future care for dying patients and their families

11.7 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 palliative 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 International Liverpool Care Pathway - Reference group (IR-LCP). These groups commit themselves to sustain the political debate, undertake collaborative research, and make a difference to care of the dying in Europe and beyond.

OPCARE Public Website

The OPCARE9 public website can be accessed via the following address www.opcare9.eu