



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>



Form for EAPC web platform about EU supported projects

Project Title:	A European collaboration to optimise research for the care of cancer patients in the last days of life		
Project Acronym:	Opcare9	Logo 	YES
Funding programme: (e.g 7 th framework...)	7 th framework		
Funding programme web page:			
Project type:	Co-ordination & Support Action		
Project number:	202112		
Coordinator:	Professor J Ellershaw		
Partner countries:	Germany, Netherlands, Italy, Slovenia, Sweden, Switzerland, New Zealand, Argentina		
Project web-site:	www.opcare9.eu		
Keywords:	CANCER, CARE, DYING, QUALITY, NEEDS, TECHNOLOGIES		
Summary of the project:	<p>Through the extension of an existing collaboration of colleagues working in end of life care across Europe and beyond, the project aims to explore, share and collate current knowledge and practice in each of the key themes identified within the work programme. It aims to reach consensus (based on current practice and available research evidence) on the optimum care to be delivered in the last days of life and gaps in the knowledge base. In addition, it aims to develop innovative research protocols to address gaps in knowledge and to make recommendations for the further development of the Liverpool Care Pathway for the Dying Patient (LCP) Framework in an international context, with the specific aim of improving care for cancer patients in the last days of life. Clearly, such improvements would also impact positively on their informal carers and health professionals delivering the care. Importantly, it aims to do this systematically and collaboratively across Europe and beyond to integrate knowledge from a range of healthcare environments and cultures and to avoid duplication of resource and effort.</p> <p>Five seminal themes that are central to the provision of quality care in the last days and hours of life have been identified: * signs and symptoms of approaching death</p>		



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<ul style="list-style-type: none"> * end of life decisions * complementary comfort care * psychological and psychosocial support for patients, families and caretakers * voluntary service
Aims (research questions) :	<p>The main aim is to reach consensus (based on current practice and available research evidence) on the optimum care to be delivered in the last days of life and to identify gaps in the knowledge base within each of these themes. In addition, the work will involve the development of innovative ways of addressing gaps in knowledge with the specific aim of improving care for cancer patients in the last days of life. Clearly, such improvements would also impact positively on their informal carers and health professionals delivering the care. Importantly, it aims to do this systematically and collaboratively across Europe and beyond to integrate knowledge from a range of healthcare environments and cultures and to avoid duplication of resource and effort.</p>
Expected Results:	<p>The primary outcomes of the planned project will include:</p> <ul style="list-style-type: none"> <input type="checkbox"/> A comprehensive and systematically evaluated 'state of the art' (published and unpublished literature and expert opinion) <input type="checkbox"/> The development of outline research protocols for future research to improve the care for patients in the final days and hours of life <input type="checkbox"/> A list of evaluated 'technologies' in each of the work package areas to provide practitioners with an up to date resource to underpin the delivery of care and/or the assessment of the quality of care <input type="checkbox"/> A list of evaluated European Quality Indicators against which to measure future care in the last days of life in each of the WPs <input type="checkbox"/> Recommendations for the further development of the LCP framework <input type="checkbox"/> A fully functioning website for use during the collaborative project and beyond to facilitate communication and the sharing of information both within the collaboration and with the wider research community. The website will also provide a repository for the results of the systematic review and Delphi Process, including the list of evaluated 'technologies' and Quality Indicators which can be used as a resource for the wider research/healthcare community <input type="checkbox"/> Published articles and conference presentations detailing the results of the project from each of the primary work packages <input type="checkbox"/> A developmental evaluation of the process of collaboration within the project to support the future collaboration of the current group and to inform and advise other collaborations
Date of application:	April 2007



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
 97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

Date of approval:	September 2007
Starting date:	1 March 2008
Duration (in months):	36 months
Amount of contribution:	EURO 2.2m
Methods:	<p>Methods - Work Packages 1-5</p> <p>The specific methodologies (systematic review and Delphi) have been chosen because they represent recognised robust and systematic approaches to the collation and critique of evidence. These approaches are commonly used within the wider research community, and several members of the current collaboration have first hand experience of using them.</p> <p>Systematic literature review of published and unpublished literature will be undertaken to identify and critique current knowledge in the five primary areas.</p> <p>In addition, an adapted Delphi process will be undertaken to explore and gain consensus re current clinical understanding in these areas particularly where the evidence base is poor.</p> <p>Methods - Work Package 7</p> <p>The developmental evaluation of the project will entail a mixed methods approach to the collection of pertinent data that can be used to explore the 'workings' of the collaborative group and sub groupings to evaluate and provide ongoing feedback throughout the 3 year project regarding performance against the stated aims.</p> <p>Another important focus of this work package will be the development of the LCP within the international arena. This will be undertaken via discussion and debate within the seven planned Colloquia.</p>
Deliverables:	<p>Steering Group Minutes</p> <p>Periodic Reports to EC</p> <p>Annual Cost Reports</p> <p>Website</p> <p>List of peer reviewed journals, conferences and potential sources of future research funding</p> <p>5 Colloquia</p> <p>1 International Workshop of Experts</p> <p>1 international Conference</p> <p>Articles for publication (WP's 1-5,7)</p> <p>Presentation at national and international conferences (WP's 1-5,7)</p> <p>Protocols for future research (WP's 1-5)</p> <p>Database of agreed technologies and Quality Indicators</p> <p>International Evaluation and Dissemination plan for the LCP</p> <p>Report re recommendations for further development of the LCP</p> <p>A plan for continued collaboration</p>



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

Time lines (milestones):	Across the project timescales as agreed with the EU, most outputs occurring between month 30 and 36.
Work package leaders (name and affiliation):	WP1, Dr S Eychmueller, KSSG, Switzerland WP2, Dr L Van Zuylen, Erasmus MC, Netherlands WP3, Dr C J Furst, SSH, Sweden WP4, Prof R Voltz, UKK, Germany WP5, Dr RM Smeding, MCPCIL, UK WP6, Prof J Ellershaw, MCPCIL, UK WP7, Prof J Ellershaw, MCPCIL, UK
Other partners (name and affiliation):	Italy - Dr M Costantini, ISTGE Slovenia - Dr U Lunder, PCDI Golnik NZ - Dr J Clark, Arohanui Hospice Argentina - Dr G De Simone, PLNGO
Work package goals:	<p>WP1 Signs and Symptoms</p> <ul style="list-style-type: none"> 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 in approaching death 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 Review the current criteria for diagnosing dying on the LCP and make recommendations regarding modification and development of the pathway <p>WP2 End of Life Decisions</p> <ul style="list-style-type: none"> To collect and collate information regarding the key end of life decisions undertaken within beneficiary countries To explore cultural and legal differences 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



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
 97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<p>evidence base for end of life decision making</p> <ul style="list-style-type: none"> To review the LCP in relation to end of life decision making and make recommendations for its modification and development <p>WP3 Complementary Comfort Care</p> <ul style="list-style-type: none"> To identify and systematically evaluate the evidence base for appropriate comfort measures in the last days and hours of life including: <ul style="list-style-type: none"> Symptom control Nursing interventions Spiritual care To determine a European consensus on the optimum management of symptoms at the end of life including <ul style="list-style-type: none"> Pain Terminal agitation Respiratory tract secretions Dyspnoea Nausea and vomiting To determine a European consensus on nursing interventions for care of the dying <ul style="list-style-type: none"> To identify and evaluate current tools/technologies available to support <ul style="list-style-type: none"> 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 <p>WP4 Psychological and Psychosocial support for families and carers</p> <ul style="list-style-type: none"> To identify and systematically evaluate the evidence base for the prevalence of psychological and psychosocial issues for: <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> Patients Families and caretakers To explore cultural differences and approaches to the identification of need and delivery of care <ul style="list-style-type: none"> To identify and systematically evaluate current tools/technologies to support <ul style="list-style-type: none"> The measurement of psychological and psychosocial support needs for patients, families and caretakers The delivery of high quality psychological and psychosocial
--	---



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
 97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<p>support for patients, families and caretakers</p> <ul style="list-style-type: none"> • 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 <p>WP5 Volunteer Services</p> <ul style="list-style-type: none"> • 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– ie 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 <p>WP6 Management, Communication and Dissemination</p> <ul style="list-style-type: none"> • To execute the project according to scientific plan and budget • To ensure effective communication between the beneficiaries and timely reporting to the Commission • to ensure successful organization and management of colloquiums • to ensure any issues pertaining to the consortium, e.g., legal, contractual, ethical, gender equality, financial, or administrative are dealt with efficiently and appropriately • to ensure a robust programme of dissemination is in place so that the products of the project are disseminated widely and appropriately, specifically through • developing a project website on which the findings of the collaborative can be published • working closely with colleagues in each of work packages 1 – 5 to o develop articles and conference presentations to disseminate the specific findings from each work package theme • technologies, • quality indicators • key research questions and suggested methodologies
--	---



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<p>for care in the last days of life (to be published on the project website):</p> <ul style="list-style-type: none"> for use by clinicians and researchers developing robust plans for continued collaboration to be in place at the project end <p>WP7 Evaluation and the LCP</p> <p>(a) A developmental evaluation of the process to:</p> <ul style="list-style-type: none"> contribute to and evaluate the continual assessment and feedback on process on a 6 monthly basis in order to strengthen the collaboration apply emerging findings regarding the process as the collaboration progresses generate knowledge about the principles underlying an effective collaborative, co-ordination and support programmes at a European level <p>(b) To potentiate the development of the LCP framework at a European level by:</p> <ul style="list-style-type: none"> Establishing a European reference group for the LCP incorporating recommendations of the Workpackages 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.
Dissemination (publications - articles):	none as yet
Dissemination online	www.opcare9.eu
Dissemination (Conferences)	<p>October 2007 Poster Presentation A European Collaboration to optimise research and clinical care for cancer patients in the last days of life Gambles M, Ellershaw JE, Marie Curie Palliative Care Institute Liverpool (MCPCIL) Research in Progress Day, University of Liverpool UK</p> <p>6th – 8th February 2008 Oral Presentation Slovenian experience with Palliative care– What can we do differently as members of EU Urska Lunder Palliative care development Institute, Ljubljana University Clinic Golnik, Slovenia</p> <p>14th Mar 2008 Oral Presentation Palliative Care at the End of Life – a Quality project in cooperation with Liverpool Care Pathway Steffen Eychmüller, Barbara Grossenbacher-Gschwend, Franzisca Domeisen Cantonal Hospital St.Gallen, Switzerland St.Gallen, Switzerland</p> <ul style="list-style-type: none"> German speaking 88 participants:



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
 97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<ul style="list-style-type: none"> - Professionals (doctors, nurses, coordinators) and volunteers - Local setting <p>29th April – 1st May 2008 Poster Presentation A European Collaboration to optimise research and clinical care for cancer patients in the last days of life Gambles M, Ellershaw JE, Marie Curie Palliative Care Institute Liverpool (MCPCIL) Palliative Care Congress, Glasgow UK</p> <p>29th – 31st May 2008 Invited Oral Presentation OPCARE9 Optimising cancer patient care J Ellershaw, C J Furst MCPCIL UK; Stockholms Sjukhem, Sweden EU 7th Framework Parallel Session, 5th Research Forum of the European Association for Palliative Care (EAPC), Trondheim, Norway</p> <p>25th – 27th September 2008 Oral Presentation Hot Topics EAPC Research Forum Trondheim 2008 C. Ostgathe Department of Palliative Medicine, University Hospital Cologne 7th Congress of the German Association for Palliative Care, Wiesbaden, Germany</p> <p>25th – 27th September 2008 Poster presentation Psychological and psychosocial support of cancer patients, family members and caretakers; Work package 4 of the EU-Project OPCARE9 M.Galushko, O. Popa-Velea, C. Ostgathe, R. Voltz</p> <p>Department of Palliative Medicine, University Hospital Cologne</p> <p>7th Congress of the German Association for Palliative Care, Wiesbaden, Germany</p> <p>26th – 28th September 2008 Oral presentation Improving psychosocial and psychological care to terminal patients: OPCARE-WP4 – an European health project O. Popa-Velea, M.Galushko, C. Ostgathe, R. Voltz</p> <p>Department of Palliative Medicine, University Hospital Cologne</p> <p>15th National Conference of the Romanian Balint Association, Miercurea Ciuc, Romania</p> <p>September 2008 Article OPCARE9 – Neues europäisches Kooperationsprojekt zum Thema "Care of the Dying" C. Ostgathe, M.Galushko, O. Popa-Velea, , R. Voltz</p> <p>Department of Palliative Medicine, University Hospital Cologne</p> <p>Zeitschrift für Palliativmedizin Z Palliativmed 2008; 9: 89-90</p>
--	---



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
97100170154



European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs
EAPC Onlus: Organisation à but non lucratifs d'utilité publique
ONG reconnue par le Conseil de l'Europe

Visit our Web – Visitez notre site Internet: <http://www.eapcnet.org>

	<p>9th October 2008 Poster A European collaboration to optimise research and clinical care for cancer patients in the last days of life. Professor J Ellershaw; M Gambles; C J Furst; R Voltz, C van Zuylen; S Eichmueller, M Constantini, U Lunder OPCARE9 PSG Marie Curie Palliative Care Institute Liverpool Conference.</p> <p>Liverpool UK</p> <p>October 2008 Oral Overview of OPCARE9 Gustavo De Simone and Team. Pallium, Argentina Palliative Care National Congress Argentina</p> <p>November 2008 Oral Overview of OPCARE9 Gustavo De Simone and Team, Pallium, Argentina Franco-Argentine Palliative Care Meeting</p> <p>November 2008 Oral Overview of OPCARE9 Members of Pallium Palliative Care Teams in Buenos Aires (Hospital Udaondo, Instituto Lanari, Instituto Fleni Buenos Aires, Argentina</p> <p>3rd – 4th December 2008 Consensus and annual congress of palliative care, Switzerland Together for life till death Steffen Eychmuller, President of Congress, Cantonal Hospital St.Gallen, Switzerland Swiss End of Life Care Coalition, Biel, Switzerland</p>
--	--



EAPC Head Office: Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milano, ITALIA
EAPC Sede: Tel: +39-02-23903390 Fax: +39-02-23903393

Fiscal Code
Codice Fiscale
 97100170154