Project Final Report

1. Summary report

Background

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It achieves this through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. While international research on palliative care has begun to develop over the past decades, it has not kept pace with the growing demand for high quality care. To meet the societal challenges accompanying the dramatic increase in patients facing the need for good palliative care in the coming decades, there is an urgent need for enhanced collaborative research training in palliative care. We need to provide the current and the next generation of researchers with the best possible skills to improve evidence based palliative care and influence palliative care policies at national and international level.

Objectives

The general aim of the Marie Curie Initial Training Network EURO IMPACT (2010-2014) –European Intersectorial and Multi-disciplinary Palliative Care Research Training– was to develop a multi-disciplinary, multi-professional and intersectorial educational and research training framework on palliative care in Europe. More specifically, EURO IMPACT trained an international pool of researchers to master:

< scientific skills in palliative care research, via a research programme aimed at describing and monitoring palliative care and its quality across Europe and identifying and evaluating tools to improve care;

< skills in societal dissemination techniques i.e. translating research results into clinical practice and policy, by bridging the gap between academic and non-academic sectors within the wider EU community.

EURO IMPACT has:

< bridged the gap between individual research institutes, multiple disciplines and different sectors involved in palliative care research training in Europe. Cross-fertilization of dispersed research activities have reduced the fragmentation of a topic of great EU relevance

< built the basis for the further development of an EU platform for palliative care PhD research training

< increased the international mobility of palliative care researchers across Europe. Hence, Europe will benefit from a new generation of researchers who have an increased cross-national impact on the development of palliative care (research) policies.

Consortium

The consortium of EURO IMPACT represents a broad array of disciplines, professions, research domains and sectors – academia and non-academic sectors – involved in palliative care in Europe.
The training and research programme of EURO IMPACT is closely intertwined, involving 5 universities, 1 private charity/company (SME), 1 private company and 4 other socio-economic actors, and training 12 junior researchers (for three years each) and 4 experienced researchers (for 18 months each) coming from different parts of the world.

Research studies

The researchers have been working on individual research projects within four closely related research programmes. They worked together, being exposed to different research methodologies and datasets gathered in different countries and from multiple perspectives. The first research programme provides an overall picture of palliative care provision in Europe. Existing individual country reports concerning the development of palliative care have been critically reviewed and the reports from resource poor countries were updated.

The second research programme provides an empirical overview of palliative care and its quality in Europe for different subgroups of patients. Over the past EURO IMPACT period, the consortium has performed a number of systematic literature reviews, analyzed retrospective cross-national data gathered from representative GP networks, and analyzed prospective trial data gathered in hospitals and palliative care units across different countries in Europe, resulting in the identification of important areas in which there is considerable room for improvement of care provided at the end of life. While palliative care has been advocated by the World Health Organisation for all people with life-threatening diseases and early in the disease course, current data show that palliative care is not always provided in this manner for cancer and particularly for non-cancer patients, such as elderly people and people dying with dementia.

The third research programme identified tools to improve palliative care in Europe. Results from EURO IMPACT underline the importance of developing and validating quality indicators for palliative care focusing on physical as well as psychosocial and spiritual patient outcomes, as a tool to improve quality of care of palliative care providers. Additionally, the research shows that the use of computers to measure these patient outcomes appears feasible and has positive effects in advanced cancer patients.

The fourth research programme provides societal dissemination tools that can be useful for guiding practice and policy. It provides tools for better outcomes assessment in palliative care, and has produced important policy recommendations for the integration of palliative care in mainstream health and social care and related policies in Europe. Based on contributions from authors all over the world, Oxford University Press will publish in 2015 the book “Palliative care for older people: a public health perspective” (ISBN: 978–0–19–871761–4) by EURO IMPACT. This book uses a public health perspective as the ageing of our society poses challenges to social and health care structures in many countries. This book demonstrates the added value of palliative care, outlines the current state of worldwide policy work, research and innovations and concludes with advice for policy- and decision-makers to improve access to and quality of palliative care for older people. The project consortium has consequently developed a set of policy recommendations for policy, practice and research which are integrated in the 2014 European Declaration on Palliative Care (http://palliativecare2020.eu/declaration/ ), launched at the closing conference on October 15, 2014 in Brussels.

Training

The training programme of EURO IMPACT has been multi-disciplinary, multi-professional, international and intersectorial and provided the next generation of European researchers with the
necessary scientific and complementary skills to influence future palliative care. In order for palliative care researchers to excel and have the best possible career prospects, they needed to develop relevant skills beyond the academic. Learning goals within EURO IMPACT concerned competences in different palliative care research methodologies, multidisciplinarity and ethics, cross-country comparisons, understanding palliative care concepts, developments, and services, translation of research into practice and policy, presentation and writing for different audiences, and the development of organizational, collaboration and networking skills.

The researchers benefited from on-the-job research training, supplemented with existing structured training courses and newly developed network-wide trainings to exploit the expertise of each partner. Additionally, researchers visited and were seconded to different partners and between sectors during their trajectory increasing their mobility within the EU. While most training trajectories have been the same for all researchers, each individual researcher has set up a personal career development plan, depending on their needs and on his/her individual project, including training, research and secondment plans.

Within the entire EURO IMPACT period, all research fellows have been enrolled in the 11 structured training courses provided within the project. An overview of the courses can be found on the EURO IMPACT website. The consortium has organised 7 network-wide trainings for the researchers, of which most were attended by external researchers from outside this project. Site visits were organized by the European Union Geriatric Medicine Society, the Palliative Care Research Center (Norway), and Cicely Saunders International (UK) to learn from, and network with, non-academic sectors and clinical practice. Secondments to partnering institutes were completed for all researchers in the project.

Conclusion

EURO IMPACT has successfully trained palliative care researchers within a European network of centers of excellence in palliative care research training, establishing a new generation of European researchers with the necessary skills to influence future palliative care policies and practice.
2. USE AND DISSEMINATION OF FOREGROUND

PUBLICATIONS

(Martin Loucka)


Loucka M. et al (2013). Self-reported knowledge, attitudes, and behaviour towards hospice care and how are these related to training in palliative care: An online survey among oncologists in the Czech Republic and Slovakia. Progress in Palliative Care, doi: 10.1179/1743291X13Y.0000000067

(Winne Ko)


(Lara Pivodic)


In revision:
Pivodic L, et al. Home care by GPs for cancer patients in the last three months of life: an epidemiological study of perceived quality and associated factors

Van den Block L, Pivodic L, et al. Transitions between health care settings in the final three months of life in four EU countries

Submitted for publication:

Pivodic L, et al. Place of death in populations that could benefit from palliative care: a population-based study in 14 countries


(Nathalie Evans)


In addition Natalie has authored four papers (two published, two submitted) based on data exclusively from the Netherlands:


A publication that examines Dutch older people’s preferences for life-sustaining treatments and factors associated with a preference to forgo treatments. The paper, titled “Life-sustaining treatment preferences: social support more important than health?” is under review.

A publication that examines Dutch older people’s advance directives possession before and after the enactment of the euthanasia law: a time trend study (1998-2011). This paper is resubmitted to Journal of American Geriatrics Society.


Papavasiliou E, Payne S. Unaddressed biases on reported prevalence of continuous deep sedation. Journal of Clinical Epidemiology 2015  DOI: http://dx.doi.org/10.1016/j.jclinepi.2014.11.007
Submitted

Abarshi E, Rietjens J, Caraceni A, Payne S, Deliens L, Van den Block L on behalf of EURO IMPACT. International Comparison of the Quality and Recommendations provided in Clinical Practice Guidelines on Palliative Sedation. BMC Palliative

Published


(Maaike De Roo)


(David Blum)


(Emily West)


West E, Onwuteaka-Philipsen BD, Philipsen H, Higginson I, Pasman HRW. Keep all thee ’til the end: reclaiming the lifeworld for patients in the hospice setting. (submitted)

West E, Pasman HRW, van der Heide A, Onwuteaka-Philipsen BD. Characteristics of the end of life across four settings in the Netherlands: care and decisions. (submitted)

West E, Pasman HRW, Galesloot C, Lokker I, Buiting H, Onwuteaka-Philipsen BD. Hospice care in the Netherlands: who applies and who is admitted to inpatient care? (submitted)

West E, Pasman HRW, Galesloot C, Buiting H, Onwuteaka-Philipsen BD. Does hospice care vary between patients with cancer, heart failure and lung disease? (submitted)

West E, Pasman HRW, Galesloot C, Lokker I, Buiting H, Onwuteaka-Philipsen BD. Does hospice care vary for patients admitted to the three types of hospice in the Netherlands? (submitted)

(Elene Janberidze)


(Barbara Antunes)


(Gwenda Albers)


(Sandra Martins Pereira)


(Liesbeth Van Vliet)


PRESENTATIONS


6. Pereira S. Palliative Care in Portugal and Europe: Different concepts and organizational models, different levels, needs and potential for development. 2nd World Congress of Health Research. Viseu, Portugal, 7/10/2014 - 8/10/2014.

7. Pereira S. A 1.5 year in a European Project:

What does it mean to be an Experienced Researcher and develop a book on palliative care for older people? QUEST meeting VUmc. Amsterdam, 1/07/2014 - 1/07/2014.

8. Ko W. International Study of Place of Death (IPoD) on COPD and Lung Cancer Patients. 8th World Research Congress of EAPC. Lleida, Spain, 6/06/2014.

9. Loucka M. Place of death in the Czech Republic and Slovakia: A population based comparative study using death certificates data. 8th World Research Congress of the European Association for Palliative Care. Lleida, Spain, 6/06/2014.


12. Ko W. Quality of Life of Patients with Advanced Lung Cancer. A Longitudinal Study in Flanders, Belgium. 8th World Research Congress of the EAPC. Lleida, Spain, 5/06/2014 - 7/06/2014.


16. Deliens L. EAPC 2014. Obtaining an international PhD in palliative care: a social sciences research perspective from Euro Impact, a FP7 Marie-Curie initial training programme. Session building your research career. 14th World Congress of the European Association for Palliative Care.. Lleida, Spain, 5/06/2014 - 5/06/2014.

17. Moens K. Where do people living with Parkinson’s disease die? A population-level study in 11 countries. 8th World Research Congress of the EAPC. Lleida, Spain, 5/06/2014 - 7/06/2014.


24. De Roo M. Quality Indicators for Palliative Care: What have I learnt so far? QUEST meeting. VUmc Amsterdam, 3/09/2013.

25. De Roo M. Dying peacefully in nursing home residents: can it be used as quality indicator? Wetenschapslunch Specialisten Ouderengeneeskunde Vrije Universiteit Amsterdam. VU Amsterdam, 12/06/2013.


27. Pivodic L. Perceived quality of home cancer care at the end of life: Which factors are associated with bereaved relatives being highly satisfied with the care provided by GPs? World Congress of the EAPC 2013. Prague, Czech Republic, 1/06/2013.


29. Pivodic L. Burden on family carers and difficulty in covering costs of care at the end of life: a cross-national retrospective study via representative networks of general practitioners. 13th World Congress of the EAPC. Prague, Czech Republic, 31/05/2013.

30. Janberidze E. Depression and the use of antidepressants in patients with advanced cancer. Results from the international multi-center study. 13th World Congress of the European Association for Palliative Care. Prague, Czech Republic, 30/05/2013 - 2/06/2013.


32. Loucka M. Oncologists' Views about Hospice Care in the Czech Republic and Slovakia. 13th World Congress of the European Association for Palliative Care. Prague, the Czech Republic, 30/05/2013 - 2/06/2013.
33. Loucka M. Death and Dying in the Czech Republic - Results of a Representative National Survey. 13th World Congress of the European Association for Palliative Care. Prague, the Czech Republic, 30/05/2013 - 2/06/2013.

34. Moens K. Does the Palliative care Outcome Scale capture the same dimensions for cancer as for non-cancer patients? A factor analytic comparison. - PosterPt. EAPC 2013 13th World Congress of the European Association for Palliative Care. Prague, the Czech Republic, 30/05/2013 - 2/06/2013.


41. Blum D. Clinical Practice Tools. 13th EAPC World Congress in Prague. Prague, 30/05/2013.

42. De Roo M. Actual and preferred place of death in 4 European countries: making sense of quality indicators. SG werkbespreking. VU Amsterdam, 27/05/2013.

43. Evans N. End-of-life medical treatment preference discussions and surrogate decision-maker appointments: Evidence from Italy, Spain, Belgium and the Netherlands. 4th International Society of Advance Care Planning and End of Life Care. 4th International Society of Advance Care Planning and End of Life Care. Melbourne, 9/05/2013 - 11/05/2013.

44. Pereira S. Palliative care for older people. Lecture - Undergraduate Degree in Psychology at Faculty of Education and Psychology – Catholic University of Portugal, Porto - Portugal. Lecture - Master Degree in Gerontology at Faculty of Social Sciences – Catholic University of Portugal, Braga - Portugal. Porto and Braga, Portugal, 18/04/2013 - 19/04/2013.


51. Loucka M. How to measure the international development of palliative care? QUEST - the seminar series for researchers from universities in Amsterdam. Amsterdam, 6/11/2012.


53. De Roo M. Quality Indicators for Palliative Care: update of a systematic review. 2nd International Seminar of the PRC and EAPC RN. Ghent, Belgium, 19/10/2012.

54. Papavasiliou E. Palliative Sedation: much to gain and loose: exploring definitions and terminology. 2nd International Seminar of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012 - 19/10/2012.

55. Pivodic L. Burden on family carers of people at the end of life: evidence from four European countries. 2nd International Seminar of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012 - 19/10/2012.

56. Loucka M. Palliative Care in Central and Eastern Europe: Provision and Challenges. 2nd International Research Seminar of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012.

57. Ko W. Actual and Preferred Place of Death in Four European Countries. 2nd International Seminar of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012 - 19/10/2012.


59. Antunes B. Implementing patient reported outcome measures (PROMs) in clinical practice. The second international seminar on palliative care research of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012 - 19/10/2012.

60. Evans N. Patient-doctor communication in the last phase of life. 2nd International Seminar of the PRC and EAPC RN. Ghent, Belgium, 18/10/2012 - 19/10/2012.

61. Moens K. Mid-term review meeting: presenting research plan, experiences and possible impact of the project on the future. Mid-term review meeting of EURO IMPACT. Ghent, Belgium, 17/10/2012 - 17/10/2012.

63. Deliens L. Euro-Impact Midterm review meeting. Het Pand Conference Center, Ghent, Belgium, 17/10/2012 - 17/10/2012.

64. Van Uden N. Quality of dying and quality of care in the last month of life of nursing home residents with dementia as judged by relatives: an international comparison. Presentation given to several board members of The Geriatric Palliative Medicine interest group of European Union Geriatric Medicine Society on the quality of end of life care and the quality of dying of nursing home residents with dementia in Belgium and the Netherlands. AZ Sint Lucas, campus Volkskliniek, 16/10/2012 - 16/10/2012.


66. Ko W. GPs' awareness of cancer patients' preferred place of death: results from EURO SNTI-MELC. XIX Italian National Congress of Palliative Care. Turin, Italy, 9/10/2012 - 12/10/2012.

67. Loucka M. Development of palliative care in Central and Eastern Europe. the Annual Meeting of the Research School CaRe. Utrecht, 5/10/2012.

68. Evans N. Theoretical considerations and methodological issues in the secondary analysis of qualitative interview data. 2nd Amsterdam Symposium on Palliative Care, preconference Masterclass with Jane Seymour. RAI Conference Centre, Amsterdam., 2/10/2012.


73. Antunes B. Palliative care outcome measurement – optimising the Palliative care Outcome scale (POS) for use in clinical practice. Researcher's meeting at the NTNU. Trondheim University, 23/08/2012 - 23/08/2012.


75. De Roo M. Group work with Winne Ko, David Blum and Maaike De Roo at Lancaster Summer School on proposed bereavement services. Group Work Lancaster Summer School. Lancaster, UK, 22/06/2012.
76. Antunes, West, Janberidze. Group work with Barbara Antunes and Emily West at Lancaster Summer School on proposed bereavement services. Lancaster Summer School. Lancaster, 21/06/2012 - 23/08/2012.

77. Ko W. Group work with Winne Ko, David Blum and Maaike De Roo at Lancaster Summer School on proposed bereavement services. Lancaster Summer School. Lancaster, 21/06/2012.


80. Blum D. [Feasibility and acceptance of electronic monitoring of symptoms and syndromes associated with cancer in daily oncology practice using a handheld computer (E –MOSAIC. EAPC. Trondheim Norway, 8/06/2012.

81. Van Uden N. Quality of care and quality of dying of nursing home residents with dementia, as judged by next of kin: A comparison between Flanders and the Netherlands. the abstract was also published in the pal. medicine journal.. Trondheim, Norway, 8/06/2012 - 9/06/2012.


83. Meeussen K. EUROIMPACT: An International PhD Training Programme in Palliative Care Research. Poster presentation at the 7th World Research Congress of the EAPC. Trondheim, Norway, 7/06/2012.


85. Pivodic L. Differences in use of palliative care services between four European countries: a retrospective, population-based study. EAPC Research Congress 2012; Presentation in parallel session. 7/06/2012.


89. Evans N. Older Patients' Experiences of Patient-Physician End-of-Life Communication: Evidence from the United Kingdom, Belgium and the Netherlands. 7th Research Congress of the European Association for Palliative Care. Trondheim, Norway, 7/06/2012 - 9/06/2012.


94. Pivodic L. Differences in use of palliative care services between four European countries: a retrospective, population-based study. Flemish-Dutch Research Forum on Palliative Care; Plenary presentation. Rotterdam, Netherlands, 23/03/2012.


96. Ko W. Palliative Care in Europe-Place of Death and Advance Directives. research meeting. Centre of Behavioral Health, University of Hong Kong, Hong Kong, 10/02/2012.

97. Ko W. Palliative Care in Europe-Place of Death and Advance Directives. Invited as a Speaker during visit to a Palliative Care Unit in Hong Kong. Tuen Mun Hospital, Hong Kong, 9/02/2012.

98. Loucka M. How "action" is to be a Marie Curie Actions funded PhD student in the United Kingdom? PhD Existence II - Czech & Slovak Psychological conference for postgraduates and about postgraduates. Olomouc, the Czech Republic, 30/01/2012 - 31/01/2012.


CONFERENCES

The EURO IMPACT fellows have successfully contributed to several (inter)national conferences. On the website you can find which fellow presented (oral or poster) during which conference: http://www.endoflifecare.be/euroimpact/conferences

The EURO IMPACT consortium organized its final conference: www.palliativecare2020.eu. Besides the website as dissemination tool, several organisations (both from within and outside EURO IMPACT consortium) covered news on the final conference:
EAPC website, August 03 2014, Palliative Care 2020: towards integration of palliative care in an age-friendly EU

The Parliament Magazine, Issue 397, 22 September 2014

Age Platform Europe: newsletter, article, save the date

eHospice, 17 October 2014, European Declaration on Palliative Care launched in Brussels

Flanders’ Care, events, Palliative Care 2020 – Towards integration of palliative care in an age-friendly EU

VUB website, events, Palliative Care 2020 – Towards integration of palliative care in an age-friendly EU

VLEVA, 28 August 2014, Palliative Care 2020: Towards integration of palliative care in an age-friendly EU

KCSE, 05 September 2014, Palliative Care 2020

IQ Healthcare, Palliative Care 2020: towards integration of palliative care in an age-friendly EU

Carer+, November 05 2014, Towards integration of palliative care in an age-friendly EU

European Social Network, October 20 2014, Towards integration of palliative care in an age-friendly EU

Palliative zh+sh, October 23 2014, Europäische Deklaration zu Palliative Care veröffentlicht

Palliatia Journal of palliative care, European Horizon

Accademia Delle Scienze Di Medicina Palliativa, 10 June 2014, Palliative Care 2020 – Towards integration of palliative care in an age-friendly EU

Societa Italiana Di Cure Palliative, Evento Internaz, Palliative Care 2020 – Towards integration of palliative care in an age-friendly EU

Associacao Portuguesa de Cuidados Paliativos, events, Palliative Care 2020

Eurodiaconia, events, Healthy ageing and long-term care

Soin Palliatif, events, Final conference of 2 European projects: IMPACT & Euro Impact: "Towards integration of palliative care in an age-friendly EU"

Additionally, we got coverage on TWITTER, FACEBOOK and LinkedIn. See attached WP update on the final conference for more information.
NEWSLETTER

Five EURO IMPACT newsletters were distributed (Jan 2012; July 2012; May 2013; February 2014 and December 2014). Each newsletter reported on recent new, trainings, events and publications and highlighted the work of researchers (‘in the spotlights’).

PRESS

A press release was launched at the start of the EURO IMPACT project which yielded some appearance in national/international media. EURO IMPACT also got coverage in other media.

- Abarshi E. EAPC Blog: Nurses’ attitudes towards the practice of palliative sedation. 27/10/2014.
- Antunes B. EAPC Blog: Trying to make a difference: One medical student at a time. 26/10/2014.
- EUROIMPACT. AIM signs the European Declaration on Palliative Care. 15/10/2014.
- Evans N. Reformatorisch Dagblad: Nederlandse arts open in communicatie rond levens einde. 10/10/2014.
- Evans N. Nu.nl: Dood vaak geen onderwerp bij patiënten. 10/10/2014.
- Evans N. Telegraaf: Dood vaak geen onderwerp bij patiënten. 10/10/2014.
- Evans N. Skipr: Dood vaak geen onderwerp bij patiënten. 10/10/2014.
- Evans N. Gezondheidsnet: Europese verschillen in communicatie rond levens einde. 10/10/2014.
- EURO IMPACT multi-sectoral training programme for European researchers. eHospice, 9/11/2012.
- Loucka M. EURO IMPACT: The International Palliative Care Research Network. IAPC News, Irish Association for Palliative Care News (4 issues per year), Spring 2012, 30/04/2012.
Lancaster University and King's College London to train researchers in end-of-life care. Lancaster University - Faculty of Health and Medicine News, 31/08/2011.

- King's College London News. King's College London Website, 23/08/2011.
- Four million for palliative care. De Huisarts, 14/07/2011.
- Europe provides four million for palliative care. Leefwijzer, 9/07/2011.
- Europe provides four million for palliative care. VUB Website, 8/07/2011.
- VUB-UGent research group coordinates big EU project about palliative care. Medinews.be, 4/01/2011.