
IMPACT FINAL SUMMARY REPORT 01/02/2011 - 01/02/2015

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EXECUTIVE SUMMARY

The overall aim of the IMPACT project was to develop optimal implementation strategies for using quality indicators to improve the organisation of palliative cancer and dementia care in Europe and to study factors influencing the effectiveness of the strategies. The main research topics were to find optimal strategies for implementing quality indicators to improve the organisation of palliative cancer and dementia care in Europe, and to pilot study the effectiveness of these strategies, as well as factors influencing their effectiveness. This information has been used to build a conceptual implementation model applicable across diverse healthcare settings that allow rigorous assessment of the effectiveness of implementation strategies.

Most important findings of the project:

- An analytic framework to characterise models of palliative care for both patient groups (patients with severe dementia and patients with progressive cancer) across Europe has been developed with the help of several qualitative research methods;
- The variation in the European healthcare systems and healthcare delivery patterns considering palliative care for cancer and severe dementia patients with regard to the national context (macro-level), the available workforce (meso-level), and the settings and professionals (micro-level) has been described in several peer-reviewed scientific papers;
- An integrative literature review has been performed to identify successful strategies to improve the organisation of palliative care;
- A set of quality indicators to be used has been developed with the help of a literature review, and a modified five-round RAND Delphi-procedure;
- Main and setting-specific barriers and facilitators to apply QIs for the improvement of the organisation of palliative cancer and dementia care have been described, using an international qualitative design;
- Barriers and facilitators regarding the application of quality indicators for the improvement of the organisation of palliative dementia and cancer care have been described, and with the help of a nominal group procedure a plan for further dissemination and implementation of the results has been performed;
- A method for the analysis of the implementation strategies used and an inventory of the factors influencing implementation of improvements in palliative care have been developed;
- The IMPACT and EURO-IMPACT consortia joined forces to emphasise the need they felt to involve policy-makers and influence the political agenda towards the implementation of policy recommendations by 2020. A declaration was created, consisting of policy recommendations, which was signed by policy-makers and the European Association for Palliative Care (EAPC), to ensure high-quality palliative care in an ageing society in Europe (and beyond). This declaration has been translated into six other languages.

PROJECT CONTEXT AND OBJECTIVES

Project context

We know that new knowledge is not necessarily readily applied in medicine and nursing, even when there is evidence of its effectiveness in helping to solve problems. In palliative care, there is a wide gap between the findings of clinical research and their use in every day clinical practice. The rapid development of our understanding of palliative care, with new insights into early identification of the patient in need for palliative care, symptom control, structured holistic proactive approaches and continuity of care, has not been followed by the implementation of these insights and the spread of 'best practice'. Systematic implementation is needed to translate clinical research into everyday clinical routines. Implementation is 'a planned process or systematic introduction of innovations and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functioning of organizations or in the health care structure' (Grol et al 2005).

As a result of the gap between knowing and doing, policy makers, professional care providers, patients and their families have benefited too little from new developments. This problem is aggravated in the case of palliative care by the ageing of the European population. An increasing number of older people with progressive, incurable, life limiting chronic diseases need palliative care. Even if professional care providers are willing to change their behaviour, altering well-established patterns of care or organization is difficult. From the point of view of implementation sciences changing palliative care is a major challenge, since adequate organization of palliative care requires collaboration between a range of different professionals and healthcare organizations.

Implementation research has developed models for stepwise implementation but it is still unclear which strategies are effective for whom and which factors influence the effectiveness of these implementation strategies. This hampers the actual translation of clinical evidence or consensus into clinical practice, especially in collaborative care processes. The implementation process in palliative care encounters challenges above and beyond the usual problems of implementation. These include hand over of information between professionals and the diversity of professional working cultures. It is crucial to identify factors influencing this complicated implementation process and to develop strategies that are applicable not only within but also between diverse healthcare settings within Europe.

Traditional strategies to convince health care providers to use research findings, such as identifying, synthesizing and disseminating evidence in reviews in journals, guidelines, continuing medical education and conferences, will not be enough to engineer changes in the complex systems of palliative care for people with cancer and dementia. Although these strategies can help to ensure the uptake of simple changes, further efforts are needed (Grol and Grimshaw 2003).

Quality indicators exist which can be used to drive the development of collaborative care in these two clinical domains. To successfully bring about improvements in the quality of care in complex systems, four levels of change need to be considered: the individual, the group or team, the overall organization and the larger system or environment in which individual organizations are embedded, as all of these levels are interdependent (Ferlie and Shortell 2001). This perspective is especially

important in palliative care, where best practices include the provision of care by caregivers as part of a group or team embedded within a complex organizational structure. As a consequence of the growing population of patients in need of palliative care, coordination of care across teams and settings will become more and more important.

Significance of studying optimization of strategies to implement changes in the organization of (palliative) care across Europe

The significance of optimizing strategies to implement changes in the organization of palliative care is:

- a) Getting insight into the implementation of complex collaborative care. Without this insight there will be a failure to apply knowledge from clinical research and people in need will continue to receive sub-optimal care.
- b) Optimising strategies to improve the organization of care. This requires profound knowledge of the organization of (palliative) healthcare throughout Europe, of available strategies, of a variety of factors influencing the effectiveness of interventions and of their potential effects. The wealth of information needed to adequately implement the quality indicators for palliative care will provide valuable information in its own right.
- c) Building a conceptual model of the process of implementation will contribute to the body of theoretical knowledge about implementation of research findings.
- d) Contributing to the improvement of the organization of palliative care and thereby to address a major challenge in the healthcare of ageing European societies.
- e) Promoting integration and excellence of European research in the area by making a consortium of excellent European researchers in the fields of implementation, palliative and dementia care and two experts from other geographical regions.

Main objectives

The main objectives of this project were: to find optimal strategies for implementing quality indicators to improve the organisation of palliative cancer and dementia care in Europe, and to pilot study the effectiveness of these strategies, and factors influencing their effectiveness. This information will be used to build a conceptual implementation model applicable across diverse healthcare settings and that allows rigorous assessment of the effectiveness of implementation strategies. By this means we aim to improve knowledge on how and to what extent health interventions can fit within real-world clinical practice, including knowledge whether the implementation remained faithful to the original conceptualisation and intent of the quality indicator.

Therefore the following steps have been taken to develop implementation strategies:

1. Selection of a set of quality indicators for the organisation of palliative cancer and dementia care from the sets of indicators developed in several European projects and Dutch projects in the past few years. This selection step is important, as feedback from users and giving users a feeling of ownership are among the most powerful implementation prerequisites (Grol et al 2005). This set of indicators

will function as a tool to assess palliative care organisation on the international, national, setting, team and individual level, respectively.

2. Identification of barriers and facilitators for the potential use of the indicators, stratified by participating country, patient group (suffering from advanced dementia or advanced cancer), setting and in the transitions between settings.

3. Development of a toolkit of implementation strategies including training of consultants and users and a web-based system to register and feed back the assessment of the organisation of palliative care.

4. Pilot study the effectiveness of the implementation strategies.

5. Study of the factors influencing the effectiveness of implementation strategies for new knowledge.

6. Building a conceptual implementation model that should be applicable across diverse healthcare settings and that will allow rigorously assessment of the effectiveness of the selected implementation strategies.

7. Adding the information to an own and other relevant websites (EAPC; Interdem). This information will be accessible to the general population, care providers and policy makers, with information on quality indicators for the organisation of palliative care and how to implement them.

IMPACT MAIN S&T RESULTS 01/02/2011 - 01/02/2015

S/T Methodology and associated work plan: Overall strategy and general description

The projects' aims and management activities were broken down into six related work packages. Each work package has its own deliverables and milestones. The work package is chaired by the work package leader who works with all other partners. The WPs used several methodologies to get their deliverables. WP 2 and 6 ran throughout the entire project period; WP3, 4 and 5 will respectively ran in year 2, 3 and 4. The content of WP 3 was built on WP2, and WP4 was built on the results of WP3. In four countries, The Netherlands, Germany, England and Norway PhD students were appointed for the project and these researchers performed most of the scientific work. The following work packages were designed:

Overview of work packages

| WP | Participant responsible | Other partners involved |
|---|------------------------------|-------------------------|
| WP1 Project Management | Dr. Y. Engels | All other partners |
| WP2 Organization of palliative care | Prof. Steve Iliffe | All other partners |
| WP3 Development of setting specific implementation strategies | Prof. Dr. M. Vernooij-Dassen | All other partners |
| WP4 Evaluation implementation quality indicators | Prof. Dr. L. Radbruch | All other partners |
| WP5 Factors influencing implementation | Prof. Dr. S. Kaasa | All other partners |
| WP6 Dissemination | Dr. R. Chattat | All other partners |

The work packages used a variety of methods to provide the deliverables. Literature reviews to get an overview of what is already known were used, qualitative methods such as focus groups, interviews and consensus meetings to derive information on barriers and facilitators in the organization of palliative care consensus conferences were used to reach agreement. Also content analysis and grounded theory approach were used to analyse the data (Hsieh 2005). In the ongoing HANDOVER (FP7), it has been proven to be feasible to use a variety of qualitative methods in a multi-centre European research.

The project was managed by RUNMC (WP1), where two scientists were involved: one with a focus on palliative care, one with a focus on geriatric care, and both with experience in indicator implementation as well as in managing international projects. Moreover, the organization had ample experience in coordinating FP6 and FP7 projects. In WP2, with a mixed methodology approach an actual and detailed insight in the models of palliative care in Europe was generated. This work package focused on the development and application of an analytic framework to characterize models of palliative care for both patient groups (patients with severe dementia and progressive cancer) across Europe. During the first consensus conference, as mentioned in WP2, it was also decided which quality indicators for the organization of palliative cancer and dementia care was to be implemented in year 3. In WP3, literature study and focus group interviews were used to develop implementation strategies and an overview of barriers and incentives. Consultants in The Netherlands, Germany, United Kingdom, Norway and Italy were trained and materials to implement the indicators were developed, as well as a web-based data registration system. The impact of this work package was a toolkit of setting-specific strategies. During year 3 (WP4), a small scale pre-test / post-test intervention study in several types of settings in five countries was carried out, and in year 4 (WP5) factors influencing the implementation process were studied. WP6 ran throughout the entire study (year 1-4), and aimed to disseminate the knowledge, the results and the tools developed within the project.

WORK PROGRESS AND ACHIEVEMENTS DURING THE PERIOD

IMPACT STUDY WORK PACKAGE 2: ORGANISATION OF PALLIATIVE CARE

The objectives of Work Package 2 were:

1. To develop and apply an analytic framework to characterize models of palliative care for both patient groups (patients with severe dementia and patients with progressive cancer) across Europe.
2. To describe and model the variation in the European healthcare systems and healthcare delivery patterns considering palliative care for cancer and severe dementia patients with regard to the national context (macro-level), the available services and workforce (meso-level), and the settings and professionals (micro-level).
3. To compare models of palliative care organization for cancer patients and for dementia to identify disease-specific determinants of 'good practice'.

Phase 1: 0 to 18 months

The tasks of Work Package 2 in the first 18 months of the IMPACT project were carried out as shown in Table 1 below; all objectives were met. Mapping of service provision was carried out across Europe on care homes and nursing homes, hospitals, home care services, hospices and networks. This allowed the IMPACT project to 1) identify the essentials of good practice organization in palliative care, and 2) identify characteristics of healthcare systems and service variations in each country relevant to palliative care. We developed a conceptual model of palliative care for cancer and dementia which was finalised in a consensus conference in June 2012 and used as a framework for comparing services between diseases and between countries. The 'realist synthesis' approach that we used takes account of the complexity and variability of both service provision and of evidence of effectiveness. This enabled us to build up a comprehensive picture of services and service deficiencies and to finalize the list of quality indicators to be implemented in the intervention phase of IMPACT. We developed an understanding of the barriers to improving palliative care services in different European countries, which was published (see page 6).

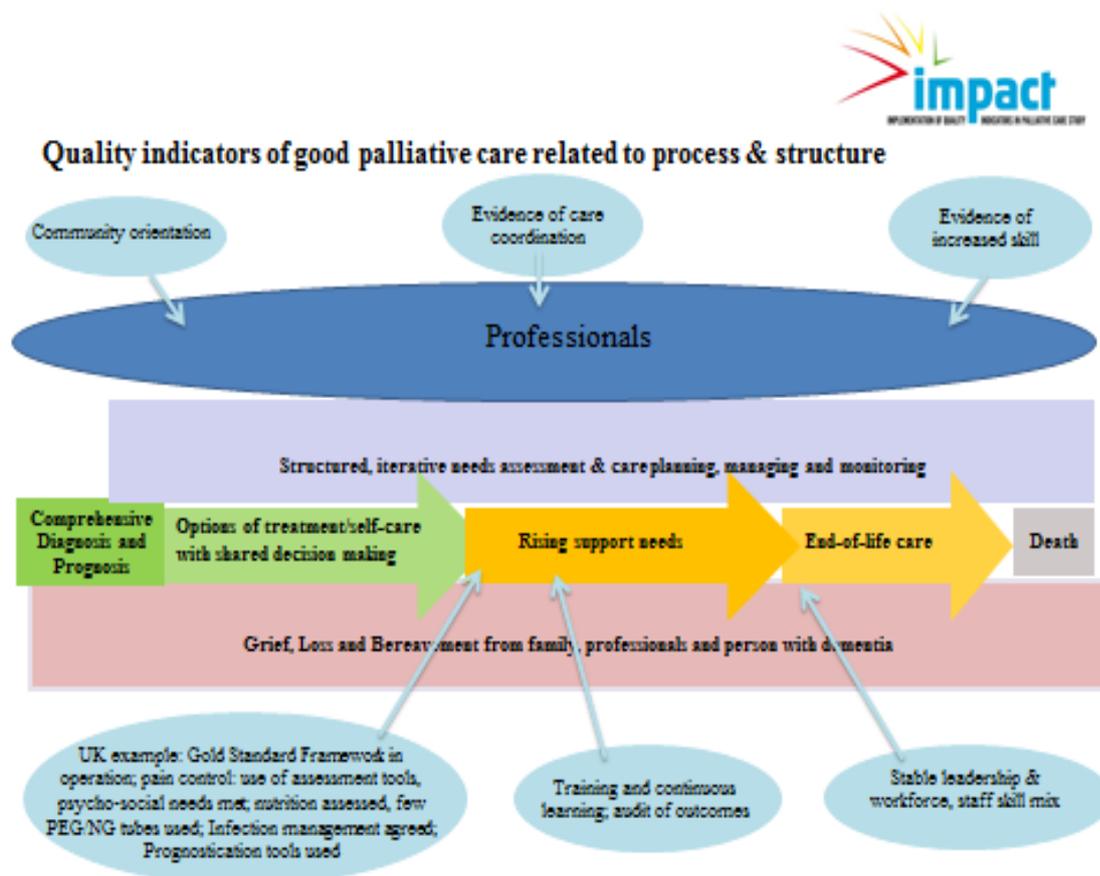
Table 1: The tasks of Work Package 2 in the first 18 months of the IMPACT project

| Task | Time period | Achievements |
|---|-------------|--|
| An extensive literature review of models for the organization of palliative care, using a methodology suited to complex areas where the robustness of the evidence may be limited. Focus will be on cancer care and dementia care | M1-4 | Literature reviews were carried out on carers' experiences of palliative care in dementia; education for palliative care; reviews of palliative care evaluations; and a bibliography of palliative care policies |
| Mapping of service provision across Europe on care and nursing homes, hospitals, home care, hospices (in all participating countries) | M1-4 | Mapping of services using a mapping matrix developed by WP2 researchers characterises services in terms of setting and organisational level (macro-, meso, micro). |
| Interview with policy makers in all countries to both validate commonalities and further explore variance | M1-4 | A structured interview with a semi-structured annex was developed by the five IMPACT teams and used to interview policy makers in all countries. Overarching themes about barriers to improving palliative care were used to inform Work Package 3 |
| Development of a concept tool to characterize models of palliative care for cancer patients and dementia patients | M1-4 | A high-level conceptual model of palliative care was developed iteratively within the five IMPACT teams, and then refined to capture features of good quality care (See publication citation on page 3). |
| Finalize the tools, adapted per setting and per condition | M5-6 | Both the interview questionnaire and the mapping tool were designed to be flexibly modified according to local circumstances at each research site. |

| Task | Time period | Achievements |
|--|-------------|--|
| Invite settings (care and nursing homes, hospitals, home care, hospices, networks) to take part in the study, in all five research centres | M3-6; | Settings were identified in each IMPACT research group and individuals from macro-meso- and micro-levels of organisation were approached for structured interviews |
| Collecting data with the help of the tools in the settings: review of palliative care practice across Europe, to identify commonality and variance at macro-, meso- and micro-levels | M7-10 | 55 interviews were carried out across the IMPACT teams. Interviews were transcribed in the national language and used to populate the mapping tool and to identify barriers to service improvement, and translated into English. |
| Make a comparison of models for cancer care organization and those for dementia care organization | M11-12 | Preliminary comparisons were made in the Milestone 6 Report– Description of services and country specific characteristics, and in Deliverable 2.02. |
| Make a comparison of models for palliative cancer care organization in the different countries | M11-12 | Preliminary comparisons are made in the Milestone 6 Report– Description of services and country specific characteristics, and in Deliverable 2.02. |
| Make a comparison of models for dementia care organization in the different countries | M11-12 | Preliminary comparisons are made in the Milestone 6 Report– Description of services and country specific characteristics, and in Deliverable 2. |
| Consensus Conference I with all participants including PhD students/researchers and members of scientific board to discuss the conceptual models and to reach consensus on the final one | M19; | This took place in Trondheim on June 6 th 2012. |

Phase 2: Months 18-36

The conceptual model of palliative care was developed at the consensus conference in Trondheim in Month 19, ahead of schedule. It was published in: Iliffe S, Davies N, Vernooij-Dassen M, van Riet Paap J, Sommerbakk R, Mariani E, Jaspers B, Radbruch L, Manthorpe J, Maio L, Haugen D, Engels Y; IMPACT research team. *Modelling the landscape of palliative care for people with dementia: a European mixed methods study* BMC Palliat Care. 2013 Aug 12;12(1):30. The figure on the next page shows the model with quality indicators added.



The research team for WP2 continued to collect data about national differences in the organisation of palliative care services in Europe, recruited care homes, community services, hospices and hospital wards to the intervention phase of IMPACT, and continued to publish findings. We were slowed down by events in the British NHS (see below) for our contribution to WP4, but work on all objectives for WP2 itself stayed on target.

Objective 1 was met and the output has been published (See page 6). For objective 2 we engaged with IMPACT colleagues in Poland, France and Belgium to capture their understandings of how palliative care works in their country, and used these insights to augment the original models of national palliative care systems (in the UK, Norway, Germany, Holland and Italy). The models continued to evolve as more publications on palliative care systems appeared, and we were able to compare service provision for people with cancer and people with dementia to achieve Objective 3.

For Objectives 2 and 3 we presented a developed and detailed model of palliative care systems in Europe that compares provision for people with cancer and with dementia to the IMPACT consortium on June 4th 2014, for further discussion and refinement.

Recruitment of settings to the intervention phase has been delayed because of the changes in the UK's National Health Service after April 2012, the effect of the economic downturn on public sector funding of services, and major restructuring of the commercial care home sector; nevertheless recruitment targets have been achieved, albeit at a slower rate than anticipated.

Phase 3: Months 36-48

The tasks of this phase for WP2 researchers were:

- To arrange a consensus conference II with all participants to discuss the concept models and tools and to reach consensus on the final ones (by M43).
- To further develop a comparison of models of palliative care organization for cancer patients and for dementia, in order to identify disease-specific determinants of 'good practice' (by M48).
The progress indicator for phase 3 was: Preparation of a scientific paper that gives an international overview of models of palliative care (M48).

The themes for Consensus conference II were discussed in a consortium meeting in Bonn in January 2014, and further refined at the consensus discussion in Lleida in June 2014 (M42), before being presented in a keynote presentation at the 'Towards integration of palliative care in an age-friendly European Union' conference, Brussels 15th October 2014 with the title *Models for organisation of palliative care in patients with cancer and patients with dementia*.

The models of palliative care have continued to evolve through iterative discussion within the IMPACT project, with other research projects and through reviews of the literature, to clarify the disease-specific determinants of good practice. This iterative discussion of models preceded the final discussion in June 2014, and made achievement of consensus easier. These models are described in a separate scientific paper.

The IMPACT PhD student working in WP2 interviewed 47 carers of people with dementia to obtain in-depth understanding of the dementia-specific characteristics of end of life care for this condition. He has successfully defended his thesis *Quality end of life care for people with dementia: the views and experiences of family carers* and has been awarded a PhD by University College London.

The WP2 team contributed to the intervention study by recruiting intervention sites in different settings: care homes, community services, hospitals and hospices. Efforts to engage primary care (general practitioners) in the intervention study were unsuccessful in England. Retention in the study was complete in community services, hospitals and hospices, but incomplete in care homes. The re-organisation of the English National Health Service affected the hospitals, community services and hospices that we approached, and slowed down their involvement in the project, but all were able to

complete their tasks. Re-structuring of the care home chain from which we obtained intervention sites led to the care home managers withdrawing from the study after baseline assessment. Given the timescale of the intervention we were unable to replace the care homes that dropped out. In any future study we will over-sample care homes to allow for replacements, and not rely on a single commercial chain.

Output:

In the final phase of the IMPACT project the team working on Work Package 2 has:

1. Published 7 papers or scientific letters;

- Raymond M, Warner A, Davies N, Iliffe S, Manthorpe J, Ahmedzhai S. *Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers*. Dementia 2014 Jan 1;13(1):96-110. doi: 10.1177/1471301212450538.
- Raymond M, Warner A, Davies N, Baishnab E, Manthorpe J, Iliffe S for the IMPACT research team: *Evaluating educational initiatives to improve palliative care for people with dementia: a narrative review* Dementia 2014; 13(3): 364-379
- Davies N, Maio L, Vedavanam K, Manthorpe J, Vernooij-Dassen M, Iliffe S for the IMPACT research team: *Barriers to the provision of high quality palliative care for people with dementia in England: A qualitative study* Health & Social Care in the Community 2014;22(4):386-94
- Davies N, Maio L, Iliffe S: *Quality end of life care for dementia: What have family carers told us so far? A narrative review* Palliative Medicine 2014; 28(7):919-930
- Davies N, Maio L, Van-Riet-Paap J, Mariani E, Jaspers B, Sommerbakk R, Gramatico D, Manthorpe J, Ahmedzai S, Vernooij-Dassen M, Iliffe S for the IMPACT research team: *Quality Palliative Care across Europe for Cancer and Dementia: some common challenges*. Aging & Mental Health 2014; 18(4):400-10.
This publication has been included in an online article collection featuring the most downloaded articles published in Routledge Behavioral Sciences journals in 2014. The collection features the top three most downloaded articles that were published and downloaded in 2014 in each Routledge Behavioral Sciences journal.
- Raymond M, Warner A, Davies N, Nicholas N, Manthorpe J, Iliffe S for the IMPACT study *Palliative and end of life care for people with dementia - lessons for clinical commissioners* Primary Health Care Research & Development 2014; 15; 406-17 (published online 2013; doi:10.1177/S1463342361300039X)
- Davies N & Iliffe S *Compassion in healthcare - lessons from a qualitative study of the end-of-life care of people with dementia* J R Soc Med 2014 107: 134 DOI: 10.1177/0141076814527870

2. Presented findings from WP2 at academic conferences;

- Talking about death with family carers of people with dementia: a taboo within a stigma SAPC Regional conference, Madingley Hall, 30th January [ORAL PRESENTATION]
- Quality End of Life Care for Dementia from a Families Perspective: A Narrative Review European Association of Palliative Care June 5-7th 2014, Lleida, Spain [POSTER PRESENTATION]
- The Experience of Living with and Caring for Someone with Dementia at the End of their Life European Association of Palliative Care June 5-7th 2014, Lleida, Spain [POSTER PRESENTATION]
- Family carers' experiences of admiral nursing Alzheimer Europe Conference, Glasgow, October 2014 [POSTER PRESENTATION]

For more presentations from WP2 please refer to the 'dissemination activities' of the IMPACT project in the Participants Portal.

More presentend findings of WP2 can be found under 'Dissemination activities' in the Participants Portal.

3. Discussed themes from WP2 at policy conferences

- Models for organisation of palliative care in patients with cancer and patients with dementia at the 'Towards integration of palliative care in an age-friendly European Union' conference, Brussels 15th October 2014 [KEYNOTE PRESENTATION]
- Evidence for care co-ordination for people at the end of life with dementia National Council for Palliative Care Annual conference, 10th December 2014, London [KEYNOTE PRESENTATION]

4. Completed the analysis of palliative care services in different European countries, framed in terms of macro-, meso- and micro-level characteristics. A scientific paper has been submitted with this report, and will be submitted for publication at the end of the IMPACT project.

The work of Work Package 2 is well captured in the following posters. These posters are found in the following attachments:

- Work Package 2 - Palliative Care in Dementia: A European View of the Models of Palliative Care
- Work Package 2 - Improving palliative care in dementia and cancer: Organisation of Palliative Care - IMPACT study
- Work Package 2 - Quality Palliative Care across Europe for Cancer and Dementia: International Challenges
- Work Package 2 - Family Carer Perspectives of Quality End of Life Care for Dementia

Work Package 2 Ethics Review

IMPACT was reviewed by two ethics committees: the National Research Ethics Committee (London Bridge) on 8/4/13; and UCL Research Ethics Committee on 19/10/12.

Please refer to the approval letters in the attachments:

- Work Package 2 - Ethicspg1

- Work Package 2 - Ethicspg2
- Work Package 2 - Favourable 13-LO-0 359-08-04-2013

UCL was compliant with the committees' recommendations.

IMPACT STUDY WORK PACKAGE 3: DEVELOPMENT OF SETTING SPECIFIC IMPLEMENTATION STRATEGIES

Developing a set of quality indicators for the organisation of palliative care

A multidisciplinary, international panel of professionals participated in a modified RAND Delphi procedure to compose a set of palliative care QIs based on existing sets of QIs on the organisation of palliative care. Panellists participated in three written rounds, one feedback round and one meeting. The panel's median votes were used to identify the final set of QIs.

The Delphi procedure resulted in 23 useful QIs. These QIs represent key elements of the organisation of good clinical practice, such as the availability of palliative care teams, the availability of special facilities to provide palliative care for patients and their relatives, and the presence of educational interventions for professionals. The final set also includes QIs that are related to the process of palliative care, such as documentation of pain and other symptoms, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

The results of the Delphi procedure have been described in the following publication (also see attachment Work Package 3 - van Riet Paap et al - Quality indicators palliative care): van Riet Paap J, Vernooij-Dassen M, Dröes RM, Radbruch L, Vissers K, Engels Y and on behalf of the IMPACT research team. Consensus on quality indicators to assess the organisation of palliative cancer and dementia are applicable across national healthcare systems and selected by international experts. BMC Health Services Research 2014 14:396.

Identifying barriers and facilitators regarding the implementation of strategies to improve the organisation of palliative care

Semi-structured individual and focus group interviews were conducted with purposefully selected health-care professionals. The constant comparative method was used to analyse the data.

Professionals working in hospitals, hospices, nursing homes and primary care facilities who provide palliative care to adult patients were interviewed (n =40) or participated in ten focus group interviews (n =59). Barriers and facilitators were inductively grouped into 16 categories and arranged into five themes: innovation, individual professional level, group dynamics, organizational context and local political-economic context. Although the barriers and facilitators identified differed in scope, context, strength and provenance, most of them were shared by professionals from different European countries.

The results of the barriers and facilitators analysis have been described in the following publication (also see attachment Work Package 3 - van Riet Paap et al - Barriers and facilitators):

van Riet Paap J, Vernooij-Dassen M, Brouwer F, Meiland F, Iliffe S, Davies N, Leppert W, Jaspers B, Mariani E, Sommerbakk R, Vissers K, Engels Y, on behalf of the IMPACT research team. Improving the organization of palliative care: identification of barriers and facilitators in five European countries. *Implementation Science* 2014, 9:130.

Identification of strategies to improve the organisation of palliative care

Using an integrative literature review, we evaluated publications with strategies to improve the organisation of palliative care. Qualitative analysis of the included studies involved categorisation of the implementation strategies into subgroups, according to the type of implementation strategy.

From the 2379 publications identified, 112 publications describing 104 studies were included, of which 68 had an experimental or quasi-experimental design (n=68). These studies described improvements using educational strategies (n=14), process mapping (n=1), feedback (n=1), multidisciplinary meetings (n=1) and multi-faceted implementation strategies (n=51). Fifty-three studies reported positive outcomes, 11 studies reported mixed effects and four studies had a limited effect (two educational and two multi-faceted strategies).

The results of the integrative review have been described in the following publication (also see attachment Work Package 3 - van Riet Paap et al - Review):

van Riet Paap J, Engels Y, Sommerbakk R, Moyle W, Hjermstad M, Leppert W, Vissers K, Vernooij-Dassen; IMPACT research team. Implementation of improvement strategies in palliative care: an integrative review. *Implementation Science*. Submitted for publication.

Identification of strategies for the continuation of improvement projects

A nominal group technique was used with members of the IMPACT consortium, including international researchers and clinicians active in cancer care, dementia care and palliative care. Participants mentioned and rated strategies. Data was analyzed using a quantitative (by summing the individual scores) and qualitative (by inductive coding) approach.

Twenty professional experts participated in two parallel nominal group sessions. In total, they recommended 52 potential strategies, which could be combined into five common themes: identify the unique selling point, disseminate the results, organize educational activities, involve stakeholders and provide incentives and sanctions.

The results of the two nominal group sessions have been described. This paper is submitted in March 2015 to a peer-reviewed journal.

van Riet Paap J, Vissers K, Iliffe S, Radbruch L, Hjermstad M, Chattat R, Vernooij-Dassen M, Engels Y, and on behalf of the IMPACT research team. Implementation strategies to improve the organisation

of palliative care: recommendations of expert opinion leaders. Implementation Science. Submitted for publication.

Identification of the start of the palliative phase regarding persons with dementia

Teams with in total 84 professionals working in 13 long-term care settings from 6 countries (France, Germany, Italy, Norway, Poland and the Netherlands) received a case-vignette concerning a person with dementia recently admitted to a nursing home. Teams were asked to discuss when they considered persons with dementia eligible for palliative care. The constant comparative method was used to analyse their answers.

Three different time points in the disease trajectory when persons with dementia were considered to be eligible for palliative care were extracted: (1) early in the disease trajectory; (2) when signs and symptoms of advanced dementia are present; and (3) from the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn't even reach consensus when considering persons with dementia eligible for palliative care.

The results of the vignette study have been described in the following publication (also see attachment Work Package 3 - van Riet Paap et al - Identifying the starting phase of palliative care): van Riet Paap J, Mariani E, Chattat R, Koopmans R, Kerheve H, Leppert W, Forycka M, Radbruch L, Jaspers B, Vissers K, Vernooij-Dassen M, Engels Y; IMPACT research team. Identification of the palliative phase in persons with dementia: a variety of opinions between healthcare professionals. BMC Palliative Care. Submitted for publication.

Training program for consultants

A manual for the consultants guiding the quality improvement of the IMPACT project was developed specifically for the purpose of WP4. However, a summary of the manual was also made in the form of a laminated pocket card. The entire implementation process was described on this laminated pocket card. All professionals participating in the WP4 intervention study received an example of the laminated pocket card.

Example of laminated pocket-size card

| | |
|--|---|
|  <p style="text-align: right; font-size: small;">www.impactpalliativecare.eu info@impactpalliativecare.eu</p> <p style="text-align: center;">How to improve the organisation of care:</p> <div style="text-align: center;"> <p>1. What is the problem?</p> <p>↓</p> <p>2. What can we change?</p> </div> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;"> <p>Act</p> <p>↓</p> <p>Study</p> <p>↓</p> <p>Do</p> </div> <div style="text-align: center;"> <p>Plan</p> </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> <div style="width: 30%;"> <p>7. Evaluation of the strategy</p> <p>6. Implementation of the strategy</p> </div> <div style="width: 30%;"> <p>3. What is the improvement objective?</p> <p>4. Which factors influence this objective?</p> <p>5. Which strategy do we need for this objective?</p> </div> </div> <p style="font-size: x-small;">© 2013 IQ health care & Afdeling Anesthesiologie, Pijn en Palliatieve Geneeskunde Huispost 114, Postbus 9101, 6500 HB Nijmegen</p> <p style="text-align: center;"></p> |  <p style="text-align: right; font-size: small;">www.impactpalliativecare.eu info@impactpalliativecare.eu</p> <p style="text-align: center;">Step-by-step guide to improve the organisation of care</p> <ol style="list-style-type: none"> 1 What is the problem <ol style="list-style-type: none"> a. What would you like to improve? 2 What can we change? <ol style="list-style-type: none"> b. Which aspects need to be changed? c. Which aspects need to receive attention? 3 What is the improvement objective? <ol style="list-style-type: none"> d. What is the current situation? e. What is the preferred situation? f. Formulate the objective in a SMART way 4 Which factors influence this objective? <ol style="list-style-type: none"> g. Why has the preferred situation not yet been achieved? 5 Which strategy do we need for this objective? <ol style="list-style-type: none"> h. Which actions do we need to achieve the objective? i. When should these actions be completed? j. Who is responsible for these actions? 6 Implementation of the strategy <ol style="list-style-type: none"> k. Do you experience challenges implementing the actions? 7 Evaluation of the strategy <ol style="list-style-type: none"> l. Has the improvement objective been achieved? m. If yes: Does the result meet the preferred situation? n. If not: Why not, what should be changed? <p style="font-size: x-small;">© 2013 IQ health care & Afdeling Anesthesiologie, Pijn en Palliatieve Geneeskunde Huispost 114, Postbus 9101, 6500 HB Nijmegen</p> <p style="text-align: center;"></p> |
|--|---|

Other publications of WP3

van Riet Paap J, Engels Y, Iliffe S, Radbruch L, Kaasa S, Chattat R, Vissers K, Vernooij-Dassen M and on behalf of the IMPACT research team. Improving the organization of palliative care by implementing quality indicators and national and setting-specific interventions: Study protocol of the IMPACT project. *Progress in Palliative Care* Volume 22, Issue 4 (August, 2014), pp. 201-205. (also see attachment Work Package 3 - Study protocol of the IMPACT project).

IMPACT STUDY WORK PACKAGE 4: EVALUATION OF THE IMPLEMENTATION OF QUALITY INDICATORS

The objective of Work Package 4 was:

- To evaluate the effectiveness and acceptability of our implementation strategies in the specific settings and across settings.

Reporting period one (M0-18)

There were no milestones or deliverables that were due during the period M0-18 in WP4.

The core tasks of WP4 began in M18. In preparation of the WP4 core tasks a thorough literature search was undertaken on the provision of palliative care, organization of palliative care, numbers of services, palliative care for patients with dementia/and or cancer. The relevant bodies in palliative and hospice care in Germany were informed about IMPACT, a search on methodologies for the implementation of improvement strategies (organizational management) was undertaken, and the settings for the pre-/posttest in year 3 of the IMPACT project were recruited and informed about all relevant issues at this stage of the project.

The researchers involved in WP 4 contributed the other WPs as follows:

WP 2:

Analytic framework

- Search of relevant national grey literature and discussion of the work progress
Development of a model of the organization of palliative care on a macro, meso and micro level
- Compilation of a 30-page questionnaire in order to collect data on all levels. This questionnaire was carefully developed over the course of some weeks: In order to facilitate comparability, the items had to be phrased and organized in a way which considered national differences regarding use of terms, health systems, the organization and provision of palliative care. This required joint work of all researchers on a number of draft versions, skype conferences on a regular basis, and translation into German.
- Interviews: WP4 researchers conducted 9 face-to-face interviews with experts in palliative care for cancer and/or tumour patients across Germany, using the open questions of the questionnaire which were mainly covering issues relating to the macro level. These interviews were fully transcribed according to an agreed set of transcription rules, and translated into English. The full translation was sent to WP 2; furthermore all results from the German interviews were analysed and inserted into a mapping template.
- Additionally, all interviewed experts filled in the (mostly) closed questions of the questionnaire for at least one level, and at least one patient group. The results were inputted into a matrix, comments translated into English.
- Along with the questionnaire, a set of vignettes was completed and used in the context of the interviews. Their use also required translation in German and translation of the results for feedback to WP 2.

WP 3:

Set of indicators to be used in WP4

- Literature search of indicators in the grey literature (Germany); recommendation of experts for the Delphi procedure, participation of researchers in the Delphi; participation (WP leader and researcher) in a Delphi meeting in the context of the EAPC World Research Congress in Trondheim in June 2012).

To describe overall and setting-specific barriers and facilitators to apply quality indicators for the improvement of the organization of palliative cancer and dementia care

- Development of an interview guide for individual and focus group interviews on barriers and facilitators.
- Conduction of 3 pilot interviews with individuals, analysis and slight adaption of the interview guide, paraphrasing of the answers, translation of the answers, coding/inductive categorization; development of a code book (including a strategic initial meeting in Amsterdam and some Skype conferences).
- Conduction of 2 focus group interviews, coding of the interviews, continuous development of the codebook and translation of relevant quotes.

To describe barriers and facilitators in national policy (policy makers, (results from WP 2) health care insurance, scientific bodies) regarding applying quality indicators for the improvement of the organisation of palliative dementia and cancer care

- Delivery of the required results from interviews, questionnaires, and literature search.

WP 5:

Factors influencing implementation

- Fine tuning of time schedules for required tasks in order to facilitate a more appropriate time slot for completing WP4/WP5 tasks at the end of the IMPACT project.

WP 6:

Dissemination

- Feedback on tools and strategies, development of website and elaboration of WP 4 internet presence (English and German).

Overall tasks

- Regular phone/Skype conferences of WP leaders and of researchers.
- Development of consented information material for interviewees, recruiting of settings, dissemination of IMPACT related issues, web-based research and data collection tasks.
- Participation in meetings in London, Nijmegen, and Lisbon (2011) with talks (PPT presentations about work progress and future collaboration).
- Participation in meetings in Bonn, Amsterdam, and Trondheim (2012), with talks (PPT presentation about work progress and future collaboration).

Reporting period two (M18-36)

Tasks

- Instructing the participating services on how to implement the indicators and how to send back the data (M25; all participants);
- Pre-test: use of quality indicators (at least 2 hospitals, 2 hospices, 2 nursing homes, 2 primary care settings per country, in The Netherlands, Germany, Norway, England, Italy) (M25-26);
- Collecting all data in database (M25-26);

- Analysing the data (M27);
- Generate feedback (M27);
- Invite each setting to mention three aspects that they want to improve, taking the feedback report into account (M30);
- Assist the settings with choosing strategies to improve their organisation;
- Post-test: use of quality indicators (at least 2 hospitals, 2 hospices, 2 nursing homes, 2 primary care settings per country, in The Netherlands, Germany, Norway, England, Italy) (M35);
- Analysing the effect of the implementation strategies (M36).

Tasks related to Process indicators

- Tool with the steps that need to be taken to assess and improve the quality of the organisation of palliative care (M24);
- Database filled with pretest data from participating settings in all five countries (M27);
- List with improvement aspects of all settings (M30);
- Database filled with pretest plus posttest data from participating settings (M36).

During this period WP4 worked on the toolkit and a manual for the consultants for the implementation phase in order to allow a unified consultation strategy. Skype meetings were held among the consultants, led by Germany. Settings were recruited, focus interviews and preparatory meetings conducted, the QIs were operationalized and the final questionnaires for the lime survey were consented among the researchers and translated into German and other national languages. After the pretest, comprehensive feedback of the results was provided and the implementation process conducted with thorough supervision. One service in Germany worked only on one improvement aspect, because none of the other QI measurement results with theoretical room for improvement fit the service's structure and philosophy. Germany finished its implementation tasks in time. The posttest had started in most countries, including Germany, but couldn't be completed because of a number of issues causing delay in the participating settings. Dates for posttest feedback in Germany were scheduled.

Milestones

MS12: Consultants appointed M24 achieved.

MS13: Recruiting settings to implement the indicators M24 achieved: 9 services in Germany .

MS14: Setting specific implementation strategies M24 achieved.

Comments: However, the milestone had been changed to a compilation of a toolkit of strategies and methods derived from the literature. The search and analysis of the literature showed that a list of setting specific implementation strategies could only be achieved in a descriptive manner.

MS15: Data pre-test pilot M36 achieved in Germany, the Netherlands (7 services), Norway and Italy; UK only for 5.

Comments: Because of the difficulties WP 2 reports regarding the health care situation in the UK, no more than 5 services had completed the pretest in M36; available were only the raw data of other countries and the cleaned data for German services.

Deliverable

D4.5: Table of strategies used in five countries: after the pilot of the intervention an overview of all strategies used in the five participating countries will be available, per type of setting and per country (M36)

Achieved for German data in M36, and for most services from other countries. However, WP4 was able to present an extensive overview of strategies used in the five countries.

Because the implementation was still in process due to recruiting problems and other problems to be reported by the partners); another, then completed version was submitted in M43. In M48, another version was submitted, in which the information from all services which dropped out of the IMPACT project before the posttest, was deleted.

The method for the analysis of strategies (additional explanatory document, together with table of strategies) was developed in a consensus process of three researchers from WP4, and was presented to researchers and WP leaders from all countries involved. It was tested for usefulness and clarity during a workshop at the meeting in Bonn and approved by all partners. The analysis was done independently by two WP4 researchers for the data from all countries, compared and discussed until consensus was reached for the final presentation of data. If required, researchers from other countries were asked for clarification.

Summary of description of the deliverable and most important results therefore see [reporting period three](#).

Dissemination

- 5th Meeting of the Network of Comprehensive Cancer Centres in Germany, German Cancer Aid (Deutsche Krebshilfe), Working Group Palliative Care 2013, Frankfurt/M, 28.11.2013, University Clinic Frankfurt/M.
Birgit Jaspers: Oral information about aims and scope of the Impact project

The researchers involved in WP 4 contributed the other WPs as follows:

Further, WP4 contributed to several publications under the 1st authorship of other WPs and the model of palliative care (WP2). An interview guide for WP5 is currently being translated into German, and interview dates (for WP 5) are being scheduled.

Overall tasks

Regular phone/Skype conference of WP leaders and researchers

Participation in meetings in Bologna, London, Prague with talks and presentations

Participation at congresses: European Association for Palliative Care, Prague, Czech Republic

Dissemination of IMPACT issues at several meetings of relevant bodies for palliative care in Germany

Reporting Period 3: M36-48

Tasks

- Analysing the effect of the implementation strategies (M36).

Tasks related to Process indicators

- Database filled with pretest plus posttest data from participating settings (M36).

WP4 completed the intervention phase in 8 services in Germany (Italy and Norway 8, Netherlands 7, UK 6).

The results of the analysis undertaken by WP4 are presented in a table of strategies (Deliverable 4.05) in another revised version, containing only the services which completed the posttest (n=37 services). Due to dropout of some services during the IMPACT project, the number of participants decreased from 40 to 37 (D 8, NL 7, NO 8, IT 8, UK 6).

As neither the pre- nor the posttest had been finished by M36 in all of the participating countries, the database was incomplete by then. But towards the end of the project, the posttest data from all countries were obtained, have been cleaned and were analysed by WP4 in M47 and 48.

The remaining 37 services implemented 1-3 quality indicators each; addressing in total 18 of the 25 indicators from the quality indicator set. Tables with an overview of all the aspects of quality indicators that were addressed by the individual settings per country are delivered separately (MS21). The top 3 indicators across all countries and settings were: QI 7b (Bereaved professionals involved in the care of a person in need of palliative care are offered support during the bereavement process if they need or wish to have support – 13x), 20 (There is a regular assessment of pain and other symptoms using a validated instrument – 13x), and 24 (The file of the person in need of palliative care contains documentation of a discussion with the person or representative (if the person lacks capacity e.g. is unable to communicate) about: medical condition; goals for treatment; the physical, psychosocial and spiritual needs of the person and family caregiver; an advance directive or advanced care plan; end-of-life decisions; the intention to return home or to another facility from the place where the person is currently staying - 11x).

Interestingly, one of the most often implemented quality indicators (7b) addressed self-care. In some cases, access to bereavement support for team members was initiated by the discussion of this quality indicator, but in most cases, existing offers had not been clearly communicated and there was a lack of a standard procedure for access. The table of strategies shows that all services that addressed this indicator chose professional-oriented strategies combined with organizational measures. The interventions included needs assessment of staff, development of a structured offer after an inventory of available support. In all cases, this implementation process was supported by the organization (e.g. cooperation contracts, time allowance for self-care etc.).

The other most frequently implemented indicator (20) stipulated a discussion about the unmet need to regularly assess also other symptoms with validated instruments, and not only pain. A regular assessment of pain was rather common, but the fact that the indicator was rated as not met if other symptoms weren't addressed as described, caused considerable concern in the

respective services. The table of strategies shows a variety of chosen strategies, mostly organizational interventions concerning the structure and interventions orientated towards health professionals. Different methods were chosen for the same objective, namely to gain information about validated instruments (reviews, inventories, local opinion leaders, research) before implementation of a new clinical routine. Educational interventions aimed at knowledge about new instruments, their use and documentation.

Aspects of quality indicator 24 were implemented by 11 services. These services either addressed the documentation system (aspects were assessed but not documented in the patient file), or they addressed the assessment and documentation of aspects that weren't yet considered in their assessment routine (e.g. psychosocial needs of family). The table of strategies shows that organizational measures and patient-oriented strategies were used for implementation, comprising changes in medical records systems and changes in arrangements to maintain or retrieve information.

A detailed presentation, comparative analysis and interpretation of the pilot data is provided in an extensive excel file (MS 21), as well as a database with the pre- and posttest results (MS16) (SPSS file and PDF file with table).

The cleaning and analysis of the pre- and posttest data showed that there was a need for adapting the operationalisations of the quality indicators in order to simplify the analysis process. Therefore the questionnaires for the tests to be used by interested services after the end of the IMPACT project (DVD/website) were adapted thoroughly by WP4 in collaboration with the researcher from WP3.

WP4 has presented the results of the implementation study to their participating services by individual written and personally discussed feedback. Further, WP4 held a final closure meeting with all participating services to celebrate the success of the project. At this meeting, the overall results and lessons learned in Germany, as compared to other countries, were presented in a talk with PowerPoint presentation. WP4 expressed their thanks by handing out a placate indicating successful participation in the project to each team. All IMPACT posters of all WPs including those from the invitational conference in Brussels were displayed on a whiteboard. The Brussels declaration was translated by WP4 for this meeting and distributed; the participants were interested in signing the declaration digitally.

At this meeting, there was time for exchange of experiences among the participants and a feedback round to WP4 about pitfalls and benefits of their participation in this research project. Most often named was that "being viewed from the outside" (by the consultant) facilitated interpreting one's own situation on a meta-level, and that the use of the QI set and the whole implementation process also showed them their strengths, not only the pitfalls.

WP4 researchers have been presenting results of their work at national and international congresses and meetings of influential bodies for the provision of palliative care, contributing to the tasks of other WPs as required, and to publications.

Manuscripts for publications of WP4 issues are in working process, submission is planned in March 2015, partly due to the rather late completion of the pre-/posttest in all services and challenges regarding cleaning the data of wrong and/or erroneous entries.

The researchers involved in WP 4 contributed to the other WPs as follows:

WP5:

Process evaluation

Several tables with comprehensive information about difficulties with the conduction of the posttest, staff issues concerning the posttest, characteristics of interviewees and the interviews themselves, comparability of this information with the procedure for the pretest, improvement aspects and implementation strategies were filled in. WP4 conducted the required interviews for WP5 with the German services. The interview guide was discussed and revised by the researchers from all countries, and translated into German. The interviews were fully transcribed and translated into English by WP4 for the report to WP5. WP4 also delivered a comprehensive country report to WP5 for the process evaluation.

WP6:

Supporting the development of tools for training and supporting QI use (books, manual, DVD)

WP4 has contributed to the manual with several manuscript revisions, translated the manuscript and all relevant material for a German version of the DVD (subtitles, instructions etc.).

Further, WP4 contributed to several publications under the 1st authorship of other WPs (8WP2, 3 and 6).

Milestones

MS16: Database filled with pretest plus posttest data from the 37 participating settings M36 achieved M48

Comments: The databases for the pretest and posttest are delivered as SPSS files. Analysed results are shown and submitted in tables.

MS21: International comparison of the pilot data M48 achieved

Comments:

The SPSS data were analysed descriptively by WP4 and are presented in tables in order to provide a concise and easy to read overview.

Deliverable D4.5: Table of strategies used in five countries: after the pilot of the intervention an overview of all strategies used in the five participating countries will be available, per type of setting and per country (month 36) final version achieved M48.

Dissemination

- Poster at the 8th World Research Congress of the EAPC, Lleida, Spain, 5.-7. June 2014
Birgit Jaspers, Daniela Grammatico, Michaela Hesse, et al. and Lukas Radbruch on behalf of the IMPACT team: Use of quality indicators across settings and countries (results from pretest, quantitative)
- Talk at the 10th Congress of the German Association for Palliative Medicine and the 13th Congress of the German Association for Health Services Research (Duesseldorf, Germany, 24.-27.06.2014)
Birgit Jaspers: Development of quality indicators for palliative care on a European level
- Poster presentation at the 10th Congress of the German Association for Palliative Medicine and the 13th Congress of the German Association for Health Services Research (Duesseldorf, Germany, 24.-27.06.2014)
Birgit Jaspers, Daniela Grammatico, Michaela Hesse, et al. and Lukas on behalf of the IMPACT team: Use of a set of quality indicators – Results of a pretest in five European countries (IMPACT project)
- 6th Meeting of the Network of Comprehensive Cancer Centres in Germany, German Cancer Aid, Working Group Palliative Care 2014, Dresden, 02.10.2014, University Clinic Dresden
Birgit Jaspers: Oral information about further development and results of the Impact project
- Two posters at the Invitational conference in Brussels, 2014
Birgit Jaspers, Daniela Grammatico, Michaela Hesse, et al. and Lukas on behalf of the IMPACT team: Recommendations for political decision makers based on results from a pretest on the use of quality indicators across 4 settings and 5 countries (I) and (II)

Overall tasks

Regular phone/Skype conference of WP leaders and researchers;
Organisation of IMPACT meeting in Bonn with talk about progress and results of work;
Participation in meetings in Bonn, Lleida, invitational conference Brussels (presentations, talks);
Participation at congresses (German Association for Palliative Medicine) Düsseldorf, Germany, European Association for Palliative Care, Lleida, Spain);
Dissemination of IMPACT issues at several meetings of relevant bodies for palliative care in Germany.

The work of Work Package 4 is well captured in the following documents. Please refer to the following attachments:

- Work Package 4 - Data Questionnaire Posttest
- Work Package 4 - Data Questionnaire Pretest
- Work Package 4 - Data medical record questionnaire Posttest
- Work Package 4 - Data medical record questionnaire Pretest
- Work Package 4 - MS21 final for delivery
- Work Package 4 -Table of Strategies Jan. 15 Deliverable 4.5 final
- Work Package 4 - Table Overview Quantitative Results Pretest final

IMPACT STUDY WORK PACKAGE 5: FACTORS INFLUENCING IMPLEMENTATION

The objective of Work Package 5 was:

- To determine factors influencing implementation of the set of quality indicators for cancer and dementia palliative care.

Phase 1: 0 to 18 months

There were no tasks, milestones or deliverables due during the period month 0-18 in Work Package 5 (WP5). According to the “Annex I - Description of Work”, the work in WP5 would begin in month 18. The main task in WP5 is to conduct a process analysis of the pretest/ posttest intervention in order to make an inventory of the setting specific barriers and facilitating factors influencing implementation. Thus, during this period, we began a search for literature to guide the process of making tools for process registration and process evaluation that would be used by each partner during the data collection in WP5. A preliminary search was done in the PubMed database and we contacted researchers with experience in process evaluation to ask for assistance in further development of the tools. A literature review on barriers and facilitators to implementing improvements in palliative care was also started during this period, in collaboration with RUNMC (WP3).

Phase 2: Months 18-36

The tasks of this phase for WP5 researchers were:

- Preparing the process registration by literature search (M18-22);
- Developing all questionnaires and documents needed for the prospective process registration (M22-24);
- Developing an interview schedule with semi-structured questions on experiences in using the strategies and the quality indicators (M22-24).

The process indicators for phase 2 were:

- Questionnaires and checklists for process evaluation available (M24);
- Interview schedule available (M32);
- Document /database that shows which data are collected during the pilot for the process evaluation (M36);

During this phase, we decided to do two studies in WP5 on factors influencing implementation of quality indicators. This reflects two different aspects of quality indicators. The first study is a feasibility study on using the IMPACT set of **quality indicators as a measuring tool** assessing whether or not services had fulfilled the quality indicators regarding the organization of palliative care.

The quality indicators were operationalized into two questionnaires, and we were interested in identifying any challenges the services had when answering these Quality Indicator Questionnaires. An interview guide was developed and one or more representatives from each participating service were interviewed for this study. Data collected right after the pretest identified quite a few

challenges the services encountered when using the web-based quality indicator questionnaires. Examples are technical difficulties, time constraints and difficulties finding the necessary information. The results were reported in *Deliverable D5.6* in month 36. However, we wanted to see if the services experienced any difficulties when filling in the questionnaires a second time, during the posttest. The interview guide was therefore updated and a representative from each service was interviewed once again during phase 3 of the IMPACT project.

The second study of WP5 concerns **quality indicators as targets** that services should strive to reach in order to provide high quality care. Each of the 23 quality indicators chosen for the IMPACT project represents such a target in palliative care. In this study, we were interested in identifying the barriers and facilitators the services experienced while working to fulfill their chosen quality indicators. To answer this, we conducted a process evaluation, including an interview study. We developed several questionnaires to collect data for the process evaluation, and they were used by each of the five countries throughout the intervention phase of the pilot study. Each of the main IMPACT partners have collected information on the participating services, the managers, the barriers and facilitators the services anticipated that they would encounter, a blueprint of the planned intervention, and the intervention as it was actually performed. There was also a questionnaire that gives a description of the IMPACT consultants' knowledge and background in palliative care and organizational change, since they played such an important role in facilitating the improvement process in the services. All questionnaires were added to the consultants' manual, developed by WP3.

An interview guide (schedule) was also developed. The questions were based on factors literature has indicated as influential when improving palliative care. To capture the presence of influential factors not identified in literature, part of the interview guide was tailored to each service by the researchers in each country. This enabled the researchers to get more information on the barriers and facilitators that had been identified in a given service during the intervention phase, and identify new ones. To tailor this part, the researchers went through the questionnaires the services had answered during the pretest and intervention phase, in addition to the activity reports the consultants filled in after each visit during the intervention phase. WP5 developed a guidance document for the researchers on how to tailor the interview guides. The interviews were conducted in the next phase of the project, after the services had completed the posttest and received feedback with the results.

A database was developed in Excel to get an overview of the data collected for the process evaluation in each service.

Phase 3: Months 36-48

The tasks of this phase for WP5 researchers were:

- Recruiting staff members of the participating services to evaluate the acceptability of the intervention and factors influencing implementation (M37);
- Performing interviews (face-to-face and/or by phone) with professionals of the settings that took part in the intervention (WP4) (M38-41);

- Analysis of web-based data on the use of quality indicators and of the results of the diary on the website (M44);
- Analysis the data with the help of Atlas-ti (M42-44)

The process indicators for phase 3 were:

- Document /database that shows which data are collected during the pilot for the process evaluation (M36);
- Scientific paper about factors influencing the implementation (M48)

For both WP5 studies, each IMPACT partner recruited and interviewed staff members that had participated in the pilot study.

WP5 study 1: quality indicators as measuring tool (feasibility study)

Methods: The aim of the first study was to identify difficulties the participants had experienced while filling in the questionnaire, and evaluate if changes had to be made to the questionnaire. Interviews were conducted twice with one or more representatives from each service that had participated in filling in the IMPACT Quality Indicator Questionnaires. Representatives from 40 services were interviewed after the pretest, and representatives from 37 services were interviewed after the posttest. Three services had dropped out in the meantime, one hospice in Germany and two care homes in England.

The data was first analyzed in the national language by two researchers in each country. A report presenting the data from each country was then written in English. Two Norwegian researchers coded each of the country reports and sorted the data into six categories following Richard Grol and

Michel Wensing's categorization of barriers and incentives to change at different levels in health care settings, i.e. 1) Innovation, 2) Individual professional, 3) Patient, 4) Social context, 5) Organizational context, and 6) Economic and political context.

Results: The table on the following page gives an overview for each country of the challenges experienced in the pretest and the posttest. *Please refer to the document attached 'Work Package 5 - Deliverable D5.6 part II 'for a further description of the challenges and lessons learned.*

Based on the feedback from the services, the IMPACT partners decided to revise the questionnaires for future use by services not participating in IMPACT. The results of this study will be submitted to a peer-reviewed journal this Spring (2015).

| Categories | Codes | UK | | DE | | IT | | NO | | NL | |
|---|---|-----|------|-----|------|-----|------|-----|------|-----|------|
| | | Pre | Post |
| 1. Innovation A) Technical issues | Deleted data | | | | | | | | | | |
| | Accessing national questionnaire | | | | | | | | | | |
| | Frozen webpage | | | | | | | | | | |
| | E-mails defined as spam | | | | | | | | | | |
| 1. Innovation B) Content | Unclear definitions | | | | | | | | | | |
| | Irrelevant questions | | | | | | | | | | |
| | Do not reflect inner organization | | | | | | | | | | |
| | Extra features wanted | | | | | | | | | | |
| | Unclear instruction | | | | | | | | | | |
| 1. Innovation C) Usefulness | Time consuming | | | | | | | | | | |
| | Not sensitive enough to measure change | | | | | | | | | | |
| | Too short intervention period | | | | | | | | | | |
| | Relevant indicators not included | | | | | | | | | | |
| 2. Individual professional | Lack of IT skills | | | | | | | | | | |
| | Lack of knowledge | | | | | | | | | | |
| 3. Patient | Finding relevant patients | | | | | | | | | | |
| 4. Social context | Manager underestimates staff | | | | | | | | | | |
| | Lack of leadership support | | | | | | | | | | |
| 5. Organizational context | Lack of time | | | | | | | | | | |
| | No multidisciplinary discussion | | | | | | | | | | |
| | Not access to information | | | | | | | | | | |
| | Badly organized patient files | | | | | | | | | | |
| | New organizational structures | | | | | | | | | | |
| | New computer system | | | | | | | | | | |
| 6. Economic and political context. | Interpreting information in patient files | | | | | | | | | | |
| | National reorganization | | | | | | | | | | |

UK: England; DE: Germany; IT: Italy; NO: Norway; NL: The Netherlands

Table 1: Challenges experienced while using online questionnaires to evaluate the organization of palliative care

WP5 study 2: quality indicators as targets (process evaluation)

Methods: The aim of the second study was to identify factors that influenced whether or not the services were successful in fulfilling the quality indicators they had chosen as improvement objectives. The IMPACT partners conducted semi-structured interviews with staff members and managers who had been involved in the improvement process. Some were interviewed individually, while others were interviewed in focus groups. The researchers tailored the interview guide to each service based on a guidance document provided by WP5.

The data was first analyzed in the national language by two researchers in each country using Astlati software. The researchers sorted the data into six categories following Richard Grol and Michel Wensing's categorization of barriers and incentives to change in health care settings. This data was filled in an Excel database developed by WP5. Other aspects of the process evaluation, such as length of intervention period, target group, the different steps in the improvement strategy and any changes to the improvement strategy, were also described in the database. In the next step of the analysis process, the Norwegian researchers were in close contact with the researchers in the other countries to ensure that they had understood all entries in the database.

Results

An inventory has been developed listing all barriers and facilitators that the participants either anticipated or experienced during the intervention phase (see Excel file "*WP5 Inventory of factors influencing implementation*"). The inventory can be sorted according to country, setting, quality indicators and the barriers and facilitators on different levels of the health care system. In the analysis, we have specifically looked at barriers considered crucial, i.e. that completely stopped the progress of the work towards reaching the improvement objective. Most of these were connected to the organizational level, i.e. management or other key staff turnover, high clinical workload and competing changes. However, some services were unable to continue working on fulfilling some of the quality indicators, because the participants had been too enthusiastic and set improvement objectives that were too ambitious.

Barriers that can be considered particular to palliative care have also been of special interest to us during the analysis. We found, for example, that there is a lack of validated symptom assessment tools for patients with dementia and the elderly. Another barrier was that some palliative care topics are considered sensitive, and therefore new procedures are difficult to implement. See *Deliverable D5.6 part II* for a further description of the barriers and facilitators experienced by the services during the improvement process. The results will be submitted to a peer-reviewed journal this Spring (2015).

Output:

1. Posters

- Sommerbakk R, Haugen DF, Hjerme stad MJ (2014). Evaluating an online questionnaire for monitoring the quality of palliative care. Palliative Care 2020: Towards integration of palliative care in an age-friendly European Union
- Sommerbakk R, Haugen DF, Hjerme stad MJ (2013). Barriers and facilitators to implementing quality improvements in palliative care: an integrative review. 13th World Congress of the European Association for Palliative Care

2. Presented findings at academic conferences and seminars;

- Sommerbakk R: Telling them what to do is not enough» - factors influencing improvement projects in palliative care. Annual seminar of the European Palliative Care Research Centre; 2012-12-07
- Sommerbakk R: Barriers and facilitators to implementing quality improvements in the organization of palliative care: «looking into the black box». 13th World congress of the European Association for Palliative Care; 2013-05-30
- Sommerbakk R: Factors influencing implementation of quality improvements in palliative care: Results from a qualitative interview study in Norway. 10th Annual Norwegian Health Sociology Conference; 2014-04-

3. Published abstracts

Sommerbakk R, Haugen DF, Hjermstad MJ: Testing a web-based tool for registration of quality indicators in palliative care services – a qualitative analysis. *Palliative Medicine: A Multiprofessional Journal* 2014; Volum 28. s. 843-843

IMPACT STUDY WORK PACKAGE 6: DISSEMINATION/RESEARCH ELENA MARIANI

The dissemination activities will be presented under the chapter 'The main dissemination activities and the exploitation of results' of the Final Report in the Participants Portal

Research Elena Mariani

Our Italian consortium member, the psychologist Elena Mariani, has the ambition to contribute more to the IMPACT project than her dissemination tasks. She developed an intervention to improve the organisation of palliative dementia care by shared decision making on care plans in nursing homes. Shared decision making is high on the agenda of both palliative and dementia care research programmes, because this might be an adequate way to stimulate personalised care.

Care plans are an opportunity to translate important organisational aims such as investigating and addressing problems and needs of patients into practice. The theoretical framework of shared decision making has been translated into an intervention to improve shared decision making in nursing homes. The European perspective will be addressed by using this approach both in Italy and in the Netherlands. This is a very promising intervention that requires evaluation.

The IMPACT project was able to fund this next step in improving the organisation of palliative care at a meso and micro level.

Permission was asked and given by our scientific officer to spend this part of the budget which initially was reserved for our Finnish partner for the evaluation of the shared decision making in a care plans project in a Dutch and Italian nursing home as we believe that this would definitely add value to the IMPACT project.

As an additional task, the researcher of Italy also started a PhD trajectory. She implemented advance care planning in two nursing homes in Italy and two in the Netherlands. She will study the effects of these intervention in a controlled prospective study. The research protocol of this study has been submitted for publication. Further results are expected in 2015 and 2016.

DESCRIPTION OF THE POTENTIAL IMPACT, THE MAIN DISSEMINATION ACTIVITIES AND THE EXPLOITATION OF RESULTS

IMPACT STUDY WORK PACKAGE 6: MAIN DISSEMINATION ACTIVITIES DURING THE PERIOD

Month 0-18

WEBSITE

In year I-II Work Package 6 has coordinated the website development, that contains the description of the project and of the Work Packages in five different languages and also contains videos about the project. Furthermore, the website was linked to the main European social networks.

As expected, the developed website was composed of:

- A consortium restricted section to share official communications, documents and reports;
- An open access section where users can read the description of the project, of the Work Package tasks, of the Research Centres and Universities involved and can retrieve information and details about the researchers.

CONFERENCES

All partners involved in the IMPACT project, during year I and year II, actively participated in national and international events to disseminate the project.

NETWORKING

In this period, each research site established networks with relevant professionals organisations, health care organisations and involvement of institutions: in particular, the researchers conducted their research in four different settings:

- Home Care Assistance
- Hospice
- Hospital
- Nursing homes

and on three different levels:

- Micro level: professionals who provide direct care to patients
- Meso level: voluntary associations and other services
- Macro level: policy makers involved in laws, regulations and guidelines about palliative care

This allowed all the European countries involved in the project to build a profound network with many organisations and institutions on regional, national and international level.

PRINTED MATERIALS

Work Package 6 has printed and delivered to the project partners the flyers containing information about the project: some of them are in English and others have been translated into the native languages of the European countries involved. The flyers have been handed out to institutions, associations and organisations involved in palliative care. Some papers have been submitted.

RESEARCH

Work Package 6 contributes also to the IMPACT project actively collecting the data of the research parts (WP2 and 3), in order to achieve the final goals of the project.

Month: 18-36

WEBSITE

In Year II-III the website was fully active and used by researchers and external users. The private sections of the website were used by researchers to store important documents, such as minutes of the meetings, lists of dissemination events, ppt. presentations shown during conferences and copies of the IMPACT published articles. All IMPACT related news was published in the 'Main Issues' section of the website, in order to keep the public users constantly updated on the project progresses and achievements.

Moreover, news and information were published on the IMPACT Social networks: Facebook, Twitter, You Tube and LinkedIn. Links to those public pages were located on the bottom of the website. The IMPACT project has entered the commHERE Network, whose aim is to improve communication on the outcome of EU-funded health research projects to the media, the general public and other target groups including the EC in all of Europe. Thanks to this network, a page on the IMPACT project was published at the web portal HorizonHealth.eu, with details on the project and downloadable materials.

NETWORKING

Relevant scientific associations and policy makers had been contacted and some of them also interviewed for research purposes (data have been published in research articles) . Where possible, depending on the privacy rules, organisations were asked to put the links to their website on the 'Links Section' of the IMPACT website.

CONFERENCES

The IMPACT project has been presented in around 30 national and international events with oral and poster presentations. In some cases, these events were lectures and symposia organised by IMPACT researchers to spread the concept and use of Quality Indicators.

PUBLICATIONS

The list of IMPACT publications in Year II and III:

- Mareeni Raymond, Alex Warner, Nathan Davies, Jill Manthorpe, Sam Ahmedzhai and Steve Iliffe "Palliative care services for people with dementia : A synthesis of the literature reporting the views and experiences of professionals and family carers"(2012). *Dementia* 0(0)1-15
- Mareeni Raymond, Alex Warner, Nathan Davies, Elora Baishnab, Jill Manthorpe and Steve Iliffe "Evaluating educational initiatives to improve palliative care for people with dementia: A narrative review"(2013). *Dementia* 0(0)1-16.
- Iliffe Steve, Nathan Davies, Myrra Vernooij-Dassen, Jasper van Riet Paap, Ragni Sommerbakk, Elena Mariani, Birgit Jaspers, Lukas Radbruch, Jill Manthorpe, Laura Maio, Dagny Haugen, Yvonne Engels for the IMPACT research team "Modelling the landscape of palliative care for people with dementia: a European mixed methods study"(2013). *BMC Palliative Care*, 12-30.
- Davies Nathan, Laura Maio, Jasper van Riet Paap, Elena Mariani, Birgit Jaspers, Ragni Sommerbakk, Daniela Grammatico, Jill Manthorpe, Sam Ahmedzai, Myrra Vernooij-Dassen, Steve Iliffe & for the IMPACT research team "Quality palliative care for cancer and dementia in five European countries: some common challenges"
- Mareeni Raymond, Alex Warner, Nathan Davies, Nirusha Nicholas, Jill Manthorpe, Steve Iliffe and for the IMPACT study "Palliative and end of life care for people with dementia: lessons for clinical commissioners" (2013). *Primary Health Care Research & Development*, 1-12.
- Davies N, Maio L, Vedavanam K, Manthorpe J, Vernooij-Dassen M, Iliffe S; IMPACT Research Team. Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences. *Health Soc Care Community*. 2014 Jul;22(4):386-94. doi: 10.1111/hsc.12094. Epub 2013 Dec 27.
- Davies N, Maio L, Rait G, Iliffe S, Quality end-of -life care for dementia: What have family carers told us so far? A narrative synthesis. SAGE Publications Ltd. UK. 10.1177/02692 16314526766

RESEARCH

WP 6 contributed to WP 2 with 16 interviews at micro-meso-macro level to develop the model of palliative care in Europe and identify common challenges.

WP 6 contributed to WP 3 with 11 interviews and 2 focus groups to describe overall and setting-specific barriers and facilitators to apply quality indicators for the improvement of the organisation of palliative cancer and dementia care.

WP 6 contributed to WP 4 involving 8 settings that provide palliative care, implementing the use of QIs and new strategies to reach the identified improvement objectives.

Month: 36-48

DVD AND MANUAL

A DVD has been developed in order to give an overview of the IMPACT process. The video explains the aim and usefulness of implementing quality indicators in order to improve the organisation of palliative care. In particular, all the steps required to implement it have been filmed so that professionals can watch how the implementation process may be organised and developed within a real healthcare setting where a multidisciplinary staff works. In order to watch the video, instructions

about the programmes and requirements to download and watch it on personal computers have been given. The video is supported by both Windows and the Macintosh system. The video is in English however, subtitles in other languages are available (Dutch, Finnish, French, German, Italian, Norwegian, Polish, Spanish). In order to disseminate the video to the scientific community, it has been uploaded on the IMPACT mass storage devices distributed during the IMPACT final conference and during meetings with the European countries involved in the project, in order to reach a large number of European healthcare settings. Besides this, in order to spread it more, it has been uploaded on You Tube and on the IMPACT website, that will continue running also after the end of project by prolonging the contract with the company that developed the website.

The Manual is a step-by-step guide that contains details on how to implement the IMPACT process. The Manual is a training tool for professionals willing to use quality indicators to assess the organisation of palliative care of their healthcare settings and to work on the areas that QIs have shown to be in need of improvement. The Manual is divided into eight main sections:

- ✓ Introduction
- ✓ Overview of the project
- ✓ Introducing the project to staff
- ✓ Assessment of the organisation of care
- ✓ Formulating the improvement objectives
- ✓ Implementing the strategy
- ✓ Evaluating the intervention
- ✓ Accessing the questionnaires: instructions
- ✓ Appendixes and checklists

Professionals will be thought how to access the questionnaires based on the selected QIs, set improvement objectives, identify specific and effective strategies to reach the objectives and evaluate the whole process. The Manual has been translated into eight languages: Dutch, English, French, German, Italian, Norwegian, Polish, Spanish and uploaded on the IMPACT website and on the IMPACT mass storage devices in order to reach many European healthcare settings.

PUBLICATIONS

The list of IMPACT publications in Year III and IV:

- ✓ van Riet Paap J. et al. "Improving the organisation of palliative care: identification of barriers and facilitators in five European countries." *Implementation Science* 2014, 9:130.
- ✓ van Riet Paap J. et al. "Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts". *BMC Health Services Research* 2014, 14:396.
- ✓ van Riet Paap J. et al. "Improving the organisation of palliative care by implementing quality indicators and national and setting-specific interventions: study protocol of the IMPACT project." *Progress in Palliative Care* 2014, 22:201-205.
- ✓ ... submitted (nominal group article)

- ✓submitted (palliative care in long term care facilities)

CONFERENCES

The IMPACT project has been presented in over 40 national and international events with oral and poster presentations. In some cases, these events were lectures and symposia organised by IMPACT researchers to spread the concept and use of Quality Indicators (a complete list of events is available in the private section of the website and in the EU Research Participants Portal).

IMPACT FINAL CONFERENCE

The final conference of the IMPACT project has been organised in collaboration with the EUROIMPACT project in Brussels on October 15th 2014 and a specific website was developed for this conference <http://palliativecare2020.eu/>. On that occasion, the project results achieved so far have been presented. Also during this final conference the European Declaration on Palliative Care has been launched, that has also been promoted via the IMPACT and EUROIMPACT social networks.

Invitational conference October 15, 2014 Brussels - Collaboration IMPACT Project Management and Project Management

Palliative Care 2020. Towards Integration of Palliative Care in an Age-friendly EU.
Museum of Natural Sciences
15 October 2014 Brussels, Belgium
www.palliativecare2020.eu

In the past four years, the researchers and health care professionals of the European Union (EU) co-funded IMPACT and EURO-IMPACT projects have worked on spreading and implementing different aspects of the 2002 World Health Organisation's (WHO) definition of palliative care. Ideally, palliative care should be available as soon as a disease appears to be incurable and life limiting, and not be restricted to patients with cancer. Yet, 12 years after publication of the WHO definition for palliative care, most palliative care is often still restricted to reactive, terminal care and to patients with cancer, as research from both projects has shown.

Both projects have studied important policy themes: integration of palliative care into education and training, integration of palliative care services into the structure and financing of national healthcare systems, quality improvement by developing tools to optimise structures, processes and outcomes of palliative care settings and implementation in daily practice and many more. Now it is time to use this knowledge to face the major EU policy challenge of delivering high quality long-term care for people with life-limiting illnesses.

The IMPACT and EURO-IMPACT consortia joined forces to emphasise the need they felt to involve policy-makers and influence the political agenda towards the implementation of policy recommendations by 2020. During their final conference on October 15, 2014 in Brussels, a lively

debate with policy-makers, key stakeholders, clinicians and patient representatives was held to build a better future for palliative care, including the integration, education and use of newly available tools. A charter was created, consisting of policy recommendations, which was signed by policy-makers and the European Association for Palliative Care (EAPC), to ensure high-quality palliative care in an ageing society in Europe (and beyond). Already over 1000 people have signed the declaration. (www.palliativecare2020.eu) Currently, the declaration has been translated into Dutch, German, Polish, Norwegian, Italian, French and Spanish in order to increase further dissemination throughout Europe.

The potential impact including the socio-economic impact and the wider societal implications of the project

A set of QIs has been developed and is expected to be published in a scientific paper in 2014 (submitted March 2014). This set of QIs has been used in the pilot test we have performed in five countries (NL, DE, UK, IT, NO), in four types of settings (hospitals, hospices, nursing homes, primary care). In each of these settings, a consultant invited the professional team to assess the quality of their organisation with the help of the set of QIs and to choose improvement topics and aims. Based on quality improvement steps (Grol et al) the teams improved the organisation of their setting. Finally, the effects were measured with the QI set. The results of this implementation study will be available in 2014. This implies that at the end we will have a set of QIs to assess the quality of the organisation of palliative care in all kind of settings and countries; an overview of barriers and incentives with regard to implementing quality improvement projects in the organisation of palliative care as well as effective implementation strategies. In the future, also other countries can use our set of QIs with the help of the available manual that describes how to use them and how to start improvement projects.

We do know that often professionals want to change, but do not want to be changed. For that reason, the use of QIs should always start as a way to provide internal mirror information: as long as using QIs and transparency are no daily practice, the QIs should not be used by external parties to make judgements, but should be used by the professionals themselves.

In the end our project will contribute to a better understanding of implementation strategies by systematically studying the process of implementation of quality indicators and improvement projects in a specific field of an urgent societal problem; the organisation of palliative care for the rapidly growing group of patients with cancer and patients with dementia. Our 'case' of palliative care for this specific group of patients can also be used as a starting point for QI development and implementation in other groups of patients.

Also after the IMPACT project has ended, we want to collect data of those settings that will use our set of QIs. A larger data set will enable comparisons, case-mix adjustments and further studies on this rich material.

We will also strive for dissemination in other European countries, and other continents. Our set of QIs has already been used in Indonesia, and parties from several Asian and African countries have shown interest to cooperate and use the QIs. The project leaders Dr. Yvonne Engels and Prof. Dr.

Myrra Vernooij-Dassen have made a successful trip to the Unites States (New York and Boston) to disseminate the project findings and indicators. They have discussed the use of the indicators with 4 highly esteemed research groups in the USA and gave several presentations and spoke to several researchers in the field of palliative care, medical oncology and dementia care, who were very interested in our indicators. We also hope to further disseminate the indicators during a palliative care conference in the USA in 2016.

Life after IMPACT and further dissemination of the project

From February 2011 until February 2015 the EU funded FP7 IMPACT project has run. In this project, models for the organisation of palliative care were developed, a set of quality indicators for the organisation of palliative care was developed, an inventory of barriers and incentives to start improvement projects was made, as well as a review of improvement strategies. Finally, the indicators as well as the improvement projects were tested in four types of settings (hospitals, nursing homes, hospices and general practices) and in five different countries.

To disseminate and implement the developed model of palliative care, the indicators and the other findings of the project, all kind of dissemination and implementation activities took place and currently are still taking place:

- We have performed a Nominal group session in June 2014, with all consortium members of IMPACT. We discussed how to further implement our findings. (van Riet Paap et al; submitted for publication) The findings of this group session will be used as a lead for the dissemination and implementation process.
- An invitational conference, together with the EU Marie Curie project Euro-Impact took place in October 2014 in Brussels , to disseminate the results of both projects to researchers and policy makers, and to launch the Palliativecare2020 declaration with 10 recommendations to emphasise that palliative care should be considered as a public health issue on the political agenda. Already over 1000 people have signed the declaration. (www.palliativecare2020.eu) Currently, the declaration has been translated into Dutch, German, Polish, Norwegian, Italian, French and Spanish in order to increase further dissemination throughout Europe.
- At the 2015 EAPC conference in Copenhagen, Prof. Lukas Radbruch and Dr.Yvonne Engels will lead a 'meet the expert' session to further disseminate the indicators. Also Prof. Steve Iliffe and Dr. Birgit Jaspers will both give oral presentations concerning the outcome of our project and IMPACT PhD students will be presenting posters.
- Prof.Dr.Kris Vissers, consortium member and chair of Palliactief, the Dutch professional palliative care organisation, will facilitate further implementation in the Netherlands. As chair of the WIP (World Institute of Pain) he will also facilitate further dissemination worldwide.
- Project leader Dr.Yvonne Engels, consortium member Prof. Dr. Kris Vissers, specialist palliative care and medical oncologist (one of the first persons in the Netherlands involved in palliative care) and Dr. Stans Verhagen will write a dissemination and implementation plan

for the Netherlands, which will prepare the ground for the other countries. The Dutch plan will be in accordance with the recently launched Care Module Palliative care, the formation of regional collaborative networks for palliative care, training and research, and will fit within the Dutch Palliative Care Program.

- Besides, as another dissemination activity, a mobile website will be developed (a website with a tool that is easily accessible via the mobile phone) to facilitate the use of the indicators. This will be done within our own organisation.

PUBLIC WEBSITE ADDRESS AND RELEVANT CONTACT DETAILS

www.impactpalliativecare.eu

www.palliativecare2020.eu

Yvonne Engels, PhD
Scientific Coordinator of FP7 IMPACT
Assistant professor
Department of Anesthesiology, Pain and Palliative Medicine
Radboud university medical center
Nijmegen, The Netherlands
Phone +31 (0)24 3616583
E-mail: yvonne.engels@radboudumc.nl