

	EUROPEAN COMMISSION RESEARCH AND INNOVATION DG	Final Report
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Project Acronym: InSup-C

Project Full Name: Patient-centered palliative care pathways in
advanced cancer and chronic disease

Final Report

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Final Report

PROJECT FINAL REPORT

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Final Report

Please note that the contents of the Final Report can be found in the attachment.

4.1 Final publishable summary report

Executive Summary

Palliative care involves an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness (WHO). However, problems including fragmentation of services and late referrals to palliative care prevent many patients from receiving the palliative care they need at the right time and right place. Therefore many patients have unmet palliative care needs, experience hospital admissions in the last weeks of life, or are not able to die at the preferred place. Following the working definition of InsupC, integrated palliative care involves “bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care”.

The InsupC project aims to contribute to the care for patients with advanced cancer and chronic disease and their relatives by investigating and comparing initiatives in integrated palliative care across Europe, in order to identify (requirements for) best/good, and promising practices. This research will focus on patients with cancer and major chronic diseases, in particular advanced stages of COPD and CHF.

The European Commission funded research project InsupC (www.insup-c.eu) has been carried out between 2012 and 2016.

Eleven partners in Europe and America (one) have been involved.

The analyses of the European guidelines showed that mentioning of the referral criteria for palliative care is often lacking (WP2). A taxonomy for integrated palliative care has been developed and published in a peer review journal (WP3). In WP4 and WP5, 22 local initiatives have been investigated that were delivering integrated palliative care in five European countries: the Netherlands, Germany, the UK, Belgium, and Hungary. Multiple embedded case study methodology was used to examine the perspectives of patients (n=156), family caregivers (n=88) and health professionals (n=133). A strategic benchmark based on a comparison of case descriptions was used to make recommendations.

Based on the case studies, requirements for good/best practice in integrated palliative care appeared to be: 1) multidimensional ‘whole patient’ treatment, 2) development of integrated care pathways, 3) provider arrangements to position palliative care in the chain of care, 3) a regional contact point where palliative care knowledge and expertise can be obtained, 4) societal accountability and visibility, 5) sustainable long term development (resources), 6) accessibility for all patients in need, not only in cancer. In the project, it was possible to identify best practice elements for integrated palliative care. However, contextual variation was important to make local integration work in practice. Dissemination took place by congresses, abstracts, and articles (WP6). A policy workshop and a congress have been organized in Brussels. Inspiring practices have been highlighted in a book (downloaded 3,500 times in 3 months) and in an online learning course (followed by 6,000 people worldwide). Scientific articles and congress presentations have been prepared.

Summary description of project context and objectives

Each year, 2.5 million European citizens die due to cancer and chronic disease, a number that is expected to increase due to the ageing of the population. Many of these persons experience pain and other symptoms and are in need for palliative care and symptom management.

This project aimed at the optimisation of palliative care delivery in Europe, anticipating current and future health care needs. As palliative care is delivered in numerous settings where patients with advanced disease live and die (at home, hospital, hospice, residence homes), the optimisation of palliative care effects raise health service delivery in many types of European health care institutions. Patients can experience burdensome transfers in the last three months of life, preferred place of death is often not achieved, treatment choices in this phase of disease vary, and family caregivers can be overburdened.

In this project, it was considered in particular how health services in European countries can improve the integration of palliative care in treatment pathways, patient care networks and institutional collaborations.

The project aimed to identify and to describe the integration of palliative care services by means of a detailed literature review and the development of a taxonomy of integrated palliative care. Patient and caregiver experiences within integrated palliative care initiatives across Europe have been investigated together with the organisational, managerial, financial and regulatory aspects of these service deliveries.

The aim was to use the results used for a strategic benchmark on integrated palliative care that identifies requirements of best/ good, and promising practices within Europe. Best practices were expected to combine optimal strategies for high quality of palliative care delivery with an effective and efficient organisation of care within the local context. Transfer of knowledge was supported by the European Association of Palliative Care (EAPC Onlus) and the World Health Organisation (WHO) and included –amongst others– a website, an e-learning module, and a book. The results of the project aimed to make a contribution to the care for European patients with advanced cancer and chronic disease.

Key objectives of the project were:

1. To perform a literature review (WP2) to collect descriptions of integrated care models in cancer and advanced diseases. This resulted in an overview of integrated palliative care with regard to patient and informal caregiver experiences and perceptions at the one hand, and organisational, managerial, financial and regulatory aspects at the other hand. In addition, another review considered existing guidelines and pathways on cancer and chronic diseases within Europe to consider whether palliative care and integrated care are part of those documents. Grey literature (that is not published in English and in peer reviewed journals) were considered together with the results of previous European initiatives like Europall and EAPC Atlas.

2. To identify existing palliative care initiatives for integrated palliative care in Europe to develop a taxonomy using a) publicly available data and reports from (inter)national European offices on health care, and b) additional qualitative interviews with experts in the field of primary and secondary care including patient organisations in selected European countries. This will result in a taxonomy (or classification scheme) with a global benchmark of existing integrated palliative care initiatives across Europe with strengths and weaknesses in terms of for example organisation, costs, and patient satisfaction.

3. To study a representative selection of integrated palliative care initiatives (WP4) in the field, across Europe, involving the experiences and perceptions of patients with cancer and chronic diseases, their informal caregivers, and their primary and secondary caregivers as well as primary and supportive processes (organisation, management, data sharing etc). This will be done in a mainly qualitative semi structured research design.

4. To identify (requirements for) best and/or promising practices in integrated palliative care in Europe (WP5) in terms of patient/family and caregivers experiences, including key prerequisites of a regulatory, cultural, organisational, financial and managerial background. These 'best/good practices' build on –and will move beyond– the identified existing models in Europe from the taxonomy and the site visits. In addition, required skill mix of health professionals, and opportunities for patient empowerment and digital support (health 2.0) will be formulated.

5. To disseminate (WP6) the - requirements for - 'best/good practices' via an interactive website including an e-learning module based on the data of the research project.

Description of main S & T results/foregrounds

The work of the project was allocated to six work packages. Each work package had its own tasks, deliverables and milestones. All partners collaborated in the consecutive WPs, which was led by one or two partners. WPs were depending upon each other: the literature review of WP1 was needed to inform other WPs and the taxonomy (WP3) and the patient and family caregivers interviews (WP4) were used in the comparison of initiatives in WP5 by means of a multiple embedded cases study. The dissemination package (WP6) contained dissemination activities based on the results and output of the several workpackages, like articles, blogs, online learning and a checklist.

WP1 Management

WP1 concerns the overall coordination of the project, assisted by a Project Management Office. This WP takes care of the management of contractual, financial, legal, administrative and scientific issues. This task has been carried out for the whole project consortium, resulting in a scientific report and related financial report. Legal issues were taken up when needed, mainly the preparation of a project amendment. Also, the monitoring of the project deliverables has been done, with updating of the planning where needed. General Assemblies were organized in collaboration with the host partner to discuss and monitor the proceedings of the project. Minutes were prepared by this WP1, send around for comments, and accepted by all partners.

Task 1.1: Management of the project consortium : Two General Assemblies and related Executive board meetings have been organized in Amsterdam (January 2013 kick-off), Leuven (November 2013), Bonn (April 2014), Pecs (November 2014), Amsterdam (April 2015), Pamplona (November 2015), Lancaster (April 2016). During these meetings, workprogress and important decisions for the several workpackages were discussed and agreed upon. The project closed with a final conference in Brussels, September 2016 with -among others- presentations concerning the aggregated output of InsupC.

Communication has been forwarded where needed and consultation with the EU project officers has been set up when needed (eg for the amendment procedure)

Task 1.2: Management of finance: Budgets were allocated according to the grant agreement. Partners in UK and USA were confronted with a changed value of the euro in contrast to the GBP and the

dollar. Due to the illness of the project manager, RUNMC experiences extra costs of illness replacement. Some budget shifts took place, based on an amendment (see next paragraph).

Task 1.3: Management of legal issues: The grant agreement and consortium agreement have been made. An amendment of the grant agreement has been prepared. A contract for the ethical review was prepared (deliverable 4.1). Project amendment has been prepared due to the termination of partner Sheffield University (at their request)

Task 1.4: Management of project reporting: Project reporting and collection of scientific progress has been coordinated by WP1 in close collaboration with the WP leaders. Monitoring of project deliverables has been carried out, resulting in finalization of deliverables with peer review from the project coordinator. Periodic reports have been prepared.

Work progress and achievements

The paragraphs below give a summary of the tasks and the deliverables of the several InsupC workpackages.

Work package 2: three literature reviews

The main objective of Work Package 2 was to identify existing models and initiatives for integrated palliative care in Europe. The following three systematic reviews of the literature were performed:

- Review 1 consisted of a systematic literature review of existing research evidence on models of integrated palliative care in cancer and chronic disease in Europe.
- Review 2 was a systematic literature review of existing research evidence on guidelines and pathways of integrated palliative care in cancer.
- Review 3 resulted in a report with a systematic literature review of existing research evidence on guidelines and pathways of integrated palliative care in non-malignant chronic diseases.

Tasks

In WP2 we conducted three systematic reviews that have been published in BMC Palliative Care journal. The objectives of these systematic reviews were to identify and evaluate the level of integration of palliative care (PC): a) in guidelines and pathways of integrated palliative care in cancer, b) in guidelines and pathways of integrated palliative care in chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) and iii) in models of in cancer and chronic disease in Europe.

The following databases were searched electronically: The Cochrane Central Register of Controlled Trials (CENTRAL), PubMed, EMBASE, CINAHL, AMED, BNI, Web of Science and NHS Evidence. The search in the databases was performed via the use of keywords, MESH terms and search terms as well as their permutations and combinations. The basic search terms and keywords that were used in PubMed and similarly in the other electronic databases are presented in appendix A. Validation of the search strategy was performed against five key papers.

Additionally, the following journals were hand-searched: BMJ Supportive & Palliative Care, European Journal of Palliative Care, Journal of Pain and Symptom Management, Palliative Medicine and Medicina Paliativa. Citation tracking was also performed for the included studies.

In the first phase, two reviewers (NS & KVB) screened all the search results on the basis of their title and their abstract. Non-English titles were screened and translated by two native speaker reviewers. The full texts of articles selected by both reviewers were sourced. Following standard practice, discrepancies were resolved by consensus.

The main findings of these reviews are summarized as follows:

As regards cancer, the majority of the guidelines/pathways emphasized the presence of a holistic approach and promoted the use of PC interventions aiming in suffering reduction. More than half of the studies did not discuss referral criteria for Palliative Care whilst grief and bereavement care were mentioned only by very few.

As regards CHF/COPD guidelines/pathways, the majority of the studies focused on suffering reduction interventions, on a holistic approach and on discussions of illness prognosis and limitations. Little elaboration was presented over the aspects of grief and bereavement care, on treatment in the last hours of life and on the continuation of patients' goal adjustment throughout the disease trajectory.

As regards to the models, there are only a few models of integrated PC in Europe whilst the geographic distribution of the origin of these interventions is imbalanced, with 6 out of 14 studies coming from the UK. These integrated palliative care models seemed to have a positive impact typically such as better symptom control, higher quality of life, less caregiver burden, improvement in continuity and coordination of care, fewer hospital admissions, patients dying more frequently at home, and improved cost-effectiveness.

We developed a generic framework that could serve as a basis for developing integrated palliative care models for malignant and non-malignant disease consisting of the following aspects:

- Focus of intervention: The focus of intervention has to be placed on symptom treatment, consulting of patients/family and training of the personnel.
- Setting: The design of the framework should be applicable to every care setting.
- Timing of intervention: The intervention can be initiated throughout the disease trajectory either concurrently or in the end-of-life.
- Composition of team: a multidisciplinary team with members that are trained in the delivery of PC. This team can consist of GPs, physician specialists, nurses and specialist nurses, psychologists, social workers and administrative assistants.
- Collaboration strategy: The collaboration strategy, which refers to the ways that the represented disciplines cooperate and assess emerging issues, should be based on the involvement of the multidisciplinary team and its meetings and the utilization of protocols.

The proposed framework has a threefold focus: treatment, consulting and training. In our context of integrated PC, treatment corresponds to the alleviation of the physical (dyspnoea, pain, constipation, nausea, vomiting, diarrhoea) and psychological symptoms (agitation, confusion, fear, delirium). On the other hand, consulting refers to discussions and communications over treatment options and at a later stage to end-of-life care decisions. Moreover wishes, desires and needs of the patients can be taken into account as part of this advance care planning. Training involves the education of nurses, physicians and other related health care providers involved in the interventions. Training programmes can be very diverse, however, their principal focus should be on PC, its benefits and its provision.

Publications:

1. Siouta N, Van Beek K, Preston N, Hasselaar JG, Hughes S, Garralda E, Centeno C, Csikos A, Groot M, Radbruch L, Payne S, Menten J. Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. BMC

Palliative Care 2016; 15:56

2. Siouta N, Van Beek K, Preston N, et al. Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliat Care*. 2016;15:18.

3. Van Beek K, Siouta N, Preston N, Hasselaar J, Hughes S, Payne S et al. To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: a systematic literature review. *BMC Palliative Care* 2016;15(1):1-17.

Deliverables and Milestones

Deliverable D2.1 (Milestone) Three reviews of the existing literature of integrated palliative care and chronic diseases

Work Package 3: A taxonomy of integrated palliative care

The main objective of Work Package 3 was to develop a taxonomy of IPC initiatives that is applicable across diseases, health care sectors and systems in Europe. The taxonomy needs to include relevant aspects of structure and process of care to compare IPC initiatives across Europe and identify best practices.

Approach:

The taxonomy was revised and finalized in a consensus conference with an international expert focus group.

During WP 3 a multidisciplinary panel of experts was recruited by the consortium of InSuP-C in order to monitor and contribute to the development of the taxonomy. The multi-professional panel consisted of 18 members from Belgium, Germany, Hungary, the Netherlands, United Kingdom and Spain. The panel members were asked to critically examine the preliminary taxonomy. In concrete terms experts were asked „Do you think the preliminary taxonomy is useful to measure IPC initiatives?“ and „Which revisions are necessary to apply the classification system across Europe?“. Experts were also asked to determine suitable indicators for benchmarking. Their input was used to revise the taxonomy. To finalize the taxonomy, a consensus conference was held in September 2014 in Bonn. The conference was attended by 10 of the 18 selected European experts on palliative care including four physicians, two social science researcher as well as four experts from psychology, nursing, social work and mental health counselling. All of them were provided with an electronic version of the revised taxonomy four weeks before the meeting. Expert feedback before the consensus conference resulted in a number of additional recommendations, though there seemed to be a general acceptance of the main characteristics of the preliminary taxonomy.

Results:

The consensus conference was focussed on the three key questions: the conceptualisation of integrated palliative care (3.1), the added value of a taxonomy (3.2) the development of the taxonomy (3.3).

Finding consent on an approach such as IPC requires a mutual understanding of underlying key concepts. Therefore the conference started by discussing IPC in health care provision. Almost all experts confirmed that a continuous process of care without gaps is of utmost importance. Integration has to be defined from the perspective of the patient and is reached when patients receive palliative care tailored to their needs. This rather vague position was challenged by the working definition of IPC in the InSuP-C project. Confronted with this concretisation of IPC, additional or deviating requirements were discussed by the experts. First of all, there was a rather normative turn by insisting that IPC should be delivered to all patients ‘in need of palliative care’ instead of patients ‘receiving

palliative care'. Experts tried to specify when patients should be enrolled in IPC schemes. For instance, experts recommended to add the term 'early integration' to the definition and to capture the 'longitudinal and service orientation of IPC'. A strong emphasis on the continuity of care would differentiate IPC from palliative care provided by single physicians at the end of patients' lives. Instead, IPC 'focuses on a network and collaboration among multidisciplinary professionals'. Hence experts did not agreed on a new definition of IPC but added aspects that are crucial from their point of view to the working definition of InSuP-C.

The preliminary taxonomy that was presented to the experts included six consecutive categories: disease, type of initiative, sector, time frame of intervention, coordination strategy and primary contact. Each category consists of two to four items. For instance the category time frame of intervention consists of the items early integration, concurrent and end of life. Feedback from the experts previous to the meeting focussed on two categories that raised concerns: sector and primary contact. In the preliminary taxonomy the category sector consisted of the items inpatient and homecare. However, most experts argued that this suggested a dualism that does not cover the diversity of IPC initiatives in practice. An additional third sector transmural care was proposed where IPC starts in an institution-based setting, i.e. in hospitals, hospices or out-patient clinics, but is continued outside these institutions, for example in the home of patients. Most experts also commented on the category primary contact, because the preliminary taxonomy did not include a separate item for general practitioners but subsuming their work under the item other. In their view general practitioners play a vital role since they often initiate and coordinate the provision of IPC. Taking these concerns into account but without making final changes yet, the preliminary taxonomy was submitted for revision at the expert consensus conference. Deriving from previous exchange and discussion on the nature of IPC and the overall necessity of a classification system, the revision of the preliminary taxonomy marked the final part of the consensus conference. At this stage, experts were explicitly asked to change categories and items of the taxonomy before the final version was to be adopted.

As it turned out, the main challenge was to consent a taxonomy encompassing the process of IPC as well as the structure. The experts expanded the revised taxonomy (see table 1) with two new categories: The category level of care including the items primary, secondary and tertiary indicating at which stage of specialization and expertise palliative care is integrated. Second, the category focus of intervention including the items treating, advising/consulting and education/training classifies specialist palliative care givers' role in IPC. Two existing categories were renamed: The category coordination strategy was changed into collaboration and communication strategy because the emphasis of the category is on the interaction between service and care givers rather than merely on organisational issues. The category primary contact was changed into key contact. This category had included the items palliative care, team and other, which were changed into non-pc specialists, pc specialists and GPs. Hence, the latter are recognized as key persons in the coordination of IPC provision.

Task 3.1: Drafting of classification system (M3-9)

A preliminary taxonomy as starting point for the discussion was developed. The set of characteristics covered: Type of initiative (pathway, model, guideline), aims/key themes, type of intervention (clinical care, education, etc.), coordination strategy, setting (hospital, hospice, nursing home, community), urban/rural context, integrational structure of model, target group, disease, prognosis on which intervention starts, referral pathway, Inclusion of quality assessment, guidelines/best practice used, covered palliative care (PC) key domains, stakeholders involved, interface of integration of PC, resources needed for implementation, if Intervention is tested/piloted, implementation Strategy, funding.

Task 3.2: An inventory of current initiatives on integrated palliative care (M6-12)

Sources for the identification of existing models, guidelines and pathways of integrated palliative care are the results from the expert interviews and an online survey conducted in WP3. In the framework of WP3 all project partners analysed the grey literature sources according to the set of characteristics predefined in T3.1.

Task 3.3 and 3.4: Database listing of the initiatives and model projects for integrated palliative care (M13-20)

The Database included all initiatives and model projects which were identified in the different work steps. First data was collected within the literature reviews.

The results of WP3 were expert interviews, an online questionnaire, literature reviews and a taxonomy.

A qualitative interview study on integrated palliative care initiatives was conducted over a 6-month period (December 2013 to May 2014). Interviewees were experts in the field of primary and secondary care in seven European countries: Belgium, Germany, Hungary, Ireland, Netherlands, Spain and the UK.

Interviewees were recruited using purposive sampling ('snowball system'). Each InSup-C consortium member was requested to identify multidisciplinary 'national champions' in the realm of palliative care. Additionally, in the InSup-C partner countries were asked to list further interview partners from national boards of cancer and chronic illnesses in accordance with the following inclusion criteria: having knowledge and experience in palliative care, chronic care and/or public health, a professional background as a physician, nurse, social worker, carer or patient organisation representative and excellent English communication skills. Particular expertise in IPC, although desirable, was no inclusion criteria due to the novelty of the discipline. A preliminary list included 53 interview candidates: 14 UK, 10 Germany, 10 Netherlands, 8 Spain, 6 Hungary and 5 Belgium. All candidates received an invitation letter explaining the scope of the InSup-C project and the aim of the interview. 34 experts accepted the invitation: 8 UK, 6 Germany, 6 Netherlands, 5 Spain, 4 Hungary, 3 Belgium and 2 Ireland. The interview guideline focused on the process behind the IPC interventions and covered four key questions: 1) How would you define IPC? 2) Which IPC interventions do you know in your country and beyond? 3) If interventions named: please describe the intervention you could give the most detailed information of; focusing on coordination strategy, professionals/organisations involved, referral strategy, quality assessment and guidelines/best practices underlying the intervention. (If no interventions named: How is palliative care integrated in your work setting?) and 4) What would you consider to be characteristics for a successful patient-centred model for IPC?

All interviews were analyzed concerning facilitators and barriers to IPC as well as experts' recommendations for improvement. In addition to what was reported before an online survey among members of the EAPC mailing list was conducted:

- 665 persons from of the EAPC data base (incl. 10848 contacts) participated in the survey
- Origin of the participants: 69% western Europe, 18% rest of the world, 11% Middle and Eastern Europe
- Background of the participants: 60% physicians, 31% care takers, 19% management/research

Key findings emanating from the survey were the following:

- Palliative care is integrated into the organisation of care (by collaboration and consultation with palliative care services and specialists) and standard care delivery
- Integrated palliative care should involve at least two different organisations
- Integrated palliative care should be focused on the homecare (community) sector (all settings)
- Preferable IPC should be based on a network approach (incl. family care givers and palliative care specialists)
- Preferable IPC should be organised by a specialist or a palliative care team with advisory function

Task 3.5.: Final drafting of the taxonomy by the InsupC team. The result is given in Figure 1. This has been published in a scientific journal (see publication list)

Deliverables and Milestones

Deliverable D3.1 (milestone) Report on the existing models of integrated palliative care

Deliverable D3.2 General taxonomy of integrated palliative care

Work Package 4: Experiences of patients and caregivers with IPC

The main objective of Work Package 4 was to study a representative selection of Integrated Palliative Care Initiatives (IPC-I) in the field across Europe, involving the experiences and perceptions of patients with cancer and chronic diseases, their informal caregivers as well as primary and supportive processes.

Tasks

Using the outcome of objective 1 and 2, we studied experiences of patients and (informal) care providers using a mixed methods research design. Although much research had already been done on patient experiences, it is a novelty that in palliative care research longitudinal trajectories within a EU context, patients and informal care providers' views were investigated on this large scale. In order to do so, WP4 was subdivided in several tasks.

Task 4.1 & 4.2.

At the end of month 18, we reported to the EU on two topics:

- ethical issues we faced in this project;
- preparation of the empirical research phase

At that time we finished the ethical procedures which were necessary for the empirical phase and we nearly finished the preparatory work which allowed us to really start with the patient and care providers' study.

Ethical issues

The INSUP-C project started with a kick-off meeting. In this meeting an external independent ethics advisor professor presented an overview of the ethical issues we needed to deal with. Next to this and in order to obtain approval from the ethical boards of the participating institutions, a template study protocol was prepared in the Netherlands. This study protocol was adjusted by each consortium member involved in the patient study in order to meet the country specific regulations. Only in the Netherlands the ethical committee stated that the patient study does not fall within the remit of the Medical Research Involving Human Subjects Act. In all other countries, the template needed to be adjusted and after a while, all other participating countries obtained approval for conducting the study. This was achieved (see also deliverable 4.1)

Preparation of empirical research

In order to really start the empirical research on patients and care providers, a couple of steps had to be taken. Some of them, (1 through 3) did concern ethics. Below, you'll find the steps we undertook.

1. Completion of a template study protocol
2. Adjusting and complementing the template study protocol to national regulations
3. Sending the adjusted study protocol to ethical committees in the participating countries and awaiting ethical approvals
4. Selection and invitation of initiatives
5. In each country 3-5 integrated palliative care initiatives were selected. International experts in

palliative care were involved in this selection. As there was no unanimous definition of integrated palliative care, the project team formulated one. This was based on literature and discussions during project team meetings: “Bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid”. Experts were requested to suggest potential initiatives that are based on this definition and meet the following criteria:

- a. It is an established local palliative care collaboration
- b. A hospital can be part of that collaboration
- c. The collaboration must contain at least two different organisations
- d. Collaborating healthcare professionals must provide direct patient care (not only advisory function)
- e. The collaboration is multidisciplinary (professionals of different professions must be involved, e.g. specialist, GP, nurse (specialist), social workers, AHP, spiritual worker, complementary therapist, others)
- f. The collaboration is supposed to provide palliative care for either one specific diagnostic group (COPD/CHF/Advanced cancer), or to all three diagnostic groups.

As the suggestions for potential integrated palliative care initiatives were not sufficient, an additional quest for initiatives was done. A final selection was made by the project team of each country.

After selection of potential initiatives that could participate, in each country five initiatives were invited. In Belgium, three initiatives were invited as this country has only a limited amount of person-months for WP4. The progress regarding recruitment of initiatives is as follows:

6. Translation procedures. Questionnaires that were not available in the national languages were translated using an adapted version of the forward / backward translation procedure

7. Building database Castor. Quantitative data will be stored in a web based database Castor which has been build and managed by RUNMC.

8. Data collection training. We developed and held a data collection training in order to guarantee uniformity of data collection procedures in the countries involved. The data collection training aimed to:

- a. support researchers with preparing their interviews
- b. train researchers in performing reliable and valid qualitative research/interview
- c. train researchers how to process their data and how to reflect on the quality of these data and on their role as interviewers.

Task 4.3, 4.4 & 4.5.

Patient and family caregiver inclusion and follow up phases were interwoven. Over the 5 countries the total timeframe was slightly different depending on numbers of patients that could be included over time and the ability to follow patients over a longer or shorter period of time because of the deterioration of their disease. In July 2015 we ended the inclusion of patients and informal caregivers. In total and over the 5 countries and 22 initiatives, we have included 156 patients and 88 family caregivers. We are very proud that we achieved this numbers in a research field which is known for difficult inclusion. In every IPC initiative more patients were ‘screened’ for participation than the amount we finally managed to include. We don’t have the numbers of screened patients as this process in general was performed in a more or less unofficial way.

Regarding data processing and data analysis several tools can be distinguished which helped us within this phase of our research project.

1. Data analysis training. Following the first training meeting on data collection, we organized 3 more meetings. In these meetings we trained the researched in data analysis and we build together an

international codebook based on which all interviews can be analyzed. Furthermore, these meetings were used to connect and communicate with WP5.

2. Skype meetings. Researchers held regular Skype meetings in order to discuss current problems and share their experiences related to interviews, coding and other issues. We took notes from every meeting, so everybody was informed about progress, discussion points and agreements. Skype meetings were of great importance in the progress of WP4. In addition in these meetings the relation with WP5 was discussed.

3. Data collection log. Via Google docs, we constructed and maintained a log in which the researchers active in WP4 were able to discuss issues that came up during their work on WP4 and share topics and experiences with data collection and data analysis. In this way we provided additional opportunities for attuning working methods and discussing issues which are important and therefore do not have to wait until Skype or training meetings.

4. Recruitment monitoring. In order to monitor the recruitment process in all 5 countries, we developed a screening log.

5. Data management program Castor. Our data could be stored, listed, retrieved and remotely accessed. Castor is a program which allowed us to process and modify our quantitative data, like the questionnaires which we retrieved from patients and family caregivers. We were able to export data directly to SPSS™ and easily see the number of records in our dataset. Every researcher entered data in Castor.

In conclusion

In our study we managed to give insight in how patients with advanced cancer, COPD and CHF and their family caregivers experience care provision in a range of IPC-I in 5 European countries. All transcripts have been made, all of them are analyzed and all quantitative data are basically analysed also

Deliverables and Milestones

Deliverable D4.1 Ethical report

Deliverable D4.2 (Milestone) Interim report: Interim report on the experiences of patients and (informal) caregivers

Deliverable 4.3 Final report on patient/care-giver experiences

Work Package 5: Identification of (requirements for) best and promising practices in integrated palliative care

WP5 contributed to the following project objective: 'To identify (requirements for) best and/or promising practices in integrated palliative care in Europe in terms of patient/family and caregivers experiences, including key prerequisites of a regulatory, cultural, organisational, financial and managerial background'.

Task 5.1: Identification of integrated care levels in European palliative care services

This task aimed to investigate the patterns of interaction as indicated by patients, using a social network approach. Local services were categorized along levels of integration using the results of WP3. This has been performed in close collaboration with WP3 and WP4 (Lancaster, Pecs, KU Leuven, UK Bonn, Radboudumc).

For the purpose of the InsupC project, we developed a social network analysis questionnaire that has been incorporated in deliverable 5.2. The questionnaire covered the following areas: 1) which (palliative) caregivers does the patient have?; 2) how often and in which ways does the patient have

contact with these caregivers?; 3) how would the patient rate the relationship with his/her caregiver? Furthermore, there were statements about the perceived level of continuity of care (caregivers appear to work together very well; caregivers seem to be well-connected; caregivers seem to pass on information well; the patient perceives friction between the caregivers). The questionnaires were filled in by the patients that were included for the patient study in WP4. Results have been presented in deliverable 5.2.

For the report on multiple embedded case study (D5.2), we considered the taxonomy of integrated palliative care (WP3) as a most helpful tool from WP3 to categorize the described services/initiatives. In this deliverable a table has been provided that categorized all initiatives that have been selected and described for the InsupC report. During our InsupC team meeting in Dublin in 2016, we discussed the preliminary findings within the insupc project group. Also preliminary results have been presented at the EAPC congress in Dublin for a broad audience.

Task 5.2: European benchmark of services: a three tier approach

In this task we used the previously collected data from WP4 on patient and family experiences of integrated palliative care. In addition, we performed group interviews with all the selected initiatives across Europe. Group interviews were executed by Radboudumc, UK Bonn, KU Leuven, Pecs, and Lancaster. These group interviews were organized following a joint protocol (reported as an attachment in deliverable 5.2). ErasmusMC and Radboudumc were leading in analyzing the group interview data.

After this, a strategic benchmark was performed with an embedded case approach in which we combined self-reported data from the initiatives (history of establishment, focus of treatment, staffing, etc) with a summary of the patient experiences and the group interviews. We developed a reporting format to capture the data of all the initiatives in a comparable way. Also, we added a strengths/weaknesses matrix, based on the data analysis. This was executed by Radboudumc, KU Leuven, UK Bonn, Pecs, and Lancaster. The multiple embedded case study has been described extensively in deliverable 5.2. In the first chapter of the deliverable 5.2 we introduced the term strategic benchmark, indicating that we did not aim at metrics, but at a comparative analysis of cases/initiatives (embedded case study). The deliverable 5.2 closes with a list of recommendations, also in the context of previous results from WP2, WP3, and WP4.

Based on this analysis, we selected one initiative per country to describe in the book as a good example of integrated palliative care (deliverable 5.3). This book is available as a download from the website in English, with a Spanish translation. Respecting the workload of the initiatives we decided not to require formal feedback from them as they were already highly involved in patient interviews, group interviews, and filmed contributions. Each of these selected initiatives were also asked to participate in the filmed content of the MOOC: Massive Open Online Course (deliverable 6.1b).

Task 5.3: Scientific evaluation of integrated palliative care

The scientific evaluation integrated palliative care involved several articles in preparation or already published by WP2-4 (see dissemination paragraph). For WP5, we considered how integrated palliative care relates to better health service outcomes. This was considered from several perspectives.

1. First perspective: barriers and opportunities. We performed a qualitative content analysis on views from leaders of national PC associations (collected in the “EAPC Atlas of PC” survey) regarding main barriers and opportunities to the development of PC. Countries with reported higher service provision levels report both more opportunities and more barriers towards the integration of PC than lower provisioned countries.

2. Second perspective: extended network analysis. Questionnaire data from 156 patients were used. The Canhelp Lite, with information about patient satisfaction and well-being, was used as an

outcome variable. The ‘social network analysis’ questionnaire was used as a measure for the level of integration of palliative care and as an insight into patients’ networks. We found a positive correlation the integration of palliative care (in particular well-connectedness and avoidance of friction), and a more positive patient rating for well-being and satisfaction with palliative care.

3. Third perspective: analysis of promising practices in Europe. Case descriptions involved 20 initiatives in five European countries including data from 133 professionals, 157 patients, and 90 family carers. Our analysis of the embedded cases showed that there is much variety in the design of the initiatives, and our strategic benchmark (deliverable 5.2) showed that there is not one best practice, but rather many good examples in their different contexts (depending on country regulations, settings etc). Initiatives struggled with integrating COPD and heart failure care, and timely referral and information transfer.

Our conclusion is that integrated palliative care relates to positive patient experiences, however the way towards better integration depends highly on the context of caregiving, although building relationships of trust seems a common feature.

Task 5.4 Identification of opportunities and barriers for best practices in integrated palliative care
In deliverable 5.1, we investigated current barriers and opportunities in Europe using the Atlas of palliative care in Europe. We compared these results with a literature investigation from the USA. Here, we used the WHO public health model for palliative care.

Deliverables and Milestones

Deliverable D5.1 Report on opportunities and barriers for integrated palliative care in Europe

Deliverable D5.2 (milestone) Report on best, good, and or promising integrated palliative care practices in Europe

Deliverable D5.3 Book on inspiring practices in integrated palliative care in Europe

Work Package 6: Dissemination

The main objective of Work Package 6 was to disseminate the (requirements for) best/good practices via an interactive website including an e-learning module based on the data of the research project. Work Package 6 has involved all aspects of internal and external communication and coordinating the dissemination of the project results using a variety of multimedia to reach as wide an audience as possible. A further important objective of this Work Package was the successful outreach to key persons active in policy making at governmental and national and international health care organization levels to stimulate implementation.

Task 6.1a: Designing and regular updating of a general project website (M1-48)

The general project website www.insup-c.eu has been monitored and updated on a regular basis since ‘going live’ in April 2013. The website has provided an opportunity to highlight some of the outputs from the project, including conference contributions and journal publications as well as detailing personnel changes and meeting schedules. The restricted consortium members’ pages have enabled the storing of project meeting minutes and pre-publication materials. All work on Task 6.1a was undertaken by Partner 3.

Task 6.1b: Interactive website elements: self-checklist and e-learning (M33-39)

Self-checklist A self-checklist for organisations was designed drawing upon the study results and the

wider literature. A first version of the self-checklist was sent to all services involved in the study with an indication of how it could be used and an open invitation of informal feedback. Due to the high workload on services who participated in the study, we decided to focus on feedback from the Partners in developing and refining the self-checklist. The work was led by RUNMC and ErasmusMC.

E-learning

As part of the Dissemination Work package 6 Task 6.1b, an online e-learning resource of the results from InSuP-C was undertaken during the final year of the project. The work was predominantly done by Partner 3 and was delivered in the form of a free MOOC (Massive Open Online Course) which launched on 17th October 2016.

The MOOC is presented over three weeks. In the first week we cover the state of integrated palliative care across Europe which involves interviews on camera with leading experts in palliative care from the five countries involved in InSuP-C. In week 2 we report on the systematic reviews from Work Package 2 (Partner 5) about guidelines for integrating palliative care across Europe. We also interview the leader of the project to explain what Integrated Palliative Care is and discuss the Taxonomy of Integrated Palliative Care developed by Work Package 3 (Partner 2). In week 3 we showcase some of the findings from the focus groups in Work Package 5 (Partners 1 and 4), including findings about how well palliative care is integrated across the five countries. The findings from the interviews in Work Package 4 (Partners 1-5) are then reported including: continuity of care; patients living alone; communication and honesty; and the role of the GP. Finally recommendations are made and participants are given the opportunity to rank these. Each week, the MOOC features two good practice videos from initiatives across Europe involved in the InSuP-C project.

Over 6000 participants from 149 countries registered for the course, the majority of whom were from Europe and Australia. These included health care professionals working in palliative care, academics, patients and their family carers.

Task 6.2: An invitational conference preparation (M36-48)

As part of the Dissemination Work package 6, Task 6.2 was undertaken in Month 46 of the project, with two international events hosted in Brussels:

- Invitational international deliberative workshop at the Sheraton Hotel, Brussels on 29th September 2016
- Symposium on Integrated Palliative Care: are we ready for change? Jointly organised by the InSuP-C Work package 6 team and European Association for Palliative Care Research Network (EAPC RN) at the Museum of Natural Sciences, Brussels on 30th September 2016

The work was led by Partner 3, in collaboration with the project coordinator partner 1.

Invitational international deliberative workshop, 29th September 2016

The purpose of the deliberative workshop was to draw upon the findings of the InSuP-C project, discuss the implications for implementation, including identifying facilitators and barriers to change in different socio-political, cultural and economic environments, and to develop strategic recommendations. We invited to this event a number of international policy makers, including national and international leaders in palliative care/cancer care, leaders of relevant NGOs/INGOs and relevant international funders (see final section for details). In total, there were 33 international attendees.

The workshop was chaired by Professor Kris Vissers (InSuP-C Partner 1) and the agenda designed to present an overview of the project and introduce analysis at three strategic levels: macro (national and regional), meso (organisational and institutional) and micro (patient, family and healthcare professional) (see attached agenda). The focus of the workshop was on participation and drawing on the expertise and professional knowledge of attendees. Attendees were seated at four round tables, with each table assigned two facilitators: one prompting discussion, the other note-taking.

Symposium on Integrated Palliative Care: are we ready for change? 30th September 2016

The symposium was designed to showcase the outcomes of the InSuP-C project and to provide a platform for presentation of the best of contemporary science, clinical and public health practices on integrated palliative care and to encourage informed debate and interaction between palliative care scientists, clinicians and policy makers. The EAPC Research Network Advisory Board adopted a proposal to co-host the Symposium and they contributed scientific and administrative resources to its organisation. A call for proffered abstracts was made with a deadline of mid July 2016. In total 43 abstracts were submitted by the deadline, which were independently reviewed against EAPC standard scientific criteria by at least two or three independent reviewers. An abstract book was published by SAGE Palliative Medicine, published online, and also delivered in hardcopy to participants. Nine abstracts with high scores were accepted as oral presentations and 34 were accepted as posters. In total 88 people attended the Symposium from over 15 countries. There were two international key note speakers, Professor David Currow from Australia and Professor Phillip Larkin (President of the EAPC) from Ireland (see attached programme). The Symposium was chaired by Dr Bill Noble. The Symposium ended with a Panel of Experts participating in a lively debate on the merits and challenges of implementing integrated palliative care. Certificates of attendance were sent to all attendees. An online survey was used to evaluate the Symposium.

Task 6.3: Publication of the project results (M24-48)

In accordance with the Dissemination Strategy developed by Partner 3 in the early part of the InSuP-C project, we have undertaken the following activities:

Publications in academic and professional journals

To date, ten papers based on the InSuP-C project have been published, all in scientific and professional journals. Of these ten journal papers, all have been published in open repositories with seven of the nine published as open access. Publications so far include the study protocol, a review of literature relating to barriers to greater integration of palliative care, taxonomy of integrated palliative care and two further systematic reviews. Data from the embedded case study of patient, family caregiver and professional views of integrated palliative care and how these services are organized, delivered and experienced, over time, were collected by Partners 1-5 (WP4 and WP5). Nine more journal papers are in preparation.

Special Edition on Integrated Palliative Care in Palliative Medicine

The purpose of the Special Edition on Integrated Palliative Care published in Palliative Medicine was to draw together the best available reviews and empirical research to strengthen the evidence base for integration in palliative care contexts. The Special Edition was edited by Jeroen Hasselaar (Partner 1) and Sheila Payne (Partner 3). An open call for papers closed on 31st March 2015, and following full peer review processes, 11 papers were selected for publication. The Special Edition was published in Palliative Medicine, March 2016; 30 (3) DOI: 10.1177/0269216315626039.

Blogs

In the reporting period, five blogs have been published via the EAPC website, providing accessible information and updates regarding the InSuP-C project and are estimated to be read by approximately 2-3000 people worldwide. The blogs are located in a separate dedicated section for the InSuP-C project and provide a searchable resource for project outcomes.

Edited book

A book drawing together project outcomes edited by Jeroen Hasselaar (Partner 1) and Sheila Payne (Partner 3). The book (deliverable 5.3) comprises eight chapters with an Annex describing the research methods and a foreword by Professor Phillip Larkin, EAPC President. It offers a highly readable account of integrated palliative care, illustrated by real-life international stories from patients and family caregivers. The book makes recommendations on how to develop integrated palliative care in cancer, heart disease and COPD. It is suitable for health professionals, health service managers and family caregivers. The book has been published in hard copy and an e-book version has also been developed to accompany the MOOC which was launched on 30th September 2016 and is available to download at: <http://www.insup-c.eu/book>. A Spanish translation is available.

Deliverables and Milestones

Deliverable D6.1 Development of interactive project website

Deliverable D6.2 Self-checklist and e-learning modules

Deliverable D6.3 Invitational conference

Deliverable D6.4 Website utilization frequency report

Deliverable D6.5 (milestone) Dissemination strategy report

All deliverables were achieved within the Milestones indicated in the proposal.

Potential impact and main dissemination activities and exploitation results

This chapter describes the potential impact (including the socio-economic impact and the wider societal implications of the project so far) and the main dissemination activities and exploitation of results. We will describe the several actions for dissemination, including potential impact and dissemination strategies.

>Main dissemination activities and potential impact

InsupC Website

Between November 2015 and September 2016, there were an average total of 980 visitors to the site each month, of which 551 were unique visitors. During this time an average of 2421 pages were served each month. It should be noted that from June 2016, when InSup-C advertised the EAPC RN/InSup-C joint symposium “Integrated Palliative Care: Are you ready for change?” held in Brussels, Belgium on the 30th September 2016, there was a marked increase in visitors. In particular, the opening day of the InSuP-C online learning MOOC, “Palliative Care: Making it Work” attracted a 16-fold increase in visitors to the site and numbers remained high for the duration of the 3-week course, as the site was used for access to the many resources contained therein.

Three systematic ‘open access’ reviews about clinical guidelines

In the first period of the project we conducted three systematic reviews that have been published in the open access journal ‘BMC Palliative Care’. The objectives of these systematic reviews were to identify and evaluate the level of integration of palliative care (PC): a) in clinical guidelines and pathways of integrated palliative care in cancer, b) in clinical guidelines and pathways of integrated palliative care in chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) and

iii) in models of in cancer and chronic disease in Europe. It is expected that the results of these three systematic reviews will significantly expand the awareness for integration of palliative care into practice guidelines in the future. Additionally, this work will serve as the basis for better understanding the existing barriers for integrated PC and thus assist in developing improved interventions for patients with both malignant and non-malignant disease (WP2). The work has been presented at several EAPC congresses (2014 Lleida, 2015 Copenhagen, 2016 Dublin, 2016 Brussels). The publications have been accessed each about 1500-2500 times since publication.

A taxonomy for integrated palliative care

Presently, the landscape of integrated palliative care models in Europe is ‘highly fragmented and lacks equity in terms of access’. In this landscape, a taxonomy can facilitate the navigation through, and the comparison of, palliative care initiatives in different health care systems. In addition, a classification system ‘may inform about the pitfalls of integrated care’ and helps to improve existing integrated palliative care schemes. The main purpose of a taxonomy was to improve the reputation and the standing of palliative care as a discipline within the health care system and to make it more visible. Classifying integrated palliative care models further contributes to its establishment within health care systems. Finally, a taxonomy contributes to future research and education provided it consists of both strong definitions to delineate integrated palliative care from non-integrated palliative care services and sufficient elasticity (MacAdam 2008) in order to be applicable to different health care contexts.

The taxonomy was highlighted in presentations at the congress of the European Association for Palliative Care (EAPC) Copenhagen and also at the congress of the European Society for Oncology, Vienna, both in 2015. For the scientific community, the taxonomy was described in an article published in *BMJ Supportive and Palliative Care* (2016 Mar;6(1):14-20). A digital video recording was made to explain to and disseminate the taxonomy among a broader audience (<https://www.futurelearn.com/courses/palliative>).

A book about inspiring examples of integrated palliative care in Europe

The book on integrated palliative care was an important outcome for dissemination, in particular healthcare professionals, family caregivers and the interested public. The book is published in English and Spanish and has been downloaded about 3,500 times during the past three months. The book was launched at the final InsupC/EAPC Congress in Brussels, September 30, 2016. Hardcopies of the books have been disseminated across Europe and beyond. An ebook version is available as a PDF for free download via the website www.insup-c.eu. The book starts with an introduction and a chapter on public health opportunities to improve palliative care integration across Europe. After this, inspiring examples for palliative care integration are described in four consecutive chapters drawing upon the experiences of healthcare professionals, patients and family caregivers as well as offering key recommendations (UK, DE, HUN, NL, BEL). The book closes with global recommendations for better palliative care integration in Europe at the patient and family level, at an organizational level, at a regional level, and at a health system level. Finally, palliative care leadership is mentioned as an important driver for change.

Digital online learning course

Education in palliative care is limited with many countries offering no local provision for this. There has been a growth in online learning which means learning conducted over the internet. This type of learning is highly accessible and means people all over the world can access learning regardless of where they live if they have access to the internet. MOOCs offer the opportunity to deliver education in interactive formats including access to key articles or videos, and also give the students a chance to

respond and take part in associated activities. We decided to create a MOOC as this seemed a good opportunity to deliver integrated palliative care education to a worldwide audience but also a good opportunity to disseminate the results of our study. We worked with FutureLearn one of the main MOOC providers in Europe to deliver the course. FutureLearn is a not-for-profit organisation and students can enrol and complete the course free of charge. However, if students wish to gain a certificate there is a minimal charge. Over 6400 participants from 149 countries registered for the course, the majority of whom were from Europe and Australia. These included health care professionals working in palliative care and in other disciplines, academics, patients and their family carers. The course was designed to be suitable and highly relevant for family carers and the public, one of very few such courses, and thereby impacting directly upon society to increase knowledge about integrated palliative care. The course ran in October 2016 for the first time, and it is the plan to repeat it next year.

International deliberative workshop (Brussels)

On 29th September 2016, we organized an invitational expert workshop for integrated palliative care in Brussels. There were 33 international attendees at this event. These international policy makers included national and international leaders in palliative care/cancer care, leaders of relevant NGOs/INGOs and relevant international funders. The international organizations represented included: Age Platform, European Association for Palliative Care, World Wide Hospice and Palliative Care Alliance, International Association for Hospice and Palliative Care, and representatives of national organizations such as Hospice UK, Marie Curie Cancer Care, National Council for Palliative Care and the Dutch Palliative Care Volunteers Association. In addition, a representative of the WHO head office (Geneva) team who is currently working to implement integrated palliative care in a series of demonstration projects following the World Health Assembly resolution on integrated palliative care in May 2014, attended.

InsupC final conference (Brussels)

On September 30, 2016, InsupC together with EAPC RN, organized a conference about integrated palliative care in Brussels. About 88 attendees from 12 countries attended the conference. Professor David Currow from Australia talked about the evidence for palliative care, Dr. Jeroen Hasselaar spoke about the preliminary results of the InsupC project and the InSuP-C book was presented to EAPC President Prof. Phil Larkin. Professor Larkin gave a lecture about integrated palliative care from the perspective of social justice. Professor Carlos Centeno spoke about opportunities and barriers for integrated palliative care. Dr. Sean Hughes, Marlieke van der Eerden, and Dr. Agnes Csikos elaborated on detailed aspects of the InsupC project results during the afternoon programme. The conference ended with a lively Panel Debate, responding to questions from the audience. A blog has been published about the congress, which can be found at

<https://eapcnet.wordpress.com/2016/10/26/integrated-palliative-care-symposium-in-brussels-are-you-ready-for-change>

Dissemination to specific target groups

Dissemination to a scientific public

Scientific dissemination of results has been provided in a variety of formats:

- 10 peer reviewed journal papers. A further nine journal papers are in preparation, based on the WP4/5 data collection.
- The Special Edition on Integrated Palliative Care published in Palliative Medicine (2016) brought together the best available reviews and empirical research to strengthen the evidence base for integration in palliative care contexts. Editors were Jeroen Hasselaar & Sheila Payne
- An abstract book, containing all abstracts of the InsupC conference in Brussels has been published

with scientific publisher SAGE (Palliative Medicine)

- Presentations and posters at international congresses. Presentations and posters have been delivered for the following congresses: EAPC 2014 Lleida, EAPC 2015 Copenhagen, EAPC 2016 Dublin, IFIC 2014 Brussels, IFIC 2016 Barcelona, EAPC/InsupC Brussels. For EAPC Madrid 2017, the InsupC team have been invited to chair and present at a dedicated parallel seminar on integrated palliative care.

Dissemination to a broad audience

Apart from scientific dissemination and the book, there has also been a wider dissemination via 10 EAPC blogs and a book. The book has been downloaded about 3,500 times during the past 3 months. Ten blogs have been published. The majority of these were via the EAPC website, providing rapid, accessible information and updates regarding the InSuP-C project and are each estimated to be read by approximately 2-3000 people worldwide. Additionally, InsupC coordinator Jeroen Hasselaar has collaborated with the advisory board member European Cancer Patient Coalition (ECPC) to provide advice on integrated palliative care for the European Commission's Expert group on cancer control (<http://www.ecpc.org/news-categories/policy-and-advocacy/134-ecpc-eu-commission/361-palliative-care-ecpc-reply-t>

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

With over 40 million people worldwide in need for palliative care, novel approaches towards palliative care delivery are therefore needed. The impact of the InsupC project is considered important, according to the words of Professor Philip Larkin (President of the European Association for Palliative Care). "through its collaborative approach this programme of investigation (insupc) has identified excellent exemplars where integration of care planning and care delivery has shown innovation, dynamism, and better outcomes for patient and families" (foreword to the InsupC book on integrated palliative care, 2016).

At this point, it is important to be aware of the wider socio-economic implications of the InsupC project. One striking socio-economic implication is that integrated care is more of an issue in economical well developed European countries (for example palliative care training and official certification). This conclusion can be drawn from the opportunities and barriers report (Deliverable 5.1), supported by the Atlas project data from our partner University of Navarra. It seems that barriers and opportunities mentioned by less developed countries were more often about development of basic resources for palliative care (greater implementation of services including strategies and business plans). In this regard, disparities still exist in Europe. A need for more palliative care development in Europe has also been mentioned in the advisory paper of the European Cancer Patient Coalition to which the project coordinator contributed (see above). Although we found good practice-based examples in several European countries, palliative care integration seems still an exception rather than commonly available. Much more efforts at a national and at a European level are needed to bring integrated palliative care forward to all patients who may benefit.

In 2014, the World Health Assembly published a global resolution on palliative care. One of the first recommendations is "integrating palliative care into all relevant global disease control and health system plans". The presence of a WHO palliative care expert at our invitational workshop (Brussels, 29 September) and the forthcoming Charter from our project provide an opportunity to disseminate the project results towards the WHO policy on palliative care. Two partners (Lancaster and Bonn) have been on the technical working group to guide the implementation of the resolution.

The InsupC book and MOOC have the potential to reach the attention of hundreds, even thousands, of interested people all over the world. Implementation of good examples of integrated care is needed, in Europe and elsewhere. There has been much research, mainly from the United States, showing that palliative care can avoid inefficient use of health care resources whilst improving

quality of life, for example by diminishing unnecessary hospital transfers in the last phase of life. When services collaborate in clinical pathways and models, integrated palliative care can become a driver for change. However, implementation in European health systems still needs much more attention. Two lessons from the InsupC conference in Brussels are important in this respect: 1) palliative care needs to be able to provide evidence and proven quality for its interventions, and 2) Palliative care offers proactive supportive interventions to enhance quality of life. Even when resources for well equipped healthcare are limited, society has the humanitarian obligation to provide care for those for those living with advanced diseases and life limiting conditions.

>Expected potential impact of InsupC and further exploitation of results

At the end of the project, tasks have been completed and deliverables have been finalized. However, dissemination and exploitation is expected to continue.

Further exploitation related to the policy workshop and conference

Outcomes of the discussions at the policy workshop in Brussels have been collated and an online survey will be conducted in autumn 2016 to rate, and establish consensus on, recommendations about integrated palliative care. We will prepare an EAPC supported paper on Integrated Palliative Care. These documents which are normally published in leading journals are regarded as highly influential throughout the world, and are used by national associations to leverage dedicated funding and promote policy developed. In addition, we will create an 'Integrated Palliative Care' action to be endorsed by the EAPC in Madrid in May 2017.

For the upcoming EAPC Congress in Madrid 2017, the project InsupC is invited to chair a parallel seminar. In this session, two project members will give a lecture on integrated palliative care. In addition, following an invitation to J Hasselaar from the ESMO (European society for medical oncology) working group on palliative care in Vienna, 2015, there are ongoing contacts and interests to bring integrated palliative care forward in the context of the certification program of the ESMO designated centers (hospitals) for palliative care and oncology (about 180 centers).

Further exploitation related to the InsupC Book and the MOOC

It is our intention to run the online learning program (MOOC), that attracted over 6,400 participants worldwide, again in 2017. These participants have also been provided with a link to the InsupC ebook via the InsupC website. A flyer about the book has been developed for the expected 3,000 participants to the EAPC congress in Madrid, May 2017. For this congress, InsupC has been selected to chair and presented at a parallel seminar on integrated palliative care. Further dissemination of the book into the Spanish speaking part of the world (South America) is foreseen by our Spanish partner from Navarra. The book has been downloaded almost 3,000 times in English in the past 3 months and the recently launched Spanish version has been downloaded about 500 times in the past month.

Further exploitation via international publications

During the InsupC project, a wealth of information has been collected from over 150 patient interviews and almost 100 family caregivers interviews together with group interviews with professional caregivers. Publications are in preparation from WP2 (a further comparison of guidelines), WP4 (at least one article per partner from UK, GER, HUN, NL, and BEL), and WP5 (group interview paper, paper on the embedded case study). In addition, project members are encouraged to write about integrated palliative care in their national journals, based on the InsupC country data. Furthermore, there is an invitation to deliver a chapter on integrated palliative care in a forthcoming book on palliative care from Springer Verlag.

Address of project public website and relevant contact details

Public website and relevant contact details.

Grant Agreement number: 305555
Project acronym: INSUP-C
Project title: Patient-centred palliative care pathways in advanced cancer
and chronic disease
Funding Scheme: Seventh Framework Programme HEALTH.2012.3.2-1
Improving the organisation of health service delivery

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The website contains pictures, details about the participating partners, links to the online learning, a PDF of the English and the Spanish version of the book, a link to the abstract book of the congress, and a link to the special edition of palliative medicine

4.2 Use and dissemination of foreground

Section A (public)

Publications

LIST OF SCIENTIFIC PUBLICATIONS, STARTING WITH THE MOST IMPORTANT ONES										
No.	Title / DOI	Main author	Title of the periodical or the series	Number, date or frequency	Publisher	Place of publication	Date of publication	Relevant pages	Is open access provided to this publication ?	Type
1	Moving the integration of palliative care from idea to practice 10.1177/0269216315626039	J. Hasselaar , S. Payne	Palliative Medicine	Vol. 30/Issue 3	SAGE Publications Ltd	United Kingdom	01/03/2016	197-199	Yes	Peer reviewed
2	Building a taxonomy of integrated palliative care initiatives: results from a focus group 10.1136/bmjspcare-2014-000841	Benjamin Ewert , Farina Hodiament , Jeroen van Wijngaarden , Sheila Payne , Marieke Groot , Jeroen Hasselaar , Johann Menten , Lukas Radbruch	Palliative and Supportive Care	Vol. 6/Issue 1	Cambridge University Press		01/03/2016	14-20	Yes	Peer reviewed
3	Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe: protocol for an international, multicenter, prospective, mixed method study 10.1186/1472-684X-13-52	Marlieke van der Eerden , Agnes Csikos , Csilla Busa , Sean Hughes , Lukas Radbruch , Johan Menten , Jeroen	BMC Palliative Care	Vol. 13/Issue 1	BioMed Central	United Kingdom	01/12/2014	1	Yes	Peer reviewed

		Hasselaar , Marieke Groot								
4	Integrated palliative care in the Spanish context: a systematic review of the literature 10.1186/s12904-016-0120-9	Eduardo Garralda , Jeroen Hasselaar , José Miguel Carrasco , Karen Van Beek , Naouma Siouta , Agnes Csikos , Johan Menten , Carlos Centeno	BMC Palliative Care	Vol. 15/Issue 1	BioMed Central	United Kingdom	01/12/2016	1	Yes	Peer reviewed
5	Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways 10.1186/s12904-016-0089-4	Naouma Siouta , Karen van Beek , Nancy Preston , Jeroen Hasselaar , Sean Hughes , Sheila Payne , Eduardo Garralda , Carlos Centeno , Marlieke van der Eerden , Marieke Groot , Farina Hodiament , Lukas Radbruch , Csilla Busa , Agnes Csikos , Johan Menten	BMC Palliative Care	Vol. 15/Issue 1	BioMed Central	United Kingdom	01/12/2016	1	Yes	Peer reviewed
6	To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: a systematic literature review 10.1186/s12904-016-0100-0	Karen Van Beek , Naouma Siouta , Nancy Preston , Jeroen	BMC Palliative Care	Vol. 15/Issue 1	BioMed Central	United Kingdom	01/12/2016	1	Yes	Peer reviewed

		Hasselaar , Sean Hughes , Sheila Payne , Lukas Radbruch , Carlos Centeno , Agnes Csikos , Eduardo Garralda , Marlieke van der Eerden , Farina Hodiamont , Ildiko Radvanyi , Johan Menten								
7	Education, implementation, and policy barriers to greater integration of palliative care: A literature review 10.1177/0269216315606645	M. D. Aldridge , J. Hasselaar , E. Garralda , M. van der Eerden , D. Stevenson , K. McKendrick , C. Centeno , D. E. Meier	Palliative Medicine	Vol. 30/Issue 3	SAGE Publications Ltd	United Kingdom	01/03/2016	224-239	Yes	Peer reviewed
8	„Der spielt im Moment nicht mehr ganz die Rolle“ 10.1007/s00103-016-2478-5	Sven Schwabe , Gülay Ates , Benjamin Ewert , Jeroen Hasselaar , Michaela Hesse , Lisa Linge-Dahl , Birgit Jaspers , Lukas Radbruch	Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz	1	Springer Verlag	Germany	23/11/2016	ACCEPTED FOR PUBLICATION	No	Peer reviewed
9	Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease 10.1186/s12904-016-0130-7	Naouma Siouta , K. Van Beek , M. E. van der Eerden , N. Preston , J. G. Hasselaar , S. Hughes , E.	BMC Palliative Care	Vol. 15/Issue 1	BioMed Central	United Kingdom	01/12/2016	1	Yes	Peer reviewed

		Garralda , C. Centeno , A. Csikos , M. Groot , L. Radbruch , S. Payne , J. Menten								
	Integrated Palliative Care	Hasselaar J.; Payne S. (editors)	Integrated Palliative Care (ebook)		InsupC	www.insup-c.e u	30/09/2016	1-56	Yes	Article
	Los cuidados Paliativos Integrados (ebook)	Hasselaar J.; Payne S. (editors)	Cuidados Palliativos Integrados		InsupC	www.insup-c.e u	31/10/2016	1-60	Yes	Article
	Abstracts for the integrated palliative care symposium, Brussels, September 30 2016	Various	Abstracts for the integrated palliative care symposium, Brussels, September 30 2016		SAGE Publications Ltd	http://journals.sagepub.com/doi/full/10.1177/0269216316665314	12/09/2016		Yes	Conference
	Online learning in Palliative Care: where are we up to?	Hughes S; Preston S.; Payne S.	Online learning in Palliative Care: where are we up to?	23, no.5 (sept. 2016)	Hayward publishing	Lancaster repository (European Journal Palliative Care)	01/09/2016		Yes	Monogram

LIST OF DISSEMINATION ACTIVITIES								
No.	Type of activities	Main Leader	Title	Date	Place	Type of audience	Size of audience	Countries addressed
1	Flyers	LANCASTER UNIVERSITY	INSUP-C flyer	30/05/2013	13th EAPC Congress in Prague, Czech	Scientific community (higher education, Research) - Industry - Civil society - Policy makers - Medias		Europe, Worldwide
2	Web sites/Applications	KATHOLIEKE UNIVERSITEIT LEUVEN	Integrated palliative care- launch of new European http://eapcnet.wordpress.com/2013/05/14/integrated-palliative-care-launch-of-new	01/05/2013	EAPC Onlus website:	Scientific community (higher education, Research) - Industry - Civil society - Policy makers		Worldwide
3	Web sites/Applications	LANCASTER UNIVERSITY	Searching Europe for best practice in integrated palliative care http://eapcnet.wordpress.com/2013/05/16/searching-europe-for-best-practice-in-integrated-palliative-care	01/05/2013	EAPC Onlus	Scientific community (higher education, Research) - Industry - Civil society - Policy makers - Medias		Worldwide
4	Posters	STICHTING KATHOLIEKE UNIVERSITEIT	Experiences of Patients, Family Caregivers and Professional Caregivers with Integrated Palliative Care in Europe: Development of a Patient Study Protocol in Five Countries	05/06/2014	8th World Research Congress of the EAPC, Lleida, Spain	Scientific community (higher education, Research)	1100	EAPC members (48 countries worldwide, 32 in Europe)
5	Posters	KATHOLIEKE UNIVERSITEIT LEUVEN	Patient-centered integrated palliative care pathways in cancer and chronic disease: A systematic review	05/06/2014	8th World Research Congress of the EAPC, Lleida, Spain	Scientific community (higher education, Research)	1100	EAPC members (48 countries worldwide, 32 in Europe)

6	Posters	UNIVERSIDAD DE NAVARRA	Is Palliative Care Setting Towards Integration in Spain? An answer from the Literature - InSup-C Consortium	05/06/2014	8th World Research Congress of the EAPC, Lleida, Spain	Scientific community (higher education, Research)	1100	EAPC members (48 countries worldwide, 32 in Europe)
7	Posters	LANCASTER UNIVERSITY	Online learning: a scoping of the literature for a study in integrated palliative care	05/06/2014	8th World Research Congress of the EAPC, Lleida, Spain	Scientific community (higher education, Research)	1100	EAPC members (48 countries worldwide, 32 in Europe)
8	Posters	UNIVERSITAETSKLINIKUM BONN	First Steps in Classifying Integrated Palliative Care Approaches - The Criteria for Analysis	05/06/2014	8th World Research Congress of the EAPC, Lleida, Spain	Scientific community (higher education, Research)	1100	EAPC members (48 countries worldwide, 32 in Europe)
9	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Experiences of patients, family caregivers and professional caregivers with integrated palliative care in Europe: development of a patient study protocol in five countries	02/04/2014	14th International Conference on Integrated Care, Brussels, Belgium	Scientific community (higher education, Research) - Policy makers	200	Europe, Worldwide
10	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Patient-centered integrated palliative care pathways in advanced disease: a mixed methods study	02/04/2014	14th International Conference on Integrated Care, Brussels, Belgium	Scientific community (higher education, Research) - Policy makers	200	Europe, Worldwide
11	Oral presentation to a wider public	UNIVERSIDAD DE NAVARRA	integrated palliative care in Spain	01/11/2013	Valladolid	Civil society - Policy makers	150	Spain
12	Articles published in the popular press	STICHTING KATHOLIEKE UNIVERSITEIT	http://blogs.ijnig.org/2014/05/30/taking-integrated-care-for-scientific-people-policy-and-practice/ integrated palliative care forward: people, policy, and practice	30/05/2014		Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries, 32 in Europe)
13	Articles published in	STICHTING	[blog] Integrated	30/05/2014	EAPC website:	Scientific	2500	EAPC members (48

	the popular press	KATHOLIEKE UNIVERSITEIT	palliativecare.net/2014/09/24/integrated-palliative-care-for-papers-for-a-special-edition-of-Palliative-Medicine			education, Research) - Civil society - Policy makers		countries worldwide, 32 in Europe)
14	Oral presentation to a scientific event	UNIVERSITAETSKLINIK BONN	Meet the expert session 'building a taxonomy'	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	100	EAPC members (48 countries worldwide, 32 in Europe)
15	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Meet the expert session: Towards practice based evidence for integrated palliative care	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	100	EAPC members (48 countries worldwide, 32 in Europe)
16	Oral presentation to a scientific event	KATHOLIEKE UNIVERSITEIT LEUVEN	Towards Integration of Palliative Care in Patients with Chronic Heart Failure and Chronic Obstructive Pulmonary Disease: A Systematic Literature Review.	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	100	EAPC members (48 countries worldwide, 32 in Europe)
17	Oral presentation to a scientific event	KATHOLIEKE UNIVERSITEIT LEUVEN	Integration of Palliative Care: Fiction or Reality? A Systematic Literature Review of Empirically Tested Integrated Palliative Care Models in Europe.	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	100	EAPC members (48 countries worldwide, 32 in Europe)
18	Posters	UNIVERSIDAD DE NAVARRA	Barriers and opportunities to integrated palliative care in Europe	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	2800	EAPC members (48 countries worldwide, 32 in Europe)
19	Posters	UNIVERSITAETSKLINIK BONN	Making integrated palliative care: what should we be talking about?	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	2800	EAPC members (48 countries worldwide, 32 in Europe)
20	Posters	UNIVERSITAETSKLINIK BONN	Integrated Palliative Care in Cancer,	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher	2800	EAPC members (48 countries

			COPD and Heart Failure: What Is the Optimal Timing?			education, Research)		worldwide, 32 in Europe)
21	Posters	STICHTING KATHOLIEKE UNIVERSITEIT	Overcoming Challenges in Conducting an International Mixed Methods Study in Integrated Palliative Care.	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	2800	EAPC members (48 countries worldwide, 32 in Europe)
22	Posters	KATHOLIEKE UNIVERSITEIT LEUVEN	Integration of Palliative Care in Patients with Cancer in Europe. Where Do we Stand and what Are the Challenges?	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	2800	EAPC members (48 countries worldwide, 32 in Europe)
23	Posters	LANCASTER UNIVERSITY	Improving On-line Learning in Palliative Care: A Comprehensive Review.	08/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research)	2800	EAPC members (48 countries worldwide, 32 in Europe)
24	Articles published in the popular press	UNIVERSITAETSKLINIKUM BONN	[Blog] Classifying the integrable: Building a taxonomy of integrated palliative care initiatives	10/06/2015	EAPC website: https://www.eapcnet.wordpress.com/2015/06/10/classifying-the-integrable/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
25	Articles published in the popular press	STICHTING KATHOLIEKE UNIVERSITEIT	[blog] Doing international research on patients/family caregivers? experiences	21/10/2015	EAPC website: https://www.eapcnet.wordpress.com/2015/10/21/doing-international-research-on-patients-families-experiences/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
26	Articles published in the popular press	LANCASTER UNIVERSITY	End of life care	25/01/2016	Published in Global Opportunity Healthcare 2016, available at: https://issuu.com/global-opportunity/	Scientific community (higher education, Research)	1000	Europe / worldwide
27	Articles published in the popular press	LANCASTER UNIVERSITY	[blog] Integrated Palliative Care: Are we ready for change? EAPC	17/02/2016	EAPC website: https://www.eapcnet.wordpress.com/2016/02/17/integrated-palliative-care-are-we-ready-for-change/	Scientific community (higher education, Research) - Civil	2500	EAPC members (48 countries worldwide, 32 in Europe)

			Research Network and INSUPC Symposium, 30th September 2016, Brussels.			society		
28	Oral presentation to a wider public	LANCASTER UNIVERSITY	What is the best approach to integration of palliative care for non-cancer patients	08/04/2016	Lisbon, 8th national conference on palliative care	Scientific community (higher education, Research) - Civil society - Policy makers	800	European countries
29	Articles published in the popular press	LANCASTER UNIVERSITY	Benefits of integrated palliative care assessed by European Research Consortium http://www.ehospice.com/ArticleView/tabid/1086/ArticleID/1125/1	26/04/2016	ehospice international newsletter:	Scientific community (higher education, Research) - Civil society	4000	Europe / worldwide
30	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Person-centred palliative care in five European countries: the experiences of patients and family carers.	23/05/2016	Barcelona, 16th international conference on integrated care	Scientific community (higher education, Research)	25	Europe / worldwide
31	Articles published in the popular press	UNIVERSIDAD DE NAVARRA	[Blog] Integrated palliative care: The experience of working in the InSuP-C European project http://eupnet.wordpress.com/2016/05/23/integrated-palliative-care-higher-experience-of-	23/05/2016	EAPC website:	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
32	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Integrated palliative care in Europe: an examination of 21 local initiatives	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	200	EAPC members (48 countries worldwide, 32 in Europe)
33	Oral presentation to a scientific event	LANCASTER UNIVERSITY	Challenges in living alone near the end of life: an international comparison from the InSup-C project.	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	200	EAPC members (48 countries worldwide, 32 in Europe)
34	Oral presentation to a scientific event	LANCASTER UNIVERSITY	Ethical approval systems across Europe: Results of a survey of practices across three	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	2500	EAPC members (48 countries worldwide, 32 in Europe)

			European studies (ACTION, INSUP-C and PACE).					
35	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Person-centred palliative care in five European countries: the experiences of patients and carers.	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	200	EAPC members (48 countries worldwide, 32 in Europe)
36	Posters	UNIVERSITAETSKLINIKUM BONN	Integrated Palliative Care Practices in Seven European Countries: The Experiences of Experts.	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	1400	EAPC members (48 countries worldwide, 32 in Europe)
37	Posters	UNIVERSIDAD DE NAVARRA	Barriers and opportunities to integrated Palliative Care in Europe and its relationship with the level of service provision	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	1400	EAPC members (48 countries worldwide, 32 in Europe)
38	Posters	UNIVERSITAETSKLINIKUM BONN	The role of General Practitioners and integrated palliative care at the end of life from a patients point of view	09/06/2016	Dublin, 9th world research congress of EAPC	Scientific community (higher education, Research)	1400	EAPC members (48 countries worldwide, 32 in Europe)
39	Articles published in the popular press	PECSI TUDOMANYEGYETEM - UNIVERSITY OF PECS	[blog] Integrated palliative care reflections on sessions as the 9th EAPC World Research Congress in Dublin	15/08/2016	EAPC website: https://eapcnet.wordpress.com/2016/08/15/integrated-palliative-care-reflections-on-sessions/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
40	Articles published in the popular press	STICHTING KATHOLIEKE UNIVERSITEIT	Patient-centred care: How can we help patients be 'active collaboration' partners?	22/08/2016	EAPC website: https://eapcnet.wordpress.com/2016/08/22/patient-centred-care-how-can-we-help-patients-be-active-collaboration-partners/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
41	Oral presentation to	UNIVERSIDAD	Europe: where are	14/09/2016	Zamora, Spain	Scientific	70	Spain, Portugal

	a wider public	DE NAVARRA	you going in palliative care?			community (higher education, Research) - Civil society - Policy makers		
42	Oral presentation to a wider public	STICHTING KATHOLIEKE UNIVERSITEIT	Integrated palliative care: A multiple embedded case study ? InSuP-C project 2013-2016	29/09/2016	Brussels, InsupC policy workshop	Policy makers	33	Europe, America, Australia
43	Oral presentation to a wider public	ERASMUS UNIVERSITEIT ROTTERDAM	Overview of macro level (national and regional policy)	29/09/2016	Brussels, InsupC policy workshop	Policy makers	33	Europe, America, Australia
44	Oral presentation to a wider public	LANCASTER UNIVERSITY	Overview of meso level (organizational policy)	29/09/2016	Brussels, InsupC policy workshop	Policy makers	22	Europe, America, Australia
45	Oral presentation to a wider public	STICHTING KATHOLIEKE UNIVERSITEIT	Overview of micro level – interactions between patients, family carers and health professionals)	29/09/2016	Brussels, InsupC policy workshop	Policy makers	33	Europe, America, Australia
46	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Introduction to the InsupC project	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
47	Oral presentation to a scientific event	UNIVERSIDAD DE NAVARRA	Barriers and opportunities to the integration of palliative care in Europe	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
48	Oral presentation to a scientific event	KATHOLIEKE UNIVERSITEIT LEUVEN	European medical guidelines need optimisation	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
49	Oral presentation to a scientific event	LANCASTER UNIVERSITY	What are the fears and support needs of those living alone in the last year of life?	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia

50	Oral presentation to a scientific event	PECSI TUDOMANYEGYETEM - UNIVERSITY OF PECS	Are we still discussing end of life questions with caregivers and not patients?	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
51	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	How to bring integrated palliative care provision forward?	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
52	Oral presentation to a scientific event	UNIVERSITAETSKLINIK BONN	What role of General Practitioners and integrated palliative care	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
53	Interviews	THE UNIVERSITY OF SHEFFIELD	Panel discussion: reflections on integrated palliative care and the way forward	30/09/2016	Brussels, InsupC/EAPC research conference 'are you ready for change'	Scientific community (higher education, Research) - Policy makers	88	Europe, America, Australia
54	Articles published in the popular press	LANCASTER UNIVERSITY	[blog] Online learning in palliative care: a review	03/10/2016	EAPC website: http://www.eapcnet.wordpress.com/2016/10/03/online-learning-in-palliative-care-a-review/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
55	Articles published in the popular press	STICHTING KATHOLIEKE UNIVERSITEIT	[blog] EAPC: Integrated palliative care symposium in Brussels; are you ready for change?	26/10/2016	EAPC website: http://www.eapcnet.wordpress.com/2016/10/26/integrated-palliative-care-symposium-in-brussels-are-you-ready-for-change/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
56	Articles published in the popular press	UNIVERSIDAD DE NAVARRA	[blog] InSup-C launches book on integrated palliative care – InSup-C publica un nuevo libro sobre cuidados paliativos integrados	07/12/2016	EAPC website: http://www.eapcnet.wordpress.com/2016/12/07/insup-c-launches-new-book-on-integrated-palliative-care/	Scientific community (higher education, Research) - Civil society - Policy makers	2500	EAPC members (48 countries worldwide, 32 in Europe)
57	Oral presentation to a scientific event	STICHTING KATHOLIEKE UNIVERSITEIT	Patient recruitment in the Netherlands: what about the law	09/05/2015	Copenhagen, 14th congress of EAPC	Scientific community (higher education, Research) - Policy makers	100	EAPC members (48 countries worldwide, 32 in Europe)

			of Lasagna?			Research) - Civil society - Policy makers		Europe)
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Section B (Confidential or public: confidential information marked clearly)

LIST OF APPLICATIONS FOR PATENTS, TRADEMARKS, REGISTERED DESIGNS, UTILITY MODELS, ETC.					
Type of IP Rights	Confidential	Foreseen embargo date dd/mm/yyyy	Application reference(s) (e.g. EP123456)	Subject or title of application	Applicant(s) (as on the application)

OVERVIEW TABLE WITH EXPLOITABLE FOREGROUND								
Type of Exploitable Foreground	Description of Exploitable Foreground	Confidential	Foreseen embargo date dd/mm/yyyy	Exploitable product(s) or measure(s)	Sector(s) of application	Timetable for commercial use or any other use	Patents or other IPR exploitation (licences)	Owner and Other Beneficiary(s) involved
General advancement of knowledge	Parallel seminar at EAPC conference in Madrid, May 2017	No		Presentations	M72; P85; S94	2017	n.a.	Radboudumc; Pecs Univeristy; Lancaster University
General advancement of knowledge	Scientific articles	No		Forthcoming scientific articles based on the results of the InsupC project	M72;P85;Q86;J58	2017	copyrights depending on the journal (to be decided)	Radboudumc; UK Bonn; KU Leuven; Pecs University; Lancaster University; Erasmus University; Universidad Navarra
General advancement of knowledge	Online education programme	No		Repeat of the 2016 online learning course with filmed content of the InsupC project	P85;Q86	2017	licenses held by Lancaster Univeristy	Lancaster University
Exploitation of results through EU policies	Paper with recommendations for future development of integrated palliative care, based on the InsupC policy workshop (Brussels, 29/09/2016), to be launched at EAPC Madrid, May 2017	No	20/05/2017	Position paper on integrated palliative care with recommendations, supported by EAPC	M72;S94;Q86	2017	n.a.	Lancaster University; Radboudumc

ADDITIONAL TEMPLATE B2: OVERVIEW TABLE WITH EXPLOITABLE FOREGROUND	
Description of Exploitable Foreground	Explain of the Exploitable Foreground
Parallel seminar at EAPC conference in Madrid, May 2017	A the Congress of the European Association of Palliative Care in Madrid, a parallel seminar about integrated palliative care is foreseen, chaired by the InsupC project
Scientific articles	Forthcoming publications are foreseen based on the InsupC data collection among patients, family caregivers, and professional caregivers. Nine proposals have been made at the InsupC General Assembly in Lancaster, April 2016. We expect about half of this realized in 2017.

Online education programme	An online education programme has been developed within InsupC. Filmed content was collected in care settings in five partner countries and presentations with InsupC project members have been filmed. The programme ran successfully in 2016 with over 6,000 participants, and will be repeated in 2017.
Paper with recommendations for future development of integrated palliative care, based on the InsupC policy workshop (Brussels, 29/09/2016), to be launched at EAPC Madrid, May 2017	A policy workshop on integrated palliative care has been held as part of the InsupC program. Based on this workshop, recommendations and further actions for integrated palliative care will be formulated in a position paper, to be launched at the EAPC congress in Madrid, 2017.

4.3 Report on societal implications

B. Ethics

1. Did your project undergo an Ethics Review (and/or Screening)?	Yes
If Yes: have you described the progress of compliance with the relevant Ethics Review/Screening Requirements in the frame of the periodic/final reports?	Yes
2. Please indicate whether your project involved any of the following issues :	
RESEARCH ON HUMANS	
Did the project involve children?	No
Did the project involve patients?	Yes
Did the project involve persons not able to consent?	No
Did the project involve adult healthy volunteers?	Yes
Did the project involve Human genetic material?	No
Did the project involve Human biological samples?	No
Did the project involve Human data collection?	Yes
RESEARCH ON HUMAN EMBRYO/FOETUS	
Did the project involve Human Embryos?	No
Did the project involve Human Foetal Tissue / Cells?	No
Did the project involve Human Embryonic Stem Cells (hESCs)?	No
Did the project on human Embryonic Stem Cells involve cells in culture?	No
Did the project on human Embryonic Stem Cells involve the derivation of cells from Embryos?	No
PRIVACY	
Did the project involve processing of genetic information or personal data (eg. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?	Yes
Did the project involve tracking the location or observation of people?	Yes
RESEARCH ON ANIMALS	

Did the project involve research on animals?	No
Were those animals transgenic small laboratory animals?	No
Were those animals transgenic farm animals?	No
Were those animals cloned farm animals?	No
Were those animals non-human primates?	No
RESEARCH INVOLVING DEVELOPING COUNTRIES	
Did the project involve the use of local resources (genetic, animal, plant etc)?	No
Was the project of benefit to local community (capacity building, access to healthcare, education etc)?	No
DUAL USE	
Research having direct military use	No
Research having potential for terrorist abuse	No

C. Workforce Statistics

3. Workforce statistics for the project: Please indicate in the table below the number of people who worked on the project (on a headcount basis).

Type of Position	Number of Women	Number of Men
Scientific Coordinator	0	1
Work package leaders	3	3
Experienced researchers (i.e. PhD holders)	14	13
PhD student	3	0
Other	22	10

4. How many additional researchers (in companies and universities) were recruited specifically for this project?	7
Of which, indicate the number of men:	2

D. Gender Aspects

5. Did you carry out specific Gender Equality Actions under the project ?	No
6. Which of the following actions did you carry out and how effective were they?	
Design and implement an equal opportunity policy	Not Applicable
Set targets to achieve a gender balance in the workforce	Not Applicable
Organise conferences and workshops on gender	Not Applicable
Actions to improve work-life balance	Not Applicable
Other:	
7. Was there a gender dimension associated with the research content - i.e. wherever people were the focus of the research as, for example, consumers, users, patients or in trials, was the issue of gender considered and addressed?	No
If yes, please specify:	

E. Synergies with Science Education

8. Did your project involve working with students and/or school pupils (e.g. open days, participation in science festivals and events, prizes/competitions or joint projects)?	Yes
If yes, please specify:	in statistical analyses: e.g. we gave the percentage male/female
9. Did the project generate any science education material (e.g. kits, websites, explanatory booklets, DVDs)?	Yes
If yes, please specify:	we delivered an online learning course (WP6)

F. Interdisciplinarity

10. Which disciplines (see list below) are involved in your project?	
Main discipline:	
Associated discipline:	
Associated discipline:	

G. Engaging with Civil society and policy makers

11a. Did your project engage with societal	Yes
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actors beyond the research community? (if 'No', go to Question 14)	
11b. If yes, did you engage with citizens (citizens' panels / juries) or organised civil society (NGOs, patients' groups etc.)?	No
11c. In doing so, did your project involve actors whose role is mainly to organise the dialogue with citizens and organised civil society (e.g. professional mediator; communication company, science museums)?	
12. Did you engage with government / public bodies or policy makers (including international organisations)	Yes, in communicating /disseminating / using the results of the project
13a. Will the project generate outputs (expertise or scientific advice) which could be used by policy makers?	Yes - as a secondary objective (please indicate areas below - multiple answer possible)
13b. If Yes, in which fields?	
Agriculture	No
Audiovisual and Media	No
Budget	No
Competition	No
Consumers	No
Culture	No
Customs	No
Development Economic and Monetary Affairs	No
Education, Training, Youth	No
Employment and Social Affairs	No
Energy	No
Enlargement	No
Enterprise	No
Environment	No
External Relations	No
External Trade	No
Fisheries and Maritime Affairs	No
Food Safety	No
Foreign and Security Policy	No
Fraud	No
Humanitarian aid	No
Human rights	Yes
Information Society	No

Institutional affairs	No
Internal Market	No
Justice, freedom and security	No
Public Health	Yes
Regional Policy	Yes
Research and Innovation	Yes
Space	No
Taxation	No
Transport	No
13c. If Yes, at which level?	International level

H. Use and dissemination

14. How many Articles were published/accepted for publication in peer-reviewed journals?	13
To how many of these is open access provided?	12
How many of these are published in open access journals?	8
How many of these are published in open repositories?	4
To how many of these is open access not provided?	1
Please check all applicable reasons for not providing open access:	
publisher's licensing agreement would not permit publishing in a repository	No
no suitable repository available	No
no suitable open access journal available	No
no funds available to publish in an open access journal	No
lack of time and resources	No
lack of information on open access	No
If other - please specify	paper is accepted but not yet published
15. How many new patent applications ('priority filings') have been made? ('Technologically unique': multiple applications for the same invention in different jurisdictions should be counted as just one application of grant).	0
16. Indicate how many of the following Intellectual Property Rights were applied for (give number in each box).	
Trademark	0

Registered design	0
Other	0
17. How many spin-off companies were created / are planned as a direct result of the project?	0
Indicate the approximate number of additional jobs in these companies:	0
18. Please indicate whether your project has a potential impact on employment, in comparison with the situation before your project:	Difficult to estimate / not possible to quantify, None of the above / not relevant to the project
19. For your project partnership please estimate the employment effect resulting directly from your participation in Full Time Equivalent (FTE = one person working fulltime for a year) jobs:	0

I. Media and Communication to the general public

20. As part of the project, were any of the beneficiaries professionals in communication or media relations?	No
21. As part of the project, have any beneficiaries received professional media / communication training / advice to improve communication with the general public?	No
22. Which of the following have been used to communicate information about your project to the general public, or have resulted from your project?	
Press Release	No
Media briefing	No
TV coverage / report	No
Radio coverage / report	No
Brochures /posters / flyers	Yes
DVD /Film /Multimedia	Yes
Coverage in specialist press	Yes
Coverage in general (non-specialist) press	No
Coverage in national press	Yes
Coverage in international press	Yes
Website for the general public / internet	Yes
Event targeting general public (festival, conference, exhibition, science café)	No

23. In which languages are the information products for the general public produced?

Language of the coordinator	No
Other language(s)	Yes
English	Yes

Attachments	Patient centred palliative care pathways in advanced cancer and chronic disease.pdf, Table B1 .pdf, insupc_spaans_a5.pdf
Grant Agreement number:	305555
Project acronym:	InSup-C
Project title:	Patient-centered palliative care pathways in advanced cancer and chronic disease
Funding Scheme:	FP7-CP-FP
Project starting date:	01/11/2012
Project end date:	31/10/2016
Name of the scientific representative of the project's coordinator and organisation:	Dr. Jeroen Hasselaar STICHTING KATHOLIEKE UNIVERSITEIT
Name	
Date	21/12/2016

This declaration was visaed electronically by Jeroen HASSELAAR (ECAS user name nhasseje) on 21/12/2016