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Conference Abstract

**Experiences of patients, family caregivers and professional caregivers with integrated palliative care in Europe: development of a patient study protocol in five countries**

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**Abstract**

**Introduction:** Integration of palliative care in treatment pathways, palliative care networks and institutional collaborations in health services delivery seems to be a promising approach to reduce fragmentation and discontinuity. Integrated Palliative Care (IPC) approaches in Europe are largely unknown and under-investigated. Evidence is largely based on evaluation of individual services and proxy views. More research is needed to explore experiences of patients, however national ethical requirements complicate doing prospective patient studies in palliative care. Patient studies at international scale that must fulfil ethical requirements of several countries are even more complicated. Therefore it is necessary to develop a patient study protocol which can be implemented in five European countries.

**Aim:** To develop a patient study protocol that can be implemented in five European countries in order to explore experiences of patients with cancer, COPD and CHF, family and professional caregivers with IPC.

**Methods:** Ethical procedures in each partner nation were investigated in order to know which requirements needed to be met. A template protocol was developed by InSup-C (EC FP7 funded) research teams and discussed in InSup-C meetings. This template was adjusted to the most strict requirements.

**Results:** A study protocol for a longitudinal patient study in five European countries has been developed. This includes perceived quality of life, quality of care, burden/rewards of care giving, symptoms and collaboration between caregivers in the patient's care network. Some regulations (e.g. safety reporting) have been adjusted to country specific regulations provided that these would not alter the study procedures.

**Conclusion:** It is feasible to develop a palliative care patient study protocol that can be executed in five European countries. The patient study protocol will be implemented in Spring 2014.

## Keywords

**palliative care, patient study protocol, ethical procedure europe**

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## Powerpoint presentation:

<http://www.integratedcarefoundation.org/content/new-research-integrated-care-0>

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