

Palliative care for older people in Europe

PACE EU FP7 Testimony

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Chair Research Programme
Ageing and Palliative Care

Public health research, health services
research, clinical research

Interdisciplinary collaborative research
group (over 30 people)

formal alliances with social and medical
departments in several universities



Aim of this presentation

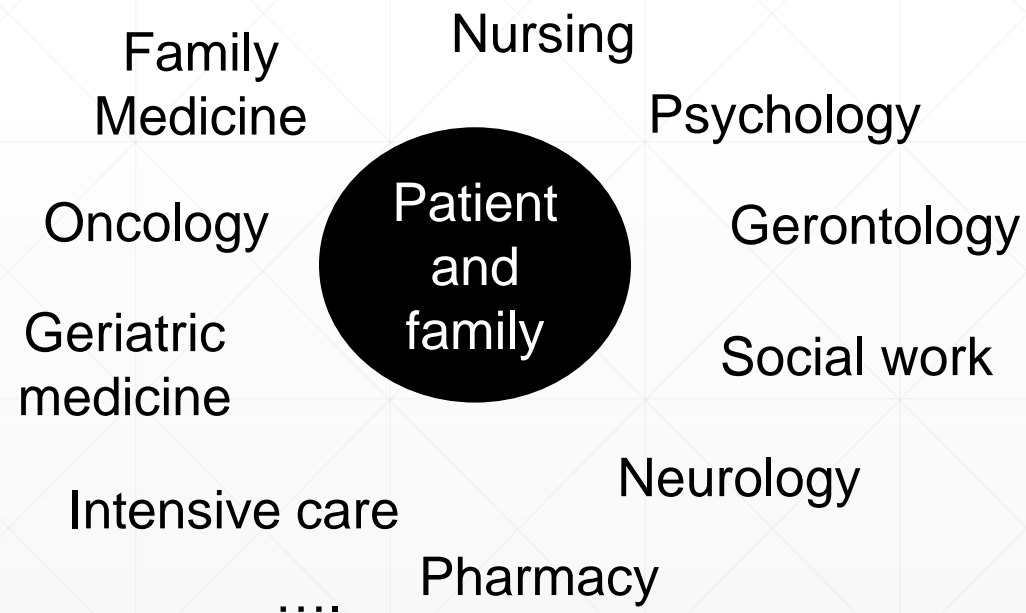
to share **experiences of bridging** between different disciplines and fields in EU funded projects and proposals,
to provide some **tips** and tricks in proposal writing and project execution
using the case example of the EU-funded project PACE 2014-2019
(FP7)

What is EU FP7 PACE?

A very brief introduction to palliative care and the PACE project

Palliative care

Approach to care for people with life-threatening illness
Assessment and treatment of physical, psychosocial and spiritual problems
Multidisciplinary team approach centred around patient and family



Not only a difficult clinical challenge
But also a **complex societal challenge**

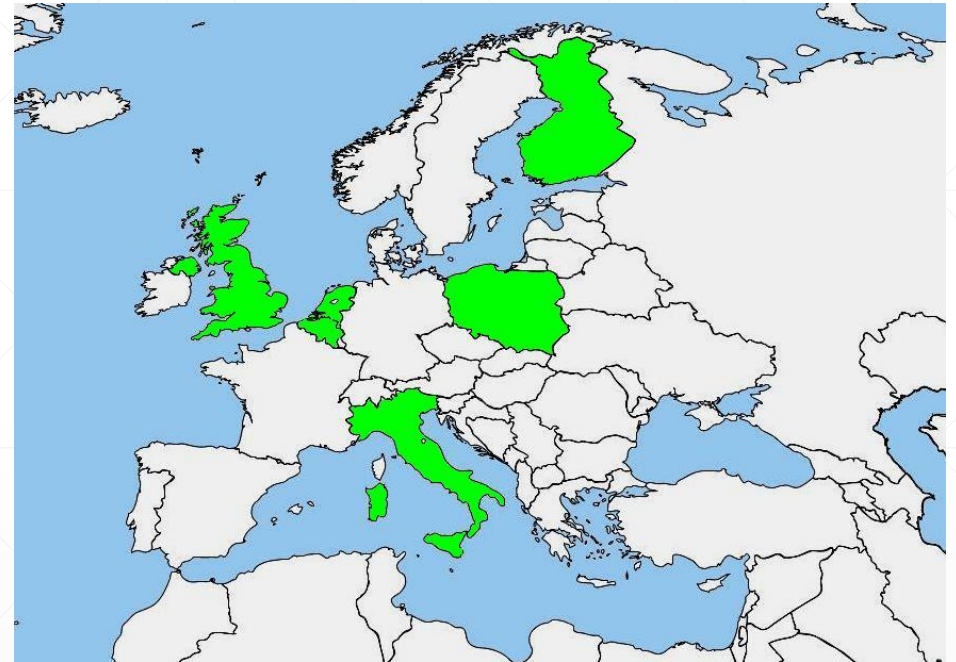
Historically developed as a medical and nursing discipline
Grown as a field in Social Sciences and Humanities over the past decades



An example of collaboration between medical and social sciences, academia and non-academia, in an EU funded project

PACE 2014-2019 FP7 Palliative care in nursing homes

1. Mapping palliative care in nursing homes in 29 countries in Europe (Taskforce European Association of Palliative Care)
2. **Describe quality of dying** in nursing homes (study I) and **compare** countries with vs without formal palliative care structures
3. Randomised controlled cluster trial to integrate palliative care in nursing homes **“PACE Steps to success” intervention** (study II)



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Ghent University & Vrije Universiteit Brussel
end-of-life care research group



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Finland



JAGIELLONIAN UNIVERSITY
IN KRAKÓW

Poland

The Netherlands



Radboudumc

International organisations



European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe



Some tips and experiences from PACE

Important to...

screen EU topics carefully and with an “open creative” mind

What also applies to your field?

Where can your team/expertise be of added value?

Spotting opportunities for PACE in EU funding

FP7

Cooperation, Collaborative research

Health Programme 2007-2013

Work Programme 2013

Health.2013.3.1-1 **Comparative effectiveness research (CER) in health systems and health services interventions.** FP7-HEALTH-2013-INNOVATION-1.

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Important to...

Carefully align research aims with call

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Study I Compare countries where formal palliative care systems (BE, NL, UK) are in place with countries where this is not (PL, IT, FI)

Study II Impact of 'Pace Steps to Success' as a health service intervention

Compare in terms of quality of care, outcomes, and costs

Important to...

Analyse which partners you need
to answer your research questions

PACE consortium covers all disciplines needed to perform the research

- Research partners from social sciences incl coordinator
 - Expertise in cross-sectional study designs, complex interventions
- Research partners from health sciences and medicine (geriatrics, primary care, dementia)
 - Expertise in clinical trials, access to specific patient populations, in specific settings
- Research partners health economics

Important to...

Carefully align project and partners with expected impact

Expected impact: Results should assist policy makers and decision makers to make informed decisions regarding the implementation or improvement of health system and health services interventions in view of improving patient outcomes, quality of life and increase the cost-effectiveness of interventions, ultimately improving health status at individual and population levels.

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PACE AIMS TO assist policy and decision-makers at **national and international level** in making informed and evidence-based decisions regarding best palliative care practices in nursing homes

PACE will develop **tools and products** to assist policy- and decision-makers eg policy briefs, open access intervention toolkit

Important to...

Analyse which partners you need
to achieve the expected impact

Analyses of the **key drivers of change** in this field: practice, policy, nationally and internationally

Which partners are needed to develop the necessary tools?

- 4 dissemination partners working to achieve this impact across Europe became part of PACE consortium (eg AGE prepares policy briefs)



- International stakeholders: who are regularly informed about results and are asked to disseminate further
- National stakeholders: to achieve impact per country

PACE bridges different

- clinical disciplines
- sectors
- research backgrounds
- countries
- individuals

Important to...

take time to understand each other
identify shared goals with all partners in the consortium
develop common language
bilaterally and as a group



Preparing PACE entailed **much more than proposal writing**.... Much discussion about:

What is palliative care? How is this different from good geriatric care?

What is high quality palliative care in nursing homes?

What are expectations for the study in each country?

What are current cultural and medico-ethical values surrounding end-of-life decision-making?

...

Why is representativity of the sample important?

Why is a Randomised Controlled Trial needed?

...

When do you have results from the study to disseminate?

Some key elements to **success in collaboration**

Communication AND communication

Mutual respect, building understanding and trust

Dedication: shared mission/goal

Participatory process with active involvement of partners

Competence of partners and leaders

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