Research in Palliative Care and End-of-Life Care

Luc Deliens
prof palliative care research

END-OF-LIFE CARE RESEARCH GROUP
Collaboration and interdisciplinary research

- established in the 90-ies as a collaboration VUB & Ghent University:
  - 3 clinicians
  - 2 ethicists
  - 1 sociologist

- addressing the first study on euthanasia and other end-of-life decisions in Belgium
EOLC research group

**Aims** to conduct high-quality scientific research in end-of-life care and palliative care in Belgium, Europe and beyond

**Type of research:**
- public health research
- health services research
- clinical research (complex interventions)

Overall **about 50 members** with interdisciplinary scientific backgrounds
composition by discipline (N=54)

**CLINICIANS 15**
- Physicians 9
  - Oncology 3
  - Geriatrics 2
  - Fam med/Pal Care 4
- RN nurses 4
- Pharmacist 1
- Social worker 1

**MANAGEMENT 7**
- MA Management 2
- Research ass 3
- Management ass 2

**SOCIAL SCIENTISTS 34**
- Psychologists 16
  - Clinical psych 12
  - Health psych 2
  - Experimental psych 2
- Sociologists 10
- Health scientists 3
- Ethicists/philosophers 3
- Economist 1
- Communication Sci 1
- Languages & Literature 1

Past: Lawyers, Antropologist, etc
End-of-Life Care Research Group

International advisory board

Directors
Luc Deliens & Simon Van Belle

Support staff
EU project manager
Societal dissemination manager, Webmaster
Research assistants

Leads research programmes
Joachim Cohen
Koen Pardon
Lieve Van den Block

Senior & junior staff members

Research Programmes

- Public Health and Palliative Care
- Palliative Care for People with Cancer
- Aging and Palliative Care
3 research programs: **research aims**

**Public Health & PC**
- describing and understanding the circumstances and the quality of dying and its determinants from a population perspective

**Pal Care in Cancer**
- acquiring the necessary insights to improve the quality of palliative care for cancer patients and understand the mechanisms of (early) integration of palliative care into mainstream oncology treatment

**Ageing & Pal Care**
- acquiring the necessary insights to improve the quality of palliative care for older people and understand the mechanisms to improve end-of-life care in long-term care facilities
EOLC research group: resources

- 1st major grant from Research Foundation Flanders (RFF) 1997-2000
- followed by a large number of local, national and international research projects and fellowships
- 3 ongoing EU funded projects (FP7 & Horizon 2020): PACE, ACTION, ITN INDUCT
- Strategic research grant VUB (2x)

output
- 37 PhDs & about 25 ongoing PhDs
- Yearly > 40 papers in scientific journals, most in D1/Q1 of domain in Web of Science
Training & supervision of PhD students

- Recruitment policies
- Education & training
Next to the research plan, we develop an educational plan for and with the junior researchers or PhD students

- Doctoral schools of VUB & Ghent University
- Pal care training (observational internship in different care settings possible)
- Internal research training:
  - workshops
  - seminars
  - conferences
- Many international collaborations
Education & training

- junior researchers/PhD students are assisted by postdoc researchers in
  - Preparing meetings with supervisors
  - Preparing conferences
  - Preparing external communication and dissemination

- Provide them with a “quality handbook” incl templates on:
  - meeting agenda’s
  - meeting minutes
  - posters
  - Paper writing
  - etc
supervision of PhD students

- Recruitment policies
- Education & training
- Supervision & collaborative decision making
Supervision & collaborative decision making

- “Project group” or team as autonomous decision making body in the research process
  - Junior researcher
  - Daily supervisor – postdoc
  - Professors responsible for PhD
  - Other supervisors
Using high standards in each step in the research process

- **Protocol developing**: in collaboration with experienced researchers and methodologists

- **Data collection**: in collaboration with experienced researchers having used the chosen design of data collection

- **Data analyses**: in collaboration with experienced statisticians, epidemiologists, economists, etc
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