

International Collaborative for Best Care for the Dying Person

Annual Research Thinktank

Date: 12 February 2026

Time: 14:00 – 16:00 CET

Chair: Agnes van der Heide/John Ellershaw

| Time | Programme | Speaker |
|----------------------|--|--|
| 14:00 – 14:05 | Welcome and introductions | Prof John Ellershaw |
| 14:05 – 14:10 | Aims and procedures | Prof Agnes van der Heide |
| 14:10 – 14:25 | Pitches from workshop leads 1. Research in International Benchmarking for Care for the Dying 2. How are we comforting at home when injectable anticipatory medication is not available? The MiMI Project 3. Training the implementation leaders of the 10/40 Model 4. The iLIVE Project Legacy | Prof John Ellershaw Dr Rui Carneiro & Dr Antonio Carneiro Dr Dröfn Birgisdottir & Anette Duarte RN Prof Agnes van der Heide |
| 14:25 – 14:50 | Workshop round 1 (attendees choose one of the groups) | |
| 14:50 – 15:00 | BREAK | |
| 15:00 – 15:15 | Pitches from workshop leads 1. Research in International Benchmarking for Care for the Dying 2. Diagnosing Dying 3. The Serious Illness Care Programme 4. The iLIVE Project Legacy | Prof John Ellershaw Dr Matteo Moroni Assoc Prof Anna Sandgren & Dr Stephen Mason Prof Agnes van der Heide |
| 15:15 – 15:40 | Workshop round 2 (attendees choose one of the groups) | |
| 15:40 – 15:55 | Reports from workshops | |
| 15:55 – 16:00 | Conclusions | Prof Agnes van der Heide |

Outlines of the workshops

Research in International Benchmarking for Care for the Dying

This workshop will be led by the International Benchmarking for Best Care for the Dying Person Project Group from the International Collaborative. The first workshop will discuss the comparison between datasets that currently exist, including NACEL from the UK, the Swedish Registry, and findings from the iLIVE project. The second workshop will look at developing an international project and potential work packages for an EU proposal in this field.

How are we comforting at home when injectable anticipatory medication is not available? The MiMI Project

When healthcare teams want to respect patients' wishes to die at home, they are confronted with a lack of access to suitable injectable medication in many countries. The use of alternative, often off-label, non-parenteral medicines is common practice. The aim of the workshop is to draw up an international survey of such common clinical scenarios and how they look in practice.

Training the implementation leaders of the 10/40 Model

In this workshop, we will present a project plan on training implementation leaders of the 10/40 Model, that includes identifying barriers and needs of these implementation leaders; creation of a digital training; and a pilot test. This workshop aims to discuss possible evaluation strategies to assess the training's impact on participants' readiness for their roles.

The iLIVE Project Legacy

In the iLIVE project, we collected information on the experiences, needs and preferences of patients in the last phase of life and their family in 13 countries. The workshop focuses on how the results of this project can inform a health policy paper on perspectives of patients and their relatives on dying and end-of-life care in the 21st century.

Diagnosing Dying

A proper diagnosis of impending death supports patients, families, and professionals by clarifying care goals, promoting shared decisions, avoiding aggressive treatments, and ensuring both quality of life and a good death. It also improves prognosis communication and enhances end-of-life care through better symptom management and emotional support. The workshop is aimed at discussing the establishment of a project group to further collaborate on this topic.

The Serious Illness Care Programme

This workshop will address questions developed from the planned SICP Project Group Seminar, exploring challenges in implementing the Serious Illness Care programme. The workshop will allow project group members to share practices and action plans for future implementation.