

# Training Volunteers to Support Dying Patients, and their Families, in the Hospital Setting - iLIVE study

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The iLIVE project includes a prospective 10-country cohort study to gain insight into 21st century experiences of dying patients and their formal and informal caregivers. The iLIVE project combines experimental studies on medication management to alleviate physical symptoms and on the development and implementation of compassion-based volunteer programme, with an observational study to better

understand the experience of death and dying.

**The aim of the volunteer study is: to develop and evaluate an international volunteer (training) programme to support patients dying in the hospital and their families.**

In five countries, patients with a life expectancy of one month or less, will be invited to participate in

the volunteer trial.

In this trial, we will evaluate whether the introduction of volunteers to support dying patients and their families in the hospital setting improves patients' quality of life in the dying phase, family bereavement and study cost-effectiveness.

**The study started in January 2019 and includes the following tasks:**

## Task 1: Protocols

Development of detailed protocols (x5) to describe the study procedures, patient recruitment and data collection will be developed.

## Task 2: Delphi study

A 3-round international Delphi study is underway to achieve consensus on the content of the international training programme.

## Task 3: Prepare service

The infrastructure is prepared for the new volunteer service in the hospitals in the five participating countries.

## Task 4: Learning Lab

A Learning Lab will be developed: a virtual forum in which Volunteer Coordinators (VCs) in all participating countries will exchange experiences with the programme and its implementation.

## Task 5: Train-the-Trainer

A three-day international 'train-the-trainer' (TtT) course is delivered to two identified VCs per hospital site.

## Task 6: Recruitment

Following the TtT-course, VCs screen and recruit a maximum of 20 volunteers per hospital and deliver the training programme.

## Task 7: Data collection

For (cost) effectiveness evaluation data will be collected with several instruments, including: EQ-5D, ICECAP-CPM, ICECAP-SCM questionnaires, Hogan Scale, phenomenological in depth interviews and cost information.

## Task 8: Focus Group

The lived experience of volunteers caring for a patient in the last days of life will be explored through a focus group interview per country. The experience of staff will also be explored through focus groups.

## Task 9: Implementation

In depth interviews and focus groups will also be used to explore factors that influence the implementation of a new hospital volunteer service for dying patients.

Volunteer services will be organized in hospitals in:

- UK: Liverpool, Royal Liverpool University Hospital
- Netherlands: Rotterdam, Maastad Hospital
- Norway: Bergen, Haukeland University Hospital
- Spain: Malaga, Cudeca Hospice
- Slovenia: Ljubljana, University Clinic Golnik



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