

A study protocol of a population-based retrospective registry trial

Background

Around 42 000 people die in Norway every year. The majority of people prefer to die at home, including elderly and terminally ill patients. 45% of the Norwegian population die in nursing homes, 32% in hospitals, but only 14% die at home – one of the lowest rates worldwide. At the same time 80% of deaths are not sudden or unexpected, and only 5-10% have a difficult dying process in need of specialised hospital treatment.

The types of health services available are likely to influence place of death. Home palliative care enables patients to die at home and reduces symptom burden without impacting caregiver grief.

Due to different health care systems, international study results are not necessarily applicable for Norwegian conditions. We have to find research based cost-effective and high quality services in order to meet the challenge of an ageing population, suitable for the Norwegian health care system. First we need to know what characterises end-of-life care, death and dying in Norway.

Aims

We will investigate the characteristics of end-of-life care and death for adult people in Norway, with a focus on those who die at home.

Method

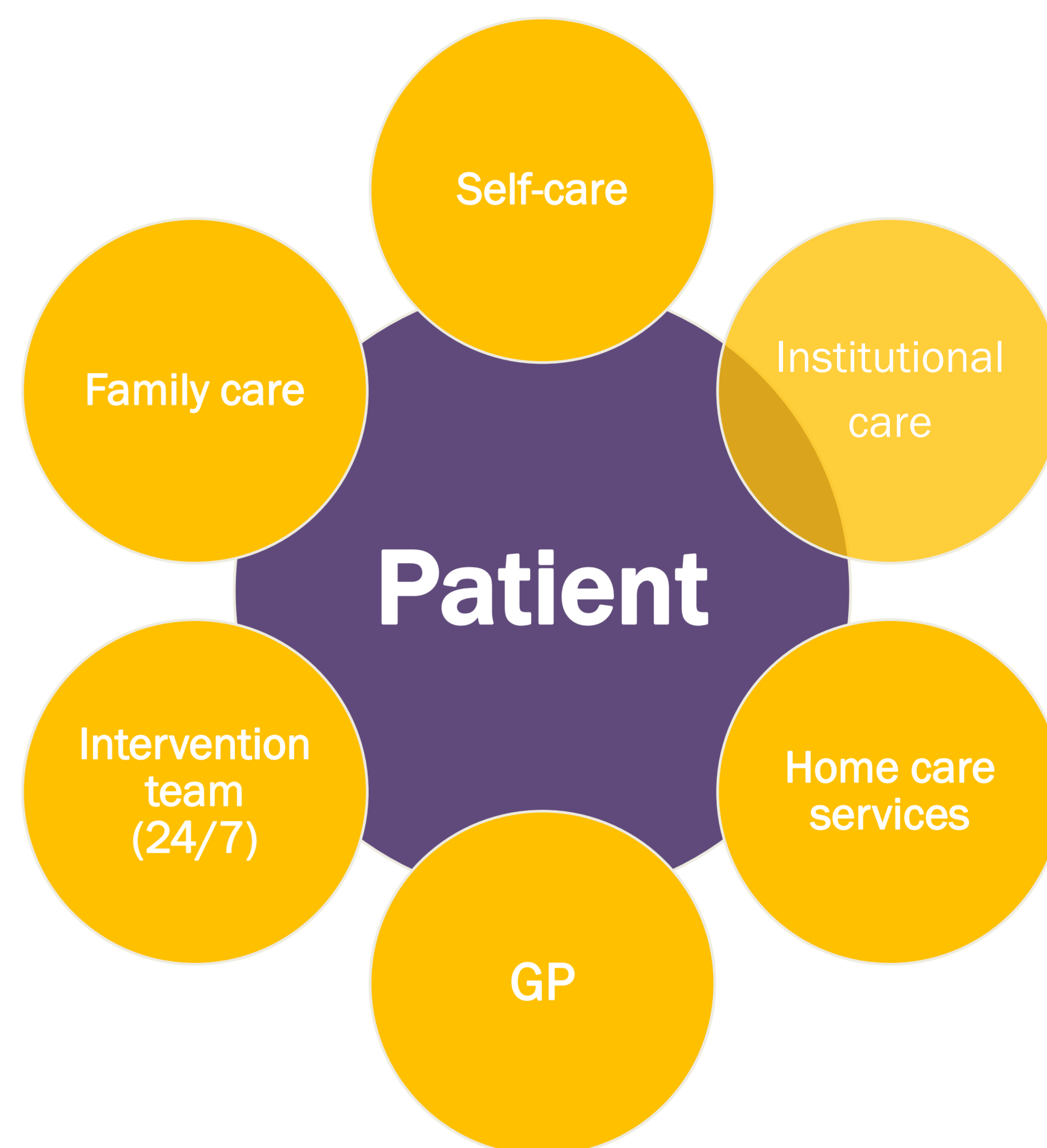
This will be a population-based retrospective registry trial, including all deaths in Norway from 01.01.2012 to 31.12.2013, N = 73 000, looking at the last three months before death. Home deaths will be compared to deaths in nursing homes, hospitals and other. We will use data from official Norwegian health registries and other official registries to look at the following outcome measures: place of death; sociodemographic data; hospital or nursing home admission; out-of-hours visits; general practitioner involvement; medications prescribed.

Registries

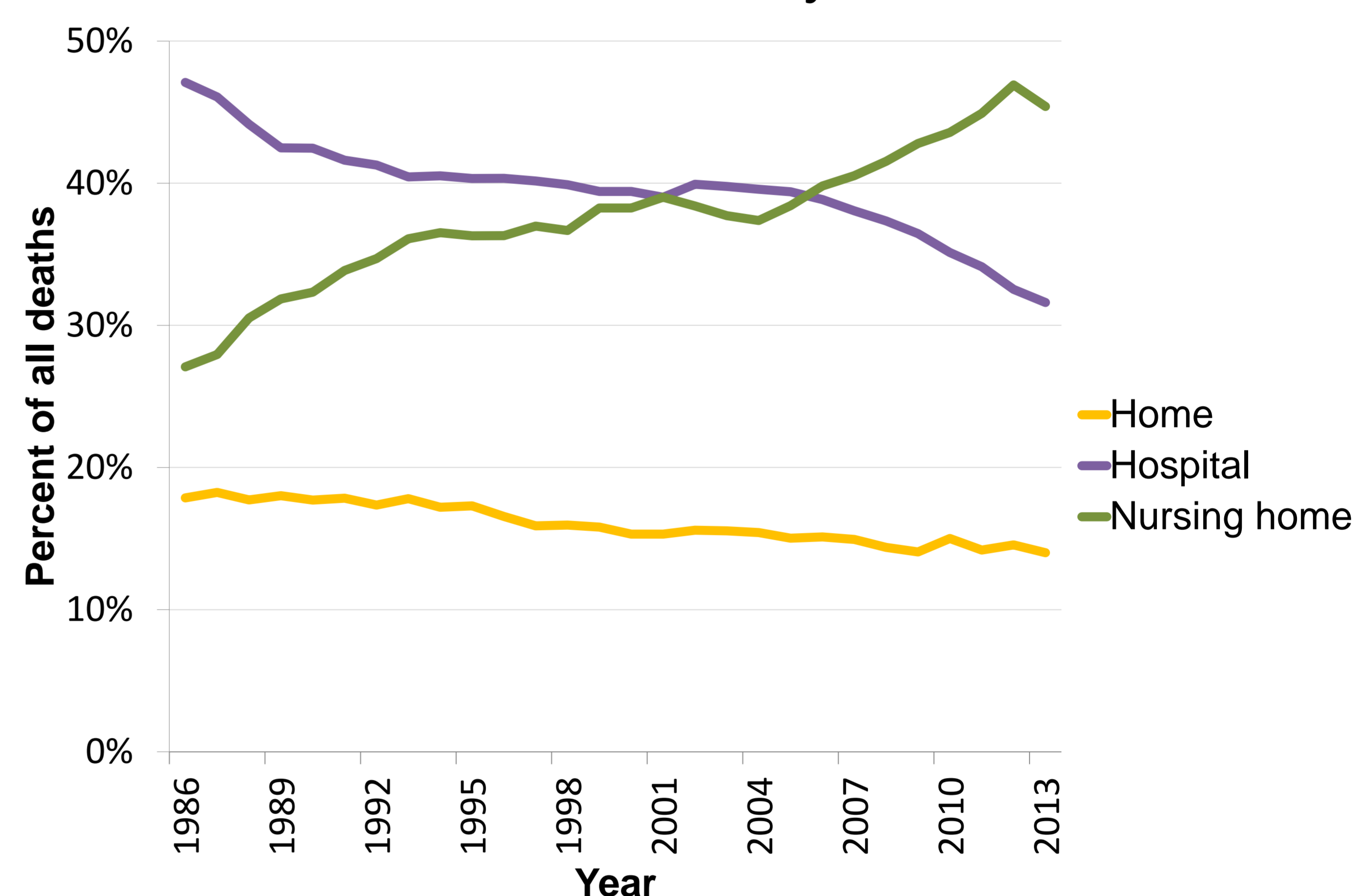
- ❖ The Cause of Death Registry
- ❖ The National Registry
- ❖ IPLOS (Municipal health care)
- ❖ KUHR/HELFO (Billing claims general practitioners)
- ❖ The General Practitioner Database
- ❖ The Norwegian Patient Registry
- ❖ The Norwegian Prescription Database

Outcome measures

Place of death; Diagnoses; Sociodemographic data; Hospital admissions; Nursing home admissions; Visit to OOH/causality clinics; General practitioner involvement; Medications prescribed; Estimation of costs of care and medication.



Place of Death 1986-2013 in Norway



Project management and collaboration

The study is initiated by the Centre for Elderly and Nursing Home Medicine (SEFAS) and the research group for General Practice at the Department of Global Public Health and Primary Care (IGS), UiB, in cooperation with the National Centre for Emergency Primary Health Care.

Funding

The study is funded by the GC Rieber Foundation.

Future plan

The study is approved by the Regional Committee for Medical and Health Research Ethics (REC North) and granted exemption from confidentiality. Collection of data will begin in 2015.

REFERENCES

1. Gomes B. et al. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev* 2013; 6: Cd007760
2. Wilson DM. et al. The rapidly changing location of death in Canada, 1994-2004. *Soc Sci Med* 2009; 68: 1752-8

