



Cicely Saunders  
International  
Better care at the end of life



# The International Access, Rights and Empowerment Study (The IARE study)



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[www.csi.l.ac.uk](http://www.csi.l.ac.uk)



# Project BuildCARE



**Aim:** to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally

**Four-year** project, supported by Cicely Saunders International (CSI) and The Atlantic Philanthropies

**BuildCARE's** components:

- International Faculty Scholar posts
- PhD studentship programme (2 clinical & 2 non-clinical)
- Dissemination, engagement & empowerment (DEE) programme
- IARE cross-national study

**BuildCARE lead:** Prof Irene J Higginson  
supported by an international BuildCARE team



# IARE: background

- Ireland, the UK and the US have ageing populations, each country is at different points of the demographic trend
- Despite their long-established palliative care systems, the chronic disease burden posed by an ageing population in these countries will challenge their healthcare systems
- Accessing palliative and end-of-life care is often regarded as a central human right
- However, access varies from country to country, by age, by social class and by disease



(Gwyther L, Brennan F, Harding R. Advancing palliative care as a human right. J Pain Symptom Manage 2009 Nov;38(5):767-74; Economist Intelligence Unit. The quality of death. Ranking end-of-life care across the world. 2010.)

# The IARE study: overall aim

To improve the rights of older palliative care patients ( $\geq 70$  years) and their carers by gathering information about access to and empowerment of people requiring specialist palliative care in order to help secure equitable access to healthcare for this population

[www.csi.kcl.ac.uk/iare.html](http://www.csi.kcl.ac.uk/iare.html)

Oliver A, Mossialos E. Equity of access to health care: outlining the foundations for action. J Epidemiol Community Health 2004 Aug;58(8):655-8.



Equity = equal access to health care by those in equal need



# Cross-national study

## London

King's Health Partners  
NIHR CRN portfolio “badged” study



## New York city

Mt Sinai Medical Centre



Mt Sinai Medical Centre

## Dublin

Mater Misericordiae University Hospital  
Beaumont Hospital



Mater Misericordiae University Hospital



Beaumont Hospital



Trinity College Dublin



# Descriptive mixed methods study: three work packages

## Work package one

### Describe and compare:

- The characteristics of, symptoms and problems
- The time between 1) initial diagnosis and death, 2) palliative care referral and death, and 3) first palliative care contact and death (within and between cities)
- Patients' preferences for: palliative care, their involvement in decision making, and determine a cognitive model that underpins preferences

**Examine** the internal factor structure of POS using exploratory factor analysis

**Develop** a measurement tool for the health economic evaluation of palliative care interventions

Comparisons between cancer and non-cancer patients and across cities

# Work package one: face-to-face surveys

In each city:

- **Pilot: 10 patients**
- **140 surveys**
- **Examination of clinical record and administrative data**

A palliative care service where:

In hospital, the team decide when to see you and make contact with you.

In hospital, you are able to see or can contact the team Monday–Friday, 9am–5pm.

In hospital, you are able to see or can contact the team 24 hours a day, 7 days a week.

Information	Questionnaire or interview
<b>Patient demographic and or clinical information</b>	Gender, age, background, ethnicity, geography (zip code for New York, postal district for London), weekly income, family support, living circumstances, housing, place of care, illnesses
<b>Experience of care received</b>	Famcare (Kristjanson LJ et al. 1996)
<b>Palliative problems</b>	Palliative care Outcome Scale (POS) v.2 (Hearn & Higginson 1999)
<b>Symptoms</b>	Condensed Memorial Symptom Assessment Scale (Chang et al. 2000) and/ or POS-S
<b>Functional status</b>	Modified Barthel Index (Mahoney FI and Barthel D 1965)
<b>Cognitive ability</b>	Short Orientation Memory and Concentration Test (SOMC)
<b>Decision-making about care</b>	PRISMA survey questions regarding preferences for quality and or quantity of life, financial hardship and decision-making involvement, preferred place of death, educational attainment

## Work package two

- Examine what **facilitates and blocks** access to hospital palliative care
- Examine what **empowerment** is and how this works within the hospital in relation to specialist palliative care



### **Methodology – in each city:**

Qualitative interviews: up to two interviews with 10 staff, 10 unpaid carers, 10 patients

Plus, ethnographic fieldwork (e.g., observations in team meetings, shadowing staff)



# Work package 3



- **Describe** unpaid carers' demographic characteristics and relationship to the deceased
- **Examine variations** in the amount and type of unpaid care provided during the last three months of life, and estimate costs associated with carers' reduced / lost employment
- **Identify grief** patterns and intensity, **risk factors** and carers' **help-seeking behaviour** before the time of death and into bereavement



## **Methodology: Followback postal survey (adapted QalyCARE survey)**

215 bereaved carer surveys involving unpaid carers who provided care to patients ( $\geq 70$  years)  
Approached four to 10 months post bereavement

# Acknowledgements

The **IARE** study forms part of project BuildCARE and has the overall aim of improving the rights of older adult palliative care patients and their carers by generating information regarding access and empowerment of people requiring specialist palliative care in order to help secure their equitable access to healthcare.

**BuildCARE** aims to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally. It is a four-year project, supported by Cicely Saunders International (CSI) and The Atlantic Philanthropies. Chief Investigator: Irene J Higginson. Project Principal Investigator: Barbara A Daveson. Research team: Melinda Smith, Caty Pannell, Susanne de Wolf-Linder, Rachel Hughes, Taja Ferguson, Katy Tobin and service-user representatives.

