

## Marie Curie Cancer Care Research Programme - Project Grant

Project details
<p><b>Dr Morag Farquhar (PI)</b>, University of Cambridge</p> <p><b>End of life care in advanced Chronic Obstructive Pulmonary Disease (COPD): identifying, understanding and meeting the changing care and support needs of patients and their carers</b></p> <p>Duration of project: 36 months Start date: 01/07/2012 (TBC) Budget: £291k (TBC)</p>

Abstract
<p><b>Background</b></p> <p>Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition with high symptom- and carer-burden, accounting for one death every 20 minutes in England and Wales. National strategy documents state that quality end-of-life care should be available to patients with any condition, yet we rely on planning tools developed for cancer with its differing trajectory. We need a new framework based on recognition of the slow relentless progression of non-malignant disease and its effect on patients and carers. To inform this we will provide new evidence on the trajectory of health and social care needs and preferences (and whether these change) of these patients, and their carers, in differing contexts.</p> <p><b>Aims</b></p> <p>To explore variation in the experience and outcome of care in advanced COPD in relation to:</p> <ol style="list-style-type: none"> <li>1) changing physical, psychological and social needs of patients and carers at the end-of-life from patients', carers' and clinicians' perspectives;</li> <li>2) care preferences (places and sources of care) at the end-of-life;</li> <li>3) barriers and facilitators to clinicians' ability to meet needs at the end-of-life; and,</li> <li>4) service-provider stakeholder (clinicians, managers and commissioners) strategies for meeting needs and preferences at the end-of-life.</li> </ol> <p><b>Methods</b></p> <p>These aims will be delivered through four linked component studies:</p> <ol style="list-style-type: none"> <li>1) a mixed-method 18-month Longitudinal Study of advanced COPD patients (n=60) and their carers: 3-monthly semi-structured interviews with flexible methodology to capture changing function, need and service-access.</li> <li>2) Care Preferences Survey: Discrete Choice Experiments (using preference vignettes) within a longitudinal postal survey (n=250) to identify change in care preferences in relation to changing need, conducted in 2-centres for geographical, social and ethnic contrast.</li> <li>3) Barriers and Facilitators Study: brief longitudinal interviews with clinicians (identified by Longitudinal Study patients), to identify barriers/facilitators to meeting need.</li> <li>4) Service-provider Stakeholder Study: focus groups with clinicians, managers and commissioners to consider implications of findings for clinical practice, management and policy.</li> </ol> <p><b>How the results of this research will be used</b></p> <p>The results will support the needs of commissioners and service-providers by highlighting variation in the experience and outcome of care at the end-of-life in COPD. Working with stakeholders it will identify innovative ways clinical teams and health systems might respond. The study has generic resonance beyond COPD with outcomes relevant to the substantial number of patients and carers living with other advanced progressive chronic conditions. It will inform a new framework for end-of-life care in non-malignant conditions.</p>

