

## Marie Curie Cancer Care Research Programme - Project Grant

### Project details

Professor Jeremy Whelan, University College London

**BRIGHTLIGHT on End of Life care for young adults – what do young adults and their families need and how can it best be delivered?**

Duration of project: 24 months

Start date: 01/05/2013 (TBC)

Budget: £247k (TBC)

### Abstract

#### Background

The impact of incurable cancer on patients and families is strongly influenced by life stage, most easily identified by age. For adults in early to mid-life, very little is known about end of life (EoL) experience or how care is best delivered although acknowledgement of its specific challenges is frequent amongst professionals. This study will define the EoL needs of 16-40 year olds, chosen as those on the borders of paediatric care but who are less often encountered in adult cancer and palliative care services.

#### Aims

The study aims to understand

- a) The core components in the pathways of care in the last year of life for people with cancer aged 16-40 years.
- b) Any differences between the experiences of people with cancer from the age ranges 16-24 and 25-40 years.
- c) How young adults and their families can be supported in the last year of life to achieve their preferences for care.
- d) The challenges that exist for health and social care professionals providing care.

#### Methods

A national multiple methods study guided by the MRC framework for complex interventions which uses realistic evaluation, a methodology particularly suited to informing practice and service improvement. The study links to BRIGHTLIGHT (NIHR RP-PG-1209-10013). It intends to explore causal mechanisms and context through five consecutive phases of research:

- (i) Preparatory phase: detailed synthesis of literature; analysis of care patterns described by national cancer data sets
- (ii) Interviews with patients, families and professionals. Longitudinal qualitative interviews with 16-24 years olds in the BRIGHTLIGHT study. Case studies of thirty 16-40 year-old cancer patients at EoL, family members, key professionals. Analysis of written communication and documentation in medical notes
- (iii) Scenarios workshop: nine workshops nationally for interactive discussion and to disclose perspectives, opinions and experience. Three workshops with patients and family, three with professionals and three with mixed participants.
- (iv) Panel of experts: presentation of findings and iterative analysis to test fit of potential outcomes to mechanisms
- (v) Development of recommendations for practice and further evaluation. An overarching account of the core components and pathways of EoL care will be developed and shared to incorporate feedback with research participants, policy makers, commissioners and other stakeholders.

#### How the results of this study will be used

Definition of national standards, pathways of care and core competencies are anticipated. Areas for potential intervention, recommendations for future empirical evaluation and testing of the effect on outcomes will be identified.