

# Marie Curie Cancer Care Research Programme - Project Grant

## Project details

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End of life care: the experiences and needs of lesbian, gay and bisexual (LGB) elders

Duration of project: 24 months Start date: 01/06/2012 (TBC)

Budget: £157k (TBC)

## Abstract

#### **Background**

While it is well known that end of life care needs are most common among older age groups (whether as patients or carers), there has been little research exploring particular sub groups and a lack of understanding of the heterogeneous needs of 'older people', particularly those living in non traditional family forms. This study addresses the needs and experiences of lesbian, gay, bisexual and trans older people (LGBT elders) in relation to end of life care (EoLC) to assist the development of equitable service provision in EoLC that addresses core principles of dignity and respect for all.

#### **Aims**

- 1. To identify particular needs and preferences salient to sexual/gender orientation relating to EoLC as identified by LGBT elders.
- 2. To examine ways in which sexual/gender orientation may impact on experiences of EoLC for LGBT elders
- 3. To explore LGBT elders' familial and friendship networks and the ways in which these personal networks may influence later life experiences towards and at end of life.
- 4. To identify recommendations for good practice in EoLC issues addressing issues for LGBT elders.

### **Methods**

A mixed methods study with three phases:

- 1. A survey (n = up to 300) of LGBT elders experiences and needs in relation to EoLC across England and Wales
- 2. In-depth interviews with a sub-sample of the survey respondents (n = up to 60) to examine indepth issues highlighted from the survey and incorporating 'eco-maps' (a participatory visual technique to map out and prompt discussions about respondents' supportive networks).
- 3. A public engagement workshop to feedback findings and to collaboratively develop recommendations to contribute to outcomes of the study.

### How the results of this research will be used.

The research team have an excellent reputation for translating research findings to inform and shape policy and practice in end of life care. We will utilise our networks to reach a broad range of policy makers and service providers in EoLC. Specific impacts on policy and practice will include:

- Development of a series of best practice guidelines for policy makers, commissioners and service delivery, identifying ways to address issues of equality and diversity and to improve access to / delivery of EoLC services to LGBT elders.
- Feeding our findings into evidence based teaching for practitioners.
- Development of materials to assist in raising public awareness of the issues for use at practitioner and user-led conferences.