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## Marie Curie Research Grants Scheme

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Supporting people with palliative and end-of-life care needs “out of hours”: a mixed-methods study of needs, demands and experiences to inform person-centred service developments

**Duration of project:** 24 months

**Start date:** 1st April 2017

**Budget:** £192,563\*

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### Abstract

#### Background

Improving palliative care outside of working hours (OOH) is the top UK priority for palliative care. A 2013 government report stated that OOH should be integral to 24/7 care along with generalist palliative care provided “in hours.” The 2015 *Ritchie Report* on OOH care in Scotland identified people with palliative and end-of-life care needs (PEoLC) as needing better care. The report also highlighted the need to better understand decision-making by patients and carers during the OOH period. We know that many people with PEoLC needs are not identified for a palliative approach before they die. Understanding how all people with PEoLC needs (regardless of whether or not they have been identified for palliative care) use and are served by OOH care is a prerequisite for future service developments both in-hours and OOH.

Scotland is starting a radical redesign of OOH services. There is a pressing need for a robust evidence to inform these developments provided by population level analyses of current OOH service use allied with an in-depth analysis of how people access and perceive OOH services.

#### Aim

To examine the Scottish OOH service as it currently operates before proposed changes are implemented, and explore how OOH services are understood and used by service users with PEoLC needs to inform redesign of health and social care delivery OOH.

#### Research Questions

1. What are the current use and costs of out of hours services and support for patients in the last year of life in Scotland?
2. What are the experiences of currently available OOH services and support among people with PEoLC needs and their carers (professional and informal)?
3. What affects the decision-making process of people with PEoLC needs when choosing which (if any) OOH services/support to access?
4. What are the key findings from Q1-3 that can inform the redesign of OOH services in Scotland up to 2020?

### **Methodology**

This mixed-methods project integrates quantitative analyses of Scottish OOH service use in the last year of life (Q1) with a qualitative study of experiences and perceptions of patients and carers (Q2-3) and integrates the findings to answer Q4.

Q1 will be answered through linking and interrogating existing out of hours datasets in order to assess demands and patterns of use during the last 12 months of life. (Figure 1) These will be combined with standard UK price weights to estimate costs with cost profiles.

Q 2-3 will be answered through qualitative research, including semi-structured interviews and focus groups, with methods based on our 2005 OOH study. We will collect qualitative data from participants in three health boards covering over 70% of the population of Scotland: NHS Lothian; NHS Greater Glasgow & Clyde; and NHS Highland. The participants will be bereaved carers; patients, linked carers and GPs. We will conduct:

1. Focus groups with 12-16 bereaved carers of people who died with a wide range of conditions (cancer and non-cancer) recruited through GP practices and support groups such as CRUSE and VOCAL.
2. Focus groups in hospice day centres in three health boards with 15-20 community patients.
3. Semi-structured interviews with 30 patients (plus family carer and GP) recruited through GP practices and hospices in the three health boards.

Experience shows that these participant numbers should achieve data saturation. We will synthesise the data using a thematic framework and present the findings at a consensus-building workshop involving professionals, service users and the Scottish Government. This will generate recommendations and metrics to inform OOH and anticipatory care planning interventions (Q4).

### **Proposed Findings**

- Trajectories of OOH service use and hospital admissions of people in the last year of life who died of conditions amenable to palliative care, whether or not they were identified.
- Service users' understandings and experiences of the OOH system and how they make decisions about which services to use: including when not to use any service.
- Recommendations and intelligence shared with the Scottish OOH services redesign.

Where costs of potential service changes are unclear, the feasibility of estimating such costs will be examined.