

Marie Curie Cancer Care Research Programme - Project Grant

Project details

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Variation in the care of patients with bowel and blood cancers at the end of life: a feasibility study evaluating the potential of data linkage in the National Cancer Data Repository

Duration of project: 12 months Start date: 01/05/2012 (TBC) Budget: £74k (TBC)

Abstract

Background:

The drive to deliver improved services at the end of life for patients with cancer has highlighted the need for better information on patterns and variation in care. This information is needed to commission and monitor high quality services, but the complexity of pathways crossing primary, secondary and specialist palliative care means that no individual dataset is sufficient. Recent developments in cancer intelligence, in particular the establishment of the National Cancer Intelligence Network (NCIN), have facilitated linkage between datasets to establish a more complete understanding of patterns of care. To date, there has been limited use of these new resources to explore end of life care and this project seeks to assess what additional information they may provide.

Aims:

We will test the feasibility of linking data held on individuals in large national health datasets and explore whether this can inform our understanding of the patterns of care delivered to patients with bowel and blood cancers at the end of life. We intend to describe variation in care seen in secondary and primary care settings, and examine factors that could be associated with differences in the place of death.

Methods:

An individual-level linked data record covering the final year of life for people dying of colorectal and haematological cancers in England in a single year (2008) will be established from the following datasets: English cancer registration data; English inpatient and out-patient Hospital Episode Statistics; ONS mortality data and the General Practice Research Database. The patterns of care received by in the last year of life will be described including, where possible, the nature of contacts with specialist palliative care, and indications of a palliative approach. We will assess whether care has varied for people with different forms of cancer, between different socio-demographic groups, and in different parts of England. We will consider the place where people have died, and identify what factors are associated with the place of death.

How the results of this research will be used:

Our analyses of the quality of information available on end of life care in routine data, and the extent to which record linkage is possible, will establish the merits and limitations of this approach. With this knowledge, we plan to develop methods that can increase our understanding of variations in the place of death and better inform cancer care commissioners in planning and monitoring end of life care.