

Marie Curie Cancer Care Research Programme - Project Grant

Project details
<p>Dr Debra Howell (PI), University of York</p> <p>Exploration of factors associated with place of care and place of death in patients with haematological malignancies</p> <p>Duration of project: 36 months Start date: 1 January 2012 (TBC) Budget: £269,728</p>

Abstract
<p>Background Home is generally considered the preferred place of care and death, however, our systematic review and meta-analysis showed that patients with haematological malignancies are over twice as likely to die in hospital as those with other cancers (Annex 1). They are also less likely to receive palliative and hospice care (Annex 2). This has implications for patients who may not be dying in their preferred place, and health care commissioners who may be funding expensive end-of-life care in inappropriate acute hospital settings.</p> <p>Haematological malignancies are common and have a high case fatality rate compared to many other cancers. Their trajectories are complex and diverse, and whilst some patients die soon after diagnosis, improvements in the treatment of others mean that patients can live long periods with what is essentially chronic disease. Despite these issues there is an absence of empirical evidence about place of care and death in haematological malignancy patients.</p> <p>Aims and objectives We aim to generate evidence about place of care and death in patients with haematological malignancies. Key areas will be identified where practical changes would facilitate care and death in the patient's preferred place.</p> <p>Methods The study is cross-disciplinary, based on the infrastructure of the Haematological Malignancy Research Network (HMRN, www.hmrn.org) and supported by the Palliative Care and Haematological Malignancy Steering Group and Haematology User Group (Annex 3). Mixed quantitative and qualitative approaches will be used to gather information from multiple sources. Initially, the hospital records of 808 patients with a haematological malignancy, dying within the HMRN area during 2009 will be examined (Annex 4). Events during the last two weeks of life will be recorded using our validated day-by-day calendar approach (Annex 5). This will complement data routinely collected by HMRN for audit on these patients. Semi-structured interviews will also take place with relatives, carers and haematology, palliative care and generalist practitioners in primary and secondary care. These will be transcribed and analysed using Atlas-ti to identify codes and themes.</p> <p>How the results of this research will be used Results will be synthesised alongside existing literature and policy in collaboration with the Steering Group. Findings will be disseminated locally at Network Site Specific meetings and will be used to instigate practitioner-led change. The HMRN area is representative of the UK in terms of both demography and clinical practice, meaning results are highly generalisable. National and international dissemination will occur via publication and conferences.</p>