Research Study: Pro-active follow-up in primary care from early in the cancer trajectory

Qualitative research study hosted by The University of Edinburgh and funded by Macmillan Cancer Support. Principal Investigator Prof Scott Murray. Duration: 1st July 2009 to 31st December 2011. Contact: Scott.murray@ed.ac.uk or tel 0131 650 2680

Scientific Summary

The focus of this project is to pilot the active follow-up of patients in primary care from diagnosis of cancer. Although the Gold Standards Framework is currently being used to a degree by most UK practices, it is only generally introduced in the later stage of cancer care to improve co-ordination of palliative care in the community. Its use is being encouraged, but is not supported educationally, for patients earlier in the cancer trajectory. Our previous research has confirmed that many cancer patients and their carers would like pro-active care not only in the “palliative stage”, but from after initial treatment. This study will assess the feasibility, advantages and disadvantages and cost of this to those most involved: patients with a new diagnosis of any cancer, their relatives and their primary care teams.

Method To do this we will use an action research and realist comparative case study approach. Working from the assumption that the effectiveness of new interventions is contingent upon the context in which these are introduced this research focuses on highlighting what works, for whom, and in what circumstances. Our concern is with understanding the causal mechanisms, and the conditions under which these are activated to produce specific outcomes.

Stage 1 The participants include 4 Scottish GP Facilitators - from Glasgow, Fife, Aberdeen and the Borders – and 3 English GP Facilitators. These GPs with extensive experience will develop & trial a framework in their practices for a 6 month period. The results will be evaluated in situ by a qualitative researcher and the participants will then meet together to share their experiences, and plan the next stage.

Stage 2 In the next stage, the participants will then each identify two other practices in their own areas which would be willing to institute pro-active cancer care from diagnosis. The participants will then provide support for these ‘daughter’ practices as they embed the framework in their practices over a 12 month period. The results will be evaluated through qualitative interviews with patients and their GPs, patient note analyses and as well as quantitative data gathered from a case note review.

Intended outcomes:
1. A community-based framework to promote the pro-active care of “survivors”.
2. Research evidence concerning how this framework as a whole, and/or read-coded elements of the framework, improves care to cancer patients from diagnosis.
3. A possible model of jointly developed (patient, primary care, secondary/tertiary care) advance care plans following completion of initial treatment.
In-depth exploration of the impact of the new Scottish Palliative Care DES on patient care.

Funded by “Living and Dying” Well as a priority research and evaluation project

Dec 09 for 12 months

Description of initiative
We plan to evaluate in an in-depth qualitative manner what is actually happening under the new DES in six primary care teams in Scotland. This will supplement and illuminate the routine data generated through the DES returns. We will identify and describe in detail how a number of practices are actually:

• identifying patients for inclusion on their palliative care registers;
• assessing these patients;
• carrying out care planning;
• notifying out-of-hours providers;
• using an end of life care framework such as the Liverpool Care Pathway.

Based on an analysis of these case studies and discussion with key professionals we aim to produce a guideline to suggest how general practices in Scotland can best carry out reliable and good quality supportive and palliative care, while being reimbursed for doing so through the DES.

How it will contribute to meeting the aims of Living and Dying Well

• Pragmatic guidance which will help practices use the principles underpinning the DES to best effect and maximise benefit for patients.
• Evidence to inform future developments of the UK Quality and Outcomes Framework of the nGMS contract and the English and Scottish end-of-life initiatives.
• Results will be fed in to the GSF on-going developments, and Scottish Executive.

Scott A Murray, St Columba’s Professor of Primary Palliative Care, University of Edinburgh.
Scott.murray@ed.ac.uk
Definition and evaluation of models of primary and secondary care collaborative working

A Multi-centre collaboration between The University of Edinburgh, The University of Warwick and Kings College, London. October 09 to Sept 11

Abstract. A particular problem in generalist settings is the coordination of care as patients encounter multiple care settings and professional carers in the last year of life. Through the conduct of three phase, mixed-method study we aim to gain consensus on the service developments and educational requirements required to improve coordination of care at the end of life in generalist settings. Following a literature review and service-user consultations in England and Scotland, we will conduct a series of ‘micro’ level ethnographic case studies of service provision in three different settings. The findings from the ethnographies will be used to inform ‘macro’ level consensus-gaining activities about best models for coordination of care at end of life.

Aims. To understand the processes by which end of life care is coordinated and managed in generalist care settings; to identify best practice in care coordination and optimum outcomes for patients and their families; and to inform service and policy development so that access to and coordination of high quality of end of life care can become more reliable and equitable.

Design. We will undertake a three-phase mixed-method study, incorporating service user consultation, an empirical study using an organisational ethnographic approach, and consensus-building methods. In the first phase we will conduct a literature review on coordination of care and best outcomes and stage a service user consultation on coordination of care and outcomes of care, working with a range of user groups across the UK. In the second phase we will conduct three ethnographic case studies of patients encounters in three different settings: two in England and one in Scotland. Service usage data will be recorded quantitatively and complemented by qualitative interviews with patients, family members and service providers around ‘critical incidents’ in the care of each patient. This will enable us to identify the factors which lead to optimum identification, assessment, co-ordination of care and optimal outcomes for patients and families and factors that result in lack of identification, poor co-ordination and gaps in coordination of care. The final stage will draw upon the data from phase 2 to enable us to identify the key components of effective coordination of end of life care. These will then be tested for generalisability using consensus building methods, incorporating a national Delphi survey with key stakeholders and two national workshops to develop service recommendations.

Outcomes. The primary outcome of this project is to seek to gain consensus on the service developments and educational requirements required to improve coordination of care at the end of life in generalist settings. outcomes. It will do so by producing experiential evidence and suggestions from patients nearing the end of their lives and their relatives about how health services could be better coordinated and delivered. It will suggest processes and outcomes that are important to users and which are feasible and acceptable to staff. By involving NHS clinicians and managers as collaborators this project will help build capacity within the NHS to carry out health services research and quality improvement cycles.