

## 2007

1. Dr Claire Foster, School of Nursing and Midwifery, University of Southampton; Dr Jane Hopkinson; Prof Julia Addington-Hall; Prof Sheila Payne; Mary Sayers; Judith Robinson

*Supporting relatives: An investigation into obstacles and aids to information exchange within families affected by cancer. (1 year)*

### **Aims:**

1. To explore family members' experiences of sharing information about cancer in the family
2. To identify the information and support needs of partners and other family members in relation to their relative's cancer
3. To examine the availability of resources to families to support them in talking about a cancer diagnosis and treatment
4. To assess the value of existing resources from the perspective of family members
5. To make recommendations about the provision of resources to support families in talking about cancer diagnosis, prognosis and treatment
6. To make recommendations for further research about how to support families in sharing information about cancer.

### **Background:**

This study responds to the top priority area identified in the Listening Study. We will explore the consequences of cancer for partners and other family members, with particular emphasis on talking about cancer within the family and the how this can be supported. Listening Study participants identified this as an area of unmet need. Evidence suggests that patients and relatives can have difficulty talking together about cancer. This can limit access to information about diagnosis, prognosis and treatment because patients are often the key source of information within the family. Talking openly about cancer has been associated with better adaptation to changes brought about by cancer and greater emotional well-being. Being unable to talk openly has been related to greater anxiety. The systematic appraisal of literature relating to the Listening Study's top priority area revealed little evidence to inform how best to support partners and relatives. Undertaking research in this area fits well with the core interests of Macmillan Cancer Support, by giving voice to under-represented people (relatives) and helping people affected by cancer by supporting self-management.

2. Christine Gratus, University of Birmingham; Prof Sue Wilson; Dr Sheila Greenfield; Dr Neil Steven; Prof Philip Routledge; Prof Robert Grieve;

*The use of herbal medicines by people with cancer. (1.5 years)*

### **Aims:**

1. To better understand how and why people with cancer use herbal remedies to support their cancer treatment
2. To explore patients' knowledge, beliefs and attitudes in relation to herbal medicines and how far they are aware of the potential for harm in herbal self-medication
3. To investigate when, why, how or if people living with cancer currently obtain information on herbal remedies they use to support their cancer treatment

4. To establish what kinds of information people with cancer want or need in relation to herbal medicines and where, how and from what sources they would like to be able to obtain it.

**Background:**

Self-medication with 'natural' remedies is becoming increasingly popular. Almost half of women with breast cancer report taking herbal remedies, vitamins or other supplements during treatment while among cancer patients in general 7% report taking herbal medicines after diagnosis. However, there is no information on which herbal remedies cancer patients use, even though some herbs may cause problems directly related to cancer – for instance, black cohosh is contra-indicated for women with oestrogen-receptor positive breast cancer because of uncertainty about its effects on oestrogen levels. Herbal remedies can also interfere with conventional treatments. St John's Wort can speed up the time that the body takes to get rid of the anti-cancer treatment, imatinib (Glivec) by 44%. Because of the possibility of unwanted side effects or interactions, people with cancer are generally advised to tell the professionals treating them if they are taking any form of medication, including herbal medicines and supplements. Studies suggest that only about half do so and that the professionals themselves have at best very limited knowledge and feel unable to give informed advice. There is no authoritative, readily accessible and independent source of information in the UK about herbal remedies and other supplements where the lay public can find out about potentially useful remedies, possible adverse effects or interactions with their prescribed medicines

This study will explore why people living with cancer take herbal medicines, when, for what purposes and with what beliefs about their role in dealing with cancer, and their needs and preferences for information. It is intended to inform the future development of information resources for cancer patients, survivors and healthcare professionals including tools for use before or during consultation to make it easier for patients to mention and healthcare professionals to ask about use of herbal medications.

3. Prof Eila Watson, Oxford Brookes University; Prof Mary Boulton; Dr Susi Lund; Prof Alison Richardson; Dr Peter Rose; Bill Savage; Prof Sue Wilson  
*The role of the primary care team in the care and support of patients diagnosed with cancer – perspectives of patients, family members and primary health care professionals.* (1.5 years)

**Aims:**

The overall aim of this study is to explore the role of primary care in caring for and supporting patients with cancer and their families.

Specific study aims are:

1. To describe patients' and their family members' experiences of GP / Primary Care Team involvement in their care in the first three years following a cancer diagnosis or a cancer recurrence
2. To describe the nature and scope of QOF cancer care reviews currently being undertaken, from the patients' perspective.
3. To describe patients' and their family members' views on the optimal role for the primary care team in the period following a cancer diagnosis or following a cancer recurrence.

4. To seek the views of primary health care professionals regarding recommendations for their involvement in the care of people diagnosed with cancer and their family members, based on the findings from 1-3 above.

***Background:***

The Macmillan Listening Study has highlighted the limited availability of evidence on what type and frequency of follow-up care and support is effective in meeting the needs of patients following a diagnosis of cancer, and also on how to provide support to family caregivers. Reports indicate that patients see an important role for primary care following a diagnosis of cancer and following a cancer recurrence. However, the role of primary care in the follow up of patients with cancer and their families is very poorly defined at present. The Quality and Outcomes Framework (QOF) of the General Medical Services Contract for Primary Care provides an incentive for practices to establish a cancer register, and to conduct a review with new cancer patients within six months of diagnosis. However, this recommendation is not evidence-based, and it is not known to what extent practices are implementing the review, the nature and scope of reviews which are being implemented, and whether or not they are perceived to be useful by patients. Furthermore, this recommendation does not address the potential needs of family members, nor the needs of patients and their families in the period following a recurrence. Currently it is also unclear what the views of patients, family members and health care professionals are on the optimal role and timing for the involvement of primary care. This information is needed to guide which primary care interventions may be useful in improving the quality of care in future.