



**DETERMINING RESEARCH PRIORITIES FOR CANCER SURVIVORSHIP:
CONSULTATION AND EVIDENCE REVIEW**

EXECUTIVE SUMMARY

**Alison Richardson
Julia Addington-Hall
Daniel Stark
Claire Foster
Ziv Amir
Michael Sharpe**

Commissioned by the National Cancer Survivorship Initiative

December 2009

ACKNOWLEDGEMENTS

We would to express our thanks to all those who took part in the survey of research priorities and subsequent consultation event. We would especially like to acknowledge the work undertaken by the researchers on the consultation and evidence reviews namely Jo Armes, Lucy Zeigler, Jane Hook, Laura Hodges, Nikki Jarrett, Sarah Brearley, Zoe Stamataki and Issy Scott. Thank you also to Susie Edwards and Anne-Marie McDonnell for their work in organising the consultation and help in preparing the final report.

The research upon which this report is based was funded by Macmillan Cancer Support on behalf of the Department of Health and the National Cancer Survivorship Initiative (NCSI). The views expressed in this report are entirely those of the authors and do not necessarily reflect the views of the funders. We would like to thank Jim Elliot and John Neate, the joint leads of the National Cancer Survivorship Initiative research workstream for their support.

EXECUTIVE SUMMARY

Aims

We aimed to identify what is known and not known about the problems faced by cancer survivors and the effectiveness of known solutions to these problems in order to identify future priorities for research investment.

The main focus was on identifying areas of research where investment could yield findings that could make a major impact on patient wellbeing within a short time frame. We also highlighted some areas for longer-term study.

Methods

Two approaches to generating the required information were used:

1. A consultation with the research community, charities and statutory bodies with an interest in survivorship research.
2. A rapid catalogue and synthesis of published research based mainly on already published systematic reviews into (a) problems with health and well-being of cancer survivors; (b) solutions for these problems.

Findings

Problems

The consultation process identified many potential problems for cancer survivors. These included long-term symptoms associated with cancer and its treatment especially psychological issues, including distress, anxiety and depression, relationships, return to work and finance. The literature review found there was substantial evidence that symptoms such as, depression, anxiety, emotional distress, pain and fatigue and social issues such as employment were problems for cancer survivors. There was much less evidence on cognitive and physical impairments, finance and relationship problems. However, the evidence was almost all from short-term survivors,

was only of moderate quality, and tended to be in specific cancer groups, particularly breast cancer.

Solutions

We limited our search for solutions to those which had been evaluated in randomised trials. We found there was good evidence of the effectiveness of treatments for the symptom of pain and moderate evidence for fatigue and depression but not for other symptoms. Furthermore, evidence was mostly for treatments (for example, opiates for pain) and did not address how survivors with needs could be identified and how treatments could be implemented. In general, there is a lack of research into innovations in services which would facilitate self-management and the delivery of care, information and support to survivors.

Current Situation

There has been a substantial amount of research describing many of the problems patients with cancer experience and this is strongest in the area of symptoms in the period that immediately follows treatment. For the common cancers, such as breast cancer, the problems are reasonably well described. The natural history of problems and solutions to these beyond this time remains under-addressed.

There has been promising work on the use of Information Technology systems to identify which patients have problems.

There has been progress in developing and evaluating systems of care to deliver effective treatments, especially the collaborative care model – a model of care in which a case manager (often a cancer nurse) is supervised by appropriate specialists (which may include a psychiatrist and oncologist) and the patient's management is mainly delivered in primary care. Interventions based on rehabilitative and self-management models are in the early stage of testing.

A combination of screening using information technology and then providing treatment for problems using a collaborative care-type model has been found to be effective in many chronic illnesses

Recommendations

Best Buys

We were struck by the degree of convergence on which problems were perceived to be especially important (symptoms, functioning, employment and social well-being) and also on the relative dearth and poor quality of the evidence available. We therefore recommend that there is a need for high quality, large-scale research to systematically identify the needs of cancer survivors in both the short and especially the longer term. Appropriate approaches would be cross-sectional surveys and preferably large, prospective cohort studies. These studies should aim to characterise the scale of each problem and to identify who is most at risk. Qualitative studies, perhaps nested within the large scale surveys, would enhance understanding of the impact of problems and the ways in which people manage these.

For solutions, there is a dearth of evidence in most areas. Whilst we have potentially effective treatments for pain, depression and fatigue, there is very little evidence to tell us how to deliver these treatments. We recommend that short-term wins would involve identifying obstacles to effective delivery of already established treatments and evaluation of new methods of service organization (such as collaborative care, telephone delivered care and guided self-help) to deliver them. In the longer term, we need to develop interventions to improve the functioning of cancer survivors and the welfare of their families and carers.

It is important to note that many, if not most, of these problems are not unique to cancer survivors and evidence gathered from other medical conditions

should be examined to see if adaptations for the cancer population can be piggy-backed on already substantial areas of work.

Don't Buys

We strongly recommend that funders do not invest limited research funding into small, methodologically weak studies and on researchers without a good track record of delivering high quality work. We strongly recommend that greater value for money will be achieved by funding a smaller number of well-designed large studies.

Summary

We have identified some areas where very short-term investment (less than two years) may produce useful information. These are mainly in the description of need using cross-sectional surveys and the identification of barriers to the implementation of already established treatments. In the medium term (up to five years) there is a need for prospective cohort studies to identify who develops problems and high-quality evaluations (mainly randomised trials) of methods of identifying and treating these problems. Developing effective ways of delivering treatment for pain, depression, fatigue and emotional distress are areas that could yield a good return on investment.

In the longer term (more than five years) important information will be gained from the setting up of long-term follow up studies identifying patients who have suffered cancer for ten years or more. Similarly, there is a need for large-scale programs of research to evaluate interventions and their long-term effectiveness.

