

PRIORITIES FOR RESEARCH ON CANCER SURVIVORSHIP

A report from the
National Cancer Survivorship Initiative
Research Workstream

June 2010

**WE ARE
MACMILLAN.**
CANCER SUPPORT

DH Department
of Health

NHS
NHS Improvement

National Cancer Survivorship Initiative Research Workstream

CONTENTS

Foreword.....	4
Acknowledgements	4
1. Executive summary	5
2. Introduction	7
NCSI vision for research	7
Aim of report.....	8
Audience	8
Context and focus of report	9
3. Evidence gathering	13
Mapping the issues faced by cancer survivors	13
Consultation exercises with stakeholders on their views of the most important areas for future research.....	14
Comprehensive review of the evidence base for cancer survivorship.....	17
<i>Background to the review and methods</i>	<i>17</i>
<i>Review findings - Problems experienced.....</i>	<i>18</i>
<i>Review findings - Solutions.....</i>	<i>19</i>
<i>Review findings - Current situation.....</i>	<i>19</i>
<i>Review findings - Recommendations.....</i>	<i>19</i>
<i>Review findings - Summary.....</i>	<i>20</i>
NCRI rapid review of research into survivorship after cancer and end of life care.....	22
Contributions from the other NCSI workstreams.....	22
<i>Assessment and Care Planning Workstream</i>	<i>23</i>
<i>Supported Self-Management Workstream.....</i>	<i>23</i>
<i>Consequences of Treatment Workstream</i>	<i>24</i>
<i>Active and Advanced Workstream</i>	<i>25</i>
<i>Work and Finance Workstream.....</i>	<i>25</i>
<i>Children and Young People Workstream.....</i>	<i>26</i>

National Cancer Survivorship Initiative Research Workstream

	<i>Research Workstream</i>	28
	Additional sources of evidence and relevant ongoing research.....	28
4.	Prioritisation of research topics and analysis of findings	30
	Developing a set of research priorities	30
	Prioritisation criteria	30
	Analysis of findings	31
5.	Recommendations and next steps	33
	Recommendations – <i>What we wish to see</i>	33
	Changes to the organisation and funding of research on cancer survivorship	33
	Priorities for research on cancer survivorship	34
	Taking forward the research priorities	34
	Next steps	35
6.	Helpful resources/ supporting information	37
	Funding	37
	Appendix 1: Membership of the NCSI Research Workstream	38
	Appendix 2: Issues identified by stakeholders as needing more research or information from the mapping studies on the aftercare of cancer survivors	39
	Appendix 3: Priorities of people living with cancer from previous work	42
	Appendix 4: Challenges for Cancer Survivorship: Research, Practice, Policy and Education.....	43

National Cancer Survivorship Initiative Research Workstream

Foreword

Improvements in the care, support and empowerment of survivors of cancer must be based on a rigorous assessment of the evidence.

One of the key tasks set out in the National Cancer Survivorship Initiative (NCSI) is to understand what we know - and do not know - about the wide topic of survivorship.

Over the past eighteen months, we have had the pleasure of working with all the members of the Research Workstream, with researchers, research funders, charities, survivors of cancer and carers in seeking to understand the most pressing concerns and issues affecting people living beyond the initial diagnosis and treatment of cancer.

It has been a complex task and we have hugely appreciated the time commitment given by so many people to this project.

We hope that what follows in this report will pave the way for the development of a UK-wide strategy for research into cancer survivorship. We also hope, in particular, that the report will help to focus the attention of researchers and the research community on those issues which are of greatest importance to cancer survivors.

Through the commissioning of a new programme of survivorship research, based on the priorities set out in this report, we trust that we will move rapidly to a future where the specific issues of cancer survivorship are far better identified and quantified and where additional research will lead to the development of a range of new interventions able to transform the lives of people living with and beyond cancer. We owe it to them to succeed.

John Neate*
Chair
Research Workstream

Jim Elliott*
Workstream Support
Research Workstream

***John Neate is Chief Executive of The Prostate Cancer Charity and Jim Elliott was, until the end of March 2010, Research Adviser, Macmillan Cancer Support.**

Acknowledgements

We would like to acknowledge with grateful thanks the input of all the members of the Research Workstream and the dedicated support provided by Julie Flynn, Jo Armes and Rosalind Stroud.

National Cancer Survivorship Initiative Research Workstream

1. Executive summary

- 1.1 This report describes the work undertaken by the Research Workstream of the National Cancer Survivorship Initiative (NCSI) to identify what is, and what is not, known about the best ways to care for and support all people living with and beyond cancer and the future areas of research that would be of greatest benefit to cancer survivors.
- 1.2 The report is intended, above all else, to be a ***practical and a useful tool*** for researchers, research funders, policymakers, service providers and commissioners in informing their work.
- 1.3 It will also be of interest to people affected by cancer in understanding the steps that are being taken to build the evidence for improved services and support for cancer survivors.
- 1.4 Finally, it sets out the basis of a recommended strategic direction for future research on cancer survivorship.
- 1.5 To achieve its task, the Research Workstream commissioned three streams of work: mapping the issues faced by cancer survivors; consultation with key stakeholders on priorities; and a comprehensive scoping review of the current evidence base on survivorship research. The National Cancer Research Institute (NCRI) also initiated a rapid review exercise to take stock of the infrastructure for research into cancer survivorship and end of life research in the UK to set a clear framework and direction for the future funding of research in these areas.
- 1.6 The Research Workstream has integrated its work with the research requirements of the other Workstreams of the NCSI to reach the recommendations on the future organisation and priorities for funding of research on cancer survivorship set out in this report.
- 1.7 To make the progress which is now required, the Research Workstream recommends that changes must be made to the way in which research on cancer survivorship is organised and funded in the UK - with a clear focus on the funding of priority areas of research through high quality, appropriately powered studies and methods, capable of producing outputs of robust value. While it will be important to continue to encourage innovation and creativity in research thinking, it is pressingly urgent to focus the minds of the research community on the areas of highest priority to survivors and to research funders. To this end, a greater degree of targeting of research calls for proposals will be necessary in future.
- 1.8 It is recommended that the NCSI should, working with the National Cancer Research Institute (NCRI), create a UK-wide strategy for research on cancer survivorship that will develop the discrete identity and focus for both researchers and funding organisations that exists for most other areas of cancer research.

National Cancer Survivorship Initiative Research Workstream

- 1.9 It is recommended that the NCSI and NCRI work with research funding organisations to develop their commitment to the strategic approach to research on cancer survivorship outlined in this report and to ensure the adoption of approaches to quality assessment that are appropriate.
- 1.10 It is recommended that the NCSI and NCRI identify a high profile individual able to provide inspirational leadership in promoting the strategic recommendations in this report and in developing a coordinated research community for cancer survivorship equipped to make the best use of available research funding.
- 1.11 It is recommended that the highest priority for research in cancer survivorship - and particularly using resources generated for joint application by research funders - is to understand the 'natural history' of survivorship and to create risk stratification tools for all cancers and for survivors of all ages to assess the most appropriate after care for each individual.
- 1.12 It is recommended that the research to develop and evaluate interventions should be based on the natural history and risk stratification work and the 'best buys' identified by the evidence review. Together, these will form a programme of secondary preventative interventions. In many cases, these interventions will be funded by individual organisations using existing research funding programmes.
- 1.13 It is recommended that measures of experience and outcome should be developed in a systematic and integrated way, reflecting the development of survivorship services and the evidence that emerges from commissioned work on natural history and risk stratification.
- 1.14 It is recommended that a systematic programme of economic evaluations is implemented to assess the benefits brought by new survivorship services to the health and social care and wider economy.
- 1.15 The research priorities identified will be taken forward in three specific ways in conjunction with the NCRI:
 - Developing a joint research funding budget with contributions from organisations with a particular interest in the area. It is recommended that the principle focus of this should be research on natural history and risk stratification
 - Targeting and maximising the use by the relevant research community of appropriate existing sources of research funding
 - Encouraging individual funding organisations to identify specific questions or areas that are of high importance to them and that they wish to pursue

National Cancer Survivorship Initiative Research Workstream

2. Introduction

- 2.1 The National Cancer Survivorship Initiative (NCSI) was announced in the Cancer Reform Strategy¹. It was formally launched in September 2008 to address the long term needs of people living with and beyond cancer that have often not been effectively met by current health and social care services, including follow-up. The aim of the NCSI is, by 2012, to have taken the necessary steps to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible.
- 2.2 Seven NCSI workstreams were established, bringing together cancer survivors, carers of survivors, representatives from cancer charities, health and social care staff and researchers². The workstreams were asked to assist the development of improved models of care and support for those living with and beyond cancer. Three of the seven workstreams - Assessment and Care Planning, Consequences of Cancer and Treatment, and Active and Advanced Disease - deal specifically with steps in the survivorship pathway. A further three workstreams are cross cutting, covering the whole survivorship pathway and are generic (i.e. not confined to a specific tumour type or age group). These are Work and Finance, Self Management and Research, which is the focus of this report. The workstream on Survivors of Childhood and Young People's Cancer also covers the whole survivorship pathway, but for a particular group.
- 2.3 The NCSI is committed to delivering a number of defined outputs as listed in its vision, published in January 2010³. The specific responsibility of the Research Workstream is to deliver – working closely with the National Cancer Research Institute (NCRI) - a new longer term research programme designed to answer priority questions on survivorship.

NCSI vision for research

- 2.4 In the NCSI vision document, a separate vision is documented for each workstream. For the Research Workstream this is:
- 2.5 To have understood clearly the current evidence on survivorship and to have commissioned and facilitated a strategic programme of new research to answer the priority areas of uncertainty – with a strong emphasis on practical interventions to improve the experience, health and wellbeing of people living with cancer.
- 2.6 This programme will include the development of tools for assessing the likelihood and significance of different events occurring in the experience of people living with cancer, enabling timely, relevant and effective support to be provided.

¹ Cancer Reform Strategy, Department of Health, 3 December 2007

² More information about the NCSI workstreams, including the contact details for the workstream chairs and supports is available at www.ncsi.org.uk

³ The vision document is available at www.ncsi.org.uk

National Cancer Survivorship Initiative Research Workstream

- 2.7 A longer term vision is to achieve a national portfolio of research trials open to patients at all stages of the survivorship pathway (not just those undergoing treatment). The trials would include a particular focus on practical support interventions for cancer survivors. Future clinical trials of treatments would also include assessment of the wide range of consequences of treatment.
- 2.8 This vision will be achieved by:
- understanding the current evidence on survivorship and identifying key gaps
 - working with the research community – funders and researchers – and understanding the priorities of survivors and carers, to commission and facilitate a research programme to address these priorities
- 2.9 In undertaking its work - leading to the publication of this report – the Research Workstream has brought together a range of research experts, people affected by cancer and representatives from research funding organisations (membership listed in Appendix 1). The group met four times between October 2008 and September 2009 to discuss and advise on the steps needed to address the first aim above.
- 2.10 This report documents the progress made in the first year of the NCSI in achieving the first aim and outlines the progress to date and the next steps in addressing the second aim.

Aim of report

- 2.11 This report is intended, above all else, to be a ***practical and a useful tool*** for researchers, research funders, policymakers, service providers and commissioners in informing their work – providing information on:
- what is and is not known about the best way to care for and support people living with and beyond cancer
 - what future research would be of the greatest benefit to cancer survivors
- 2.12 The report will also be of interest to people affected by cancer in understanding the steps that are being taken to build the evidence for improved services and support for cancer survivors.
- 2.13 Finally, it sets out the basis of a recommended strategic direction for future research on cancer survivorship

Audience

- 2.14 This report has been produced for a range of different audiences, who may also find it helpful to refer to the more detailed reports of work that have been undertaken to date and which are described in the next section. The different audiences are:
- ***People affected by cancer*** – to gain an overview of the current research evidence on survivorship and where future effort is proposed to be

National Cancer Survivorship Initiative Research Workstream

targeted. This will enable and encourage their involvement with the future agenda. (With particular reference to Section 3 paragraphs 3.4 to 3.13 and Appendix 3)

- **Researchers** – to inform thinking on future priorities and to seek engagement in addressing them both individually and in collaboration with each other, with the NCSI / NCRI and with funding organisations. (With particular reference to Section 3 paragraphs 3.14 to 3.35 and referenced reports)
- **Research funders**, including charities – to inform funding of priority areas and the need for more robust and preferably large-scale research and to promote coordination and collaboration with each other, both through the NCSI / NCRI and more widely. To encourage the identification of areas of common interest and a commitment to taking the research agenda forward, both collectively where it meets their aims and individually in specific areas of interest. (With particular reference to Section 3 paragraphs 3.14 to 3.35)
- **Policy makers and campaigning organisations**, including charities and UK governments and health departments – to gain an overview of the current research evidence on survivorship and the priorities for future research, in order to encourage dialogue with the research community and funding organisations, and influencing strategic research direction (With particular reference to Section 3 paragraphs 3.4 to 3.7 and 3.14 to 3.38)
- **Health and social care providers and commissioners**, including charities – to understand the strengths and weaknesses of the current research evidence on survivorship, to identify services / interventions that require evaluation, and to encourage partnership with the research community and research funding organisations to ensure that evidence-based services are implemented and/or services evaluated where evidence is lacking. To encourage the collection of outcomes data as routine

Context and focus of report

- 2.15 There are different definitions of cancer survivorship in use. Anyone who is living following a diagnosis of cancer can be described as a ‘survivor’, though many people prefer to think about survivorship in terms of ‘living with and beyond cancer’. Survivorship therefore encompasses those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease.
- 2.16 While many aspects of longer-term care and support need to be in place from the point of cancer diagnosis, the focus of the NCSI is on the assessment, care and support given to people from the end of primary treatment onwards. There is a separate strategy for End of Life Care, including research, and so the NCSI does not include this element.
- 2.17 Since the launch of the NCSI in September 2008, the NCSI workstreams have focussed on developing the vision for the improved care and support we need

National Cancer Survivorship Initiative Research Workstream

to see for cancer survivors in the future. The NCSI has identified five key shifts necessary to achieve this vision and these are:

- A cultural shift in the understanding of the several different illness patterns included in the term 'cancer' and in the approach to care and support for people affected by cancer – to ensure greater focus on recovery, health and well-being after cancer treatment
- A shift towards improved assessment and personalised care planning. This is a shift from a 'one-size fits all' approach to follow up practices, to personalised care planning based on assessment of individual risks, needs and preferences
- A shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on appropriate clinical assessment of individual needs and preferences
- A shift from surveillance based clinical follow up to a personalised information prescription and specialist support that enables early recognition of, and preparation for, adverse consequences of treatment as well as early recognition of signs and symptoms of secondary, recurrent or advanced disease
- A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services

2.18 Appropriate evidence is required in order to effectively achieve these shifts and new services will need to be set up on the basis of demonstrated need and thorough evaluation of effectiveness. Responsibility for identifying the evidence base for the shifts lies with the Research Workstream.

2.19 In order to aid identification of key priorities for the NCSI, a 'survivorship care pathway' has been developed [Figure 1] for the use of all workstreams. Using this model, work has been undertaken to identify problems and potential solutions at each step in the pathway.

2.20 In the initial stages, the research work stream used the framework outlined by Feuerstein⁴ particularly for the mapping work. The evidence review also used the Feuerstein framework but later the findings were mostly translated to the agreed survivorship care pathway at Figure 1.

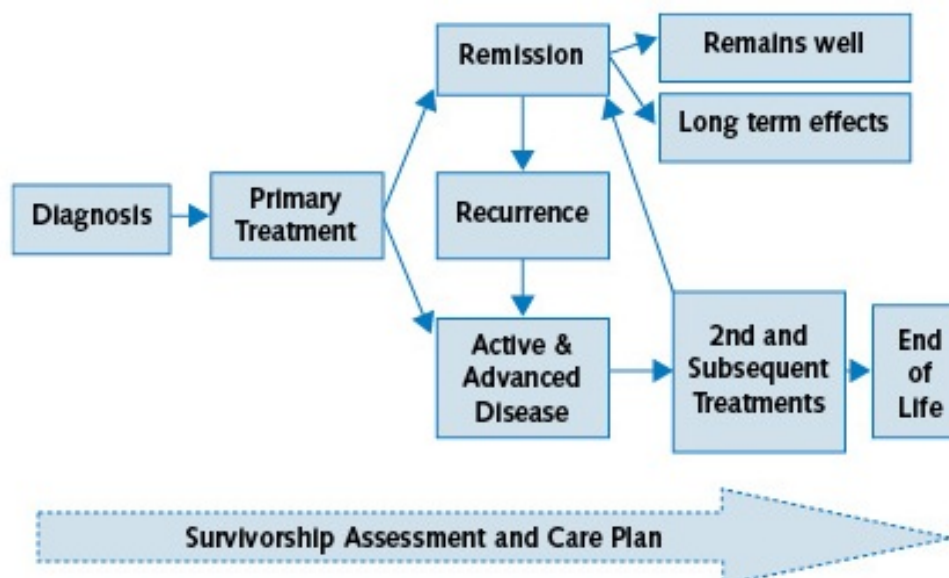
2.21 The purpose of the pathway is to map cancer survivors' post-treatment experience and to identify problems and potential solutions at each step in this journey. It is important, of course, to recognise that individuals will have their own priorities and needs along their own survivorship journey. It should be noted that a number of other pathways have also been developed and it is important to ensure that these are taken into account, e.g. the draft

⁴ *Handbook of Cancer Survivorship*, M Feuerstein Ed, Springer, 2008, pp 489-490, *Cancer Survivorship: Research, Practice and Policy* by Michael Feuerstein

National Cancer Survivorship Initiative Research Workstream

rehabilitation care pathways⁵ developed by the National Cancer Action Team (paragraph 3.65).

Figure 1: Survivorship care pathway



- 2.22 Until recently, the majority of cancer research has historically centred on biological mechanisms and pathogenesis [the development of the disease], aetiology [the causes], diagnosis and treatment, with a more recent initiative on prevention. There has been relatively little research focussed on the period from the end of primary treatment covering supportive and palliative care and end of life care. These areas were highlighted as gaps that needed further investment by the strategic analysis conducted by the NCRI in 2002.
- 2.23 The NCRI has since supported research in the field of supportive and palliative care (SuPaC) through the initiation of the two SuPaC research collaboratives: The COMPASS Collaborative (Complex Assessment, Trials and implementation of Services) – www.compasscollaborative.com; and The Cancer Experiences Collaborative, CECO – www.ceco.org.uk. As a result, improvements are beginning to be delivered through their collaborative working that builds on the combined strengths of several institutions. They are securing increased research funding and addressing areas that the individual groups were not working on previously.
- 2.24 The NCSI and therefore the Research Workstream are largely focused on the period from the end of primary treatment up to, but not including, the end of life and so will complement and build on the initial work NCRI has done in supportive and palliative care, but now using the distinct but linked terms, 'survivorship' and 'end of life care'.

⁵ http://www.cancer.nhs.uk/rehabilitation/rehab_pathways.html

National Cancer Survivorship Initiative Research Workstream

- 2.25 In 2008, an initial overview of the published literature was commissioned as part of the early work to establish the NCSI. Although not a systematic review, it provided an indication of what further work would need to be done, and served as the starting point for the NCSI and the Research Workstream in particular to develop the evidence base for what has now evolved into the vision for the NCSI overall.

National Cancer Survivorship Initiative Research Workstream

3. Evidence gathering

- 3.1 The Research Workstream addressed its first aim of establishing what is and is not known about the best way to care for and support people living with and beyond cancer, by commissioning the following three streams of work:
- Mapping the issues faced by cancer survivors
 - Consulting with key stakeholders
 - Commissioning an evidence review
- 3.2 In order to achieve the second aim of developing a future research strategy for cancer survivorship to address the priority 'not knowns', findings from the above elements of work will be synthesised, together with:
- The Rapid Review undertaken by NCRI
 - Outputs from the six other NCSI workstreams
- 3.3 Each of the five elements of work is described in more detail below.

Mapping the issues faced by cancer survivors

- 3.4 The initial task for the Research Workstream was to map the survivorship 'journey', aiming to identify issues and challenges that are important for people affected by cancer and to clarify where research is needed to better understand their needs. This was carried out initially for the four most common cancers, led by the site-specific charities, Breakthrough Breast Cancer, Bowel Cancer UK, The Prostate Cancer Charity and the Roy Castle Lung Cancer Foundation. Cancer 52, a consortium of 38 organisations representing the less common cancers, mapped the issues for the less common cancers.
- 3.5 In each case, the lead charities consulted with a wide range of stakeholders including patients and carers using the two survivorship models (Feuerstein model and NCSI model) to guide the process. Stakeholders' views, organisational knowledge provided, and grey literature, were collated and validated with stakeholders in a range of ways including meetings and focus groups. A separate report was prepared for each cancer group. These reports are available on the research page of the NCSI web site, along with a summary document (<http://www.ncsi.org.uk/research/>) and provide a great deal of valuable information and insights.
- 3.6 The reports from the mapping work enabled identification of themes which are common to all cancers and those which are unique to individual cancers. These themes, along with the Macmillan Cancer Support 'Listening Study'⁶, were tabulated and Table 1 below shows those mentioned as a pressing issue

⁶ Corner J, Wright D, Foster C, Gunaratnam Y, Hopkinson J and Okamoto I (2006) The Macmillan Listening Study: Listening to the views of people affected by cancer about cancer research. Macmillan Cancer Support: London and Okamoto I, Wright D and Foster C (2007) *The Impact of cancer on everyday life: A systematic appraisal of the research evidence*. Macmillan Cancer Support: London

National Cancer Survivorship Initiative Research Workstream

or priority by the majority (≥ 4) of the reports. The relative priorities of these reflected how frequently they were reported and were not controlled in any way for the prevalence of the cancers to which they related. Consequently, there may have been issues that affected large numbers of survivors that were not among the commonest themes reported. The mapping, in common with the original Macmillan Listening Study, did not take account of whether or not there was a body of research on the issues reported and as such cannot be taken as research priorities.

Table 1: Common themes identified in mapping reports and the Listening Study

Rank order	Theme
1	Remission & follow up - process evaluation & effectiveness of models
1	Remission & follow up - information required by patients
1	Remission & follow up - co-ordination of primary & secondary care
1	Long-term effects - interventions for carers
2	Long-term effects - prevalence & natural history
2	Work & finance - Information for patients (including children)
2	Work & finance - Information for employers & government agencies
2	Socio-economic - impact on information, care and service needs
3	Care plan - best methods for assessing supportive needs
3	Long-term effects - impact on quality of life
3	Long-term effects- emotional – anxiety & depression
3	Long-term effects - interventions – anxiety & depression
3	Long-term effects - impact on access to services
3	Long-term effects - cultural perceptions of cancer & stigma

1 = mentioned by all 6 reports

2 = mentioned by 5 reports

3 = mentioned by 4 reports

- 3.7 The four commonest themes identified were the development and testing of alternative models for disease surveillance and follow-up, a specific focus on identifying patients' information needs, ensuring co-ordination of care and support between primary and secondary care, and the need to address the long term effects of cancer and its treatment. The full results are shown in Appendix 2.

Consultation exercises with stakeholders on their views of the most important areas for future research

- 3.8 Part of the comprehensive review of evidence reported below (paragraph 3.14 onwards) included a consultation on stakeholders' views of the most important areas for further research, the objectives of which were:
- To consult the UK research community involved in research on survivorship to gain their views on the main areas of unmet need for further research and to identify unpublished and ongoing research, and collections of clinical and research data

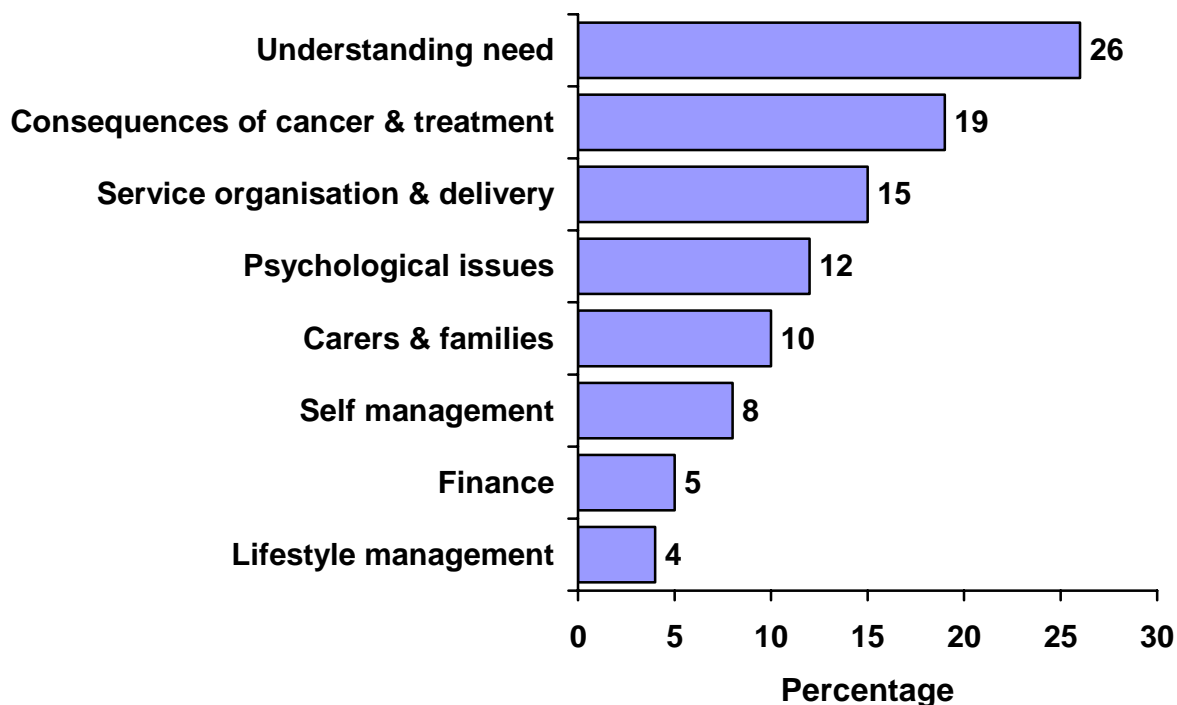
National Cancer Survivorship Initiative Research Workstream

- To consult charities and statutory organisations with an interest in survivorship research to identify unpublished reports of relevance to the health and well-being of cancer survivors
 - To synthesise the results from the above reviews and consultations into a report that sets out the current evidence base for survivorship mapped as far as possible against the survivorship pathway
- 3.9 It was initially intended to seek the views of the research community only, to complement the formal review of published evidence and to assess how the two compared. However, the survivorship research community tends to be inclusive in the way it works and the participants involved in the view-seeking exercise expanded to include people affected by cancer and clinicians with whom they work closely.
- 3.10 The consultation process involved over 200 participants completing a questionnaire (paper, email or online). Analysis of the questionnaire was undertaken to identify issues about which little is perceived to be known. From responses to the survey, a list of ten key themes was generated as follows:
- Understanding need - epidemiological data on the prevalence and severity of psychological, social and physical needs
 - Carers and family – addressing their needs and providing effective support
 - Consequences of cancer and treatment – development and testing of interventions including management of symptoms, long term and late effects and sexual issues
 - Cost-effectiveness of self management
 - Models of surveillance for disease recurrence (included with understanding need in Figure 2 - see below)
 - Return to work or education and financial matters
 - Psychological issues - identification and management of the psychological impact of survivorship
 - Service delivery and organisation – including how services should be organised and innovative service evaluation
 - Health outcome measurement (included with service delivery and organisation in Figure 2 – see below)
- 3.11 These themes were then used at the consultation event as a starting point for discussion and prioritisation of research in relation to survivorship. The consensus conference was held on 16th September 2009 and was attended by over 90 stakeholders, including consumers and academic and NHS researchers. The key priorities which emerged as a result of the discussion and reprioritisation at the consensus conference are shown in figure 2. The consensus meeting identified a broad range of topics, but because of methods

National Cancer Survivorship Initiative Research Workstream

used, it was not possible to prioritise any particular aspect of a research topic further.

Figure 2: Results of final vote at consensus meeting



3.12 A second consultation was subsequently run, specifically for people living with cancer, following feedback at both the consultation workshop and the NCSI National Conference in September 2009 about the need to ensure maximum involvement by those directly affected. No issues were identified in this exercise additional to those emerging from the main consultation.

3.13 It should also be noted that the mapping exercises (paragraphs 3.4 to 3.7) involved a considerable number of people living with cancer and the comprehensive review of the evidence base (paragraphs 3.14 to 3.35) included the outputs from the Macmillan Cancer Support 'Listening Study' and its follow-up report, 'The Impact of Cancer', that identified the research priorities of people affected by cancer⁷.

⁷ Corner J, Wright D, Foster C, Gunaratnam Y, Hopkinson J and Okamoto I (2006) The Macmillan Listening Study: Listening to the views of people affected by cancer about cancer research. Macmillan Cancer Support: London and Okamoto I, Wright D and Foster C (2007) *The Impact of cancer on everyday life: A systematic appraisal of the research evidence*. Macmillan Cancer Support: London

National Cancer Survivorship Initiative Research Workstream

Comprehensive review of the evidence base for cancer survivorship

Background to the review and methods

- 3.14 The initial overview of the published literature conducted in 2008 concluded that although there is a growing literature on cancer survivorship, a significant proportion has focused on adult survivors of cancer diagnosed in childhood and adolescence, with a particular focus on problems associated with late effects of treatments and much of the research on long-term survivors of adult cancer is based in the USA. Further, there is relatively little research on the long-term implications for adults diagnosed with cancer and most of that is focused on physiological consequences of surgical interventions and toxicity associated with radiotherapy and drug treatments. Far less is known about psychological and social implications after cancer, how best to support self management or the optimal care of long term survivors in primary care, especially in terms of the management of co-morbid conditions.
- 3.15 To build on the above and the mapping of the survivorship challenges outlined above, the Research Workstream commissioned a comprehensive review of the evidence base for cancer survivorship. This review was undertaken by members of the COMPASS and CECo Supportive and Palliative Care Collaboratives, using accepted approaches to published literature review and also by engaging and consulting with a wide constituency of relevant stakeholders as reported above (paragraphs 3.8 to 3.13) in order to identify other survivorship related research currently underway but not captured by other sources such as the NCRI Cancer Research Database (CRD).
- 3.16 The aim was to review UK and international evidence (insofar as the latter is relevant to the UK situation) on unmet needs and opportunities in order to describe what is known about the health and well-being of cancer survivors, with a particular focus on solutions and on interventions to address identified needs. A key consideration was to identify the readiness of existing research knowledge to be implemented in practice, including research that could be rolled out within the context of the NCSI and the NHS Improvement test communities.
- 3.17 The review focused on people who had been diagnosed with cancer as adults, as several reviews have already been undertaken of the evidence base for adults who were diagnosed with cancer as children or young adults. A follow up study has been conducted for the Children and Young People Workstream on models of care and is reported in paragraphs 3.57 to 3.59.
- 3.18 The evidence considered included both research published in academic journals and other widely available publications and also unpublished reports, work currently underway and collections of data.
- 3.19 The evidence review has considered two types of research – first, the scope and quality of research on the **health and wellbeing** of cancer survivors and second, **interventions** to improve health and well being. It identified areas where research funding investment could have a significant impact in the very

National Cancer Survivorship Initiative Research Workstream

short term (up to two years), medium term (3 to 5 years) and longer term (over 5 years).

3.20 The review 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 with major potential for impact on wellbeing within a short time frame.*** Some areas were also highlighted for longer-term study.

3.21 The results of the review were written up into a report (the executive summary of which has been incorporated into paragraphs 3.23 to 3.35), which can be found on the NCSI web site at www.ncsi.org.uk/research :

Richardson, J, Addington-Hall, J, Stark, D, Foster, C, Amir, Z and Sharpe, M, (2009). Determining research priorities for cancer survivorship: consultation and evidence review

3.22 The above report is supported by three separate technical appendices containing the detail of the three stages of the work, which can also be found on the NCSI web site at www.ncsi.org.uk/research

1. Foster, C Amir, Z Jarrett, N Stamataki Z. Brearley, S Scott, I (2009). Scoping of research evidence regarding the health and well-being of cancer survivors: Psychological and social problems faced by cancer survivors, and their physical and practical well-being: Technical report. University of Southampton and University of Manchester.

2. Armes, J Richardson, A Addington-Hall, J (2009). Report on National Cancer Survivorship Consultation on research priorities: Technical report. King's College London and University of Southampton.

3. Ziegler, L, Hook, J Stark, D Neilly, L Hodges, L Sharpe, M (2009) Systematic scope and collation of research evidence regarding interventions: Technical report. University of Leeds and University of Edinburgh

Review findings - Problems experienced

3.23 The consultation process identified many potential problems for cancer survivors, including long-term issues associated with cancer and its treatment, especially psychological issues, including distress, anxiety and depression, relationships, return to work and finance.

3.24 The literature review found substantial evidence that symptoms such as depression, anxiety, emotional distress, pain and fatigue and social issues such as employment were difficulties 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.

National Cancer Survivorship Initiative Research Workstream

Review findings - Solutions

- 3.25 The search process was limited to evidence on solutions which had been evaluated in randomised trials. Good evidence was found for the effectiveness of treatments for the symptoms 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 effectively 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.

Review findings - Current situation

- 3.26 There has been a substantial amount of research describing many of the problems experienced by patients with cancer and this is strongest in relation to symptoms experienced in the period immediately following treatment. For the common cancers, such as breast cancer, the problems are reasonably well described. The natural history of problems and solutions to these problems beyond this timeframe, however, remains under-addressed.
- 3.27 There has been promising work on the use of information technology systems to identify which patients have problems.
- 3.28 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 (who 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.
- 3.29 A combination of screening using information technology, coupled with treatment for problems using a collaborative care type model, has been found to be effective in many chronic illnesses

Review findings - Recommendations

- 3.30 **'Best buys'** - The authors of the evidence review were struck by the considerable agreement on which problems were perceived to be especially important (symptoms, functioning, employment and social well-being) which contrasted markedly with the relative dearth and poor quality of the evidence available on solutions to address the problems. The authors went on to recommend that there is a need for high quality, large-scale research to identify systematically 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

National Cancer Survivorship Initiative Research Workstream

surveys, would enhance understanding of the impact of problems and the ways in which people manage these.

- 3.31 In terms of solutions, there is a dearth of evidence in most areas. Whilst there are potentially effective interventions for pain, depression and fatigue, there is very little evidence on how best to deliver these interventions. It was recommended by the authors of the evidence review that short-term wins would involve identifying obstacles to effective delivery of already established interventions 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, there is a need to develop interventions to improve the overall functioning of cancer survivors and the welfare of their families and carers.
- 3.32 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.
- 3.33 **'Don't buys'** - It was strongly recommended by the authors of the evidence review 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. It was also strongly recommended that greater value for money will be achieved by funding a smaller number of well designed large studies. However, it should be noted that there will always be the need for pilot and feasibility studies before larger studies can be supported and that new and emerging researchers also need support to increase research capacity in what is a reasonably limited field of research.

Review findings - Summary

- 3.34 A number of areas have been identified where very short-term investment (less than two years) may produce useful information. These are mainly in the description of need (natural history and risk factors) 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 addressing these problems. Developing effective ways of delivering interventions for pain, depression, fatigue and emotional distress are areas that could yield a good return on investment.
- 3.35 In the longer term (more than five years), important information will be gained from the setting up of long-term follow up studies identifying individuals who have lived with cancer for ten years or more. Similarly, there is a need for large-scale programmes of research to evaluate interventions and their long-term effectiveness. The 'best buys' are summarised in Table 2.

National Cancer Survivorship Initiative Research Workstream

Table 2: Survivorship Research Best Buys compiled from *Determining Research Priorities for Cancer Survivorship: Consultation and Evidence Review (Richardson et al 2009)*

	Up to 2 years	2-5 years	5 years plus
Fatigue & Physical functioning	(a) pilot studies of simple, feasible methods of identifying fatigue in survivors (b) studies of barriers to implementing treatments such as guided self-help, telephone delivered treatment based on CBT principles and exercise.	Large, multi-centre studies of fatigue management with adequate follow up period that integrate screening and treatment.	Prospective cohort studies with age-matched comparisons to study course of fatigue and physical function in relation to factors such as cancer site, treatment history and stage.
Pain	(a) secondary analysis of existing data on prevalence of pain and risk factors in survivors (b) pilot studies of simple and feasible methods of identifying pain in survivors (c) studies of the barriers to implementing pain management models such as collaborative care.	Large trials of interventions based on feasible models of delivery that integrate screening and treatment systems such as collaborative care	Cohort study to identify risk factors for long term pain
Sexual function	Surveys of prevalence and psychological and social associations.	Feasibility studies of integrated systems of assessment and management	Large trials of interventions
Cognitive functioning	Prevalence and risk factor studies of cognitive impairment and its association with functional and psychosocial ability.	Pilot studies of methods to identify and intervene with those suffering from cognitive impairment.	Large trials of preventative and treatment interventions (if these are identified).
Employment, Finance, Return to work	(a) theoretical and modelling work to establish the transferability of vocational rehabilitation approaches used in other contexts to cancer survivorship (b) in-depth studies to understand the financial effects of cancer (c) studies to evaluate the best way to educate and support employers to support cancer survivors whilst returning to work.	Well designed pilot trials of feasible methods of intervention.	Large, prospective cohort studies to identify factors that impact on return to work and vulnerable sub-groups and large scale intervention studies.
Emotional distress	(a) secondary analysis of existing data on long term outcome (b) well designed pilot trials of feasible methods of intervention.	Large trials of interventions based on patient education including guided self-help and telephone delivered treatment based on CBT principles.	(a) large, prospective cohort studies of mixed cancer groups. (b) studies to improve understanding, identification & management of distress in men and BME groups.
Depression	(a) secondary analysis of existing data on prevalence and risk factors in long-term survivors (b) pilot studies of simple feasible methods of identifying depression in survivors in hospital and primary care (c) studies of the barriers to implementing established treatment models such as collaborative care.	Large trials of interventions based on feasible models of delivery that integrate screening and treatment systems and have an emphasis on primary care provision such as collaborative care.	Studies to improve understanding of how we can identify and manage depression in men and BME.
Anxiety	Secondary analysis of existing data to determine prevalence of anxiety in the long term and associations with fear of recurrence.	Well designed pilot trials of feasible methods that combine detection and intervention suitable to address minor, modest and severe anxiety and interventions for fear of recurrence	(a) large scale, multi centre trials of simple feasible interventions (b) cohort study to identify risk factors for persistent anxiety
Social needs	(a) exploratory studies to identify forms of social support that might prove effective and factors that dictate whether families do or do not seek support (b) secondary analysis of existing data on long term outcome and moderating factors.	(a) pilot trials of feasible methods of intervention to minimise or manage the effect of cancer on relationships (b) studies of the effect of a diagnose if cancer on relationships.	Cohort studies of mixed cancer groups that include family members. More understanding of how to identify and manage those who perceive they have unmet need, especially in those with cancers other than breast cancer and in BME and other disadvantaged groups.

National Cancer Survivorship Initiative Research Workstream

NCRI rapid review of research into survivorship after cancer and end of life care

- 3.36 The NCRI initiated an exercise in early 2009 to take stock of the infrastructure for research into survivorship after cancer (the term that NCRI has adopted for this work) and end of life research, in order to set a clear direction for the future in both areas from the perspective of organisations who fund research in these areas. A draft report summarising the initial findings from a workshop in July 2009 and associated work was circulated for consultation between November 2009 and February 2010. The draft report, along with more information on the rapid review, is available on the NCRI web site, <http://www.ncri.org.uk/default.asp?s=1&p=5&ss=12>. A final report will be published later in 2010.
- 3.37 The Rapid Review has addressed its aims firstly, by identifying active researchers in this area and their particular areas of interest, and secondly, by identifying organisations that fund survivorship research and their particular areas of interest. It has not considered the actual research undertaken, as this is covered by the comprehensive evidence review above. The review has identified a number of actions which will be taken forward during 2010, including the promulgation of existing funding sources, targeted new funding streams, and promotion of already funded studies to increase uptake in the cancer networks. These actions will be a key determinant of how the priority areas for research in survivorship are taken forward.
- 3.38 The final report will contain a summary of data from the NCRI Cancer Research Database (CRD) of ongoing research funded by NCRI partner organisations. It will be used in the implementation of the recommendations of this report to ensure that all new studies commissioned as a result do not duplicate ongoing work and where appropriate build on or even link directly to such work.

Contributions from the other NCSI workstreams

- 3.39 The research priorities for survivorship must meet the needs of the initiative as a whole. A key criterion for future research is that it must have the potential to make a difference to the lives of people living with cancer in the near future and contribute evidence to support the five key shifts in survivorship care and support set out in paragraph 2.17. Therefore, the priorities identified must have both the support of the other workstreams and meet some or all of their needs for research based knowledge.
- 3.40 Each workstream, including the Research Workstream, has identified a number of immediate needs for research to help them develop their work, as well as longer term needs. Listed below is additional work that each workstream has commissioned or will be commissioning in 2010 that will complement the evidence review led by the Research Workstream and will be taken into account in implementing the recommendations of this report:

National Cancer Survivorship Initiative Research Workstream

Assessment and Care Planning Workstream

3.41 *Evaluations of new approaches to assessment and care planning for aftercare and GP Treatment Record Summary in NHS Improvement test communities*

- Twelve test communities were commissioned in late 2009 to pilot the NCSI assessment and care planning framework and summary treatment record at different trigger points in the survivorship pathway. This piloting work started in January 2010 and will be completed in summer 2010. The impact on quality of life for cancer survivors in these test communities will be evaluated by Tribal Healthcare using both qualitative and quantitative methods
- There are 16 adult test communities set up in late 2008 which are piloting new approaches to care based on effective management of the patient pathway. All of these communities are now in the testing phase and this will continue through to late summer 2010. They have been using an experience of care survey conducted by the Picker Institute Europe to provide a baseline showing where experience of care can be improved in these 16 adult test communities. The results of the first round of the survey can be found at www.ncsi.org.uk/test-communities/. A second survey will be conducted during the summer of 2010 to provide evidence of the national and local impact of the testing work

3.42 *Piloting and evaluation of health and wellbeing clinics (the 'big clinic')*

Health and Wellbeing Clinics will be set up from April 2010 in 10-15 NHS Trusts across the UK. The clinics are designed to support people with a cancer diagnosis and their carers immediately post treatment. An evaluation has been commissioned with The Office for Public Management to assess the extent to which the clinics will improve: knowledge and awareness of cancer survival; sense of empowerment and confidence; social functioning; the ability to self-manage cancer and treatment related problems; access and uptake of information services; and the quality of patient experience of cancer services. See www.ncsi.org.uk/assessment-care-planning/

Supported Self-Management Workstream

3.43 *Self-management support: a review of the evidence*

This report reviewed evidence of self-management support in cancer, some of which is informed by self management support for long-term conditions which is more established in research terms. The report provides an overview of the research evidence for self-management interventions and strategies used in cancer care. It also identifies gaps in the research with specific recommendations for areas where further work needs to be undertaken. The report can be found at <http://www.ncsi.org.uk/wp-content/uploads/Self-Management-Evidence-Review.pdf>

National Cancer Survivorship Initiative Research Workstream

3.44 *Self-management programmes for cancer survivors: a structured review of outcome measures*

This review addressed the seventh recommendation from the above report: that any changes in survivorship practice, such as self-management programmes, be fully evaluated. This is to ensure that there are clearly defined criteria for the expected benefits of a self-management programme and a rigorous evaluation of the most appropriate patient-reported outcome measures (PROMs) for use with cancer survivorship self-management. The report covers instruments measuring six areas of outcomes, which were evaluated for psychometric properties and operational characteristics. The report can be found at <http://www.ncsi.org.uk/wp-content/uploads/Self-Management-A-Structured-Review-of-Outcome-Measures.pdf>

3.45 *Cancer follow-up: towards a personalised approach to aftercare services - a review of current practice and selected initiatives*

The aim of this review was to update an earlier review conducted by the Centre for Reviews and Dissemination at the University of York as well as to identify studies and initiatives highlighting current alternative approaches to follow-up. Overall, as reported in the CRD review, there is a paucity of good quality evidence for the clinical and cost-effectiveness of cancer follow-up for most cancer sites. The report presents the evidence from studies of cancers of the breast, lung, prostate, colorectal cancer and all cancers. The results are being used to inform the development of new aftercare services to be piloted and evaluated through the NCSI. The report can be found at <http://www.ncsi.org.uk/wp-content/uploads/Self-Management-Review-of-Current-Practice1.pdf>

3.46 *Lifestyle factors during cancer treatment, and in the survivorship period – living with and beyond cancer*

This study is reviewing the evidence in relation to specific lifestyle factors and cancer treatment and survivorship, with a particular focus on evidence that would support professionals to be able to guide and advise patients and evidence regarding resources which would support patient self-management in relation to lifestyle factors and change. The report will be finalised by the end of April 2010 and will be posted on the NCSI web site at www.ncsi.org.uk/supported-self-management/

Consequences of Treatment Workstream

3.47 The workstream is developing its approach to the NCSI's fourth key shift (paragraph 2.17) to ensure that the consequences of treatment are understood by patients and professionals including the risks related to the person, treatment and cancer. A number of initiatives were commissioned in the first quarter of 2010 linked to the natural history / risk stratification work being commissioned with the Research Workstream (paragraph 3.63). Research will focus on identifying specific patterns of resource usage in the NHS including exploring the use of quality of life data collected routinely and

National Cancer Survivorship Initiative Research Workstream

as part of research and audit studies and assessments of self assessment tools (e.g. Oncolink). See www.nsci.org.uk/consequences-of-cancer-treatment/.

Active and Advanced Workstream

- 3.48 *Scoping study on 'living well' services* and the evidence to support their effectiveness in the UK and elsewhere for cancer and chronic conditions that might be applicable to cancer. It will report in April 2010 and is being conducted by a freelance researcher.
- 3.49 *Review of evidence on transitions to end of life care*

This is a rapid review of research evidence on what makes a good transition to end of life care when further curative treatment is no longer possible from the perspective of the patient and communication with and between health and social care professionals – this is being conducted by the University of Southampton and will be complete in early 2010.

Work and Finance Workstream

- 3.50 *Evaluation of Department for Work and Pension employment programmes for cancer patients*

This study aimed to explore whether the existing DWP programmes meet the needs of cancer patients. It will report in April 2010 and is being conducted by Matrix Insight.

- 3.51 *A model of vocational rehabilitation in cancer* has been developed and pilot sites are being invited to be set up by April 2010. An evaluation is being commissioned to run alongside the pilots, also to start in April.
- 3.52 *A population-based survey of survivors of working age* has been commissioned from the University of Manchester to start in April 2010 to establish the extent and nature of the employment issues faced by people living with a cancer diagnosis with a view to enabling the development of new approaches to their support.
- 3.53 *Employment and cancer issues for small and medium-sized enterprises* - a scoping study will be commissioned towards the end of 2010 to explore the specific issues affecting small and medium-sized enterprises as employers of people diagnosed and living with cancer.
- 3.54 *Benefits advice services in NHS settings* - a scoping study will be commissioned in 2010 to identify the barriers and opportunities to long term funding of funding of benefits advice services in NHS settings services by PCTs.
- 3.55 *Work and cancer self management tools* - a study will be commissioned in 2010 to develop and test self management tools to enable patients to seek

National Cancer Survivorship Initiative Research Workstream

and obtain the information they need about cancer and employment from health professionals and employers, including occupational health professionals.

Children and Young People Workstream

- 3.56 *Mapping of the evidence base for models of care for survivors of childhood cancer* - this study was conducted by the Centre for Reviews and Dissemination at the University of York between December 2009 and April 2010. A wide range of models of care for survivors of cancer have been developed and previous reviews have focussed primarily on the effectiveness of alternative approaches in the adult cancer population. Because there was uncertainty as to the most effective mode of follow-up, this review aimed to examine the following: a comparison of alternative communication modalities to face-to-face clinic visits (for example telephone, postal, email or SMS/text-based); the use of physician- vs. nurse-led follow-up; the value of hospital staff vs. primary care staff to provide clinical contacts.
- 3.57 The review concluded that despite a rigorous search for studies of relevant designs, the authors were unable to identify any controlled studies that evaluated methods of providing follow-up care for survivors of childhood cancer. From the small number of studies that assessed follow-up care, it was difficult to draw any overall conclusions as to benefits or perceived patient needs. However, it appeared that clinical care was valued highly by the majority of follow-up clinic attendees; supportive care was perceived as more important by patients who required more interventions and were experiencing more late-effects symptoms. There were contrasting findings between a report showing 'missed' diagnoses when non-attenders were recalled and assessed, and further reports demonstrating efficacy of stratified low intensity follow-up. These studies were not formally quality assessed. Therefore, caution is advised when considering these findings.
- 3.58 The review further concluded that whilst there has been a prevailing view that survivors of childhood cancers should be followed-up for life, it is unclear whether this is necessary or beneficial. The literature to date does not appear to provide answers for the follow-up of persons diagnosed with cancer during childhood. Therefore, the authors of the review made a number of recommendations for future research:
- Ideally, suitably powered, well-conducted, controlled trials of adequate duration that directly compare the interventions and comparators specified within this review would be required to provide robust evidence on the optimal follow-up or aftercare for these patients. These trials should be conducted in appropriate settings and should focus on deriving meaningful outcomes. Most studies within this review appear only to report satisfaction with service, whereas relevant outcomes should also focus on patient experience, detection of morbidities and mortality rates. The economic implications of these interventions should also be assessed, given the resource implications of providing care and services over a protracted timeframe

National Cancer Survivorship Initiative Research Workstream

- There is a clear need for evaluation of follow-up programmes and comparative studies
- Risk stratification may be particularly relevant, as published guidelines advocate a stratified follow-up programme, although there has been no evaluation of these recommendations to date. Following childhood cancer, 60% of people who are more than 5 years from completion of therapy will experience at least one or more treatment - or disease-related late effect of therapy; over 30% of these problems are moderate or severe
- Potential areas for further systematic reviews may include: health promotion; smoking prevention/cessation; alcohol/substance abuse; diet; and sexual health. An appropriate priority-setting exercise should be conducted to assess which, if any, aspect of these health promotion strategies could be subject to systematic review. Such a review should explicitly draw on evidence from other chronic diseases to maximise the value of the information collected.

3.59 *Evidence-based risk stratification for adverse outcomes of treatment for childhood cancer*

This study will be the first large-scale population-based investigation to evaluate the performance of the current methods used to classify survivors of childhood cancer into three groups (high, medium and low), based on their cancer type and its treatment, ranking them according to their anticipated risk of serious adverse health outcomes resulting from the cancer and its treatment. The work is being led by the University of Birmingham, based on data available from the British Childhood Cancer Survivor Study and The Children's Leukaemia Group.

3.60 *Recommendations for areas of future research in relation to survivors of childhood cancers*

- Individuals treated for childhood, teenage or young adult cancers have most of their adult life ahead of them at the end of treatment, unlike the bulk of the survivors of the common cancers of adulthood which are in the main diagnosed after the age of 60 years. As a consequence, even the two largest comprehensive studies of adverse health outcomes among survivors of childhood and teenage cancer (the Childhood Cancer Survivor Study in the USA and the British Childhood Cancer Survivor Study) currently have relatively few survivors who are aged over 50 years
- Some of the biggest remaining concerns associated with survivors of cancer when young relate to their risk of common diseases of mature adulthood (cancer, circulatory disease, lung disease etc) in the general population, as they enter those decades of life when these diseases affect considerable numbers in the wider population. The extent of excess premature deaths which will be observed among existing survivors as they reach their 50's and 60's and beyond is not known. It must be remembered that in young people, their major organs are immature and still developing when they receive radiotherapy and chemotherapy. Of the

National Cancer Survivorship Initiative Research Workstream

excess deaths observed among British survivors of childhood cancer beyond 45 years from treatment, 77% are due to two causes - second primary cancer and circulatory disease⁸. It is critically important to monitor such survivors as they age, as these issues have major implications for risk stratification and the health service

Research Workstream

- 3.61 *Comprehensive review of the evidence base* as reported above in paragraphs 2.14-2.34
- 3.62 *Natural History of cancer survivorship / risk stratification of cancer survivors - The Research and Consequences of Treatment Workstreams* are working with the National Cancer Intelligence Network (NCIN) to develop a systematic approach to stratifying cancer survivors on the basis of their risk of a range of outcomes of their cancer or its treatment. The aim of the work is to develop a tool or framework which will enable the aftercare of cancer survivors to be planned based on likely or predicted need. Events or stages along the survivorship journey will be identified that are important to patients for particular cancers. The likelihood of these occurring will be based on a range of factors relating to cancer type, treatment and health, demographic and lifestyle factors, including co-morbid conditions. A range of methodological approaches will be used to quantify the likelihood of the events or stages occurring and from that, a predictive model can be developed over time for each cancer type. The work will start with cancers where there are the most data available and relevant research undertaken. An initial project has been commissioned with the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) and Monitor Group on colorectal and haematological cancers, which started in March 2010 for 12 months.

Additional sources of evidence and relevant ongoing research

- 3.63 *Priorities of people living with cancer from previous work* – a summary of previous work from other studies published by Macmillan Cancer Support is included at Appendix 3. These reports, which were some of the first to develop an understanding of the concerns of people affected by cancer, provided a starting point for the activities of the Research Workstream.
- 3.64 National Cancer Action Team. *Cancer and palliative care rehabilitation workforce project: A review of the evidence*. November 2009 - The National Cancer Action Team (NCAT) has recently carried out an evidence review looking at the existing evidence base for cancer and palliative care rehabilitation. Much of the evidence reviewed is relevant to cancer survivorship and the report of that review should be considered alongside the other evidence in this report in taking forward the recommendations of the Research Workstream. In addition to their evidence review, NCAT has also developed draft rehabilitation care pathways⁹ for nine tumour sites as well as

⁸ M Hawkins, personal communication

⁹ http://www.cancer.nhs.uk/rehabilitation/rehab_pathways.html

National Cancer Survivorship Initiative Research Workstream

ten symptom-specific pathways (for example for lymphoedema in people living with and beyond cancer). It will also be important for these to be taken into account when using the survivorship pathway to plan services (paragraph 2.19).

3.65 *Cancer survivors and cancer survivorship: Quantifying cancer prevalence and modelling its dynamics in England and the UK* – this project is being conducted at the Thames Cancer Registry funded by Macmillan Cancer Support. The project aims to produce a comprehensive and detailed account of cancer survivors and cancer prevalence in the UK and has three main strands:

- A detailed account of the size and demographics of the population of cancer survivors in the UK, using national cancer registry data from England, Scotland, Wales and Northern Ireland. This work has been completed and published in the British Journal of Cancer¹⁰;
- Further classification of the population of cancer survivors, according to their interaction with the health service. Rules and algorithms will be developed to classify survivors into groups (e.g. recently diagnosed, in remission, treatment for recurrence, end of life care). This will be achieved through an analysis of the linked Hospital Episode Statistics/Cancer Registry database that is held at the Thames Cancer Registry;
- Defining how cancer prevalence will change in the future. A flexible demographic model of cancer prevalence and cancer survivorship will be developed. Projections of cancer prevalence in the United Kingdom will be made under various scenarios (considering trends in population, incidence rates and survival).

3.66 *Survivors of adult cancer: A feasibility cohort study - To develop and test a UK-wide scalable and sustainable system for repeated collection of patient-reported outcomes from adults living with and beyond cancer* – this project is being conducted at the University of Leeds funded by Macmillan Cancer Support. The aim is to test out a new approach to recruiting cohorts of cancer survivors for research and a new way to routinely collect information on their quality of life once recruited. It is currently very difficult to recruit, cost effectively, large numbers of survivors once they have completed their treatment. Being able to do so however, is key to understanding survivors' needs (along with population studies using registry and hospital data) and how they can best be addressed, as well as testing if potential solutions to the problems they face are working.

¹⁰ Cancer prevalence in the United Kingdom: estimates for 2008 J Maddams, D Brewster, A Gavin, J Steward, J Elliott, M Utley & H Møller Br J Cancer 2009 101: 541-547

4. Prioritisation of research topics and analysis of findings

Developing a set of research priorities

- 4.1 A large number of future research requirements have been identified by the Research Workstream and the other NCSI workstreams. Therefore, a prioritisation process is needed to determine what specific areas of survivorship research should be targeted.
- 4.2 In order to ensure that the research priorities identified are acted upon, follow up to the NCRI Rapid Review will include approaching cancer research funding organisations to establish their interest in funding future survivorship research.
- 4.3 It would be naïve to imagine that a simple list of '1 to 100' research priorities could be established. There are too many considerations and too many perspectives to make this possible. However, following the survivorship evidence review and the extensive associated consultation, we can be much clearer about the nature of the priorities going forward.

Prioritisation criteria

- 4.4 To assist in determining priorities, the Research Workstream has identified a series of criteria against which potential topics can be assessed:
- 4.5 **Potential impact on care**, i.e. what will make a difference to patients most quickly?
- 4.6 **Breadth of impact and cost-benefit** - either for a large group of survivors, or dealing with more than one aspect of care, or making an impact for a more targeted group, but where interventions would make a very significant difference, i.e. weighing up a small difference for many vs a large difference for few.
- 4.7 **Long term benefit** to people affected by cancer or health and social care systems.
- 4.8 **Feasibility** of conduct of the research or of implementation of the results. There is no point in attempting to conduct new research where no suitable methods are available or in developing an intervention that could not be implemented in the health and social care system.
- 4.9 **Availability of existing funding streams and fit with other initiatives**, i.e. where funding streams already exist, then relevant work should be signposted in that direction. This allows a joint survivorship research programme to concentrate on what is unlikely to be funded elsewhere.
- 4.10 **Research to identify 'unknown unknowns'**, i.e. does a question address topics currently not recognised as important? Given that people are living

National Cancer Survivorship Initiative Research Workstream

longer, there might be issues related to longer term side effects and consequences of treatment of which we are currently ignorant.

- 4.11 **'Quick wins'** - Research into areas of clear need or where there is a paucity of evidence; where a minimal amount of work is required to get the research into practice; or into areas of particular concern and importance to patients.
- 4.12 **Critical mass of opinion** in favour of pursuing the area in question, including input from carers who can often be ignored.
- 4.13 **Research which could be undertaken using existing data** which has been under-used or which builds on existing work.
- 4.14 The above criteria will be used in taking forward research to address the recommendations in Section 5 to ensure that the aims and vision of the work stream are met.

Analysis of findings

- 4.15 The review of the research evidence base and consultation exercise show that the research that has been undertaken to date - and that which is ongoing - is being driven largely by particular areas of interest rather than addressing a clear strategy focused on greatest need.
- 4.16 In order to ensure that future research effort has the maximum benefit for people affected by cancer, a strategy will need to be developed to ensure that the areas of need are systematically identified and that solutions to these issues are developed according to greatest need and or benefit.
- 4.17 The issues and problems faced by cancer survivors following the completion of treatment need to be systematically quantified, building on the mapping exercises commissioned by the Research Workstream. This process is known as defining the 'natural history' of cancer survivorship.
- 4.18 Mapping the 'natural history' involves identifying what happens to cancer survivors in the years following the completion of their treatment. This enables the prediction of the likelihood of particular outcomes and events happening, based on a range of factors relating to cancer type, treatment and health and lifestyle factors (including other health conditions patients may have in addition to cancer).
- 4.19 This work will, in turn, lead on to the development of a risk stratification tool or framework that will enable aftercare for cancer survivors to be personalised on the basis of likely or predicted need.
- 4.20 Part of the NCSI vision is that risk stratification will enable a personalised approach to assessment and care planning. Cancer survivors will understand the likelihood of consequences of treatment and of recurrence of their cancer and will be aware of the signs and symptoms to look out for. Through specialist assessment and support, they will know what they can do to

National Cancer Survivorship Initiative Research Workstream

manage the immediate effects of treatment and minimise long-term effects, and they will know how to access specialist services when this level of support is needed. Symptoms which require specialist assessment and management will be identified at an early stage. Aftercare will be based on identified needs and the known likelihood for individuals of long-term consequences of treatment or of recurrence. This will need to include the survivors of cancers diagnosed when young as well as those diagnosed as adults.

- 4.21 Interventions will then need to be developed, which should be evaluated in practice, to prevent or lessen the impact of these outcomes,
- 4.22 The mapping exercises (paragraphs 3.4 to 3.7) provide the framework for determining the outcomes that are most important to cancer survivors. It is reasonable to assume that all survivors will want to know the likelihood of death, recurrence and second cancers, but what is most to them important beyond that will depend on the cancer type and treatment and personal preferences. There will also be demographic differences, for instance younger survivors are likely to want to know the likely impact on their fertility, whereas this will not be of interest to older survivors, although issues around sexuality can impact all ages.
- 4.23 Work to develop a comprehensive natural history for all cancers - and from that a risk stratification framework for all cancers - will take many years. However, work has already been initiated in a number of areas, so delivery will be a continuous process from now on, piecing together the cancer journey for each cancer type, step by step.
- 4.24 Finally, work is also required both at population level through the use of cancer registry and Hospital Episode Statistics data, and at the level of individual survivors.
- 4.25 The evidence gathered together is entirely consistent with the challenges identified by Feuerstein in 2008 from analysis of research, practice and policy in the USA as summarised in Appendix 4. The key challenges Feuerstein identified were around the need to be able to comprehensively define the actual problems that survivors of all types of cancer face, to identify the characteristics and risk factors that define optimal survivorship and develop approaches to deliver this for survivors.

5. Recommendations and next steps

Recommendations – *What we wish to see*

- 5.1 The Research Workstream recommends that changes should be made to the way in which the research on cancer survivorship is organised and funded in order to take forward the areas of highest priority that it has identified. These changes are set out below, followed by the priorities and how these would best be delivered by the NCSI in collaboration with the NCRI secretariat and others. There is no single means of delivering the identified priorities and therefore, a number of different approaches will be required to ensure success. These are also set out below.

Changes to the organisation and funding of research on cancer survivorship

- 5.2 Research on cancer survivorship lacks the discrete identity and focus for both researchers and funding organisations that exists for most other areas of cancer research. Therefore, it is recommended that the NCSI and NCRI should develop a UK-wide strategy for research on cancer survivorship research to cover all cancers and survivors of all ages including those diagnosed when young. The NCSI vision and the five key shifts in the approach to the care and support for people living with and beyond cancer (paragraph 2.17) provide the framework for this. From this, the research strategy will address the needs of cancer survivors by establishing a robust evidence base to support the development of solutions to the issues and problems they face.
- 5.3 Much of the research identified as priorities in the evidence review could be addressed by a wide range of funding organisations. However, to do this effectively, research funding across the UK should be focused on studies sufficiently powered to deliver statistically significant results that build on appropriate feasibility studies and by making use of existing cohort studies where possible. This, in turn, will need the recognition by funders that many of the types of interventions that will be needed require specialist professional intervention, which may not be available in many centres and therefore increases the cost of necessary multi-centre studies. Therefore, it is recommended that the NCSI and NCRI will need to work with funders to ensure their commitment to the strategic approach to research on cancer survivorship and ensure approaches to quality assessment that are appropriate.
- 5.4 The lack of identity and strategy for research on cancer survivorship makes it difficult for researchers to focus and coordinate their efforts to address the areas of highest priority for future research. Therefore, it is recommended that the NCSI and NCRI identify a high profile figure to unite and develop a coordinated research community for cancer survivorship that can then, in turn, make the best use of available research funding.

National Cancer Survivorship Initiative Research Workstream

Priorities for research on cancer survivorship

- 5.5 It is recommended that the highest priority is to understand the 'natural history' of survivorship and to create risk stratification tools for all cancers and for survivors of all ages to assess the most appropriate after care for each individual. Only by systematically determining the nature and scale of the problems faced by cancer survivors can the areas of highest need for interventions be targeted. Understanding how likely a range of health and social care outcomes, important to people living with cancer, are to occur, will address the NCSI vision and key shifts. This work should build on the initial scoping studies that have been commissioned by the Research, Children and Young People and Consequences of Treatment Workstreams, working with the NCIN. These are testing approaches for a small number of cancers initially and will need, in time, to be extended to all cancers.
- 5.6 It is recommended that the more specific areas of research identified by the evidence review and from the other NCSI workstreams should be addressed once a clear way forward has been agreed for the highest priority work on natural history and risk stratification. This could be conducted in parallel, but should not precede or take precedence.
- 5.7 It is recommended that the research to develop and evaluate interventions should be based on the natural history and risk stratification work and the 'best buys' identified by the evidence review. Together these will form a programme of secondary preventative interventions.
- 5.8 The fifth key shift in the NCSI vision is towards the routine use of measures of experience and outcome. It is recommended that these should be developed in a systematic way to reflect the development of survivorship services and the evidence that emerges from the natural history and risk stratification. Experience and outcome measurement tools should be closely linked to, and emerge from, research on interventions, rather than being established in isolation.
- 5.9 The different approaches to planning and delivering health and social care for cancer survivors that are being developed by the NCSI are being tested as they are developed. However, evidence will also be needed to demonstrate their broader impact, in order to ensure that they are sustainable. It is therefore recommended that a systematic programme of economic evaluations should be carried out of the benefits of services to the health and social care and wider economy.

Taking forward the research priorities

- 5.10 The research priorities identified will be taken forward in three ways, working with the NCRI:
- Developing a joint research funding budget with contributions from organisations with a particular interest in the area. It is recommended that the principal focus of this should be research on natural history and risk stratification

National Cancer Survivorship Initiative Research Workstream

- Targeting and maximising the use by the relevant research community of existing relevant sources of research funding, e.g. NIHR, Medical Research Council, etc. This is where the most funding will be available, but as indicated above, will require some changes in the way funders assess proposals in cancer survivorship
- Encouraging individual funding organisations to identify specific questions or areas that are of high importance to them and that they wish to pursue. This route may be more important for tumour specific charities and or for those with relatively modest research budgets

5.11 Both the first and second routes are explicit objectives arising from the NCRI Rapid Review. All three approaches will need leadership from the NCSI / NCRI to ensure that they are driven forward to meet the areas of highest strategic need and answer the most important questions underpinning improvement in the health and wellbeing of cancer survivors.

Next steps

- 5.12 There are a number of areas of work which now require to be taken forward to start to address the recommendations above, as follows:
- 5.13 Identifying the areas of interest of research funding organisations in contributing (a) to a joint NCRI survivorship research budget and (b) funding specific areas they wish to take forward themselves. This should include consideration of the recommendation from the evidence review not to fund further small scale and underpowered research, but to seek to work collaboratively on larger scale research and preferably on prospective cohort studies in addition to contributing to a joint budget.
- 5.14 Commissioning a programme of research focussed principally on the highest priority area from a joint NCRI survivorship research budget to address areas unlikely to be taken forward by other research funding sources.
- 5.15 Clarifying and publishing the range of different funding routes / schemes currently available and the scope of each, which is one of the actions identified in the NCRI rapid review.
- 5.16 Identifying a high profile figure to unite and develop a coordinated research community for cancer survivorship that can then, in turn, make the best use of available research funding
- 5.17 Working with professional researchers to understand their areas of interest, mapping these against the available sources of funding and encouraging them to address the areas of highest priority for future research.
- 5.18 Mapping ongoing research, especially cohort studies, against the priority areas of need and investigating the opportunities to build on this work, both in terms of the willingness of the research community to do this and the availability of funding to support it. This will include work commissioned by the NCSI and link to the work of the National Cancer Intelligence Network (NCIN).

National Cancer Survivorship Initiative Research Workstream

- 5.19 Facilitating the development of research proposals targeted at areas of greatest need, based on the evidence review and natural history / risk stratification work and matching these to the funding sources most likely to support them.
- 5.20 Mapping the skills and interests of the research community to the areas of highest priority for future research.

6. Helpful resources/ supporting information

Funding

- 6.1 The NCRI is developing a catalogue of funding opportunities in cancer survivorship as part of the implementation of its rapid review (paragraphs 3.36 to 3.38). This is expected to be completed during summer 2010 and will be complemented with a number of workshops for researchers to advise and support them in obtaining funding to support their research, in pursuit of the recommendations of this report. In the meantime, this section includes a number of references to sources of funding and advice, which we hope will be useful.
- 6.2 <http://www.rdinfo.org.uk/> This comprehensive web resource contains three separate web sites:
- <http://www.rdfunding.org.uk/> - a regularly updated and catalogued database of research funding opportunities
 - <http://www.rdlearning.org.uk/> - training events for health researchers
 - <http://www.rddirect.org.uk/> - a telephone signposting service supported by a panel of experts
- 6.3 The National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC) is the organisation that runs the NIHR research programmes. On its web site are a number of useful resources to help researchers determine the best funding schemes to which they can apply for their particular areas of interest. Among these are:
- http://www.netscc.ac.uk/funding/cancer_research.asp - This page sets out some information to guide applicants for research grants, so that they can decide whether their idea best fits the NIHR HTA programme or Cancer Research UK. In line with the requirements of both organisations, parallel applications will not be accepted. The page provides a table that lists some of the priorities for studies funded by the two programmes, with links to the relevant web-sites for further information on these and other funding schemes. Although Cancer Research UK have indicated that they will no longer fund research in psychosocial oncology, they will support a number of areas identified in the evidence review for interventions
 - http://www.netscc.ac.uk/funding/which_programme.asp - an interactive page to help researchers determine which NIHR programme run by NETSCC is right for them

National Cancer Survivorship Initiative Research Workstream

Appendix 1: Membership of the NCSI Research Workstream

John Neate (Chair)	Chief Executive, The Prostate Cancer Charity
Jim Elliott (Support)	Research Adviser, Macmillan Cancer Support
Members	
Maggie Alexander	Breakthrough Breast Cancer
Deborah Alsina	Bowel Cancer UK
Roma Armstrong	Scottish Government Health Directorates - Chief Scientist Office
Louise Bayne	Ovacome
Ian Beaumont	Bowel Cancer UK
Victor Boulter	Service User Representative
Helen Campbell	Research and Development, Department of Health
Philippa Carr	Target Ovarian Cancer / Cancer 52
Jane Cope	National Cancer Research Institute
Lesley Fallowfield	University of Sussex
Karen Finney	Medical Research Council
Julie Flynn	National Cancer Research Institute Complementary Therapies Clinical Studies Development Group
Rosemary Gillespie	Roy Castle Lung Cancer Foundation
Irene Higginson	King's College London
Louise Jones	Marie Curie Cancer Care
Roberta Lovick	Service User Representative
Karen Luker	University of Manchester
Henrik Møller	Thames Cancer Registry, King's College London
David Rabjohns	Service User Representative
Fiona Reddington	Cancer Research UK
Karen Robb	St. Bartholomew's Hospital / King's College, London
Peter Rose	GP, Oxford
Joy Todd	Economic and Social Research Council
Leslie Walker	University of Hull
Anne Wilkinson	NHS Improvement
Penny Wright	University of Leeds
Annie Young	Network Lead Nurse, Avon, Somerset and Wiltshire
Gary Young	Service User Representative
Observers	
Kevin Bolster	Macmillan GP Adviser
Karen Groot	National Cancer Research Institute
Stephen Wibberley	Macmillan Cancer Support

The late Brian Cottier, Director of the National Cancer Statistics Analysis Team, was also a member of the work stream

National Cancer Survivorship Initiative Research Workstream

Appendix 2: Issues identified by stakeholders as needing more research or information from the mapping studies on the aftercare of cancer survivors

	Listening Study	Breast	Colorectal	Lung	Prostate	Less common cancers
Care plan						
- type, level & amount of information required in plan		√				
- method for optimal information sharing (pt & HCP)	√	√	√			
- optimal models for rapid re-entry to secondary care		√	√			√
- best methods for assessing supportive needs	√	√			√	√
Remission/Follow-up						
- process evaluation & effectiveness of models	√	√	√	√	√	√
- information required by patients		√	√	√	√	
- co-ordination of primary & secondary care	√	√	√	√	√	√
- access to CNS					√	√
Active/advanced disease						
- Incidence & prevalence		√				
- impact on QoL		√				
- Interventions – psychological problems		√			√	
- interventions – improve QoL		√			√	
- interventions – complementary therapies	√					√
Long term effects						
- prevalence & natural history	√	√	√		√	√
- identify at-risk group & methods of prevention	√	√				
- interaction with clinical factors		√				
- impact on QoL	√	√		√	√	
- impact on carers	√				√	
- physical – lymphoedema		√				√
- physical – sexual function		√			√	√
- physical – hormone-related	√	√			√	
- emotional – anxiety & depression	√	√	√	√		
- emotional – sexual function					√	

National Cancer Survivorship Initiative Research Workstream

	Listening Study	Breast	Colorectal	Lung	Prostate	Less common cancers
- emotional – fear of recurrence			√	√		√
- interventions – QoL	√					√
- interventions – anxiety & depression		√	√		√	√
- interventions – menopause	√	√				
- interventions – sexual function		√	√			
- interventions – lymphoedema		√				
- interventions – complementary therapies	√	√				√
- interventions – symptom control	√			√		
- interventions – physical function	√			√		
- interventions – carers	√	√	√	√	√	√
- interventions - process evaluation & effectiveness	√					√
Work/education & finance						
- Information for employers & government agencies		√	√	√	√	√
- Information for pts (including children)	√	√	√	√		√
- prevalence of work/finance problems	√					√
- prevalence of insurance problems	√					√
Self-management (SM)						
- assessment of need		√			√	√
- peer support	√			√		√
- effectiveness & process evaluation				√		√
Information						
- process evaluation & effectiveness		√			√	√
- needs of caregivers	√	√				√
- needs of disadvantaged groups	√	√				
- development of needs assessment tool		√				√
- lifestyle factors	√		√	√		√
- cancer genetics	√					√
- children						√
Commissioning						
- common long term effects		√				

National Cancer Survivorship Initiative Research Workstream

	Listening Study	Breast	Colorectal	Lung	Prostate	Less common cancers
- rare long term effects		√				
- less common cancers						√
- effectiveness & process evaluation						√
Socio-economic (age, ethnicity, gender, sexuality, deprivation)						
- impact on incidence & survival	√		√	√		
- impact on information, care and service needs		√	√	√	√	√
- impact on QoL with advanced disease		√		√		
- impact on access to services		√	√	√	√	
- cultural perceptions of cancer & stigma	√	√		√	√	
Individual						
- impact of health behaviour on QoL		√				
- impact of coping on QoL	√	√				
- Impact of self-esteem on QoL		√				
Environmental						
- urban v rural		√				
- barriers to implementation of research	√	√			√	
- disparity in quality of service			√			√

1 Macmillan Cancer Support (2006). We listen to patients: The research priorities of people affected by cancer.

2 Breakthrough Breast Cancer (2009). Mapping the needs of breast cancer survivors: Information from qualitative stakeholder research and grey literature.

3 Bowel Cancer UK (2009). Bowel cancer survivorship report.

4 The Roy Castle Lung Cancer Foundation (200). Lung cancer NSCI research workstream report.

5 The Prostate Cancer Charity (2009). Identification of research needed into the experience of men living with and beyond prostate cancer.

6 Cancer 52 The common voice for less common cancers (2009). Cancer 52 & NSCI research workstream less common cancers consultation report.

Key

- All reports endorse as research priority
- 5 reports endorse as research priority
- 4 reports endorse as research priority

National Cancer Survivorship Initiative Research Workstream

Appendix 3: Priorities of people living with cancer from previous work

- A3.1 Previous work from other studies published by Macmillan Cancer Support has begun to develop our understanding of the concerns of people affected by cancer and provides a useful reference point for the development of research priorities through the activities of the research work stream. A summary of these is provided below.
- A3.2 Many people living with cancer found the physical after effects of cancer treatment the most difficult to cope with, particularly if they were working, though this varied by age, gender and parental responsibilities. Moreover, they were often not forewarned and had no access to advice and support in the survivorship phase^{11 12}. There is poor recognition by health care professionals of late effects due to cancer treatment and few specialist services are available for dealing with complex late effects¹³. This is further compounded, as there is no routine collection of information and the scale of the problem is therefore unknown and survivors are often unaware of the physical long-term side effects of treatment¹³.
- A3.3 For others, the emotional after effects of cancer treatment were frequently the most problematic, but this varied by parental status, lower socio-economic status and gender. Whilst many people want information, advice or support, less than half report receiving it^{11, 12}. Consequently, a significant proportion of individuals reported experiencing anxiety and or depression following treatment for cancer^{11, 13}. A cancer diagnosis places a significant strain on relationships, inhibiting usual sexual activity¹³. Up to a quarter of those reporting marital difficulties following treatment for cancer go on to separate¹³.
- A3.4 Caring can negatively affect not only informal caregivers' mental and physical health, but also their employment prospects and financial circumstances. However, there are few services available to meet their information and support needs¹³. The number of carers who experience anxiety or depression is similar to that reported by people living with cancer. However, the proportion of them who do not receive help is much higher¹³.
- A3.5 When asked what would improve the situation for cancer survivors, it was suggested that attention needs to be focused on providing information, advice and support - for both those with cancer and their relatives - on the physical and emotional impact of cancer, returning to work, dealing with financial difficulties and how to look after themselves, so as to return to as normal a life as possible^{11, 12, 13}. The notion of an end of treatment 'patient passport', care plan has been mooted, along with the provision of a named 'key' worker to ensure continuity of care and seamless service between primary and secondary care¹⁴. These ideas are, of course, being developed by the assessment and care planning work stream.

¹¹ Worried Sick: the emotional impact of cancer, Macmillan Cancer Support, 2006

¹² The future of Cancer Care, Macmillan Cancer Support, 2007

¹³ Two Million Reasons, Macmillan Cancer Support, 2009

¹⁴ It's No Life. Follow up to Macmillan Cancer Support, Health and well-being survey, 2008

National Cancer Survivorship Initiative Research Workstream

Appendix 4: Challenges for Cancer Survivorship: Research, Practice, Policy and Education

from: *Handbook of Cancer Survivorship*, M Feuerstein Ed, Springer, 2008, pp 483-494,
Cancer Survivorship: Research, Practice and Policy by Michael Feuerstein

Challenges	Factors
Comprehensive and representative data on the actual problems of survivors	<ul style="list-style-type: none"> • Patterns of occurrence • How long they persist • Recurrence
More accurate case definitions of survivors	<ul style="list-style-type: none"> • Based on observable natural history
Long-term surveillance of cancer survivors across major dimensions of optimal survivorship both health and functional outcomes	<ul style="list-style-type: none"> • Multiple studies that follow survivors treated in tertiary care centres and in general practice • Routine monitoring of general health along with tumour activity • Use of more specific measures of function over time
Systematic research on empirically validated risk factors for optimal survivorship	<ul style="list-style-type: none"> • Operational definitions of risk factors • Research specific to major cancer types • Use of cancer-specific outcome measures and operational definitions of optimal cancer survivorship • Development of a wide range of measures to assess the many concerns of survivors • Greater focus on functional outcomes and important biological markers
Studies on the mechanisms of risk factors and how they interact with each other	<ul style="list-style-type: none"> • Studies of biological plausibility • Greater understanding of psychoneuroimmunology • New animal and human models
Development of new approaches that truly modify risk factors	<ul style="list-style-type: none"> • Determine effective interventions for a number of critical outcomes indicative of optimal survivorship
Focus on all stages of cancer survivorship	<ul style="list-style-type: none"> • Greater understanding of late or advanced stages of cancer • Better understanding and management of dying and grieving processes • Greater use of systematic, qualitative and quantitative research • Scientific research along with religious analysis
Train diverse groups of health professionals	<ul style="list-style-type: none"> • Workshops/web-based/clinical training on survivorship management • Training in medical school and health professional schools
Long-term innovative services for cancer survivors	<ul style="list-style-type: none"> • Better structured services to facilitate access, provide unique modes of delivery • Better reimbursement or insurance coverage
Better understanding and effective approaches to smoothly reintegrate the cancer survivor into society	<ul style="list-style-type: none"> • Learn about challenges in order to create policies • Effective and cancer-survivor-specific accommodations should be developed and evaluated • Development of approaches to improve stamina, reduce fatigue and improve cognitive abilities • Greater understanding of the risk factors for breakdown or stress within the family