

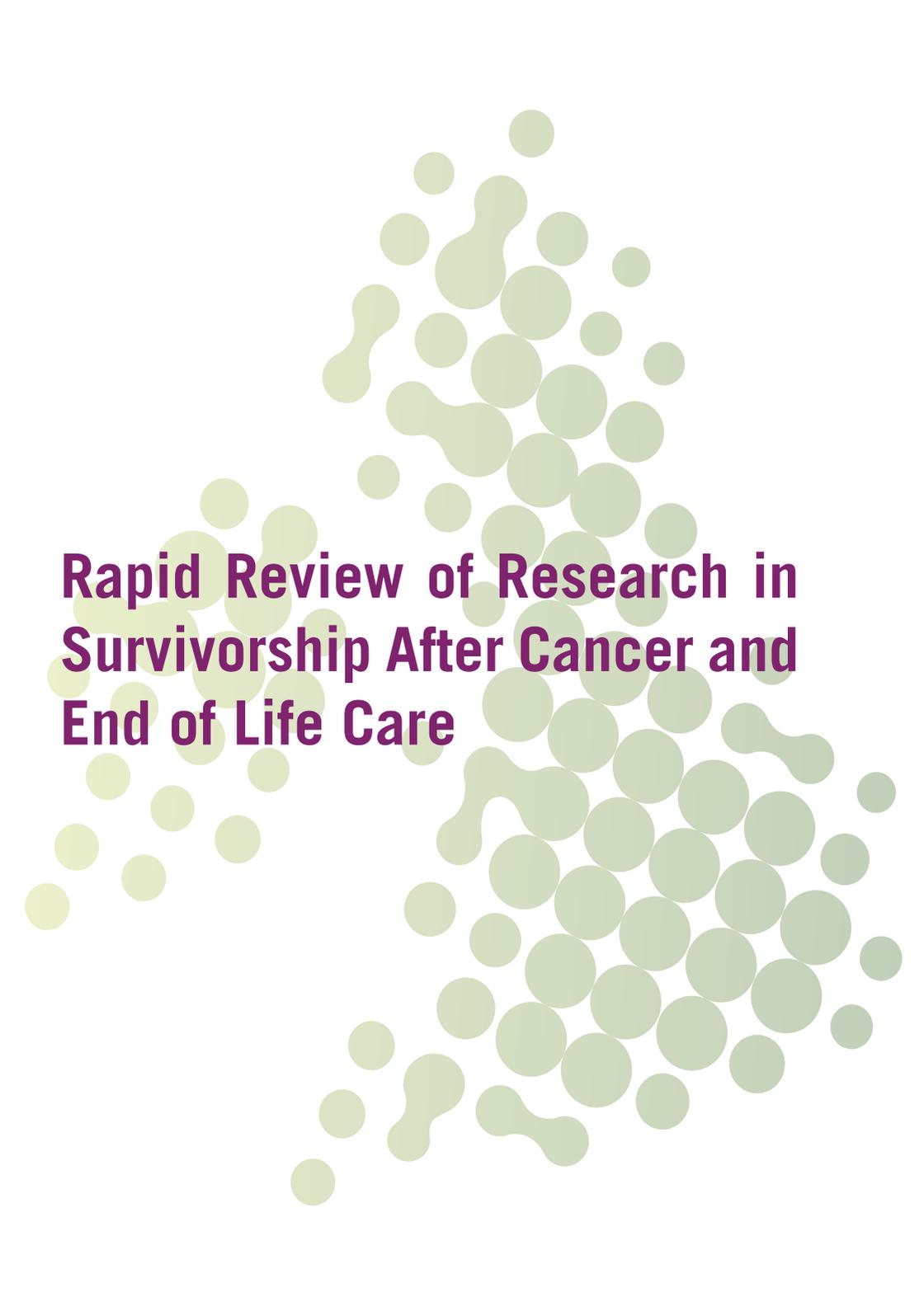
# Rapid Review of Research in Survivorship After Cancer and End of Life Care



**NCRI**  
National  
Cancer  
Research  
Institute



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# **Rapid Review of Research in Survivorship After Cancer and End of Life Care**

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## Executive Summary

In early 2009 NCRI decided to take stock of research in survivorship after cancer and end of life care because of the wealth of scientific need and opportunity and a wish to integrate the strategies of government and charity sector research funders in these areas.

The focus of the review was to assess progress since the 2004 NCRI report on Supportive and Palliative Care (SuPaC) Research in the UK, to bring together research priorities which had been identified elsewhere, and to produce a framework and action plan which enables funders to place their own work in a broader context.

This report is a distillation of many discussions during 2009 and 2010 between NCRI, research funders, active researchers, consumers<sup>1</sup> and independent advisors. It also takes on board outputs from the National Cancer Survivorship Initiative and End of Life Care Strategy in England. The report acknowledges current financial uncertainties in highlighting modest but practical actions for the short term, as well as ambitions which may only be realistic in the longer term.

## Leadership

Professor Sir Kenneth Calman will be the first chair of a UK Steering Group for research in survivorship after cancer and end of life care. In this role, he will champion research in these areas, raising its profile and leading the coordination and integration of the three strands of the action plan. The Group will comprise research funders, experts and consumers, and will be supported by dedicated resource within the NCRI Secretariat. The Steering Group will make regular reports on progress to the NCRI Board.

## Action 1: Promote investigator-led research through existing funding schemes

To make best use of existing funding schemes NCRI has developed the Grantsmanship Gateway to help to develop the confidence and grantsmanship skills of researchers, particularly early career researchers. This resource will be supplemented by stakeholder meetings to promote the guidance and foster collaboration and networking. This resource will enable NCRI to promote the full range of research priorities that has been identified, bearing in mind that limited resource is currently available for specifically targeted funding streams.

Professor Sir Kenneth Calman and the NCRI Secretariat will also work with the leaders of the NCRI SuPaC Collaboratives to ensure that the capacity they have built will be sustained when their funding comes to an end in 2011.

## Action 2: Target specific areas of research need

### Action 2.1: End of life care research

Marie Curie Cancer Care and Dimbleby Cancer Care already have dedicated funding schemes in this area. The National End of Life Care Intelligence Network was launched in England in 2010 and is developing a data repository which will be a valuable resource for research. In May 2010 NCRI, the Wellcome Trust and the UK Age Research Forum convened a meeting of research funders who may be interested in supporting a broader programme of research in end of life care individually or through joint action. A number of themes emerged at the meeting, including the need for improved communication at the end of life and interventions to control symptoms and improve quality of life in patients nearing the end of life. This is new territory for many funders and NCRI will need to facilitate a

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(1) Consumers are cancer patients, carers and others affected by cancer.

further period of discussion and reflection before specific joint actions emerge.

### **Action 2.2: Natural history of cancer survivorship and risk stratification**

The research workstream of the National Cancer Survivorship Initiative (NCSI) has recommended that “the highest priority for research in cancer survivorship is to understand the ‘natural history’ of survivorship and to create risk stratification tools for all cancers and for survivors of all ages”. Macmillan Cancer Support, working closely with the National Cancer Intelligence Network (NCIN) will commission additional research in this area and will in the first instance arrange a workshop meeting with other potential funders to discuss the shaping of such research.

### **Action 2.3: Health services research and economic assessment**

Research to evaluate care pathways including economic assessment is ripe for consideration. In the first instance the focus will be cancer survivorship and a number of NCRI partners have expressed interest, as and when resources allow. Such work may evolve later into other long-term conditions and/or end of life care, with the possibility of attracting a wider range of partners in either case.

### **Action 3: Enhance collaboration with the research networks in the NHS**

The National Cancer Research Network (NCRN) Coordinating Centre will take steps to increase awareness and interest amongst the local cancer networks to extend the number of networks involved in survivorship after cancer and end of life care studies. Similar approaches will be explored in the comprehensive local research networks (CLRNs) and other topic-specific networks and in the relevant research networks in

Scotland, Wales and Northern Ireland. The NCRI Clinical Studies (Development) Groups in Palliative Care, Psychosocial Oncology, Primary Care and Complementary Therapies will continue to develop the portfolio of studies that are offered to the networks.

# 1. Introduction

## 1.1 Background

NCRI decided that it was timely to take stock of research in survivorship after cancer and end of life care for a number of reasons, including:

- The wealth of scientific need and opportunity at the current time combined with a need for research prioritisation, especially during a period of financial restraint
- The need to integrate the strategies of government and charity sector research funders into a coherent framework and action plan
- A wish to place these needs in the context of progress since the earlier NCRI report on Supportive and Palliative Care (SuPaC) Research in the UK (2004)

In 2006, the Department of Health in England (DH) launched the National Institute for Health Research (NIHR) as the new vehicle for DH-funded Research and Development, as well as new policy-driven initiatives in cancer survivorship and end of life care. At the same time, Health Departments in other countries of the UK have been reviewing their strategies for cancer, and there have been significant strategic changes within the charity sector. Cancer Research UK launched a new strategy in late 2008, indicating a focus which no longer includes research in palliative care and psychosocial oncology research and a few months later Marie Curie Cancer Care announced an intention to develop a new focus in end of life care research. So much change in a short space of time has left both funders and researchers without a clear picture of the funding environment as a whole.

## 1.2 Scientific needs and opportunities

The NCRI Cancer Research Database (CaRD) shows that while there is substantial research on front-line treatments for cancer, only around £11.5m per annum is currently being spent by NCRI partners on the wider needs of those who are living with cancer, who have had cancer and are seeking to return to 'normal' life, or those at the end of life.

It has been estimated that there were 2 million cancer survivors in the UK at the end of 2008<sup>2</sup>. Due to improved treatments and demographic changes this figure is expected to rise at a rate of 3% per annum. The National Cancer Data Repository (NCDR) being set up by the National Cancer Intelligence Network (NCIN) will provide a means to track prevalence in the years to come and provide new opportunities for epidemiological research involving cancer survivors.

Work undertaken for the National Cancer Survivorship Initiative (NCSI) has shown that these people have many and varied needs which depend on their tumour type, disease trajectory and individual factors such as co-morbidities or socio-economic status. They may need help in dealing with, for example, psychosocial problems, returning to work, consequences of treatment or a recurrence of cancer. While summary information is provided in section 3 of this report, readers are referred to the NCSI vision document<sup>3</sup> and the outputs from the NCSI research workstream<sup>4</sup> for more detailed consideration of research priorities in this area.

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(2) Maddams *et al* (2009). Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*, volume 101, pp 541 - 547.

(3) NCSI vision (January 2010). Available from: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111230](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230).

(4) The reports from the group are available from: [www.ncsi.org.uk/research](http://www.ncsi.org.uk/research).

Around half a million people die in England each year, and the large majority of these deaths follow a period of chronic illness<sup>5</sup>. While much research in end of life care has focused on cancer patients, there is a need to extend this to other causes of death, including heart disease, stroke, chronic respiratory disease, neurological disease and dementia, and hence to engage and include a much wider range of research funders. Initial delineation of research priorities emerged from a 2-day workshop held in April 2008 and these are summarised in section 4 of this report. There is currently very little research being supported by NCRI partners in this area and no collective data on what is being done outside the NCRI partnership.

### 1.3 Objectives

The objectives of the Rapid Review were to capture and understand what has been achieved in the last 5 years in supportive and palliative care research and to seek agreement amongst funders on a way forward for research in survivorship after cancer and end of life care in the UK over the next 5 years. Specifically, the intention was to integrate the following into a coherent way forward:

- Priority research themes
- Alignment of the needs, policies and other drivers of all the relevant research funders, thus enabling them to collaborate
- How to sustain and build on the achievements of the last 5 years to maximise value for money and the leverage of other funding sources
- The most appropriate funding instruments (programme/project grants, capacity-building grants, fellowships etc.)

### 1.4 Scope of field

For present purposes, survivorship after cancer is deemed to start with diagnosis. However, front-line treatment with curative intent is excluded as this is a heavily-funded research field in its own right. In some circumstances it may be more helpful to give this work a focus of improving well-being during and after illness, rather than overcoming ill-health. Survivorship includes consideration of the impact of illness on carers and families and interventions to help them as well as patients.

End of life care helps all those with advanced, progressive and incurable illness to live as well as possible until they die<sup>6</sup>. It applies to those in the last year, months and days of life and includes death from any cause (i.e. not just cancer), and the management of bereavement as well as death and dying. One challenge is identifying those approaching the end of life and how the transition into the final period of life is managed by the individual, close family and friends and professionals.

It should be noted that survivorship after cancer and end of life care are not mutually exclusive categories when research needs are considered. For example work on pain and the control of other symptoms, due either to disease or treatment, is relevant to both. In developing strategies or initiatives, care needs to be taken not to create artificial boundaries.

In order to align with government initiatives, NCRI proposes to use the terms 'survivorship after cancer' and 'end of life care' in future in place of 'supportive and palliative care'. At the same time, partners wish it to be understood that this is a change in focus rather than content and they recognise the importance of ensuring a seamless transition

(5) Department of Health, England (July 2008). End of Life Care Strategy. Available from: [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_086345.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf).

(6) Attributed to the National Council for Palliative Care (2006) in the Department of Health, England End of Life Care Strategy (July 2008).

from existing initiatives in supportive and palliative care to the new framework for action.

## 1.5 Format of the Rapid Review

The main focus of the Rapid Review was a meeting held in July 2009 comprising a full day in which funders met with active researchers in the UK, consumers<sup>7</sup> and independent advisors. A further half-day session was held the following day for funders, consumers and independent advisors. See Appendix A for a list of review attendees.

The papers for the Rapid Review meeting included:

- A compilation of actions which followed the publication of NCRI's report in 2004, including comments from the research community on how well the actions have addressed the issues in the research field
- Analysis from the NCRI Cancer Research Database (see Appendix C)
- An updated bibliometric analysis (see Appendix D)
- Information on clinical trials on the National Cancer Research Network (NCRN) Portfolio with relevance to survivorship after cancer and the end of life<sup>8</sup>

During the months following the meeting, the NCRI Secretariat held a variety of further discussions with individual funders and others in order to shape the action plan. Information was also fed in from the evidence review conducted for the NCSI. The Rapid Review report and action plan is a product of all these analyses and discussions.

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(7) Consumers are cancer patients, carers and others affected by cancer.

(8) The NCRN Portfolio, and specifically the clinical trial portfolios of the Complementary Therapies, Primary Care, Palliative Care and Psychosocial Oncology Clinical Studies (Development) Groups, can be accessed at <http://public.ukcrn.org.uk/Search/Portfolio.aspx?level=1>.

## 2. Achievements since 2004

### 2.1 Progress with actions

The 'proposed way forward' that came out of the earlier review spelled out actions to be undertaken to tackle the organisation, workforce, infrastructure support, funding and methodological issues within the supportive and palliative care research field.

A major vehicle for overcoming the deficiencies in all these areas have been the NCRI Supportive and Palliative Care (SuPaC) Research Collaboratives, CECo and COMPASS<sup>9</sup>. Their funding was provided for infrastructure, capacity-building and collaboration activities. During their first three years of operation the Collaboratives have challenged the competitive culture of academia and fostered greater collaboration and cross-disciplinary working. In addition they have set up a variety of training and mentoring activities and have had increased success in gaining grants in open competition. The Collaboratives have been commended for their early work and having demonstrated its effectiveness it is timely for the research community to champion and promulgate the new collaborative way of working to others in the research community.

Core funding for the Collaboratives has been supplemented by small-scale capacity-building grants aimed specifically at supporting isolated or new investigators in achieving their research potential and addressing some of the gaps in the evidence base. The total funding for the Supportive and Palliative Care Research Collaboratives and the capacity-building activities was £5m over 5 years.

Around 2004, at the time of NCRI's earlier

report, Clinical Studies Development Groups (CSDGs) were set up in Psychosocial Oncology, Primary Care, Palliative Care and Complementary Therapies. The study portfolios in these areas were meagre then and have now grown to a total of 114 studies of which 43 are open to recruitment as of early September 2010. All groups have had successful peer reviews and the Palliative Care and Psychosocial Oncology Groups are now fully fledged as Clinical Studies Groups having completed their development phase<sup>10</sup>.

The Collaboratives and the CS(D)Gs have different and complementary aims. Interaction between the two has grown during the 5 years, though it may take different forms in the four topic areas. Further development of the interaction between researchers within and outwith the CS(D)Gs will be important to sustain and widen the network of collaboration, and extend the sharing of ideas and expertise in research in survivorship after cancer and end of life care.

While these two activities have been the most clearly targeted actions, others with broader applicability have played a smaller part in starting to develop critical mass:

- NCRI has accredited a total of 9 Clinical Trial Units (CTUs) some of whom have particular expertise in areas such as psychosocial oncology or end of life care. These complement the work of the CS(D)Gs in developing trial proposals which can then be implemented in the research networks.
- The Medical Research Council (MRC) has set up a methodology research programme and issued updated guidance on evaluating complex interventions<sup>11</sup>. MRC has also established a network of 7

(9) CECo (Cancer Experiences Collaborative) is funded by Cancer Research UK, Economic and Social Research Council (ESRC), Macmillan Cancer Support, Marie Curie Cancer Care, the Medical Research Council and Department of Health (England). COMPASS is funded by Cancer Research UK, Macmillan Cancer Support, Marie Curie Cancer Care, the Medical Research Council and Department of Health (England). The NCRI SuPaC Collaborative awards are administered by Marie Curie Cancer Care on behalf of the funding partners.

(10) Hereafter these four groups are referred to collectively as the CS(D)Gs.

(11) MRC (September 2008). Developing and evaluating complex interventions: new guidance. Available from: [www.mrc.ac.uk/Utilities/Documentrecord/index.htm?id=MRC004871](http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?id=MRC004871).

Trial Methodology Research hubs across the UK, with a further All-Ireland hub currently under development. The hubs will develop new and improved methods to design, conduct, analyse and report clinical trials.

- A variety of fellowship schemes from a number of funders are open to the research community in these areas.
- An NCRI grant-call in 2007 targeted at supportive and palliative care in lung cancer led to the award of 9 grants totalling over £2m.
- The NIHR, MRC and ESRC have collaboratively launched an initiative to boost research capacity in the economics of health including funding for a number of early-career post-doctoral fellowships and MSc studentships.

## 2.2 Success factors

A bibliometric analysis, carried out as part of the Rapid Review, highlighted that in the period from 1997 to 2008 the annual percentage growth in the UK's output of supportive and palliative care research<sup>12</sup> has been higher than the growth in the field of cancer research as a whole and the biomedical research field. The analysis also showed that the UK has an average annual output second only to the USA. However when productivity is adjusted for gross domestic product (GDP), the UK falls behind that of Sweden, Israel, and Canada (see Appendix D).

International participants in the Rapid Review meeting expressed the view that the UK supportive and palliative care research community has achieved a great deal in the last few years and has provided a solid platform for further development of the field. It was highlighted that there was potential for UK researchers to make a greater impact with their research by generating a larger

number of multicentre, as opposed to single centre, studies and by seeking to publish research in the highest impact international journals.

NCRI's brief survey of opinion in the research community elicited the view that critical mass is developing though still in a localised manner. Progress has been made in overcoming fragmentation, and continued investment is needed. Targeted funding initiatives have been welcomed and it is thought that there remain gaps in the career pathways for some relevant disciplines, which will need further action to address.

The Supportive and Palliative Care Collaboratives are collecting other data such as peer-reviewed grant income though it will take a while for any trend in this area to become evident.

Taken together, these considerations suggest that the earlier NCRI report has led to some success in developing capacity and productivity. However, these achievements need further action to be sustained and developed further.

## 2.3 Consumer involvement

Consumers have voiced a particular interest in involvement in research on survivorship after cancer and end of life care, as their experience can be especially valuable to researchers, and policy makers, in these areas. Consumer involvement is being developed effectively with researchers getting input to studies and strategies by way of local consumer panels in addition to the consumer groups embedded in the Collaboratives and the CS(D)Gs. Consumers are starting to be seen as 'research partners' in a number of studies and activities such as the Macmillan user-led grants competition have exemplified how consumers may be

(12) The earlier terminology was used in order to generate data as comparable as possible with that which was prepared for the 2004 NCRI report on Supportive and Palliative Care Research in the UK.

involved in ensuring that research ideas are translated into research projects. At the Rapid Review meeting, and in discussions since, consumers have echoed others in acknowledging progress and have expressed a particular wish to see evidence from research being implemented in practice for the benefit of patients and families and highlighted the role consumers could have in disseminating research findings.

A full description of consumer involvement in the Rapid Review can be downloaded from the NCRI website<sup>13</sup>.

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(13) Available from [www.ncri.org.uk/includes/Publications/general/Rapid\\_Review\\_Consumer\\_Involvement.pdf](http://www.ncri.org.uk/includes/Publications/general/Rapid_Review_Consumer_Involvement.pdf)

### 3. Research priorities in survivorship after cancer

The National Cancer Survivorship Initiative (NCSI), a partnership between the Department of Health, England and Macmillan Cancer Support, aims to improve the services and support available for those living with and beyond cancer. The NCSI research workstream, as one of seven workstreams of the NCSI, set out to establish what is and 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. To inform the work of the group the research workstream commissioned three projects: mapping the issues faced by cancer survivors, a comprehensive scoping review of the current evidence base on survivorship research and a consultation with key stakeholders on research priorities.

The scoping review produced by the NCRI SuPaC Collaboratives assessed the evidence relating to problems faced by adult cancer survivors and the effectiveness of interventions to address these problems. The analyses identified a number of areas in which there are opportunities for research with a high probability of generating impact in the short term and the longer term including:

- Fatigue and physical functioning
- Pain
- Sexual function
- Cognitive functioning
- Employment, finance and return to work
- Emotional distress
- Depression
- Anxiety
- Social needs

It was also found that there is a need for further research at time points significantly removed from diagnosis as current research is focused on the period during or immediately after primary treatment.

The consultation on research gaps and priorities, coordinated by the NCRI SuPaC Collaboratives, led to the identification of a number of research priority themes which were further discussed and prioritised at a consensus conference. The research priorities identified in the NCSI research workstream consultation and consensus conference were:

- Understanding the extent of psychological, social and physical need among cancer survivors; incidence, prevalence and severity
- Development and testing of interventions to address the consequences of cancer and its treatment, including management of symptoms, long term and late effects, and sexual issues
- Questions relating to service organisation and delivery including how services should be organised, innovative service evaluation and outcome measurement
- Development and testing of psychological interventions
- Addressing the needs of carers and families
- Self management

The multiple streams of work commissioned by the NCSI research workstream have led the workstream to conclude that the greatest emphasis should be given to understanding the natural history of cancer survivors and the development of risk stratification tools. As laid out in their 'Priorities for research on cancer survivorship'<sup>14</sup> report there is need to systematically quantify the problems faced by cancer survivors and understand the

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(14) NCSI research workstream (June 2010). Priorities for research on cancer survivorship. Available from: [www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf](http://www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf).

issues faced by survivors of all cancers and for survivors of all ages to enable the most appropriate aftercare for each individual to be put in place. The natural history and risk stratification work will also provide a way of identifying the areas in which there is the greatest need for development of effective interventions to prevent or manage the issues of cancer survivors.

At the NCRI Rapid Review meeting attendees also highlighted the importance of patient-centred choice and empowerment, assessment of stepped-care whereby patients self-manage and are progressed to more comprehensive interventions subject to need, and the development and testing of innovative needs assessment tools including IT-based tools. In addition, discussion at the meeting also emphasised the importance of ensuring that interventions and innovations should be shown to be effective before implementation into practice.

## 4. Research priorities in end of life care

The Department of Health, England End of Life Care Strategy published in July 2008 acknowledged that a considerable body of useful research has been done and is currently underway. Gaps in the evidence base were nevertheless identified as was a need to now give particular emphasis to research in areas other than cancer, which have received little attention. The following topics were listed as providing significant research opportunities:

- Social attitudes to death, dying and bereavement
- Attitudes to end of life issues amongst health and social care professionals
- Demographics of dying – especially for causes of death other than cancer
- Environments of care
- Economics of end of life care
- Prognostication
- Advance care planning
- Communication about end of life issues
- Changing cultures in health and social care
- Education and training
- Understanding current care provision
- Support for carers (during a patient's illness and after bereavement)
- Effectiveness of different models of bereavement care
- Spiritual care
- Care in the last days of life

In discussions at the Rapid Review meeting particular emphasis was placed on the need to develop models of care which are relevant to different settings and different diseases. Investigators with good quality research proposals in this area would be well-placed to secure funding from the Department of Health, England's NIHR and other government Health Departments in the devolved nations. This was one area where partners thought that facilitating access to existing schemes could help to boost

research which had already been identified as strategically important.

Other topics on the list were also endorsed and the potential for use of modern information technology in communication was particularly highlighted. An additional topic was added by the palliative care doctors present who reported that they do not have the necessary tools for fully effective management of pain and other symptoms. Research in these areas would need to include some basic understanding of biological mechanisms and translational research to develop new interventions which should attract a different range of funders including the Medical Research Council, Cancer Research UK and some other NCRI partners that operate in response mode.

As part of their End of Life Care Strategy, the Department of Health, England commissioned an End of Life Care Intelligence Network (NEoLCIN) for England which came on stream in May 2010. Modelled in part on the NCIN this will provide data and analysis on issues such as place of death and service utilisation during the months before death.

It was also acknowledged that diseases other than cancer would bring their own issues needing attention, for example the management of dementia. These will need to be addressed in detail with a wider group of funders, including, though not exclusively, members of the UK Age Research Forum.

While some appropriate funding streams are available, it will take more than money to move this field forward in the UK. There is also a need for leadership, further capacity-building and access to a range of expertises including health economics and evaluation methodology. Means should be sought to speed up the pathway from innovation to implementation, whilst also ensuring a sufficient evidence base. The Macmillan Palliative and Cancer Care Research Collaborative model is one that can be built upon<sup>15</sup>.

(15) [http://learnzone.macmillan.org.uk/file.php/229/delegate-showcases/Palliative\\_and\\_Cancer\\_Care\\_Research\\_Collaborative\\_poster.pdf](http://learnzone.macmillan.org.uk/file.php/229/delegate-showcases/Palliative_and_Cancer_Care_Research_Collaborative_poster.pdf). Requires registration to the Macmillan Learn Zone.

## 5. Challenges

NCRI partners agree that the progress made since 2004 shows the merit of funders working in partnership and of investigators collaborating across disciplines and institutions: they wish to continue this approach. The opportunities described above, together with challenges set out below, and the complexity of a multi-funder environment, suggest that there is scope for partnership working to become both deeper and wider, in particular to extend well beyond cancer in so far as end of life care research is concerned. Notwithstanding a difficult financial climate, this does not necessarily mean the setting up of many more specialised funding streams. There are schemes available for researchers in the areas of survivorship after cancer and end of life care, though they do need to be more clearly signposted and researchers should be encouraged to make full use of them.

Other needs which emerged from the Rapid Review meeting and other discussions, and which may prove challenging include:

- How to bring the Collaboratives to a point of sustainability in both developing early career scientists and securing more competitive programmatic funding amongst established investigators – especially as a second round of dedicated funding is not being made available
- Promulgating collaboration and partnership beyond the Collaboratives
- Developing a genuinely national collaborative network which is professionally and geographically inclusive and outward-looking
- Moving towards reaping tangible benefits for patients from the research which is already under way – the challenge of implementation
- Bringing in more expertise in health economics

- Developing and applying more pragmatic research methods – recognising the merits of practice-based evidence as well as evidence-based practice
- Aiming for a higher profile for UK research by publishing more work in international journals
- Increasing the involvement of younger researchers in implementing the actions arising from this review and in particular in the CS(D)Gs and their subgroups and working groups
- Developing the academic workforce and ensuring that career pathways exist across the full range of disciplines needed, bearing in mind their diversity

Some issues raised are largely outside the remit of NCRI. They include concerns that the successor to the Research Assessment Exercise, known as the Research Excellence Framework, will similarly disadvantage multi-disciplinary research, and the place of palliative medicine within medical school curricula. These issues will be brought to the attention of the relevant authorities.

## 6. Action Plan

A portfolio of actions is needed to fully address needs, opportunities and challenges, as well as accommodating the interests of all stakeholder groups. As this review was being completed, a new government has been elected in the UK and has indicated a commitment to reduce public expenditure in order to address the national debt. All government partners and Research Councils in NCRI will be affected by this and other sectors will experience knock-on effects. NCRI needs to be realistic in its plans, looking for imaginative solutions that leverage existing resource in the short-term, while larger-scale ambitions can be identified but are unlikely to be financed until later.

### 6.1 Leadership

Underlying all the actions which follow is a wish among research funders to work together in a way that fosters collaboration in the research community, and enables them to meet their own organisational goals, whilst also contributing to a coherent national effort that achieves best value and benefit for patients from the available investment. This needs leadership, the support of a range of partners, and coordination. This is no less important in the current financial environment; in some respects it is now even more important to be able to demonstrate best value. To achieve these aims, Professor Sir Kenneth Calman will chair a UK Steering Group for research in survivorship after cancer and end of life care. In this role, he will champion research in these areas, raising its profile and leading the coordination and integration of the three strands of the action plan. The Steering Group will comprise research funders and experts and will be supported by dedicated resource within the NCRI Secretariat.

Consumers also have a leadership role to play in helping to empower patients and inform them about research and the benefits of participation; they can also help to ensure that the results of research are fed back to patients and families. Consumers will continue to be represented in all NCRI's actions in survivorship after cancer and end of life care, to help shape plans and give an added dimension to the debate.

### 6.2 Action 1: Promote investigator-led research through existing funding schemes

The fastest way to inject more funding into the areas of need is for investigators to submit proposals through existing funding streams. A number of research funders have programme, project and training grant schemes which can be tapped for research in survivorship after cancer and end of life care, and they believe that investigators could be taking much greater advantage of them. All aspects of research highlighted in sections 3 and 4 above could in principle be pursued in this way.

Another cost-effective approach to support research would be to develop proposals which build on existing cohorts of cancer patients or prospective population-based cohorts with a significant incidence of cancer.

NCRI is seeking ways to raise the awareness of researchers to funding schemes, and to help less-experienced investigators to build confidence and develop grantsmanship skills. The funding environment is fluid; many funders now issue calls for proposals which are each targeted differently, rather than having standard grant schemes. A simple catalogue of funding opportunities will soon be out of date unless it is constantly updated which is unlikely to be feasible. During 2010, action has therefore focused on developing

guidance on how to keep up to date with all the opportunities and to make the most of them, with an emphasis on links to other websites rather than developing a detailed information repository of our own. This Grantsmanship Gateway ([www.ncri.org.uk/grantsmanship](http://www.ncri.org.uk/grantsmanship)), which went live in October 2010, will be supplemented by meetings which will promote the guidance, foster collaboration and may provide opportunities to meet the funders and research networks and establish protocol development groups. Progress will be reviewed early in 2011 and further actions agreed as necessary.

NCRI partners have decided not to provide further funding to the Supportive and Palliative Care Collaboratives beyond the initial £5m, and this is in part recognition that they have already delivered increased capacity for research in this area. Professor Sir Kenneth Calman and the NCRI Secretariat will work with senior investigators from the Collaboratives to identify any remaining infrastructural needs and consider how best they can be met.

### **6.3 Action 2: Target specific areas of research need**

The Rapid Review meeting, and some subsequent meetings of funders, have considered the areas of research priority that were emerging and how well these are matched by current funding opportunities. There are many areas of need and at present it is not possible to target all of them specifically. Three will be focused on in the first instance:

### **6.4 Action 2.1: End of life care research**

In October 2009, Marie Curie Cancer Care announced their plan to invest £1m per annum in a new national programme for end of life care research in the UK and a call for proposals was released in March 2010.

The Marie Curie Cancer Care research programme is being run in collaboration with Cancer Research UK who will provide expert advice on research applications, grants funding and the peer review process. Outcomes from the first call are expected in November 2010.

In October 2010, Marie Curie Cancer Care and Dimbleby Cancer Care released a call for proposals for research on the use of volunteers to support end of life care<sup>16</sup>. This fund, which has £0.5m to allocate for the highest quality research in 2010/11, seeks to support research to understand the potential for effective interventions using volunteers, establish the evidence base for how volunteers may improve care and understand the limitations and costs of using volunteers.

In addition NCRI will start to foster networking among funders and researchers in end of life care, and links to other organisations such as the NEoLCIN. As a first step, NCRI, the Wellcome Trust and the UK Age Research Forum convened a meeting in May 2010 of research funders who may be interested in supporting a broader programme of research in end of life care, to identify where they may have common interests and how to take them forward. A number of themes emerged including the importance of communication at the end of life, preparation for bereavement for carers and the need to develop and evaluate interventions to improve the well being and manage the co-morbidities and co-conditions of those at the end of life: these, and other, themes will form the focus of future discussion and debate. By ensuring that all major funders with an interest in end of life care research are brought together, NCRI will seek to ensure that activities are coordinated whether taken forward individually or through joint actions.

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(16) Available from [www.dimblebycancer.org/upload/file/N475\\_call%20for%20research\\_Dimbleby\\_DL\\_pres4.pdf](http://www.dimblebycancer.org/upload/file/N475_call%20for%20research_Dimbleby_DL_pres4.pdf).

## **6.5 Action 2.2: Natural history of cancer survivorship and risk stratification**

The research workstream of the NCSI has recommended that “the highest priority for research in cancer survivorship is to understand the ‘natural history’ of survivorship and to create risk stratification tools for all cancers and for survivors of all ages”<sup>17</sup>. Macmillan Cancer Support, working closely with the NCIN, is committed to commissioning additional research in this area and will in the first instance arrange a workshop meeting with other potential funders to discuss the shaping of such research. This will include defining what is meant by ‘natural history’ and identifying where the greatest gains might be made from investment, for example in which tumour types is there the greatest scope to improve quality of life.

## **6.6 Action 2.3: Health services research and economic assessment**

Another area ripe for commissioned research is the evaluation of care pathways including economic assessment. The starting point may again be a workshop and there will need to be consideration of the most appropriate methods and how they can be standardised, so that evaluations are comparable. In the first instance the focus will be cancer survivorship, with an intention to link to the NCSI, and a number of NCRi partners are potentially interested, as and when resources allow. It may evolve later into other long-term conditions and/or end of life care, with the possibility of attracting a wider range of partners in either case.

## **6.7 Other possible areas for targeted actions**

The research community and portfolio of projects investigating the psychological and

social impact of cancer remain modest in size. While the Psychosocial Oncology CSG has helped to develop new work, confidence has been dented by the decision of Cancer Research UK to withdraw from the field. NCRi will initially promote existing funding schemes as outlined in Action 1 and will work with researchers in this area to ensure that psychological and social research is given the boost that it needs.

At the Rapid Review meeting, clinicians agreed that they need better tools for dealing with physical symptoms experienced by cancer patients, including pain, fatigue and cachexia. The modest capacity-building grants provided as part of the initial NCRi SuPaC initiative have been successful in providing stepping stones for investigators to secure further grant funding or more senior appointments. This is one model that might be used again or further developed by NCRi partners, as and when resources allow.

## **6.8 Action 3: Enhance collaboration with the research networks in the NHS**

While the CS(D)Gs in Palliative Care, Psychosocial Oncology, Primary Care and Complementary Therapies now all have established portfolios of trials in the NCRN Portfolio, only a subset of cancer networks are entering patients. The NCRN Coordinating Centre will take steps to increase awareness and interest amongst the local cancer networks and will provide a conduit for further interactions with relevant primary care research networks and comprehensive local research networks (CLRNs) in England. Similar approaches will be explored in Scotland, Wales and Northern Ireland. Opportunities for collaboration between research networks and researchers will be promoted in the events referred to in Action 1. For end of life care research, links with other topic-specific networks will also be explored.

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(17) NCSI research workstream (June 2010). Priorities for research on cancer survivorship. Available from: [www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf](http://www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf).

# Appendix A: Participants in the NCRI Rapid Review of research in survivorship after cancer and end of life care meeting, held 13–14 July 2009

## Chair

Professor Sir Mike Richards, National Cancer and End of Life Care Director for England

## Independent experts

Professor Sir Kenneth Calman, Chair, NCRI

Professor Neil Aaronson, The Netherlands Cancer Institute, The Netherlands

Professor Stein Kaasa\*, Norwegian University of Science and Technology, Norway

Professor Sir Andy Haines\*, London School of Hygiene and Tropical Medicine, London

## Researchers

Dr Bill Noble\*, University of Sheffield

Professor Julia Addington Hall\*, University of Southampton

Professor Sheila Payne\*, University of Lancaster

Professor Michael Sharpe\*, University of Edinburgh

Professor Alison Richardson\*, Kings College London

Professor Mike Bennett\*, University of Lancaster

Professor Eila Watson\*, Oxford Brookes University

Professor Galina Velikova\*, University of Leeds

Professor Henrik Møller\*, London School of Hygiene and Tropical Medicine

## Funders

Dr Sarah Cant, Breakthrough Breast Cancer

Dr Fiona Reddington, Cancer Research UK

Dr Helen Campbell, Department of Health, England

Dr Joy Todd, Economic and Social Research Council

Dr Jim Elliot\*, Macmillan Cancer Support

Dr Catherine Boyle, Macmillan Cancer Support

Dr Jane Maher, Macmillan Cancer Support

Dr Teresa Tate, Marie Curie Cancer Care

Dr Karen Finney, Medical Research Council

Dr Ian Lewis, Tenovus

Mr John Neate, The Prostate Cancer Charity

Dr Serena Carville, UK Age Research Forum

## Consumers

Mr Derek Stewart OBE

Mr Roger Wilson

Ms Joanna Eley

Mr Peter Rainey

## Secretariat

Dr Jane Cope, NCRI

Dr Karen Groot, NCRI

Ms Julie Flynn, Research Development Coordinator, Complementary Therapies CSDG

## NCRN

Dr Karen Poole, Assistant Director

Those marked with \* attended 13 July only while all others attended both days of the Rapid Review meeting.

## Appendix B: Glossary of terms and acronyms

<b>ACI</b>	Actual Citation Impact	<b>ESRC</b>	Economic and Social Research Council
<b>BIOMED</b>	Filter used by Evaluametrics to identify research articles and reviews on biomedicine	<b>GDP</b>	Gross Domestic Product
<b>CaRD</b>	NCRI Cancer Research Database	<b>MRC</b>	Medical Research Council
<b>CECo</b>	Cancer Experiences Collaborative, one of the NCRI SuPaC Research Collaboratives	<b>NCDR</b>	National Cancer Data Repository
<b>CLRNs</b>	Comprehensive Local Research Networks	<b>NCIN</b>	National Cancer Intelligence Network
<b>Collaboratives</b>	NCRI SuPaC Research Collaboratives – CECo and COMPASS	<b>NCRI</b>	National Cancer Research Institute
<b>COMPASS</b>	COMPLex interventions: Assessment, trials and implementation of Services Collaborative, one of the NCRI SuPaC Research Collaboratives	<b>NCRN</b>	National Cancer Research Network
<b>CS(D)G</b>	Clinical Studies (Development) Groups, specifically in the case of this report the Palliative Care CSG, the Complementary Therapies CSDG, the Psychosocial Oncology CSG and the Primary Care CSDG	<b>NCSI</b>	National Cancer Survivorship Initiative
<b>CSO</b>	Common Scientific Outline	<b>NEoLCIN</b>	National End of Life Care Intelligence Network
<b>CTU</b>	Clinical Trials Unit	<b>NHS</b>	National Health Service
<b>DH</b>	Department of Health, England	<b>NIHR</b>	National Institute for Health Research
		<b>ONCOL</b>	Filter used by Evaluametrics to identify research articles and reviews on oncology and cancer
		<b>PCI</b>	Potential Citation Impact
		<b>SuPaC</b>	Supportive and Palliative Care
		<b>SUPAC</b>	Filter used by Evaluametrics to identify research articles and reviews on supportive and palliative care
		<b>WoS</b>	Web of Science

# Appendix C: Summary of data from the NCRl Cancer Research Database

## Introduction

The NCRl Cancer Research Database (CaRD), which includes the cancer research spend of all NCRl partners, was analysed to determine how much NCRl partners spent on research in survivorship after cancer and end of life care<sup>18</sup>. For each research award NCRl collects an abstract of the research and details of the funding awarded. Every project is subsequently coded according to the Common Scientific Outline (CSO) which classifies the research to at least one of 7 major categories from biology (CSO 1) to scientific model systems (CSO 7)<sup>19</sup> and by disease site.

## Method

Awards with relevance to survivorship after cancer and end of life care have codes within the CSO 6 major category (cancer control, survival and outcomes research). All studies with a CSO 6 code, sometimes in combination with another code, were individually assessed for relevance. In the majority of cases awards were considered 100% relevant, and thus 100% of the funding was included in our analyses, although in some cases, for example where quality of life is studied as a secondary endpoint to a trial, the relevance could be considered as low as 10%.

Our analysis excludes grants which fund generic research support infrastructure, for example funding for the NCRN, which would otherwise swamp the portfolio, however funding for the NCRl SuPaC Research Collaboratives is included at 100% because this infrastructure is directly applicable to

research in survivorship after cancer and end of life care.

In order to understand in greater depth the survivorship after cancer and end of life care research funded by NCRl partners, the awards were categorised on the basis of the primary aim of the research into one of a number of mutually exclusive research themes.

## Analysis

A total of 138 studies with relevance to survivorship and end of life care research were identified, funded by 10 of NCRl's 20 research funding partners. In 2009 the total annual spend on survivorship after cancer and end of life care research by NCRl partners was £11.5m, constituting 2.3% of the total NCRl partner cancer research spend in 2009.

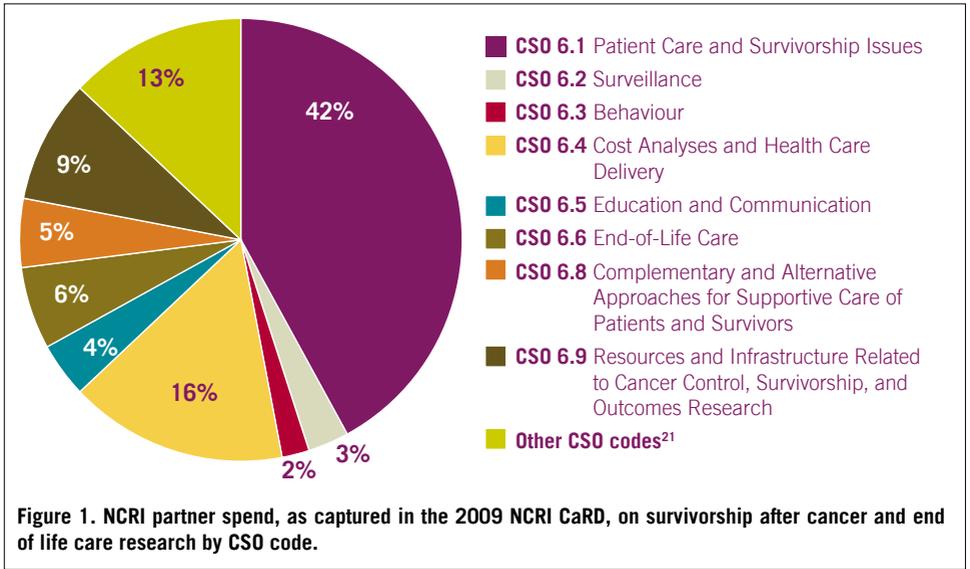
Figure 1, overleaf, shows that the largest portion of this spend was on CSO 6.1 (patient care and survivorship issues), followed by CSO 6.4 (cost analyses and health care delivery). A significant amount of spend was also attributed to CSO 6.9 which identifies spend on resources and infrastructure related to research in cancer control, survival and outcomes research.

Analysis of spend by disease site shows 45% of the research was considered relevant to all cancer types while the remainder was considered relevant to a specific cancer type or types. Specifically 22% of site-specific research spend was focused on breast cancer, 20% on prostate cancer<sup>20</sup>, 17% on lung cancer, and 13% on colon and rectal cancers.

(18) The NCRl CaRD includes details of the direct spend on cancer research (consumables, salaries etc) and spend that directly supports and enables cancer research of NCRl partners in a given year. The NHS Support Costs of cancer research provided by government Health Departments is not included in CaRD, except where the support is provided via cancer specific networks such as the NCRN.

(19) The 7 CSO categories are CSO1 – Biology; CSO2 - Aetiology (causes of cancer); CSO3 – Prevention; CSO4 - Early detection, diagnosis, and prognosis; CSO5 – Treatment; CSO6 - Cancer control, survivorship, and outcomes research; CSO7 - Scientific model systems. For more information on the CSO please go to [www.cancerportfolio.org/cso.jsp](http://www.cancerportfolio.org/cso.jsp).

(20) The large-scale NIHR ProtecT trial has been included in this analysis. This study, which is focused on evaluating the effectiveness, cost-effectiveness and acceptability of different prostate cancer treatments, has been given 33% relevance to survivorship after cancer which is equivalent to around £0.8m per year.



Further analysis of the awards, as shown in Table 1 opposite, indicates that 29 of the projects were focused on service delivery and health economics exploring for example different follow up regimes, different palliative care services and continuity of care. The specific physiological consequences of cancer and its treatment, for example difficulties in swallowing and infertility, were the focus of 27 projects while a further 17 were on understanding and managing generic symptoms of cancer principally, cachexia, fatigue, and pain. Surveys of patient experience and general quality of life studies also make up a significant proportion of the portfolio.

(21) Awards may be given more than one CSO code, including CSO codes outside the CSO 6 major category. For example awards on the immediate side effects and toxicities of cancer treatment may be given a CSO 6.1 code alongside a CSO 5 (Treatment) code: the 'Other CSO codes' category within Figure 1 includes this spend. For further information on CSO codes and sub-codes please go to [www.cancerportfolio.org/cso.jsp](http://www.cancerportfolio.org/cso.jsp).

<b>Research theme</b>	<b>Number of projects within the 2009 CaRD</b>
Service delivery and health economics	29
Specific physiological consequences of cancer and its treatment	27
Understanding and managing generic symptoms of cancer	17
Surveys of patient experience including care needs, experience of care and dying with cancer	16
Quality of life studies	14
Psychological and mental health issues relating to disease, treatment, dying	9
Socio-cultural aspects of cancer	7
Other and general projects	19

**Table 1: Primary aim of the survivorship after cancer and end of life care projects supported by NCRI partners in 2009. The 'Other and general projects' category includes for example studies on self-management, work and finance, and end of life care and bereavement research which did not fit into any of the other research themes.**

# Appendix D: Bibliometric analysis of supportive and palliative care research

## Introduction

NCRI commissioned Evaluametrics to undertake a bibliometric analysis of supportive and palliative care research to build on an analysis of the same topic carried out for the 2004 NCRI Supportive and Palliative Care Research in the UK report. This latest study covers research outputs between 1997 and 2008.

## Methodology

The subject, supportive and palliative care (SuPaC) in cancer and palliative care in non-malignant diseases and disorders, was defined as follows:

*Supportive and palliative care research in cancer includes research to help patients, and their families and carers, to cope with the physical and psychological effects of cancer and its treatment. It includes: self help and support, symptom control, social and spiritual support, complementary therapies and rehabilitation, and it extends into end-of-life and bereavement care. It also includes palliative care for all diseases and disorders.*

Papers (articles and reviews) in the subject area were identified by means of a custom-built filter (designated SUPAC). Papers published between 1997 and 2008 were taken from both the Science Citation Index (expanded) and the Social Sciences Citation Index on the Web of Science (WoS). The output in the supportive and palliative care field was compared with the output within all cancer research and the biomedicine field using filters, ONCOL and BIOMED respectively, previously developed and

assessed by Evaluametrics. The outputs were also analysed at a world-wide and country level.

Further analyses were undertaken on research quality as indicated by the numbers of citations received and the impact factors of the journals in which the papers of concern are published: Actual Citation Impact (ACI) and Potential Citation Impact (PCI) respectively. Research esteem was measured by the percentage of reviews in research output (articles and reviews)<sup>22</sup>.

## Results

### *World and UK research output in supportive and palliative care*

Over the twelve-year period (1997-2008), the number of papers published world-wide per year in SuPaC increased by almost a factor of three from 1089 to 3021. This is a much faster rise (annual average percentage growth = 8.5%) than for cancer overall and for biomedicine (Figure 2). There has also been a higher annual percentage growth in the UK's output of SuPaC papers when compared to output in cancer research overall and biomedicine (Figure 3). SuPaC papers represented just 5% of all UK cancer research in 1998, but this proportion had risen to almost 8% by 2007.

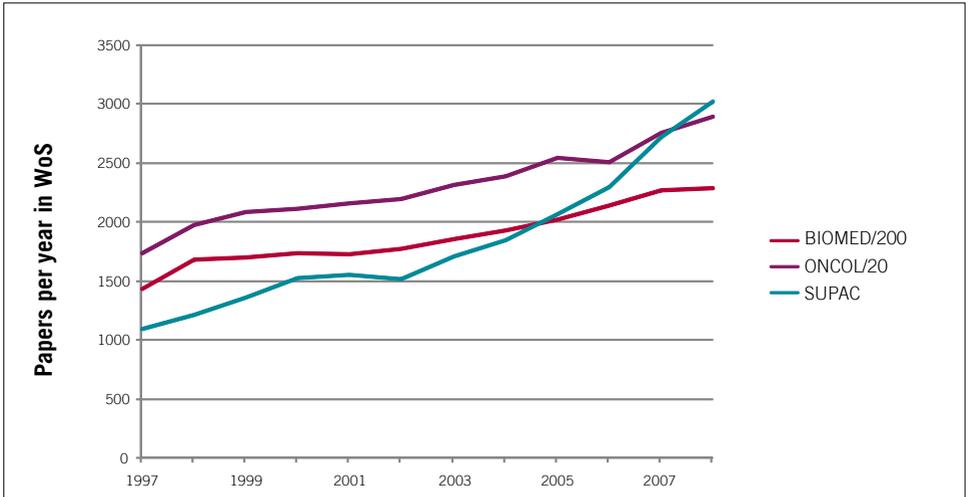
Comparison of the average annual SuPaC output from different countries between 1997 and 2008 indicates that the UK is maintaining its position in the SuPaC field, coming second behind the USA in this study and the previous bibliometric study which assessed SuPaC papers published 1994-2002<sup>23</sup>. In the latest study, the average

(22) Lewison (2009). The percentage of reviews in research output: a simple measure of research esteem. Research Evaluation, volume 18, no 1, pp 25-37.

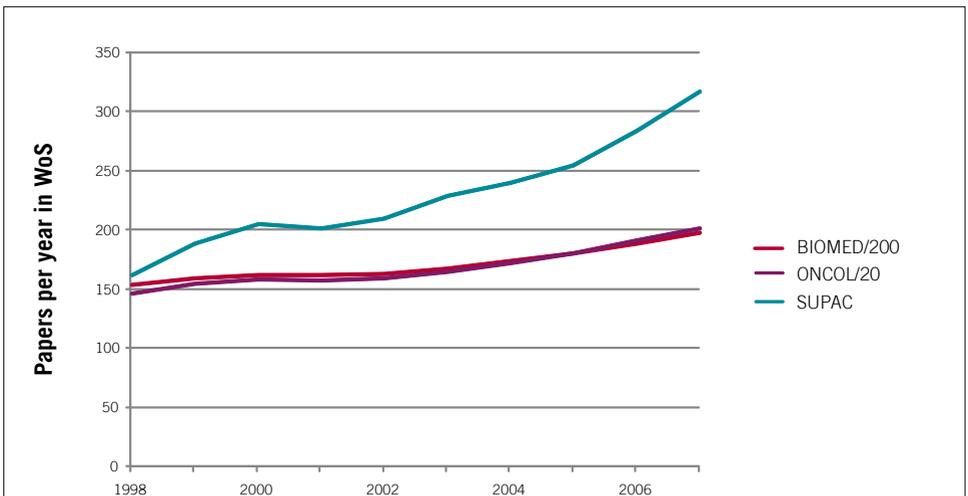
(23) For further details of the previous bibliometric analysis see the NCRI Supportive and Palliative Care Research in the UK report (2004) available from: [www.ncri.org.uk/includes/Publications/reports/ncri\\_support\\_and\\_palliative\\_report\\_web.pdf](http://www.ncri.org.uk/includes/Publications/reports/ncri_support_and_palliative_report_web.pdf).

annual output of the UK is 196 papers, while that of the USA is 662 papers. The UK average annual output in SuPaC is greater than that of Germany (116), Canada

(115) and Japan (73). When the figures are adjusted for gross domestic product (GDP), to give average annual output of papers per 10 billion of GDP, the UK (at 0.89) is level



**Figure 2. World-wide annual output of papers in supportive and palliative care (SUPAC), all cancer research (ONCOL/20) and in all biomedicine (BIOMED/200); articles and reviews in the WoS.**



**Figure 3. The UK's annual output of papers in supportive and palliative care (SUPAC), all cancer research (ONCOL/20) and in all biomedicine (BIOMED/200); articles and reviews in the WoS; three-year running means.**

with the Netherlands and ahead of the USA (at 0.47) however it falls behind Sweden (at 1.39), Israel (at 1.01) and Canada (at 0.94).

### *Research quality and impact*

Potential and actual citation impact scores (PCI and ACI) were obtained for SuPaC papers from 1997-2004. The world averages were 10.3 and 9.5 cites in 5 years per paper; the latter is substantially lower than the figure for the oncology field as a whole (about 14 cites). The UK lies in 12th and 11th place by PCI and ACI respectively behind the USA, the Netherlands, Denmark, Norway and Canada.

Research esteem, as measured by the percentage of reviews within the research output, for SuPaC is almost equal to the value of the oncology field as a whole and is rising. The UK rates highly by this measure, as do Belgium, Italy, Greece, the USA and France.

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