Suggested citation
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I am delighted to introduce the report ‘Impact of the NCRI Supportive and Palliative Care (SuPaC) Initiative’, a review of the development of research capacity in supportive and palliative care and of the benefits of the initiative to patients, the public and the NHS.

This initiative was established following the identification of the low level of NCRI Partner funding for research in this important area and a number of barriers to progress including the fragmentary nature of the workforce and a lack of interdisciplinary working and consumer involvement. Supported by a number of NCRI Partners with an investment of £5m it was a new model of funding, one which principally aimed to support activities which promoted collaboration and research capacity development through support of two SuPaC Research Collaboratives CECo and COMPASS and the Capacity Building Grant (CBG) scheme.

This analysis has shown that the work undertaken by researchers linked to the initiative was broad and generated impact on a number of different levels including influencing clinical guidelines, developing tools for the clinic and research and generating changes in practice. The research undertaken within the SuPaC Collaboratives and by CBG grantees was facilitated and strengthened by the many interactions it generated between researchers and consumers across disciplines, organisational boundaries and at all stages of the research process. These interactions were an important component to the success of this initiative bringing new researchers into the field, generating an increased awareness of researchers’ skills encouraging greater collaboration and co-working and developing effective ways of consumer involvement.

The impact seen as a result of this initiative is encouraging however it is important for researchers, consumers, research funders and policy makers to continue to undertake and support research in this important area and to ensure routes for implementation of research findings into policy and practice are identified and followed up in a timely manner.

Professor Sir Mike Richards
Chief Inspector of Hospitals, Care Quality Commission
Chair of the NCRI Board (2006-2008)
Chair of the NCRI Strategic Planning Group on Supportive and Palliative Care Research in the UK (2003-2004)
The 2002 NCRI Strategic Analysis identified the low levels of funding by NCRI Partners in supportive and palliative care research.\(^1\) In response to this a group of research funders and a consumer assessed research outputs, research underway, the size and makeup of the research workforce and sought the views of researchers through a consultation.* The resulting publication - the 2004 NCRI Supportive and Palliative Care Research in the UK report - identified that the research workforce was fragmented, with relatively little interdisciplinary working and collaboration with researchers outside the field of cancer.\(^2\) It also identified a lack of support for specific research and research support roles, a need to develop and refine research methodologies in an area in which trial designs are often complex, and a need to develop consumer involvement.

To begin to overcome the issues six NCRI Partners (Department of Health, England, Medical Research Council, Cancer Research UK, Marie Curie Cancer Care, Macmillan Cancer Support and the Economic and Social Research Council) invested a total of £5m over five years into the Supportive and Palliative Care (SuPaC) initiative. From 2006 the SuPaC initiative supported the establishment of two SuPaC Research Collaboratives and a Capacity Building Grant (CBG) scheme.

The objectives of the SuPaC initiative were to develop critical mass with a span of expertise, increase capacity for high quality research in supportive and palliative care, nurture and develop high quality researchers of the future, tackle methodological challenges, develop consumer involvement and generate maximum impact on policy and practice. The funding supported activities such as research workshops, methods development, pilot studies, career development of early stage researchers and consumer involvement, as opposed to full-scale research projects.

With a focus on research capacity development the funding model was new to NCRI Partners and during 2013 it was considered timely by NCRI Partners to undertake an evaluation of the SuPaC initiative in order to:

- understand the benefit to the research community of the SuPaC initiative and how they are being sustained
- understand the benefits that are beginning to accrue to patients, the public and the NHS as a result of the initiative, and other related research activity.

During 2013 the NCRI Secretariat undertook an evaluation based on interviews with key members of the SuPaC Collaboratives and analysing the contents of the final reports submitted by the SuPaC Collaborative directors and CBG grantees and other relevant materials including reports and peer-reviewed journal articles.

The evaluation has highlighted, through a series of case studies, a significant amount of objective evidence of the positive and broad impact of the SuPaC initiative. The impact seen includes the engagement with supportive and palliative care research of novice researchers and the personal career development of researchers at all levels and from a wide range of clinical and non-clinical research disciplines. The research undertaken had led to the development and implementation of clinical guidelines into practice and a number of assessment tools into practice and research. There is more extensive consumer involvement in supportive and palliative care research, and greater confidence of researchers in undertaking consumer involvement.

* Consumers are cancer patients, carers and others affected by cancer.

Executive summary
There is also evidence of a more collaborative ethos within the research community, the leveraging by researchers of substantial resources from national and international sources, and increased recognition of the strength of the UK supportive and palliative care research field as exemplified through the launch of a new journal in the area and the international collaborations of many of the researchers linked to the SuPaC initiative.

The SuPaC initiative, and the collaborative way of working it encouraged, is one that has significantly benefitted the research community. Going forward it will be important to continue to foster the culture of collaboration and interdisciplinary working through encouragement from funders, support from universities and willingness from researchers.
The 2002 NCRI Strategic Analysis identified the low levels of funding by NCRI Partners in supportive and palliative care research (approximately 4.3% of the NCRI Partner cancer research portfolio).\(^1\) In response to this a group of research funders and a consumer, chaired by Professor (later Sir) Mike Richards, assessed research outputs, research underway, the size and makeup of the research workforce and sought the views of researchers through a consultation.* The analyses led to the publication of the 2004 NCRI report: Supportive and Palliative Care Research in the UK.\(^2\) This identified that the research workforce was fragmented across multiple sites, with relatively little interdisciplinary working and collaboration with researchers outside the field of cancer. The group also identified a lack of fellowships, the need for specific and dedicated administrative and statistical research support, the need to develop and refine research methodologies in an area in which trial designs are often complex with a lack of agreement on outcome measures, and the need to develop consumer involvement.

To begin to overcome the issues a consortium of six NCRI Partners pledged a total of £5m to establish Supportive and Palliative Care (SuPaC) Research Collaboratives linking universities and supporting research groups to develop research capacity and collaborate more widely and effectively. It also supported a Capacity Building Grant (CBG) scheme. The whole initiative was supported by the Department of Health, England, the Medical Research Council (MRC), Cancer Research UK (CR-UK), Marie Curie Cancer Care, Macmillan Cancer Support and the Economic and Social Research Council. A management committee comprising the funders, a consumer and Professor Richards was set up to steer the initiative. The grant awards were administered by Marie Curie Cancer Care and the management committee, which also included a consumer, was chaired by their Medical Adviser, Dr Teresa Tate.

This evaluation of the NCRI SuPaC initiative has been undertaken by the NCRI Secretariat, in order to:

- understand the benefit to the research community and how they are being sustained
- understand benefits that are beginning to accrue to patients, the public and the NHS as a result of the initiative, and other related research activity.

* Consumers are cancer patients, carers and others affected by cancer.
The specific objectives of the SuPaC Collaboratives were to:

- Create the necessary critical mass in an area where expertise is spread thinly; each Collaborative was to consist of a number of academic organisations working together as a single partnership.
- Develop the necessary span of expertise to address this area; each Collaborative was to consist of individuals and groups from a wide range of different research disciplines and clinical professions working in collaboration.
- Develop methodological approaches to tackle challenges in this area; each Collaborative was to develop effective collaboration between researchers in supportive and palliative care for cancer, and those working in other relevant areas.
- Increase the capacity of the UK to conduct high quality research in this area; each Collaborative was to conduct some of its research in collaboration with other smaller or less well developed research groups.
- Ensure that the research can have the maximum positive impact on policy and practice; the Collaboratives were to involve service users, and other policy and practice stakeholders, in all their research. This could include user-led research. The Collaboratives were also to communicate their research findings to stakeholders in an active manner.
- Ensure the nurture and development of high quality researchers of the future; each Collaborative was to incorporate a strong, well-managed research training/career development programme.

The SuPaC Collaboratives aimed to complement the set up, during 2003 and 2004, of NCRI Clinical Studies Development Groups in Palliative Care, Primary Care, Psychosocial Oncology and Complementary Therapies. These groups were particularly focussed on the development of large scale late phase clinical studies in areas including supportive and palliative care.

Following a competitive call for proposals for NCRI SuPaC Research Collaboratives during 2005 four proposals were received and two were funded. In 2006 the Cancer Experiences Collaborative (CECo) and the COMPlEx interventions: ASsessment, trials and implementation of Services (COMPASS) Collaborative, were each awarded five year grants of £1.9m. These funds were awarded for activities such as research workshops, methods development, pilot studies, career development of early stage researchers and consumer involvement. They were not intended to support full-scale research projects but to develop capacity and improve the chances of securing support for full-scale projects and programmes from mainstream competitive funding sources.

The CECo Collaborative comprised a partnership between researchers at five universities: Lancaster University, University of Manchester, University of Nottingham, University of Liverpool and the University of Southampton. Professor Sheila Payne (Lancaster University) and Professor Julia Addington-Hall (University of Southampton) co-directed CECo in the early years with Professor Payne acting as sole Director of CECo latterly. The research strands of CECo were:

- Innovative approaches to complex symptoms
- Older people towards the end of life: Priorities, processes and places
- Methodology.

The COMPASS Collaborative was led through three universities: the University of Edinburgh, University
of Leeds and King’s College London (KCL), with Professor Alison Richardson (then KCL) and Professor Michael Sharpe (then University of Edinburgh) as co-Directors in the first instance and latterly Dr Dan Stark (University of Leeds) and Professor Irene Higginson (KCL). The research strands of COMPASS focussed on three questions around complex interventions in supportive and palliative care.

- What is the best way of measuring the problems and assessing the need for interventions?
- What is the best way of treating problems for the illness stage and setting?
- How can these treatments best be delivered in clinical practice in a range of settings including hospitals, hospices, the patient’s home and primary care?

The two successful proposals had strengths in areas including the psychological and social impact of cancer, methodological development and service delivery. Because clinical research was less well-represented in the plans of the SuPaC Collaboratives, the management committee decided to set up an additional scheme to boost the capacity for clinical research, in particular in symptom management. This CBG scheme was used to award small grants totalling £830,000 to 11 early-career, largely clinical, researchers. The specific objectives of the CBGs were to:

- support isolated or new investigators in achieving their research potential
- address some of the gaps in the supportive and palliative care evidence base
- link grantees with the funded SuPaC Collaboratives such that they could provide them with the necessary scientific and/or infrastructure support, and thereby help to build sustainable capacity.

In this report, the term ‘SuPaC initiative’ is used to include both the SuPaC Collaboratives and the CBG scheme.
3 Evaluation methods

In undertaking this analysis, we used a number of methods and sources to gain insight into the impact of the SuPaC initiative. Specifically the NCRI Secretariat analysed the contents of the final reports submitted by COMPASS and CECo directors and CBG grantees to the NCRI SuPaC Management Committee in December 2011. This was followed up during 2013 through semi-structured interviews with a number of key members of the SuPaC Collaboratives, further email exchanges and telephone calls with individuals and organisations, and through searches of relevant databases, websites, newsletters, clinical guidelines and journal articles. In what follows references to journal articles, websites or specific sources of information are included where appropriate and available. Appendix 1 includes the names and affiliations of the individuals highlighted in the report who were supported by way of the SuPaC initiative. By looking at examples of the impact of the SuPaC initiative up to 2013 we have also been able to give preliminary consideration to how far they might be sustainable beyond the funding period itself.

In analysing and presenting this material we have borne in mind that the essence of the SuPaC initiative was to catalyse the development of expertise and capacity in a relatively new research field. Therefore standard research outputs such as publications in academic journals are only part of the story. As with evaluating any specific research investment it is also impossible to disentangle its impact from that of other work being funded at the same time. While we cannot demonstrate a direct causal link, we can say that there is a significant amount of circumstantial evidence that the SuPaC initiative has made a difference. As will be shown, this impact can be seen in the personal career development of many specialists, the leveraging of substantial resources from national and international sources, the development and implementation of clinical guidelines and other tools, a more collaborative ethos within the research community, and international influence. In fact, the breadth of impact is such that we cannot hope to capture every example and what has been compiled is effectively a series of case studies. While some of this work may have been done without the investment in the SuPaC initiative, it seems unlikely that such volume of work would have been generated since 2006 without it.
Aside from publishing research findings in academic journals there are other ways that research findings may be disseminated and reach those that can influence policy or practice. CECo and COMPASS associated researchers have been involved in, and led, a number of projects to, for example, develop clinical practice guidelines, information leaflets or training manuals. In undertaking these activities researchers have employed their research expertise and involved others, including other researchers with whom they established collaborations as a result of the SuPaC initiative. A few examples of the impact of the SuPaC initiative on policy and practice are described below.

4.1 Depression in patients with cancer

Professor Michael Sharpe, co-lead of COMPASS and previously based in Edinburgh, has undertaken a succession of trials of care for people with cancer and major depressive disorder which have been facilitated by the collaborations and interactions which COMPASS funding helped to develop and support. Initiated in 2006 with Symptom Management Research Trial (SMaRT) Oncology 1 Professor Sharpe and his team tested a multi-component complex intervention - Depression Care for People with Cancer (DCPC) - in a small proof of concept study. DCPC is an intervention which is delivered by a team including specially trained cancer nurses and psychiatrists working with a General Practitioner (GP) and an oncologist. This was based on a model of care for the management of depression in primary care, ‘collaborative care’, adapted for use in a specialist setting.

Whilst the SMaRT oncology trials and associated studies were led by Professor Sharpe, expertise of researchers in the other COMPASS hubs fed into this work. For example, the experience of Professor Amanda Ramirez and Professor Alison Richardson on nurse training fed in to how to implement the training in the DCPC intervention and ensure that delivery of the intervention remained consistent throughout the trials. Technical exchanges on out-patient screening and psychological trials in cancer also came through the longstanding collaboration between the research groups at the Universities of Leeds and Edinburgh that was further strengthened through COMPASS. Members of COMPASS also served on the SMaRT Oncology Trials Management Committee, including Mr Peter Rainey, a COMPASS Advisory Group member and consumer, and were able to advise the team on aspects of the trials such that they ran smoothly and recruited well.

The first trial, SMaRT Oncology 1, which recruited 200 cancer patients, showed DCPC to be a feasible, acceptable and effective model of care. The proof of concept trial led to two further trials, funded by CR-UK, during the time of COMPASS. The second trial, SMaRT Oncology 2, focussed on cancer patients with estimated life expectancies of over 12 months (cancer survivors) and recruited over 500 cancer patients. It aimed to determine the effectiveness and cost-effectiveness of the intervention. The third trial, SMaRT Oncology 3, focussed on lung cancer patients whom have lower life expectancies. This efficacy trial used an adapted version of DCPC and aimed to recruit 200 patients.

Prior to this research there was little evidence for the prevalence of depression in cancer patients or the optimal care for cancer patients with major depressive disorder as identified by reviews carried out by the group. Recruitment to the SMaRT Oncology studies required patients to complete self-report questionnaires in out-patient clinics to evaluate their symptoms including their level of emotional distress. This evaluation was followed up by a brief telephone-delivered depression
screening interview to identify those patients with major depressive disorder. Through recruitment to the SMaRT trials at cancer centres throughout Scotland the team have data from over 100,000 screening events providing more reliable estimates of prevalence than previously feasible for the UK. The results from SMaRT Oncology 1 give insight into the potential of collaborative care for patients with chronic medical conditions. Since its publication in 2009 it has been cited in National Institute for Health and Clinical Excellence (NICE) guidance for the treatment and management of depression in patients with chronic physical health problems.9 SMaRT Oncology 2 and 3 have found DCPC to be strikingly effective and cost-effective, with publication of the detailed findings of the trials expected in early 2014.8 Professor Sharpe and Dr Jane Walker, who led on the SMaRT Oncology 3 trial, have been invited speakers at a number of prestigious conferences during 2013, including the Association of Psychosomatic Medicine in Atlanta, Georgia, the Royal College of Psychiatrists Faculty of Liaison Psychiatry Conference, Cambridge, UK and American Academy of Psychosomatic Medicine in San Francisco, California. The talks have generated considerable interest from a number of cancer centres, particularly in the USA, in implementing the intervention. In the UK once the trial results are out opportunities to implement this model of care, and measure the effectiveness of such implementation, will be explored further.8

4.2 Planning for the end of life

During the development of CECo’s research priorities Professor Jane Seymour and colleagues identified the need to better understand the self-perceived priorities for care, and needs, of older people at the end of life. This led to a successful application to the Burdett Trust for Nursing to gather the views, experiences and concerns of people about end of life care, and for the further refinement and expansion of a volunteer peer educator training programme for Advance Care Planning (ACP). ACP is the process of discussing and planning ahead in anticipation of the deterioration of a person’s condition and includes establishing a person’s preferences and wishes for care at the end of life. Involving a number of CECo-linked researchers: Dr Katherine Froggat, Dr Amanda Clark and Dr Kathryn Almack, and other collaborators including consumers, the study went on to inform the development and roll out of the ‘Thinking and Planning Ahead: learning from each other’ peer education training in ACP course in 2011 available via the National End of Life Care Programme (NEOLCP) and the Dying Matters Coalition.10

Since its roll out there is known uptake of the peer educator training programme in Devon, London and the Midlands. In North London, Gentle Dusk have developed the Future Matters programme which is based on peer education. They have provided training to over 30 volunteers from five boroughs in North London on end of life care and ACP. These volunteers have since gone on to have over 600 conversations on end of life care and ACP with members of the local community. More recently a number of the volunteers have been matched with GP practices to work alongside them in the primary care setting to deliver end of life care and ACP awareness raising activities.11 Gentle Dusk are currently developing a toolkit for other organisations to learn how to set up and implement the programme.12 In North Devon, following a joint bid by Age UK Devon and Rowcroft Hospice, 12 members of different community groups were trained as peer educators in March 2012. An evaluation undertaken by the facilitators of the North Devon courses showed that the course increased the confidence of the volunteers in initiating difficult conversations on ACP and death and dying and in some cases encouraged people to document their views and preferences.13 Beyond the UK there is planned uptake of the peer educator model in the USA and in New Zealand with a programme focussed in Maori elders, while in the Netherlands it is being used to inform research bids to enable evaluation of the same model.14

The work of Professor Seymour and the wider research group, which included other CECo-linked researchers, went on to inform the 2008 and
2011 NEOLCP guides for health and social care professionals on ACP and the public information leaflet ‘Planning your future care – a guide’. The leaflet, which helps services users have a discussion with those who provide their care on their views and preferences for their future care and should their condition deteriorate, was evaluated in 2010 by the Institute of Healthcare Management. The evaluation concluded that the leaflet helped ‘break the ice’ in conversations that are often difficult to hold and highlighted the different uses made of the leaflet by a wide range of healthcare professions.

In planning and undertaking the work to seek the views of older people at the end of life, within the Burdett Trust for Nursing grant, the research team identified a gap in knowledge regarding the views of lesbian, gay, bisexual and transgender (LGBT) people in the published literature. Addition of a strand focussed on LGBT people enabled their views to be captured and the work has since been published in the top ranking journal Sociology. Generating interest from the NEOLCP Dr Almack and others were subsequently supported through a NEOLCP knowledge transfer grant to develop a guidance document for use by health and social care professionals and others engaging with LGBT people, or their partners, at the end of life. The ‘Route to Success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people’ resource has since been published by the NEOLCP.

Up to December 2012 over 600 hard copies of the ‘Route to Success’ resource had been distributed to individuals and organisations, with copies also available to download from the NEOLCP website. In addition the research and report have been presented at numerous conferences attended by researchers, consumers, policy makers and health and social care staff including the 2012 Showcasing Research, Policy and Practice about End of Life Care for LBGT People conference in London organised by the NEOLCP, National Council for Palliative Care and the University of Nottingham.

A working group has been set up to build on the ‘Routes to Success’ resource involving researchers and representatives from Marie Curie Cancer Care, Help the Hospices, Macmillan Cancer Support, the Social Care Institute for Excellence and hospices. The aims of the LGBT End of Life Stakeholder Group are currently being finalised and may include assessing possibilities for influencing service development, intelligence gathering, workforce development and developing resources for LGBT people and/or mainstream healthcare providers. The Stakeholder
Group also recognise, and aim to act on, the opportunity to develop a model of best practice for ensuring LGBT people’s needs are assessed and met appropriately in all healthcare settings, not just at the end of life.

To further develop recommendations for good practice in end of life care for older LGBT people Dr Almack has secured funding through the Marie Curie Cancer Care Research Programme for a study entitled ‘The Last Outing’. This two year study will examine the impact of sexual and gender orientation on the experience of end of life care for older LGBT people, and explores the familial and friendship networks of older LGBT people that may influence later life experiences towards, and at, the end of life.

4.3 Understanding the needs of carers

Carers are central to enabling older people to remain at home towards the end of life and thus it is important that their needs and concerns, be they psychological, physical, social or financial, are understood and appropriately addressed. Professor Gunn Grande led work to support the routine assessment of carers’ support needs with the development of the Carer Support Needs Assessment Tool (CSNAT) together with Dr Gail Ewing from the University of Cambridge. This tool was developed and psychometrically tested in initial projects involving carers and hospice providers with support from other CECo researchers including Professor Sheila Payne. Further grants, which have also involved Professor Chris Todd, University of Manchester, have led to the testing of the tool ‘on the ground’ in a feasibility trial supported by Dimbleby Cancer Care and a full ‘stepped-wedge’ trial supported by National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB), which opened to recruitment in 2012. Implementation and testing of the tool is also underway in Australia through Silver Chain, a Hospice Home Care (HHC) provider in Western Australia, and funding is being sought for a further project in British Columbia by a group affiliated to the University of Victoria, Canada.

Early engagement with hospices, particularly through the National Association for Hospice at Home, has supported the identification of sites in which to pilot and test CSNAT. In addition to those UK sites involved in the NIHR RfPB trial an additional 40 HHC services are committed to implementing the CSNAT in late 2013 which could go on to benefit 18,000 – 20,500 carers per year. In Australia a report for the Department of Health, Victoria has assessed tools for use in specialist palliative care and recommended the CSNAT for use in assessing the needs of family caregivers over a number of others.

4.4 Assessing and predicting nausea and vomiting

Nausea and vomiting are significant and distressing side-effects for patients receiving chemotherapy and radiotherapy and can lead to reduced quality of life for patients, additional visits to specialists and emergency hospitals and can discourage patients from completing their treatment regimen. In 2009 the European Society for Medical Oncology (ESMO) and Multinational Association for Supportive Care in Cancer (MASCC) held a conference to consider the latest evidence on prevention of chemotherapy- and radiotherapy-induced nausea and vomiting. The conference brought together the findings from ten subcommittees and distilled these into the final clinical guideline published in the Annals of Oncology. Professor Alex Molassiotis, one of the theme leads of CECo, as an expert in the field, was an active member of the ESMO/MASCC Guidelines Writing Group collaborating with researchers and clinicians from across ten countries and five continents.

MASCC have since supported the development of a tool to assess acute and delayed nausea and vomiting particularly focussing on that related to chemotherapy. MAT - the MASCC Antiemesis Tool - is accessible as a free download and has been validated for reliability, clarity and ease of use by the team in Manchester. Furthermore Dr Zoe Stamatak and Professor Molassiotis led translation and testing of the eight-item scale into Greek.
MAT is now available in 11 languages facilitating conversations between clinicians and patients on chemotherapy-induced nausea and vomiting around the world.26

Predicting which patients undergoing which chemotherapy regimens are likely to experience nausea or vomiting has the potential to reduce the symptom burden of patients and to ensure that patients are on the optimal antiemetic regimen earlier in their cancer treatment. Using some remaining funds from CECo Professor Molassiotis was able to commission the development of a Chemotherapy-Induced Nausea and Vomiting (CINV) risk prediction tool.27 Validation of the tool by researchers at Manchester, including Professor Molassiotis and Dr Stamataki, showed that younger age, a history of nausea or vomiting, anxiety and fatigue are all associated with a higher risk of CINV.28

A 2011 study undertaken by Alex Molassiotis and two CECo fellows, Dr Stamataki and Dr Sarah Brearley, suggested that uptake of the MASCC/ESMO guidelines was slow despite a later study highlighting the benefits of guideline-consistent antiemetic therapy use: guideline-consistent antiemetic use is particularly effective in reducing acute nausea and vomiting and has some benefits in reducing delayed nausea and vomiting.29, 30 Treatment according to guidelines also reduces emergency hospital, specialist and GP visits thereby having the potential to reduce costs.

### 4.5 Management and measurement of cough

Cough is a common symptom of cancer patients, particularly in those with lung cancer, however management of the condition is often suboptimal as no high quality cancer-specific guidelines are available. During 2009/10 Professor Alex Molassiotis led the set up of a UK task force on cough bringing together experts with clinical, research and academic roles including other CECo and COMPASS researchers, specifically Professor Mari Lloyd-Williams from University of Liverpool, Dr Amélie Harle from Christie NHS Foundation Trust, Manchester and Professor Mike Bennett then at Lancaster University. CECo funds helped to support a meeting to assess the evidence and define the methodology to be used in the development of the guidelines and a second to review the evidence and develop the recommendations. The guidelines have since been published in the journal Cough.31 The article is classified as ‘highly accessed’ by BioMed Central with over 19,000 accesses since publication.32

MASCC have more recently agreed to set up and support a Respiratory Symptoms Study Group, to be chaired by Professor Sam Ahmedzai, University of Sheffield, which will consider issues around breathlessness, cough and other respiratory symptoms.33 The new group, for which members will shortly be sought, will provide a route for UK researchers and clinicians to engage with others from around the world and generate further guidance for clinicians supporting patients with respiratory symptoms.

To support patients and clinicians to discuss and assess severity of cough a number of CECo researchers, including CECo fellows from Manchester, Southampton and Liverpool, were involved in the development and preliminary assessment of a patient-reported outcome measure: The Manchester Cough in Lung Cancer Scale.34 This ten-item scale is a positive step in the development of a tool for assessing cough in cancer patients in the clinic and for the measurement of cough as an outcome in intervention studies, and it has been further validated in a sample of 179 patients showing good indications of validity, compared to other scales, and repeatability.35

### 4.6 Death in usual place of residence

People when asked say they would prefer to die at home or in a hospice, rather than a hospital. The team at KCL, led by Professor Irene Higginson, have had a long standing interest in how and where people die. Professor Higginson alongside others including Dr Wei Gao, as statistician associated with COMPASS, were able to develop this area of work during the
time of COMPASS and have gone on to expand this further since. In 2011 the KCL team were able to successfully apply to the NIHR Health Services & Delivery Research Programme for funding of an in depth analysis of trends in place of death since 1984. This study (GUIDE_Care: Geographical and temporal Understanding In place of Death in England [1984-2010]: analysis of trends and associated factors to improve end of life Care) involved a number of people also associated with the work stemming from the Department of Health, England End of Life Care Strategy including the NEOLCP and the National End of Life Care Intelligence Network (NEOLCIN). These links and the understanding of the datasets helped to define ‘death in usual place of residence’ as a Key Performance Indicator for the success of the NEOLCP which was focused on the implementation of health services and policies to improve the quality of end of life care for people in England and increasing the proportion of people who die at home. Findings recently published in PLOS Medicine highlight a decrease in the relative number of people dying in hospital and an increase in the proportion of people dying at home which coincides with the launch of the NEOLCP.36

4.7 Assessment tools for research and clinical practice

CECo and COMPASS researchers have been involved in research on a number of assessment tools for use in the clinic or in research, in addition to those described above. A few of these are described in brief below.

The Zarit Burden Interview (ZBI) assessment tool measures subjective caregiver burden associated with the functional/behavioural impairments of the person for whom they care and the home care situation. Short forms of the ZBI were evaluated by members of COMPASS and a six-item version was found to be as accurate and sensitive as a longer 12-item version in advanced cancer, dementia and acquired brain injury.37 There are indications that this short-form tool is gaining increased recognition and is being used in research as an outcome measure and in the clinic as a screening tool.

The General Health Questionnaire (GHQ) measures current mental health focussing on the inability to carry out normal functions and the appearance of new and distressing experiences. A short form (12-item) version of the questionnaire, GHQ-12, was tested by researchers from a number of COMPASS hubs in a study led by Dr Wei Gao. The team were
able to show that this outcome measure, unlike many other measures, can be used across the disease trajectory from survivorship to end of life care, a useful feature for studies in which patients are followed over a number of weeks or months.\textsuperscript{38}

A number of Patient Reported Outcome Measures (PROMS) assessment projects which though not directly initiated within one or other Collaborative have benefitted from the expertise of those within the Collaboratives or from the experience of collaboration gained during the time of CECo and COMPASS. This is exemplified in the PRISMA study led by the COMPASS team at KCL.

During 2008 Professor Irene Higginson, supported by Dr Richard Harding, KCL, were able to use their learnings from work in, and coordination of, COMPASS to help secure a European Framework 7 grant: PRISMA to harmonise research in end of life care for cancer patients across Europe. The grant which ran from 2008 to 2011 brought together a number of different research groups from across Europe. Work undertaken within PRISMA included analyses of outcome measures and launch of the Palliative care Outcome Scale (POS) website which is making this tool more widely accessible.\textsuperscript{39}

Created in 1999 the POS is a tool for use in the clinic and in research to measure a patient’s physical symptoms, psychological, emotional and spiritual needs and provision of information and support at the end of life. POS has now been translated and validated for use in 28 different languages, and is in use in over 44 countries.\textsuperscript{40} Analyses carried out on POS by Dr Gao, allowed the concordance between patient-reported measures, gained through the POS, and carer perceptions, gained through the ZBI, to be assessed.\textsuperscript{41} More recently the POS has been designated ‘the’ outcome measurement tool to use in clinical palliative care in South London while the POS symptoms module is in use in Wales following recommendations from clinicians to the Wales Assembly Government body overseeing the development of the Specialist Palliative Care Patient Record to be held on Canisc, the Wales national Cancer network computer system holding information on patients’ interactions with healthcare professionals.\textsuperscript{42,43}
5 Impact on research methodology

The 2004 NCRI Supportive and Palliative Care Research in the UK report identified the need for further work to develop research methods, particularly those to support the evaluation of complex interventions. Both CECo and COMPASS tried to address methodological issues and there have been significant outputs from researchers in both Collaboratives in this arena.

During 2008/9 CECo-associated researchers published a book on narrative methods in palliative care research and parallel academic papers. The book and papers developed the narrative approach, which is widely used in sociology, for use in palliative and end of life care research studies. A greater familiarity with this methodology is enabling more researchers to use it in their research. A recent Marie Curie Cancer Care funded study on home deaths included narrative analysis of 30 relatives’ experience of facilitating the death of an older person at home generating insight into the positive and challenging aspects of the experience including a sense of achievement and satisfaction and indications on where further support, coordination or communication is needed.

Professor Alex Molassiotis’ team in Manchester developed recommendations for undertaking longitudinal qualitative research in health services, particularly around cancer survivorship and end of life care. This work, which was recently published in BMC Medical Research Methodology, drew on the experience of a number of CECo researchers of longitudinal qualitative trials and was developed following further discussion with members of the Supportive and Palliative Care Research Group in Manchester which included a number of CECo-linked researchers.

During the time the Collaboratives were supported CECo and COMPASS each held a number of meetings on methodologies for research in supportive and palliative care, bringing in outside speakers, considering the gaps in the methodologies and developing research proposals in the area, including running some jointly. These collaborations and discussions paved the way to a successful joint CECo and COMPASS research proposal in response to a targeted call from the MRC/NIHR Methodology Research Programme in 2008/9.

The Methods Of Researching End of life Care (MORECare) team, led by Professor Irene Higginson as Principal Investigator (PI) and Professor Chris Todd as co-PI, brought together researchers from CECo and COMPASS hubs to undertake extensive consultations and systematic reviews on for example, attrition, health economics and integration of mixed methods. These consultations which involved consumers, clinicians and researchers have led to the publication of the ‘MORECare Statement’.

Published in 2013 the statement lays out 36 best practice solutions for research evaluating services and treatments in end of life care. As an open access article it is intended that researchers, as well as funders of research, journal editors and ethics committee members, use the best practice guidance thereby reducing the duplication of effort of individual researchers considering the issues each time, and promoting the development, undertaking and funding of more interventional studies in end of life care that have the potential to change practice.

Since publication of the MORECare Statement a further four peer-reviewed articles have been published providing for example, recommendations for tackling ethical issues, guidance on dealing with missing data, attrition and response shift and on the selection and use of outcome measures in palliative and end of life care research. The group, led by Professor Higginson, have also disseminated
their findings through the Cicely Saunders Institute, KCL website, social media and face-to-face teaching and have secured MRC funding to support the development of e-learning modules. The e-learning modules will use the MORECare findings to provide guidance and solutions on research and enable reach to a wider audience, including clinicians, policy makers and research funders.
A major aim of the SuPaC initiative was to strengthen the capacity for research in supportive and palliative care in the UK, particularly focusing on the research workforce.

### 6.1 Supporting novice researchers

The CECo scholarship scheme was set up to bring research naive professionals into supportive and palliative care research, particularly those individuals who were more isolated or from outside traditional supportive and palliative care research disciplines such as nursing and palliative medicine. CECo awarded 15 scholarships during its lifetime, each of up to £10k. Each scholar was typically supported by two mentors, more senior CECo researchers, based at different CECo hubs to encourage collaboration across sites. The scheme has proved very successful with scholars publishing 16 peer-reviewed journal articles, preparing further articles for submission, and securing five grants up to October 2011. Ms Penny Towler, a palliative care nurse and acupuncturist, was awarded a scholarship in 2011 to undertake a systematic review of the evidence for the use of acupuncture as an intervention for symptom management in supportive and palliative care. During her scholarship Ms Towler was supervised by Dr Sarah Brearley and Professor Alex Molassiotis at the University of Manchester. The scholarship enabled Ms Towler to attend the International Research Summer School at the International Observatory on End of Life Care at Lancaster University providing an introduction to methods and issues relevant to health and social care research and networking opportunities. The funding also enabled her to reduce her working hours giving dedicated time for research and provided Ms Towler with the skills and opportunity to apply for, and secure a place on, the highly competitive NIHR-funded Masters in Clinical Research, delivered at the University of Manchester. Ms Towler has since completed her Masters, published the findings from her systematic review and is currently in the process of drafting an article on the outcomes of her Masters. Ms Towler will shortly take up a Macmillan Palliative Care Nurse Specialist post, with a greater understanding of, and ability to practice and support others to practice, evidence-based medicine and may look to undertake further research in the future. The scholarship scheme has enabled a number of people to gain experience in the supportive and palliative care research field and a number are maintaining their links with, and interest in, the field. The scheme has been a positive, and relatively low cost, one that the All Ireland Institute for Palliative and Hospice Care (AIIHPC) have been able to replicate, in the form of the AIIHPC Clinical Research Fellowships for Health and Social Care Professionals, as a result of interactions with CECo, and in particular Professor Sheila Payne.

### 6.2 CECo and COMPASS research fellowships and statistician support

A proportion of the SuPaC Collaborative funding was dedicated to research fellowships and statistician posts to overcome the shortage of specific funding for such posts identified in the 2004 NCRI Supportive and Palliative Care Research in the UK report. Through CECo and COMPASS more than ten research fellows with an interest in supportive and palliative care research were supported with each fellow based at one of the SuPaC Collaborative hubs. The fellows were able to be involved in, and lead, a wide variety of projects during the time of the SuPaC Collaboratives. The fellows received wide exposure to the research of others and were able to receive mentorship from researchers locally as well as those based in other SuPaC Collaborative hubs giving them a very solid grounding for a career in research. Since
completion of the funding a significant number of the fellows continue in research roles. As it is not possible to describe the work of all the fellows and statisticians supported through the Collaboratives we have focused on two examples below.

Dr Wei Gao was employed as a full-time statistician in COMPASS, with half of the funding for her post coming from the Collaborative grant, based at KCL. Not having previously worked in supportive and palliative care research, and somewhat isolated as a statistician within the KCL research group, mentoring by Professor Julia Brown, as statistician linked to the Leeds COMPASS hub and Head of the Leeds Clinical Trials Unit, proved particularly important and effective. Professor Brown helped Dr Gao to fully develop her skills in exploiting primary and secondary datasets to understand palliative care and become involved in a wide range of challenging and successful projects. During her time in COMPASS Dr Gao developed her grant writing skills successfully applying for both NIHR and Marie Curie Cancer Care funding, published a number of high impact articles, represented the Cicely Saunders Institute, KCL at national meetings including the NEOLCIN Stakeholder Group and was promoted from Research Fellow to Lecturer at KCL where she continues to be actively engaged in supportive and palliative care research.

Dr Katherine Froggatt joined CECo as a Senior Research Fellow and co-led the ‘Older people towards the end of life’ theme with Professor Jane Seymour. Dr Froggatt’s research has focused on palliative care for older people, with a particular focus on those with dementia and/or in long term care settings as well as collaborating with Professor Seymour on peer education. Within CECo Dr Froggatt, working with Dr Elisabeth Reitinger, Austria, was able to establish a European Association for Palliative Care (EAPC) Taskforce on palliative care in long term care settings for older people. The aim of the taskforce was to identify and map the different ways of developing palliative care in long term care settings across Europe. A report from the Taskforce and a compendium of initiatives have since been published, Dr Froggatt has also been part of a successful European Framework 7 application led by colleagues in Belgium to undertake a comparative effectiveness trial evaluating a palliative care intervention in long-term care settings, has published numerous peer-reviewed journal articles including a number with the three CECo scholars she co-supervised and worked with the Lancaster Research Partner Forum (LRPF). Since completion of CECo
funding Dr Froggatt has continued her research in palliative care for older people, contributed to the ENRICH website – a resource to support and encourage more research in care homes and supported the LRPF alongside Dr Nancy Preston (for more information on the LRPF see section 7).

6.3 Capacity Building Grants scheme grantees

A separate call for proposals saw nine clinical specialists and two non-clinical researchers take up CBGs with a total value of £830k. The grants were awarded in November 2006 and were for between 12 and 24 months. The grants provided funds for example, to support clinicians to take time out from their clinical duties for research or for the costs of the research.

By the end of 2011, at the time of the SuPaC Management Committee review meeting, a significant number of academic and clinical achievements were identified based on the work of the CBG grantees including the establishment of over 30 collaborations with research groups in the UK and internationally, and supervision cumulatively of more than 25 MSc, PhD and MD students. The grantees themselves had also built their academic standing through the completion of PhDs and MDs, establishing and running clinical trials and publishing a number of peer-reviewed journal articles based on their research with a number also having gained promotions to more senior positions. Significantly by the end of the funding period all grantees had secured further research funding in the form of project grants, research fellowships or clinical trial funding. The career development achieved by some of the CBG grantees is exemplified through Professor Miriam Johnson and Dr Bee Wee’s experiences below.

During her CBG Professor Miriam Johnson was promoted from Senior Lecturer to Reader in 2010, with a promotion since this time to Professor at the Hull and York Medical School. The CBG enabled Professor Johnson to undertake a feasibility trial for the non-pharmacological management of breathlessness. This trial proved effective and led to an NIHR RfPB funded Phase 3 randomised controlled trial (RCT) of breathing training in people with lung cancer of which Professor Johnson is PI and which has just completed recruitment. She is also co-PI on another completed NIHR RfPB study on the diagnosis and management of venous thromboembolism (VTE) in patients with advanced cancer and co-Investigator on two NIHR Health Technology Assessment studies. Professor Johnson has developed a portfolio of work around palliation for people with non-malignant disease, breathlessness and VTE and is the co-director of the Supportive care, Early Diagnosis and Advanced disease (SEDA) research group at the University of Hull which now has 27 researchers. She is also a member of the NCRI Palliative and Supportive Care Clinical Studies Group (CSG), regional Specialty Group lead for palliative care, and the co-director of the Thrombosis Research in Advanced Disease Alliance.

Dr Bee Wee undertook a CBG while a Senior Clinical Lecturer and Consultant in Palliative Medicine at the University of Oxford. The grant enabled her to take time out from her clinical duties to learn from COMPASS members at KCL about the management, leadership and general running of a fully developed research department. During this time she also prepared a proposal for a trial funded through the 2006 NCRI Lung Cancer SuPaC project grant scheme (an output from NCRI’s report on the state of lung cancer research in the UK in 2006), published a number of papers including reports commissioned from the World Health Organisation and undertook a piece of qualitative research at St Joseph’s Hospice and KCL.

Since the CBG Dr Wee has completed the NCRI Lung Cancer SuPaC trial and developed the capacity for research in palliative care at the University of Oxford to cover three strands - symptom management, end of life care and rehabilitation. As a research-active clinician Dr Wee has established a network of Association for Palliative Medicine of Great Britain and Ireland (APM) Research Champions while Chair of the APM Science Committee, has completed a three year term as President of the APM, and since moving on from these roles taken over...
from Professor Sir Mike Richards as National Clinical Director for End of Life Care for NHS England.

In terms of the influence on practice a number of CBG grantees cited examples including:

- Development and launch of two CR-UK funded RCTs in cancer pain. The trials, which are nearing completion, are expected to have a direct impact on patient care. (Dr Barry Laird, University of Edinburgh)

- Local implementation of a four-item Fear of Recurrence measure at Aintree University Hospital, Liverpool. (Dr Godze Ozakinci, University of St Andrews)

- Local implementation of a Cancer Appetite and Symptom questionnaire in the out-patient palliative care lung cancer clinic in Nottingham University Hospitals NHS Trust. (Dr Vanessa Halliday, Nottingham University Hospitals NHS Trust)

- Reviews and meta-analyses on drug therapies for fatigue and cachexia. These studies indicated the positive effects of methylphenidate and the increased adverse outcomes associated with the use of erythropoietin for the treatment of fatigue.65,66 (Professor Paddy Stone and Dr Ollie Minton, St George’s University of London)

- Development of European Palliative Care Research Collaborative Clinical practice guidelines on cancer cachexia in advanced cancer patients which has provided a framework for the classification and management of cancer cachexia.67 (Professor Kenneth Fearon, University of Edinburgh)

- Development of a Phase 3 RCT, funded by the NIHR RfPB, of a Breathlessness Intervention Service (BIS) for intractable breathlessness. The trial is now closed for follow up while the service continues to be delivered, via the NHS, in Cambridge through the BIS team at Addenbrooke’s Hospital. (Dr Sara Booth, Cambridge University Hospitals NHS Foundation Trust)

6.4 Developing leaders in research

In addition to supporting more junior researchers SuPaC Collaborative funding helped more senior researchers to develop their research portfolios and leadership skills on the back of the research and activities supported within CECo and COMPASS.

As a Senior Lecturer based in Manchester’s Supportive and Palliative Care Research Group led by Professor Alex Molassiotis, Professor Gunn Grande, then Dr, became a member of CECo. During the lifetime of CECo Professor Grande was also able to take on a leadership role - leading CECo’s capacity building activities including running the CECo scholarship scheme, State of the Science meetings and supporting mentorship of PhD students and postdoctoral researchers. Professor Grande’s success in developing and testing the CSNAT, in collaboration with Dr Gail Ewing in Cambridge, developing a strong and broad research portfolio particularly around the needs of carers, and the skills gained through CECo have played a part in her promotion to Professor of Palliative Care at the University of Manchester.

With the establishment of COMPASS Dr Stephen Barclay, a GP and researcher based in the University of Cambridge Department Of Public Health and Primary Care, was able to become integrated in a supportive and palliative care research environment. Taking an active part in COMPASS seminars and meetings and receiving an Honorary Senior Lecturer position at KCL Dr Barclay was able to benefit from the subject expertise available within the Collaborative which was not available more locally. Dr Barclay continues to maintain an active research interest in palliative care leading the end of life care theme in the NIHR Collaboration for Leadership in Applied Health Research (CLAHRC) for Cambridgeshire and Peterborough and in 2011 successfully applying for a Higher Education Funding Council for England Clinical Senior Lectureship.68

In 2006 when CECo started Professor Sheila Payne was already a very accomplished researcher and
research leader however the experiences and opportunities that CECo afforded gave her a good background to take on international leadership roles. In addition to the skills gained ‘on the job’ the CECo Senior Management Team undertook formal leadership training through the Lancaster Business School. This gave the team further insight into their management styles, strategies for how to deal with conflict and strong personalities and how to work more effectively across organisational boundaries. In 2007 Professor Payne became Vice President of the EAPC and in 2011 was elected for the four year term of President of the EAPC.

Professor Payne, as the first non-clinical specialist in this role, is using her Presidency as an opportunity to extend the remit of the EAPC to include wider aspects of the multidisciplinary team involved in palliative care. Recent activities have included the establishment of an EAPC Spiritual Care Taskforce and publication of EAPC White Papers defining optimal palliative care in patients with dementia and on palliative care education for generalists.69,70,71 These activities follow on the back of EAPC Taskforces, previously initiated by Professor Payne and which resulted in White Papers, on the role of family caregivers and the role of psychologists in palliative care (co-lead with Dr Saskia Junger).72

President of the EAPC and the links it facilitates will provide an ongoing route through which the research activities in which CECo was, and the UK more generally is, involved can be extended across Europe.

### 6.5 Further benefits for the supportive and palliative care research community

In addition to specific support and development of researchers associated with the initiative those we interviewed also identified less tangible benefits of the funding mechanism which will continue to benefit them in their research careers.

The call for proposals for the SuPaC Collaboratives brought together many researchers whom had not previously collaborated. Having been awarded funding trust was able to develop between researchers involved, encouraging collaboration and co-working to form cohesive research networks, as described in an editorial in Palliative Medicine in 2007.73 The long term and collaborative nature of the funding particularly helped in this regard as the groups had five years in which to build relationships and work together on shared objectives or specific research projects. Many cited that previous
positive joint working experiences means it is now easier to re-use these contacts as new projects or opportunities arise.

Researchers reported an increased awareness of other researchers with an interest in supportive and palliative care. In addition there is increased recognition, by researchers and research funders, of the importance of multi-disciplinary research particularly in supportive and palliative care. Effective multi-disciplinary research requires a well-balanced research team with the necessary methodological, clinical, psychological, lay and/or statistical skills in place in each case. The greater awareness and interaction with a broad range of experts as brought together through the SuPaC initiative activities has increased the ease with which researchers find collaborators for studies where specific skills are needed in order to make a strong proposal.

Funding of the Collaboratives brought together a number of different research groups and led to a significant amount of cross-institutional working. Working across academic institution boundaries did create some tensions particularly around the allocation of funds and the need for universities to maintain the quality of the research it supports and as assessed through the Research Assessment Exercise (now Research Excellence Framework). Despite these difficulties researchers indicated their continued enthusiasm for, and the importance of, cross-institutional research as having the right research team for a research proposal is key to grant application success.

Experience of each other’s ways of working also meant that in cases where projects needed a quick turnaround members of the SuPaC Collaboratives were able to take on the opportunities and effectively divide up roles and responsibilities. Examples include the development of the MORECare research proposal and identification of the research priorities as part of the Department of Health, England and Macmillan Cancer Support National Cancer Survivorship Initiative. This latter piece of work, which was undertaken by members of COMPASS, included a consultation, workshop and a rapid synthesis of published research on the problems with health and well-being of cancer survivors and solutions for these problems and was completed in a tight timeframe.74

Discussions with members of the Collaboratives highlighted a number of examples of capacity building activities, including Masterclasses in which lectures and debates helped to introduce members to new research areas and ideas, mentorship and funding for research fellows and skills in working across locations, are being incorporated into research grant applications including those submitted to the 2013 CLAHRC funding round. The structures proposed in the CLAHRC bids stemmed from lessons learnt through the COMPASS and CECo models and highlight a greater awareness of the importance of building research capacity and effective mechanisms through which to do so. Applications from teams in Southampton, including Professor Alison Richardson, and KCL, including Professor Irene Higginson, have both been successful. The NIHR CLAHRC Wessex includes a theme on minimally disruptive healthcare: complex pathways, patient experience, and organisational behaviour with a specific focus on life limiting conditions while the NIHR CLAHRC South London includes a theme on Palliative and End of Life Care.75
7 Consumer involvement in supportive and palliative care research

7.1 Developing the role of patients and carers in research

As identified in the 2004 NCRI Supportive and Palliative Care Research in the UK report the involvement of patients and carers, or consumers, in research was in its early stages at that time. The development of consumer involvement activities and skills was a key part of the work of CECo and COMPASS, and took different forms in each case.

In CECo consumer activities were led by Mr Roger Wilson with support from CECo leaders. Two lay members of the CECo International Advisory Board, Dr Chris Kerr and the late Mr John Belcher contributed a consumer perspective to the strategic oversight of the collaborative. Other contributions included specific advice and contributions to study development, participation in the LRPF, which was specifically set up as a result of CECo, and in Southampton participation in a variety of face-to-face workshops and virtual forums. In COMPASS consumer involvement was led by Professor Scott Murray at Board level with support from Dr Marilyn Kendall as Consumer involvement coordinator and consumers Mr Peter Rainey and Mrs Carolyn Morris. As lay members of the COMPASS Advisory Group Mr Rainey and Mrs Morris were able to become embedded in COMPASS processes and events.

7.2 Examples of consumer contributions to Supportive and Palliative Care Collaborative studies

In Edinburgh, Mr Peter Rainey, a member on the COMPASS Advisory Group, was able to become a member of the SMaRT Oncology Trials Management Committee providing a consumer perspective particularly to SMaRT Oncology 2 and 3. Recruitment to SMaRT Oncology 3, which was focussed on lung cancer patients, proved relatively difficult. In his role as Management Committee member Mr Rainey, as a consumer and lung cancer patient, was able to inform the research team how a lung cancer patient may feel at different stages of their cancer journey and what locations and timings may be most appropriate to approach a patient regarding recruitment to the study. He also provided input into how to reduce the number of patients lost to follow up.

During COMPASS Professor Galina Velikova’s group at the University of Leeds successfully applied for an NIHR Programme Development Grant for the development of an integrated web-system for patients to report symptoms and side effects during and after cancer treatment. The study is called eRapid: Towards safer delivery and monitoring of cancer treatments. Electronic patient self-Reporting of Adverse-events: Patients Information and aDvice. Mrs Carolyn Morris was able to contribute to the eRapid application and later during the development phase through participation in the project management group. The developmental work has since been completed and a successful application made for a NIHR Programme Grant for Applied Research with these diverse and extensive activities Mr Rainey and Mrs Morris were able to become embedded in COMPASS processes and events.
Mrs Morris as a co-applicant leading the consumer involvement aspects of the programme. The eRAPID Programme Grant, which started in July 2013 and will run until 2018, will develop the web-system (QTool) such that data reported by patients is entered directly into their electronic health records in three participating hospital in Leeds, Manchester and Bristol. Patients are then also given appropriate advice by way of QTool: for mild side effects patients receive advice on how to manage them and to seek timely medical advice while for serious side effects a system of alerts will be sent to clinicians for follow up. The programme will evaluate this approach in terms of patient experiences, patient safety and cost-effectiveness in an RCT.

During CECo members of the LRPF contributed to the APPROACH study, which was supported by the NIHR Service Delivery Organisation. The study aimed to develop integrated working between primary health care services and care homes, and involved interviews with care home residents, their relatives and care home and primary care staff. It developed a typology of integrated working between health services and care homes to inform future service development and research in these settings. Ahead of the study consumers were involved in the development of the research proposal, once funded: reviewing study documentation including ethics approval submissions, and development of survey questions and data collection tools. Fieldwork undertaken by the consumers included study recruitment by initiating discussions with care home residents on the study and their potential to contribute to it, facilitating in interviews or focus groups and supporting residents after their involvement in the study to address any questions or concerns their involvement had raised.76

7.3 Sustaining consumer involvement skills in the research workforce

In their capacity as lay members of the COMPASS Advisory Group Mr Peter Rainey and Mrs Carolyn Morris put forward the idea of developing a Masterclass on consumer involvement for researchers. This idea was warmly received and led to four such Masterclasses being held across the COMPASS hubs between 2009 and 2010. Developed and led by consumers the Masterclasses took the form of interactive workshops which encouraged researchers to involve consumers earlier in the development of their research ideas and at a greater number of steps in the ‘research cycle’. Developing
the confidence of researchers in consumer involvement and building relationships between consumers and researchers helped the collaborations to become particularly effective.

The Masterclass in consumer involvement was independently evaluated by TwoCan Associates, by way of interviews with researchers 6-18 months after they had participated in the workshop.\textsuperscript{77} The evaluation highlighted that participation in the Masterclass did make a difference to a researchers’ practice in the long term and recommended that funders should provide appropriate training in consumer involvement ahead of calls for proposals or in parallel with the annual grant cycle. The Masterclass format is often cited as a positive example of teaching researchers good practice in consumer involvement and helping them overcome barriers to consumer involvement, for example, in the report: Impact of Patient, Carer and Public Involvement in Cancer Research and the INVOLVE newsletter.\textsuperscript{78,79} Furthermore the learnings from the Masterclass and the recommendations from the evaluation have influenced the development and delivery of consumer involvement training for researchers, which are now more frequently delivered by consumers themselves, including Macmillan Cancer Support’s Building Research Partnerships training courses which are regularly run around the country.

To communicate the learning from the consumer involvement activities within CECo Dr Nancy Preston and Dr Katherine Froggatt who currently support the LRPF, alongside others from CECo, have submitted a short report for British Medical Journal (BMJ) Supportive and Palliative Care. The report will cover the benefits and challenges of consumer involvement identified through semi-structured interviews with eight consumers involved in CECo.

Since the completion of the Collaborative funding consumer involvement has been supported and coordinated in different ways. The LRPF provides a route for consumer involvement to those based at Lancaster University and around the UK. The Macmillan Cancer Survivorship Research Group in Southampton is involving lay people predominantly through online consumer forums while in Manchester access is sought via Dr Anne Caress, Professor in, and lead for, consumer involvement there. In the case of the consumers involved with COMPASS they have continued to be active in research through their participation in consumer-involvement panels, including NIHR Strategic Patient and public involvement Advice, Delivery and Evaluation Group, the NCRI Hub, NCRI CSGs and the NIHR Consumer Liaison Group, and wider involvement in specific research proposal and trial development groups. COMPASS-associated researchers continue to access the support of Mr Rainey and Mrs Morris or seek the support of other consumers through them.
8 Impact on the wider supportive and palliative care research environment

8.1 Launch of a new international journal

April 2011 saw the launch of BMJ Supportive and Palliative Care at the COMPASS final ASM in Edinburgh. This was in part due to the influence of COMPASS researcher Professor Scott Murray, as a long-standing editorial advisor to the BMJ. In addition, a BMJ ‘Spotlight’ issue on end of life care beyond cancer in 2008, and the groundswell generated by the Collaboratives, highlighted the extent of high quality research in this area of interest to both generalists and specialists. Although the journal does not yet have an impact factor, this will follow in time, already it is proving to be popular and is well respected. Since the launch of the journal the APM, the official representative body of the Palliative Medicine specialty, has forged a link with the journal. This link ensures the over 1000 members of the APM have free access to this quarterly journal which can only benefit patients through the potential of quicker and better uptake of research evidence into practice.

8.2 Establishing international networks

Members of CECo and COMPASS have spread awareness and understanding of the SuPaC Collaborative model through one-to-one interactions and conference and meeting presentations, for example at the international MASCC conference and the Latin American Palliative Care Congress in Brazil. These interactions and engagements have helped to encourage the further development of collaborative networks and groups in, for example, Australia and Ireland.

The Victorian Cancer Agency and Victorian Department of Health in Australia have supported the set up of the Palliative Care Research Network Victoria with advice sought from Professor Sheila Payne, as CECo lead, in the early stages. The network currently brings together a number of universities and health care providers in the State of Victoria with the aim of fostering a “productive, collaborative and sustainable programme of clinical and community intervention research aimed at enhancing the quality of palliative care.”

The AIIHPC was set up in October 2010 with significant support from The Atlantic Philanthropies and additional support from others including the Irish and Northern Irish Health Department research boards. It brings together 12 health agencies and universities focused on developing capacity for research, improving practice and supporting education. A number of members of CECo and COMPASS have been involved in supporting the set up of the network which includes workstreams on leadership, capacity building, user involvement and public engagement, many continuing to act as Expert Collaborators.
The investment of roughly £1m per annum over five years in the SuPaC initiative was relatively modest. The funds provided research infrastructure support including administrative support, access to statistical expertise, in addition to funding for research fellowships and CBGs and costs for meetings including protocol development meetings and educational meetings. Despite the modest investment it does appear that the way the funds have been targeted, in order to have a catalytic effect, has been successful. While much of the evidence cited is qualitative, there is objective evidence of increased capacity, collaboration and ability to raise funds in open competition.

In their final report CECo attributed over £4m of grant funding success as a direct result of CECo’s activities with a further £14m that had benefitted from CECo’s activities, while COMPASS reported COMPASS researchers had secured over £50m of grant funding up to October 2011. Up to October 2011 each Collaborative had also published over 500 peer-reviewed journal articles which were entirely the result of, or had benefitted from, the Collaboratives’ activities. In addition to peer-reviewed publications the groups also published many book chapters, reports, newsletters and contributed to conferences. Each of these activities have played a part in disseminating the work undertaken by the Collaboratives, highlighting the strength of the UK supportive and palliative care research field and encouraged new researchers to become involved.

The CBG scheme was developed to support isolated or new researchers to develop their research careers and support further research in symptom management. Each CBG was for up to a maximum of £80k with a total of 11 grants awarded. These small grants have been particularly effective with all the researchers funded through this scheme securing further research funding and continuing to be involved in research. CBG grantees were also encouraged to engage with the Collaboratives and many benefitted from this added interaction with a number of examples of ongoing collaborations identified during the course of this evaluation.

A component of the SuPaC Collaborative funding was used to develop and embed consumer involvement in supportive and palliative care research. The consumer involvement groups and the ways of working developed as a result of the initiative have been very valuable: ensuring that the work undertaken within the Collaboratives was focussed on the needs of patients and increasing the awareness of the importance and benefits of consumer involvement to a wide spectrum of researchers around the UK.

As an alternative to channelling the funds pledged by NCRI Partners into the SuPaC initiative funds could have been targeted to more traditional funding schemes, for example (two to three) programme grants. In evaluating the outcomes of a specific funding mechanism it is not possible to definitively conclude what would have happened if it had taken a different form however there is objective evidence that funding more defined and discreet research programmes would not have had the far reaching effects seen as a result of the SuPaC initiative. Funding of the initiative brought a significant number of researchers into the supportive and palliative field who may not otherwise have been exposed to it, or had the opportunity to become involved. It also enabled researchers at all levels to get extensive experience of working across organisational boundaries and disciplines. The emphasis on collaboration and mentoring in the SuPaC initiative also exposed researchers to a new way of working and one which many are continuing to benefit from.
10 Discussion

10.1 Summary of the impact of the initiative to date

The original objective of the SuPaC initiative was to develop SuPaC Collaboratives with the aim of creating critical mass, developing a span of expertise, increasing capacity for high quality research, nurturing and developing high quality researchers of the future, tackling methodological challenges, developing consumer involvement and generating maximum impact on policy and practice. The CBG scheme aimed to bring other researchers into the field and support them also to become high quality independent researchers. As highlighted in the report the SuPaC initiative has met those objectives.

CECo and COMPASS each brought together researchers from a large number of geographical areas as well as organisations including university research departments, hospitals, hospices, community services and social care providers. Bringing together people previously isolated with those in more established research groups helped develop the critical mass for high quality supportive and palliative care research. With the diverse groups involved the disciplines engaged in the research was also broad and included oncology and palliative care nurses, allied health professionals including nutritionists, arts therapists, health psychologists, and those from social care and sociology research backgrounds. Researchers from a number of different clinical disciplines were also represented including palliative medicine, geriatrics, oncology, surgery, general practice and psychiatry.

The Collaborative research fellowships, the CECo scholarships alongside the CBG scheme all encouraged more junior researchers into the supportive and palliative care research field with the majority continuing to be actively involved. The researchers engaged in this way had access to the meetings and educational events organised by the Collaboratives and to extensive dedicated mentoring and support from within and outside their host organisation. Through this support they have developed wider networks and research skills, and appreciation of the importance of mentorship which can be taken forward in their further research careers.

The work undertaken by the SuPaC Collaboratives addressed a number of methodological issues including the development of methodologies for testing and implementing complex interventions, narrative research approaches and the development of guidelines for the evaluation of end of life care services research in the MORECare study. The outcomes of the latter study, in particular, will support the undertaking and funding of more interventional studies in end of life care.

At the start of the SuPaC initiative consumer involvement was a new skill and process for many of the researchers in the supportive and palliative care research field. Since completion of the initiative many of the consumer groups involved in the work of the Collaboratives continue to be active, while in other cases, as the SuPaC Collaborative funding for consumer involvement ceased other national or local groups through which to seek consumer involvement have been identified. These groups and the individuals involved continue to promulgate good practice in consumer involvement ensuring that consumer involvement is more embedded and more widely practiced than previously and encouraging researchers to develop the necessary skills for timely and effective consumer involvement early in their research careers.
Our evaluation has captured a number of examples of impact on policy and practice generated from the SuPaC initiative. These include:

- development of an intervention for people with cancer and major depressive disorder and its inclusion in NICE Clinical Guidelines and implementation in the USA
- development and dissemination of resources for peer education on ACP and end of life issues
- development and uptake in the UK and Australia of a tool to support carers of people at the end of life with the potential to benefit over 18,000 carers per year in the UK alone
- development and dissemination of tools to assess and predict chemotherapy induced nausea and vomiting
- development of clinical guidelines for the management of cough in lung cancer
- supporting policy to increase the number of people able to die in their usual place of residence.

Other examples of impact on policy and practice as a result of the activities of the SuPaC Collaboratives and the CBG grantees were identified but these have not been expanded upon in this report. In the case of other projects it may be too early to capture their full impact. Implementation of research findings into policy and practice remains difficult however it will be for researchers, and other stakeholders, to support the dissemination of important research findings and promote their implementation where appropriate.

10.2 Looking ahead

The SuPaC initiative, and the collaborative way of working it encouraged, is one that has significantly benefitted the research community expanding on the number of people involved, strengthening the research ideas developed and ensuring that the research meets the needs of patients, carers and their families. Many of the researchers and consumers that became linked with the activities supported through the SuPaC initiative continue to be active in research.

In addition to the benefits in research capacity reaped from the SuPaC initiative a number of researchers and consumers linked with it are involved in the Palliative and Supportive Care, Psychosocial Oncology and Primary Care CSGs. The CSGs, and their associated subgroups, will continue...
to play an important role in the development of trials and other studies in supportive and palliative care and for the development of research skills of more junior researcher.

Furthermore following the 2009/10 NCRI Rapid Review of research in survivorship and end of life care, which took stock of research in supportive and palliative care and survivorship and end of life care, the NCRI developed the NCRI Grantsmanship Gateway to support researchers to make the best of available funding opportunities.83 The website acts as a signposting tool for more junior researchers to find resources useful for the development of high quality research proposals. The Rapid Review also brought together research funders with an interest in end of life care, including those with interests beyond cancer, to tackle barriers to research in this area and encourage communication amongst the funders. These discussions have since led to the launch of the UK end of life care Research Interest Group (UK eolcRIG) which now boasts 30 members with 17 full members who operate one or more competitive peer reviewed funding streams which welcome high quality proposals in end of life care.84 From late 2013 Marie Curie Cancer Care will take over the running of this group providing ongoing support for communication amongst funders and to tackle the barriers to funding research in end of life care.

In late 2013 Marie Curie Cancer Care initiated a partnership to find out what palliative and end of life care research is important to people who are likely to be in the last years of life, their families, and the professionals who work with them. This Partnership, which involves the James Lind Alliance and a number of research funding organisations, will help to define the research priorities in palliative and end of life care based on the experiences of the people who use their services and clinicians. Once completed this will help inform the research agenda of a number of research funders generating further opportunities for researchers with an interest in this area of research.

These resources, groups and opportunities alongside the impact generated from the SuPaC initiative will be key to maintaining research capacity and ensuring that new talent, from all the relevant clinical and non-clinical disciplines, comes in to the supportive and palliative care research field. Going forward it will be important to continue to foster the culture of collaboration and interdisciplinary working through encouragement from funders, support from universities and willingness from researchers.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
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<tr>
<td>AllIHPC</td>
<td>All Ireland Institute of Hospice and Palliative Care</td>
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<tr>
<td>APM</td>
<td>Association for Palliative Medicine</td>
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<tr>
<td>APPROACH</td>
<td>Analysis and Perspectives of integrated working in PRimary care Organisations And Care Homes</td>
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<td>ASM</td>
<td>Annual Scientific Meeting</td>
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<td>BIS</td>
<td>Breathlessness Intervention Service</td>
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<td>BMJ</td>
<td>British Medical Journal</td>
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<td>CBG</td>
<td>Capacity Building Grant</td>
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<td>CECo</td>
<td>Cancer Experiences Collaborative</td>
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<td>CINV</td>
<td>Chemotherapy Induced Nausea and Vomiting</td>
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<tr>
<td>CLAHRC</td>
<td>Collaboration for Leadership in Applied Health Research</td>
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<tr>
<td>COMPASS</td>
<td>COMPlex interventions: ASsessment, trials and implementation of Services</td>
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<td>Cancer Research UK</td>
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<tr>
<td>CSG</td>
<td>Clinical Studies Group</td>
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<td>CSNAT</td>
<td>Carer Support Needs Assessment Tool</td>
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<td>DCPC</td>
<td>Depression Care for People with Cancer</td>
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<td>EAPC</td>
<td>European Association for Palliative Care</td>
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<tr>
<td>ENRICH</td>
<td>ENabling Research In Care Homes</td>
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<tr>
<td>eRAPID</td>
<td>Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice</td>
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<tr>
<td>ESMO</td>
<td>European Society for Medical Oncology</td>
</tr>
<tr>
<td>GHQ</td>
<td>General Health Questionnaire</td>
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<td>GUIDE_Care</td>
<td>Geographical and temporal Understanding In place of Death in England</td>
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<td>Hospice Home Care</td>
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<td>Multinational Association for Supportive Cancer Care</td>
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<td>MD</td>
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<td>MORECare</td>
<td>Methods Of Researching End of life Care</td>
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<td>Medical Research Council</td>
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<td>NCRI</td>
<td>National Cancer Research Institute</td>
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<td>NEOLCIN</td>
<td>National End of Life Care Intelligence Network; now part of Public Health England</td>
</tr>
<tr>
<td>NEOLCP</td>
<td>National End of Life Care Programme, now part of NHS England</td>
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<td>NHS</td>
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<td>National Institute for Clinical Excellence</td>
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<td>PI</td>
<td>Principal Investigator</td>
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<td>POS</td>
<td>Palliative care Outcomes Scale</td>
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<td>PRISMA</td>
<td>Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-life Care</td>
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<td>Patient Reported Outcome Measures</td>
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<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
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<td>RfPB</td>
<td>Research for Patient Benefit</td>
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<td>Symptom Management Research Trial in Oncology (Trials 1-3)</td>
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<td>UK end of life care Research Interest Group</td>
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<td>ZBI</td>
<td>Zarit Caregiver Burden Interview</td>
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Appendix: Supportive and Palliative Care initiative-linked individuals

The SuPaC initiative-linked researchers and consumers highlighted in the report, including their current role and affiliation, and where different their affiliation during part or all of the SuPaC initiative funding period. A great number of individuals were involved in the initiative whom are not highlighted below including, amongst others, a number of the CECo and COMPASS co-applicants, CECo and COMPASS affiliated fellows and CBG grantees.

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