



‘Cancer Experiences’ Research Collaborative

NCRI Supportive and Palliative Care Research Collaboratives

ANNUAL PROGRESS REPORT

Year 3: May 2008 – April 2009

Welcome
to the
Cancer
experiences
Collaborative



July 2009

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Preface

The 'Cancer Experiences' supportive and palliative care (SuPaC) research collaborative (CECo) is now entering its fourth year. In this report, we document our activities during our third year. We have continued to set our standards high – to conduct the best possible research, informed by the latest theoretical and scientific developments; to find new ways to overcome the methodological challenges common in this field; to work together as academics, service users and health professionals to ensure our research is needed and will have a real impact on the lives of people affected by cancer; to investigate effective dissemination methods; and to continue to develop tomorrow's researchers. We have now moved beyond our first tentative steps at working together to become an active, productive community.

Some indication of CECo's success comes from the fact that we have been successful in winning 19 research grants totalling over £2.5 million resulting directly from the work of the Collaborative. £1.4 million of this total has been awarded in Year 3, an increase of over 300% on Year 1. This was derived from 8 grants, a small increase in number from Year 1 when 6 were awarded, indicating increasing success in winning major grants. A further 39 successful grant applications totalling over £4,060,000 have benefited from the Collaborative's work since its inception.

The Collaborative has a mixed funding portfolio, with success in obtaining research grants from the ESRC, from the National Institute for Health Research (HTA, SDO and Research for Patient Benefit programmes), cancer charities (including Breast Cancer Campaign, Breakthrough Breast Cancer, Dimpleby Cancer Care Research Fund, Macmillan), other medical research charities, the Department of Health, and other funders. Collaborative members are now working together on multi-centre studies in both clinical and health services research in collaborative groupings which did not exist before CECo. Our first outputs are now emerging, with eight peer-reviewed publications resulting directly from our work in Year 3, compared to one in Year 1 and four in Year 2.

We have held a successful Annual Scientific Meeting, along with State of the Science, protocol development and a range of capacity-building meetings. These meetings have continued to attract academics and clinicians from within and beyond supportive and palliative care, as well as research partners (service users). We have continued to develop innovative methods of engagement with our research partners.

We have supported two successful NIHR Post-Doctoral fellowships and one successful NIHR Career Development Award. We have awarded two CECo research scholarships to enable practicing clinicians to have dedicated research time to begin to build research careers. In partnership with Help the Hospices we have explored the research training needs of hospice staff. We have disseminated our experience of building a collaborative in Europe, Australia and USA.

Collaboration is a creative, dynamic activity and change is therefore to be expected and welcomed. This report includes information on how one of our original Research themes, Narrative Research, has evolved into the broader Methodology research theme. We also continue to adapt and change our working methods as we work together to discover the most effective ways of collaborating to bring about change in SuPaC research. We would like to thank the many CECo members who have made this progress possible.

We look forward to continuing to work together in Years 4 and 5 to continue to decrease fragmentation in SuPaC research, to increase interdisciplinary and inter-professional working and thereby to conduct research which improves patient care.

Professor Julia Addington-Hall

Professor Sheila Payne

CECo Co-directors

I. Introduction

The 'Cancer Experiences' Research Collaborative (CECo) was funded by the National Cancer Research Institute Supportive and Palliative Care (SuPaC) Management Committee for five years from May 2006. It brings together researchers and academics from five universities (Lancaster, Liverpool, Manchester, Nottingham, and Southampton), as well as clinical partners and user representatives. In total, 24 organisations are represented amongst grant holders and collaborators named in the original funding application, with others now participating in the activities of the collaborative.

The aims of the Collaborative are, firstly, to work together to make significant and substantial progress in both research capacity and the quality of research in supportive and palliative care over the five years of its funding and, secondly, to do so in a way that ensures progress is maintained beyond this period.

This report is an account of CECo activities in this third year of funding, 1st May 2008 to 30th April 2009. The report first gives an account of the activities of the Collaborative's research themes: 'Innovative approaches to complex symptoms' (Section 2), 'Older people towards the end of life' (Section 3), and 'Research Methodology' (previously Narrative research) (Section 4). CECo's research capacity building activities (Section 5) and its Annual Scientific Meeting (Section 6) are then described, followed its User Involvement (Section 7) and International activities (Section 8). Its Year 3 and Year 4 Milestones are then considered (Sections 9 and 10). Research grants (Section 11) and publications (Section 12) follow.

2. Innovative Approaches to Complex Symptoms Research Theme

This research theme is led by Professor Alex Molassiotis (University of Manchester), Professor Mari Lloyd-Williams (University of Liverpool) and Dr Claire Foster (University of Southampton).

Research Grant Development

As outlined in CECo's Year 2 report, the Theme has been focusing on developing collaborative research grants in the areas of nausea and vomiting, depression, nutrition, self-management and sleep (Figure 1). Research into survivorship has been an emerging theme this year, building on the strengths of CECo's participating universities in this increasingly important research field. The Collaborative has particularly welcomed the opportunity to work with the COMPASS Collaborative to conduct the Comprehensive Review of the Evidence Base for the National Cancer Survivorship Initiative.

Since the inception of the Collaborative, the theme has used some of its funding for Protocol Development Meetings, at which interested researchers from inside and outside CECo, at various levels of seniority and from a range of academic and professional backgrounds, have come together with research partners (service users) and health professionals to discuss funding priorities and then to work in small groups on developing research grants from initial ideas to fully worked up proposals. This has, of course, involved considerable commitment on the part of participants and work between meetings. The relationships and trust developed in this way have enabled effective response to 'Calls for proposals' from funders such as the HTA (with the ANCHor Trial funded and underway; see below) and the submission of a number of collaborative bids, with others nearing completion (Table 3).

The ANCHor Trial was awarded just under £500,000 by the HTA to assess the clinical effectiveness and cost effectiveness of acupuncture for the control and management of chemotherapy-related acute and

delayed nausea (ANCHor Trial). The research is being led by Professor Alex Molassiotis, with co-applicants including Professor Mari Lloyd-Williams, and the CECo Symptom theme Research Fellows, Drs John Hughes and Sarah Brearley. This is a multi-centre trial which forms part of the portfolio of the Complementary Therapies Clinical Studies Group, and which is now in progress in Manchester, Liverpool and Plymouth. Box I below summarises the aims, methods and timetable of the study. Dr John Hughes has been successful in obtaining a post-doctoral position on ANCHor, further developing his career and expertise within supportive care.

The NCRI have funded a non-pharmacological supportive care intervention for patients with lung cancer and their caregivers in the management of the respiratory distress symptom cluster. The research is being led by Professor Alex Molassiotis, with co-applicants including Professor Mari Lloyd-Williams (Liverpool) and Dr Chris Bailey (Southampton). Again this is a multi-centre study, with data collection taking place across these three sites. Active clinical research collaborations between these sites in this field did not exist prior to CECo, demonstrating the value of the collaboration.

A collaborative project between the Universities of Southampton, Manchester and Dundee, including nurses, psychologists, statisticians, medical oncologists and others, has been developed directly from Protocol Development Meetings to develop a scale to identify people with cancer experiencing physical and psychological barriers to eating well. Although not funded, this received good feedback from the MRC-MRP funding stream and will be re-submitted for funding.

Merck, Sharp and Dohme have funded Professor Alex Molassiotis to develop a risk model for chemo-related nausea and vomiting.

Dr Sarah Brearley and Carole Farrell (nurse clinician from The Christie) as co-investigators, along with co-applicant Professor Alex Molassiotis, were awarded the European Oncology Nursing Society (EONS) Major Research Grant for a prospective study to clarify the cluster of symptoms related to chemotherapy-induced nausea.

The Theme leadership decided this year to re-direct some of its budget into small grants to fund small feasibility studies or systematic reviews. It was recognised that this would increase the competitiveness of the research bids emerging from the Protocol Development Meeting working groups. To date there have been two small grant schemes run by the Theme and eight small scale/pump priming projects have been funded (total of £17,000.00). Current funded projects include:

- The development of an interventional study to alleviate suffering in patients with advanced cancer.
- Adjusting to life after cancer (funds for grant application development).
- Systematic review of psychological interventions for pain in patients with cancer.
- Feasibility study of auricular therapy and self-administered acupressure for sleep disturbance in patients with cancer.
- A pilot study of the effectiveness of Nevasic – an audio CD intervention for the control of chemotherapy-induced nausea and vomiting.
- Use of antiemetic approaches in the management of chemotherapy-related nausea and vomiting in current UK practice.
- Systematic review of the literature for non-pharmacological interventions for joint pain in non-cancer conditions.
- An investigation of clinical strategies for the management of palmar plantar erythrodysesthesia in the UK.

Box 1. The ANCHor Trial

Aims:

To assess the clinical effectiveness and cost effectiveness of acupressure for the control and management of chemotherapy-related acute and delayed nausea.

Background:

Chemotherapy-related nausea remains a significant problem in clinical practice, and is associated with negative effects on daily life and overall quality of life. The direct and indirect costs of the experience of nausea, especially delayed symptoms, are considerable. As antiemetic medications do not fully control nausea during chemotherapy, research has investigated the impact of non-pharmacological interventions in addition to antiemetics. Acupuncture and its non-invasive form of acupressure have been evaluated several times, with findings indicating that both treatments may be effective at reducing nausea. However, these trials have been hampered by small sample sizes, the wide variety of (non-standardised) antiemetics used, differences in the risk factors for nausea and vomiting in their samples, the range of emetogenicity of chemotherapy regimens used and sampling issues.

Methods:

A randomised controlled trial with three arms is being conducted. 700 chemotherapy patients are being recruited from three geographic regions of the UK. Each trial arm consists of usual care plus one of (1) self administered acupressure wristbands, (2) sham acupressure wristbands, and (3) no additional treatment. Usual care consists of standard antiemetics, based on ASCO and MASCC international guidelines. In the acupressure groups, patients are additionally being provided with a pair of acupressure wristbands. These bands are elastic wristbands with a round plastic button, which is positioned at the P6 acupoint.

Clinical Research

As can be seen from the topics of peer-reviewed grants obtained in Year 3 and in the course of the collaboration (Tables 3 and 4), as well as those of the CECo small grants, this theme is essentially clinical in focus: it is concerned with funding innovative solutions to difficult symptoms which affect people with cancer throughout the 'cancer journey'.

At the strategic level Group members are actively involved in the NCRI Clinical Studies Groups (CSGs), with theme representation on the Palliative Care, Complementary Therapies, Primary Care and Psychological Oncology CGGs, as well as tumour specific CSGs: twelve active theme members are members of CGGs helping to facilitate collaboration and ensuring that the theme's studies are also represented within the CGGs' portfolios where appropriate. Dr Jane Hopkinson (University of Southampton) and Dr Barbara Hanratty (University of Liverpool) were appointed to the Palliative Care CSG in the latest appointment round, strengthening a previously under-developed link.

The Theme has strong clinical links both within the NHS, particularly within the Christie Hospital, Manchester and (increasingly) SUHT, Southampton, and in hospice settings (see Section 5 on Capacity Building).

Theme Meetings in Year 3.

I. State of the Science Meeting

The third State of the Science Meeting of the Complex Symptoms Theme took place on 1st July 2009 at the University of Southampton, School of Health Sciences. Over 40 delegates attended including research partners, researchers, and hospice, hospital and primary care clinicians. The day included two thought provoking key note talks by Professor Jessica Corner (Head of School of Health Sciences, University of Southampton) and Professor Sally Wyke (Chair of Health and Social Care, Director of Alliance for Self Care research, based in the Department of Nursing and Midwifery, University of Stirling). Professor Corner talked about cancer survivorship in relation to current

strategy and research areas. Professor Wyke addressed self management of cancer related problems and what might be learnt from long term conditions.

Other speakers included Dr Alison Farmer who spoke from a service user perspective about survivorship and self management, highlighting fatigue and sexual/hormonal issues for young women as particular areas in need of research and information. Dr Helen Campbell (DoH/NIHR); Dr David Wright (Macmillan Cancer Support) and Professor Alex Molassiotis (University of Manchester) all gave highly informative presentations regarding available funding and highlighted the importance of keeping a close eye on what grants are available and are coming up. Professor Alex Molassiotis highlighted possibilities of funding by industry in particular. Dr Deborah Fenlon from the University of Southampton presented her work on survivorship and self management problems associated with breast cancer including hot flushes.

In addition updates for three CECofunded small grants were presented. Dr Christina Lioffi from the University of Southampton updated the meeting on the systematic review of psychosocial interventions for pain in patients with cancer, Dr John Hughes from the University of Liverpool on the progress in the feasibility study of auricular therapy and self administered acupuncture for sleep disturbance in patients with cancer, and Professor Mari Lloyd-Williams from the University of Liverpool on the systematic review of suffering in palliative and supportive care and interventions to alleviate suffering.

The meeting generated much discussion about new areas of research, in particular around the area of survivorship and these were taken forward in the Protocol Development Meeting that followed on 2nd July 2009.

II. Other Meetings

A successful meeting has been held to develop clinical guidelines on cough in lung cancer. A meeting investigating the evidence base of depression in advanced cancer and developing guidelines will take place later in 2009.

Influencing Practice and Policy

This year the Theme linked research developments and practice/policy by investing in the development of clinical guidelines. So far two clinical guidelines are almost complete: one in the management of cough in lung cancer (supported by a CECofunded event) and one, working in collaboration with the Association of Palliative Medicine in the UK, to develop clinical guidelines for the management of cough in palliative care. The international antiemetic guidelines (MASCC/ESMO) have membership from within the Theme and recently the updated guidelines and consensus meeting has taken place, again with Theme involvement. Another guideline for the management of depression in advanced cancer is in preparation.

In Year 3 it is still too early for the first research studies resulting directly from the work of the Collaborative to have reached completion and for their findings to influence policy and practice. As demonstrated by the Theme's development of clinical guidelines it, like CECof as a whole, is however committed to improving patient care.

Figure 1: CECo Complex Symptoms Research Theme: 2008-2009 Programme (Part 1)

Complex Symptoms Research Theme: work resulting directly from the Collaborative

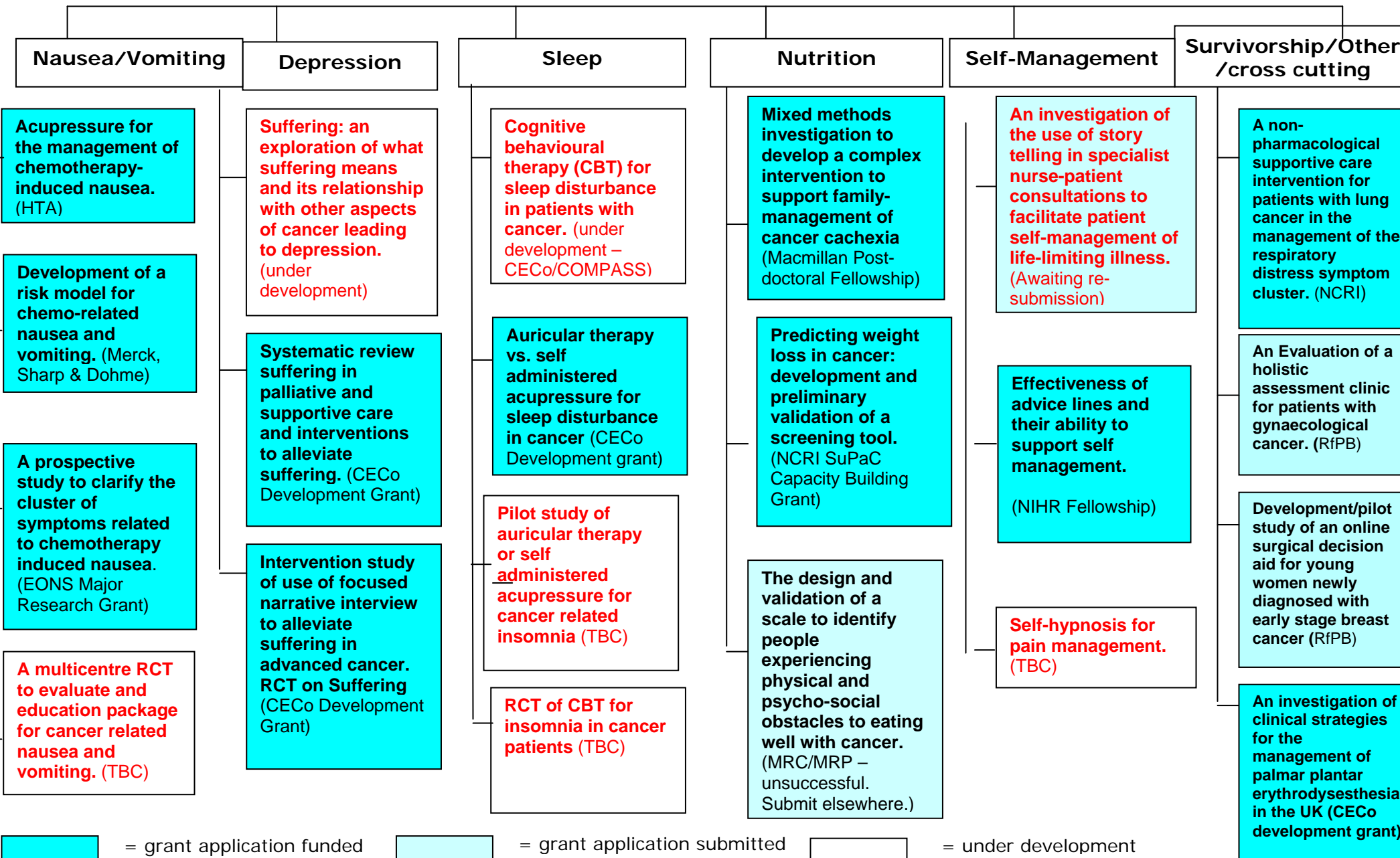
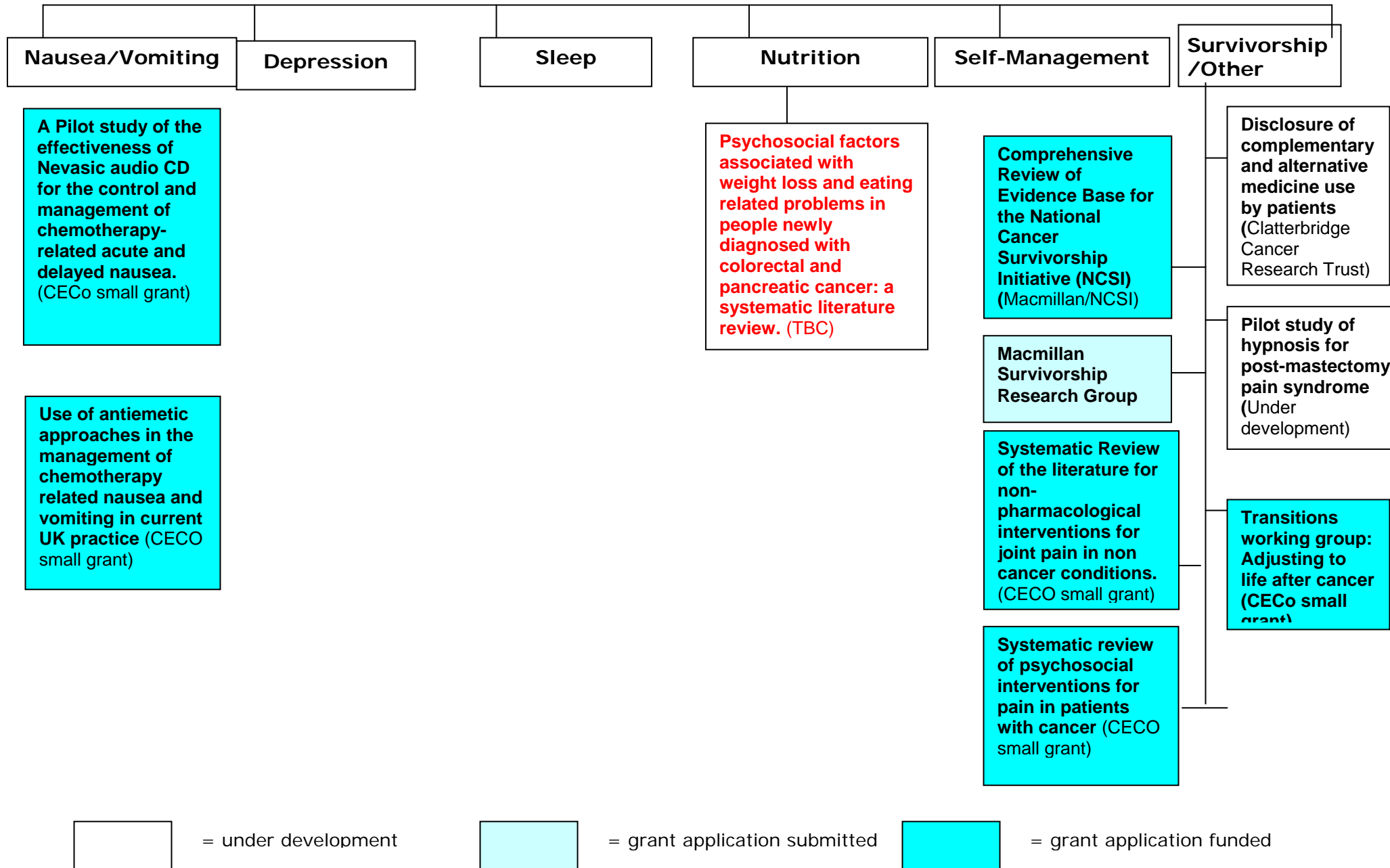


Figure 1: CECo Complex Symptoms Research Theme: 2008-2009 Programme (Part 2)

Complex Symptoms Research Theme: work resulting directly from the Collaborative



3. *Older People Towards the End of Life: priorities, processes and places* Research Theme

This Research Theme is led by Professor Jane Seymour (University of Nottingham) and Dr Katherine Froggatt (Lancaster University). The overarching aim of this theme is to develop a programme of work relating to the improved care and support of older people and their family carers, taking into account socio-demographic and ethnic diversity and introducing methodological innovation, especially in user involvement.

There are four strands of work:

- **Self perceived priorities for end of life care:** we seek to explore how preferences and perceived priorities for care are influenced by different socio-demographic characteristics, ethnicity, culture, cohort and stage of life transition. A key concern for our programme of work is the impact of changing demography, which means that an increasing number of older adults living in their own homes towards the end of life, live alone.
- **Processes of care decision making at the end of life:** social scientific research published by collaborators prior to the launch of the CECo collaborative suggests that many older adults have beliefs about the role of their family and other carers in decision making which do not correspond neatly to the predominant professional/policy rhetoric of 'control' and 'choice'. In CECo we seek to therefore to further unpack these understandings, how they relate to matters of decision-making and what related information needs they give rise to.
- **Places of care at the end of life:** this strand seeks to identify and inform effective and acceptable interventions to enable care and death in the preferred place of care. One focus is on new approaches to palliative care in care homes, emphasising the study of current practice with respect to care planning towards the end of life, the development of tools to aid consultation for advance care planning with residents, and the location of care homes in their wider environment and how this constrains or enables quality of end of life care provision. Another emerging focus is on the issue of 'transitions' in care, bearing in mind that during that 'older people will be transferred many times between different settings in their final years, months, days and hours'.
- **User involvement:** We are using a variety of models of user involvement, from the inclusion of users as project advisory group members, to working with older adults as 'research partners' and co researchers. Very often we find that there is little out there to guide us, so to some extent we are breaking new ground in this activity. We are mindful and wary of strong pressures to go with the 'user involvement' agenda promoted by government, statutory and non- statutory research funders, but seek to maintain a critical stance to this activity, which goes beyond the 'tokenistic' efforts that can easily be made, towards making a contribution to a deeper understanding of the methodological and ethical issues involved.

Research Grant Development

In this theme, we have active portfolios of research activity encompassing these strands with a particular focus on living alone; care homes and older carers (Figure 2) Our research is supported by considerable success in gaining funding from diverse sources spanning local practice development funds to NIHR and research council funding.

As in the Complex Symptoms theme, our portfolio includes projects which have developed as a direct result of CECo, as well as ones which have benefited from CECo. The former are the product of collaboration between members of the Older People Theme Group, with funding used to support Protocol Development working groups and conference calls. In total, the theme gained additional funding worth £995,000 in 2008/09 for thirteen new projects supporting the strands of work, including a funded PhD scholarship under the ESRC 'case' studentship scheme. These demonstrate a range of PIs and co-applicants from various Universities. One of our members (Walshe) won second prize in the EAPC new investigator's award. In addition, the major SDO grant which arose directly from CECo for which a collaborative team of CECo researchers led by Dr Barbara Hanratty (University of Liverpool) had been short-listed at the time of last year's report has subsequently been awarded (£486,254).

We have also collaborated with international colleagues: in Year 2 we held a joint seminar with Professor Luc Deliens (a member of our Advisory Group) and his research teams from Amsterdam and Brussels in which we identified that we had qualitative datasets from England, Holland, Belgium and Switzerland on the perspectives of older people on end of life care. A Research Initiation Grant from the Foundation for Sociology of Health and Illness has enabled a multi-national research team to be formed to conduct a secondary analysis of these data, to prepare publications and to inform a research grant proposal to study older people's perspectives on these issues across several European countries. The team has met several times in Year 3, completed data analysis, and is drafting papers and a grant proposal (J. Seymour, S. Payne, R. Deschepper, B. Onwuteaka-Philipsen, S. Pleschberger, J. Brown (until her untimely death)).

Theme Meetings in Year 3

The Theme held three successful Capacity Building and State of the Science Meetings in Year 3 which were attended by 127 people, including academics, practitioners, policy-makers and research partners (Table 1).

Influencing Practice and Policy

This year the Theme has seen eight of its early projects through to completion and begun the process of dissemination of their findings to inform practice, policy and further research development.

An example is the Innovations and Solutions in Care Homes project, funded by the NHS End of Life Care Programme. Recommendations from the study are listed below (Box 3). The research study is a good example of the Older People's Theme actual and potential impact on policy and practice related to the Department of Health's End of Life Strategy. A comparison of the research underway within this theme with key research priorities in the strategy makes this potential even clearer (Table 2).

Box 2. 'End of Life Decision Making' conference. 27th January 2009

Dr Philomena Swarbrick (PhD student)

The conference hosted over seventy delegates, focusing on aspects relating to the conversations, and their contexts, that do, could or should take place at the end of life. Speakers took complementary approaches; clinical, philosophical, ethical and legal, and were drawn from many areas of professional practice; medicine, nursing, palliative care organisation and research. Twelve posters presented widely varying methodologies for examining end of life situations and attracted much interest. The conference brought together early and experienced researchers from UK-based and international institutions. The experience was excellent for placing my own PhD study within the wider current research field. It was gratifying to have my work commented on by experienced researchers and even more so to receive a second place commendation for my first ever poster.

Table I. Research Events and Capacity Building Activities

Date	Meeting	Venue	Participants
8 th May, 2008	'Open Space' user and research partner consultation informing ESRC Seminar	Edinburgh. In collaboration with the Centre for the Older Person's Agenda, Queen Margaret University, Edinburgh	11
15 th May, 2008	ESRC Seminar 4/CECo State of the Science meeting: Planning for Death in Old Age	Edinburgh. In collaboration with the Centre for the Older Person's Agenda, Queen Margaret University, Edinburgh	39
27 th January, 2009	Joint conference with the Palliative Care Research Society 'End of Life Decision Making' (See Box 2)	Birmingham	77 (32 from academic institutions, 37 practitioners, 8 other)

Box 3. The Innovations and Solutions in Care Homes Project.

Funder: The NHS End of Life Programme

Project Team: Jane Seymour(1), Katherine Froggatt(2), Arun Kumar(1)

(1) University of Nottingham (2) Lancaster University

Many care homes feel isolated and do not have the support they need to provide top quality end of life care. The National End of Life Care Programme commissioned a study to examine how these issues affected the care of older people in nursing homes. The study looked at the drivers and barriers to good quality end of life care for older adults in nursing homes through an in-depth study of two nursing homes in northern England and a survey of surrounding nursing homes in the areas.

Recommendations:

For care homes and staff:

- Consider setting up local networks to encourage practice development.
- Bear in mind that NHS Continuing Healthcare funded care is available for end of life care and can be delivered in care homes.
- Be aware of the National End of Life Care Strategy and the responsibility of local authorities and PCTs to provide ongoing support.
- Implementing end of life care tools such as the GSF and LCP can improve practice and help bring in external support.
- Consider strategies to develop leadership, including designating some homes good practice 'beacons'.

For SHAs, PCTs and local authorities:

- Commissioning needs to ensure proper levels of nursing, medical and equipment support to care homes, particularly in relation to out of hours practice and availability and maintenance of syringe drivers.
- Consider how to involve nursing home representatives in your end of life care strategy.
- Ensure residents receive consistent and coordinated medical care from a GP familiar with their needs.
- All homes should be able to access outside support regardless of whether they are implementing end of life care tools.
- Many deaths in care homes are not from cancer and a growing proportion of residents have dementia. The community matron can play a vital role in addressing the management of people with long-term conditions.
- The provision and accessibility of training for care home staff needs to be examined urgently.

For acute hospitals:

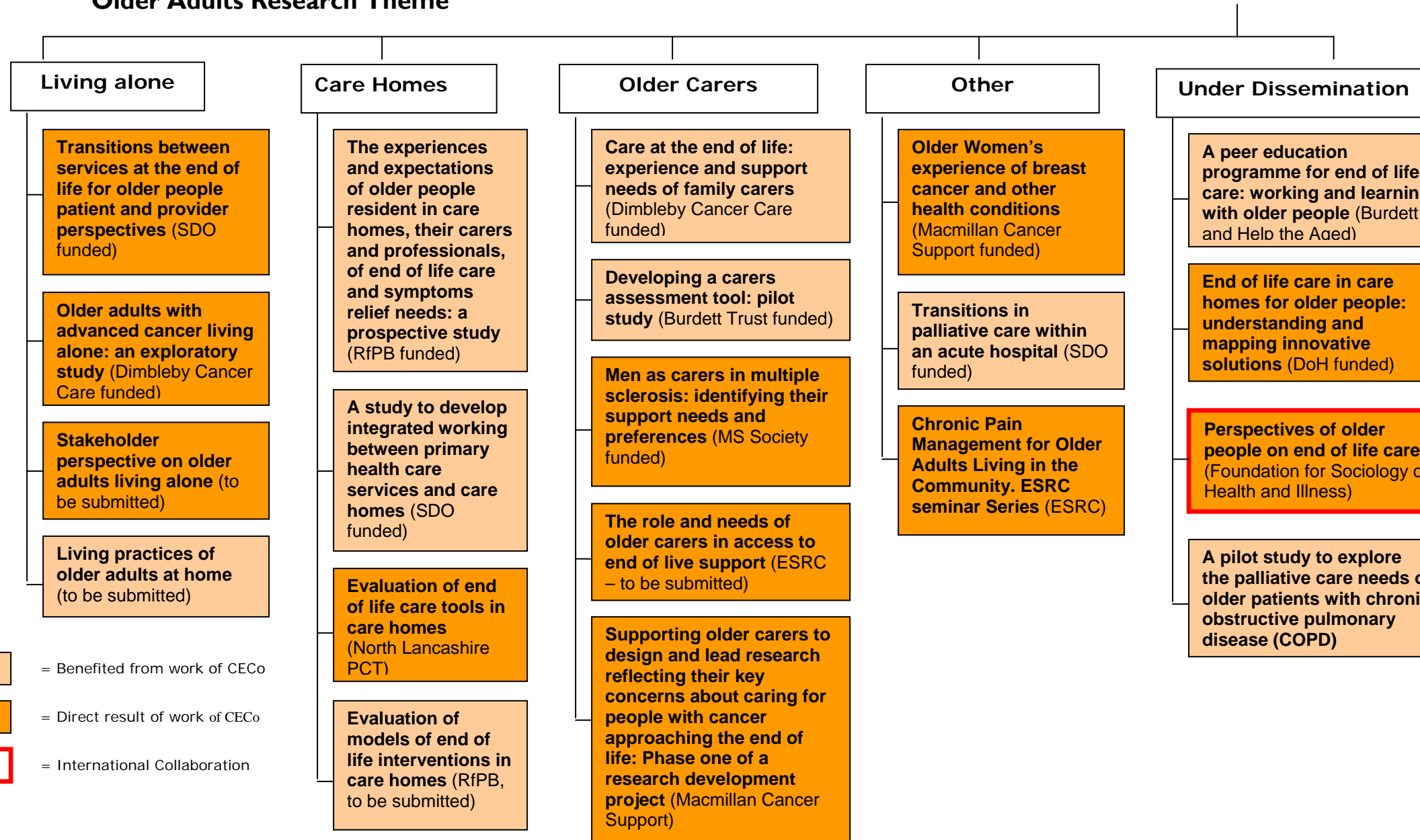
- Consider how information is provided to care homes about residents discharged from hospital.
- Think about monitoring admissions of residents from care homes in the last days of life as well as auditing the reasons for admissions and informing PCTs and SHA end of life working groups.

Table 2. Comparison of Research in CECo’s Older People Theme and key research priorities of End of Life Strategy

Key Research Priorities in End of Life Care Strategy	Current CECo research in the Older People research theme
Social attitudes to death, dying and bereavement.	Research programme in Peer Education for End of Life care (JS).
Attitudes to end of life issues amongst health and social care professionals	6 funded studies with elements which consider professionals’ perspectives on end of life care (JSx2, CG, MG, BH, CW, JAH).
Demographics of dying – especially for causes of death other than cancer	<ul style="list-style-type: none"> • 2 SDO funded studies (BH, MG) and others under review providing new demographic data. • Use of VOICE’s after-death questionnaire to evaluate impact of EOL strategy will provide national epidemiological data on demographics, symptoms, service use etc (see RSCD) (JAH). • National and international reputation for research beyond cancer including CHF, stroke, COPD (JAH, SP), and neurological conditions (JS, JAH).
Environments of care	<ul style="list-style-type: none"> • Programme of work concerning care homes with 2 completed studies (JS, KF) 4 funded studies (JS, CGx2) (SP) and 1 under review. • Three funded studies in hospitals (MG, JAH). • 5 funded studies in domestic homes (BH, BH, CB, JAH). • Long-term research programmes into

	primary care (JAH, CT) (including post-doctoral fellowship (CW), and major collaborative study recently funded, and community hospitals (SP).
Economics of end of life care	Attracted health economist – Dr Karen Gerard – to EOL care (NIHR Career Development Award).
Prognostication	<ul style="list-style-type: none"> Major UK study (CT)
Advance care planning	<ul style="list-style-type: none"> One completed study (KF), one underway (JS), one funded PhD studentship and other studies under development. Also addressed through advisory work with NHS End of Life care programme; a recently completed CECO ESRC seminar series on dying in older age will inform publications.
Communication about end of life issues	Addressed in Peer Education and care home programmes.
Changing cultures in health and social care	Addressed in Peer Education and care home programmes.
Education and training	This has been specifically addressed in the Peer Education project for end of life care (JS). JAH led evaluation of DH national education programme for DNs.
Understanding current care provision	Two SDO funded studies on transitions in care for older people (BH/JAH, MG). A key theme in studies of environments of care, as in a number of other studies. A multi-disciplinary approach is taken to enhance understanding, drawing on theories and methods from the social sciences where appropriate and using both qualitative and quantitative research methods.
Support for carers (during a patient's illness and after bereavement)	Three funded studies (CB, JAH, GG) and two international collaborations, with a range of associated publications and other work under development.
Effectiveness of different models of bereavement care	<ul style="list-style-type: none"> One PhD student (JAH). One PhD studentship application submitted and under review. Long-term research programme (SP).
Care in the last days of life	Specifically addressed within both SDO transitions studies (BH, MG).
<p>Principal Investigators: JAH: Julia Addington-Hall, Southampton CB: Chris Bailey, Southampton KF: Katherine Froggatt, Lancaster CG: Claire Goodman Hertfordshire MG: Merryn Gott, Sheffield; GG: Gunn Grande, Manchester BH: Barbara Hanratty, Liverpool JS: Jane Seymour, Nottingham CW: Catherine Walshe, Manchester SP: Sheila Payne, Lancaster</p>	

Figure 2: CECo Older Adults Research Theme: 2008-2009 Programme
Older Adults Research Theme



4. **Narratives / Methodology Research Theme**

This theme has been created to expand the scope of the theme of Narratives of Cancer and Life-threatening Illness which was part of the original CECo bid. This report therefore reports on the Narrative theme up until end of November 2008 and then the Methodology Theme from 1st December 2008 until the end of the current reporting period 30th April 2009. We are greatly indebted to Janice Brown who played a major role in co-leading the Narrative theme before her untimely and sudden death in December 2008.

Whilst the Narrative theme has successfully pursued its goals since the inception of CECo, internal review of the Collaborative's work whilst preparing for the Mid-Term Review convinced the Executive that there was clear benefit to be had in being broader in our work related to methods. Hence it was agreed to create a new Methodology theme and subsume the Narrative theme within this. Funding allocated to the Narratives theme has thus now been allocated to the new extended Methodology theme. The Theme is being led by Professor Chris Todd and Dr Clare Stevinson (University of Manchester).

Methodology is broadly defined as the systematic study of methods. Research in supportive and palliative cancer care is methodologically challenging. Patients are often very unwell, and they, and their families, may understandably experience periods of emotional fragility. Participating in research may be the last thing they want to do, and clinicians sometimes want to protect their patients from the burden of taking part in studies. Common methodological problems faced by researchers in this area include recruitment, outcome assessment, and study adherence. The Methodology theme has been established to help address these challenges.

The aim of this theme is to study the suitability of methods used in supportive and palliative care research, and to provide evidence that contributes to improving the research process and outcome.

This covers a broad range of issues relating to any quantitative or qualitative research methods. Examples include:

- recruitment and retention of research participants
- selection or development of appropriate outcome measures
- participant understanding of research design or terminology
- involvement of service users
- use of narrative
- innovative methods or approaches.

Current programmes

Narrative research continues to be a programme of work within the Methodology theme and represents a major part of the completed work reported herein. Given the newness of the Theme one would not realistically expect there to be any programmes of current work. However, two projects clearly provide the nuclei of programmes (below 2 and 3) and ongoing development work provides real expectation of an emergent programme (4).

- 1) Narratives
- 2) Prognostication
- 3) Methods for evaluation of models of end of life care
- 4) Recruitment into studies

I. Narratives

Work in this programme has focused on publishing the considerable resources on use of narratives in SuPaC research which the collaborative has collected in an accessible and scholarly form. The result is a publication from the International Observatory at Lancaster University entitled 'Narrative Methods in Supportive and Palliative Care: An Annotated Bibliography'. Readily accessible via the internet, this publication provides an introduction and critique of narrative research, advice on how to critically read narrative research papers, as well as an annotated bibliography of narrative research in this field.

Professor Arthur Frank, an acknowledged expert and seminal thinker in this field has written the Preface and emphasises both the value of the publication and of CECO itself. Other publications have resulted from the completion of research associated with the Collaborative by, for example, Professor Carol Thomas.

Work continues into projects in this programme with, for example, a research project on the identification of support needs of bereaved same-sex partners due to be submitted to ESRC in Autumn 2010. Dr Janice Brown has, however, been greatly missed since her untimely death, as she provided the programme with strong leadership and vision.

II. Prognostication

Prognostication, or the prediction of outcome based on present signs and symptoms and especially the estimation of life expectancy, has been repeatedly demonstrated to be problematic for clinicians, patients and families. The Prognosis in Palliative care Study (PiPS) is an ongoing collaborative study funded by CRUK (Investigators: P Stone St George's Hospital Medical School, L Kelly East Surrey Hospital, V Keeley Derby Hospitals Foundation Trust, C Todd University of Manchester) which comprises a prospective, observational study to develop a novel prognostic index for use in patients with advanced cancer. Patients with advanced cancer (both competent and incompetent) who are no longer undergoing disease modifying treatment are being recruited in a number of sites across England and studied on two occasions approximately one week apart. Patients are flagged with the Office of National Statistics and survival times are calculated. A prognostic model will be developed and validated using bootstrapping techniques. The study started in November 2006 and is scheduled to complete in October 2010, with recruitment of some 1200 patients currently achievable. This study contributes to the theme in two ways: firstly, it will provide a novel prognostic index for patients with advanced cancer which will have clinical utility, and secondly, a prognostic indicator such as this will have future utility as a research tool especially as a recruitment entry criterion.

A State of the Science meeting on prognostication will take place in October 2009 and we expect to continue to develop this work with future funding applications to further validate and develop the PiPs index.

III. Methods for evaluation of models of end of life care

This is a two year project funded by the MRC/NIHR Methodology Research Programme in collaboration with researchers from the COMPASS collaborative (Investigators: I Higginson KCL, P Fayers University of Aberdeen, G Grande University of Manchester, R Harding KCL, M Hotopf Institute of Psychiatry, P Lewis KCL, P McCrone Institute of Psychiatry, M Morgan KCL, S Murray University of Edinburgh, C Todd University of Manchester). It is based on the finding that research into End of Life Care (EoLC) services is patchy and faces complex difficulties. Guidance on best practice is needed so that timely evaluation can help optimal services be developed to improve care for patients and families. This study aims to identify, appraise and synthesise 'best practice' methods for the evaluation of EoLC, particularly focussing on complex service-delivery interventions and reconfigurations. The objectives are to:

- a. Critically review the current methods used in evaluation research in EoLC
- b. Characterise the different care settings, organisational contexts, and patient groups where EoLC research may be conducted and the implications of these for different methodological approaches

- c. Identify practical, ethical, legal and methodological issues pertinent to EoLC research
- d. Appraise the needs and views of key stakeholders
- e. Evaluate potential solutions to barriers created by issues identified
- f. Synthesise the findings of the review and stakeholder consultation to develop guidelines for undertaking evaluation research in EoLC.

The project uses a combination of methods in parallel to deliver the above aims and objectives. Initial literature scoping will clarify the questions for the reviews and consultation. Then literature appraisal and evidence synthesis will be used to address aims 1 to 4, combined with consultation with stakeholders, using the Transparent Expert Consultation technique for aim 5. This process involves web-based consultation followed by face to face consultation similar to the Nominal Group Technique. The findings from appraisal and consultation will be integrated to provide initial guidance. Then in year 2 of the project a series of methodological 'think tank' workshops will be held. These will be similar to the retreats organised in the development of MRC-Guideline for Developing and Evaluating Complex Interventions drawing together experts to identify and evaluate potential solutions to barriers in areas of contention and difficulty. All aspects of the project will then be synthesised into a final guideline. The development, evaluation and implementation components of MRC guidelines will provide a structure for the reviews, consultation and synthesis across the whole project. The final guidance will be structured in a similar way to that of the MRC guidelines, including case studies of best practice. Consumers and the public will be involved in the consultation and through activities already established by the applicants. The study is due to start in September 2009.

IV. **Recruitment into studies**

Recruitment of participants into research studies in supportive and palliative care has long been recognised as a major challenge. This is true both to randomised controlled trials and to other well designed studies whether they are using quantitative or qualitative methods. A protocol development meeting was held in Manchester in April to develop this research interest. The focus of the work is to identify the facilitators and barriers to recruitment to studies and specifically to focus on the role of health care professionals as gatekeepers. This project is being worked up for submission to the MRC/NIHR Methodology Research Programme. A systematic review of the literature related to all research areas not just cancer, supportive and palliative care is underway. This work is being supported by the CECo Fellow on the Theme, Dr Nancy Preston.

Theme Meetings

The Theme held its first protocol development meeting in April in Manchester. The meeting focused on the topic of recruitment. Fifteen attended and three sent apologies for absence. After a brief introduction to the Methodology Theme and its aims and scope, there was a lively group discussion regarding the challenges associated with recruitment in supportive and palliative care which generated several topics with potential for development into a proposal. It was decided to focus on one of these: engaging health professionals in the research process to improve access to, and recruitment of, cancer supportive and palliative care participants. Provisional plans were discussed for an exploratory study to help understand the factors inhibiting/facilitating the role of health professionals in recruiting participants in primary/secondary/tertiary care settings. This exploratory work would be intended to provide the basis for subsequent experimental work to test the effectiveness of strategies for improving recruitment.

Following this meeting, several conference calls have been held between nine researchers with the intention of submitting a grant to the MRC-NCRI Methodology Research Programme Investigator-Led competition in 2010.

The first State of the Science meeting is planned for 15th October 2009 in Manchester. It will be on the subject of Prognostication. Dr Paul Glare from the Memorial Sloan Kettering Cancer Centre,

5. Capacity Building Activities

Research Capacity Building activities are an important part of CECo's function, with the aim of improving both the quality and quantity of researchers in supportive and palliative care.

The Collaborative aims to have a mixed portfolio of research capacity activities; in response to the need it perceives to increase quality and quantity across the whole continuum of expertise in supportive and palliative care research. It places great emphasis on providing mentorship and support to emerging independent researchers, so necessary for the future sustainability of the field, and to challenging the intellectual boundaries of Collaborative members.

However, the Collaborative also sees an important, albeit limited role, at the lower end of the continuum. It recognises, for example, the importance of developing a basic understanding of and appreciation of research amongst practitioners, particularly in the independent hospice sector, who are essentially research naïve and do not have access to NHS research support. The Collaborative has, as outlined in Year 2's report, made a strategic decision to invest some time and resources to this in collaboration with Help the Hospices in order to facilitate the development of a more research-friendly environment in these settings, and promote evidence-based practice to benefit patient care, and to give talented individuals the opportunity to pursue research.

The Collaborative funds a scholarship programme to enable clinicians to have protected time to prepare PhD or MD applications, or to do specific pieces of research for publication, because it recognises that Fellowship programmes have become increasingly competitive, and access to expert researchers and protected time may make a significant difference in the process.

CECo conceptualises capacity building as any activity which increases the research knowledge or expertise of participants. Many activities of the research themes fulfil this requirement: Protocol Development Meetings, for example, provide a valuable practical learning exercise particularly (but not only) for junior researchers in how to conceptualise research questions, to design studies which work within the realities of funding, and to write proposals convincingly. The Collaborative does have, however, a theme dedicated specifically to Capacity Building activities, under the leadership in Year 3 of Dr Ziv Amir (University of Manchester). The activities of this Theme are reported below.

I. CECo Scholarships

These enable a clinician to focus on research for up to three months full-time. They are targeted at clinicians at the beginning of their research careers, and the grant award committee (chaired by Professor Jessica Corner) is concerned to identify evidence of research potential, of good mentoring arrangements, a feasible project likely to result in a published paper and/or fellowship application, and of support from the applicant's employer. This year's scholarships were awarded to Michelle Wood, an art therapist, and Janet Rigby, a hospice staff nurse. They summarise their experiences in Box 3.

Box 3 CECo Scholars in Year 3.

Michelle Wood.

'In thinking about how to summarise my CECo scholarship the analogy of mountaineering comes to mind. With the support of Professors Sheila Payne and Alez Molassiotis I was carefully guided through rough terrain and up daunting cliff faces. Librarians and staff at the Centre for Reviews and Dissemination also helped along the way providing anchor points for the ropes up which I climbed. At times I was fearful about getting lost and worried that the journey was either too difficult or pointless, but I eventually completed my trek through the research literature and was able to tackle the question 'How effective is art therapy in the management of symptoms in adults with cancer'. The findings have been presented at the 11th World Congress of the International Psycho-Oncology Society (IPOS) in Vienna, as well as at the British Association of Art Therapists conference. The CECo scholarship also helped my clinical work by increasing the value and profile of art therapy, which in turn has released more resources from my employers. I have now been successful in gaining a part-time NIHR-funded studentship at Manchester University'.

Janet Rigby.

'I am a staff nurse at the East Cheshire Hospice in Macclesfield. The Scholarship funding has enabled me to attend the International Observatory of End of Life Research Summer School at Lancaster University, and has allowed me to reduce my hours of work so that I can complete a research study over the next nine months. The Summer School was a great experience for me, as I was able to meet a group of health care professionals from many countries, and benefit from very high quality teaching on research methods. I also received support and tuition on my own study, which is a literature review on the specific environmental needs of older hospice patients. I am privileged to have the support of Professor Sheila Payne and Dr Katherine Froggatt.

II. Workshops:

Following the success of the first Research Methods Workshop held in Liverpool in 2008, a second workshop was held at St Christopher's Hospice in 2009. Led by Christine Ingleton from the University of Sheffield, the two-day workshop was an introduction to research in palliative care. The aims of the two-day event were to work with participants to develop an understanding of research and its relevance to palliative care, identify researchable questions, explore ethical issues in the conduct of research in palliative care, and explore barriers to translating research into practice and examine how these may be overcome. Feedback from the course was excellent.

In February 2009, Dr John Hughes, CECo Research Fellow for the Complex Symptoms theme, and Professor Mari Lloyd-Williams, along with colleagues from the Academic Palliative and Supportive Care Studies Group (APSCSG) at the University of Liverpool, organised a basic research awareness course for the network of 25 hospices which have been set up in the North West and North Wales. This successful day included presentations on literature reviews, how to get started on research, ethics, differences between audit and research and obtaining funding. The day was attended by hospice staff and some trustees – one delegate said afterwards “this day has really helped me to understand how we as a hospice can contribute to research and by developing our own ideas with the academic palliative and supportive care studies group at the University of Liverpool and with CECo to develop a research framework.”

III. Doctoral and Post Doctoral meetings:

In March 2009, successful doctoral and post doctoral meetings were held at the University of Manchester. The event was largely organised by the PhD students and post-doctoral fellows who had participated in previous years. We thank them for their hard work and inspiration (Dr Sarah Brearley (CECo Research Fellow in Complex Symptoms), Dr Lynn Calman and Gemma Bryan).

One of the aims of the meetings was to facilitate and develop wider engagement of doctoral and post doctoral researchers. To facilitate this, doctoral students gave presentations on their research to an expert panel of senior researchers (Professor Sheila Payne (Lancaster University), Professor

Chris Todd (University of Manchester), Professor Alex Molassiotis (University of Manchester), Dr Katherine Froggatt (Lancaster University)), who provided constructive feedback. Post doctoral researchers from the CECo institutions collaborated with each other to synthesise SuPaC research activity in their centre, which was then presented to the rest of the post doctoral group. The aim was to facilitate greater understanding of the research happening at the CECo centres and to encourage collaboration.

The meetings also aimed to allow participants to focus on “what’s next?” and strategies for the future. Four post doctoral fellows (all members of the Complex Symptoms theme) therefore gave presentations to the PhD students about their journey from PhD to post-doctoral research fellow. This was followed by a ‘next steps’ planning session, and small group sessions led by post-docs, where doctoral students were able to discuss career development issues and ask questions. During the post-doctoral fellow workshop, Dr Lisa Cotterill from the NIHR gave a well received presentation on funding opportunities, and exactly what NIHR are looking for in post-doctoral applications.

The final elements of both meetings were sessions which focused on strategies to manage challenges associated with doctoral and post doctoral research. This was led by Mary Walsh from the counselling service of the University of Manchester. The evaluation forms for both days were extremely positive and further events are planned for 2010 (Box 4).

Box 4.

**Feedback on the CECo PhD meeting, March 2009.
Wendy Lambert.**

Attending the CECo meeting provided me with the opportunity to be with other like minded persons and to spend time talking about each others’ research. The two days were informal, informative and very enjoyable. As a part time student it provided me with ‘time out’, a rest from working plus a chance to be a student.

I enjoyed listening to the other students’ research (both during their presentations and informally sat in the lounges). Each student was at different stages in their research, each having their own set of anxieties and hurdles that they were trying to overcome. I learned a lot from ‘just listening’ and reflecting on my own progress. Being with other PhD students made me feel comfortable and confident as to where I am, and that in fact I am making sound progress.

The presentations were particularly invaluable (each student I spoke to after their presentation described this). The presentations were divided into two slots. I (plus other students) felt that those students who were in the first group actually received more useful feedback.

The two days were very much about networking, particularly during the evening when we had a chance to chat ‘very informally’. There were several characters amongst the group and you recognised that they had a vast wealth of experience and knowledge to bring into this field of health care research. As a PhD student it can get a bit lonely out there doing your research, but sitting together that evening made you realise that ‘actually you were not alone at all’. It also brought it home to me that to be successful and complete my PhD I would need to be very focused and self driven.

The benefits of attending the CECo meeting were enormous. Firstly the 8 minute presentation really focused my mind on my research. It made me really consider which methodology to use and the various methods for data collection, also it provided me with the opportunity to present my presentation skills. Secondly the meeting was informative; I gained a great deal from listening to established researchers talk about their work and where they sit within CECo. Thirdly, I enjoyed listening to other students and the processes that they had gone through with their research, all of which I feel will be invaluable for my own development. Finally, I enjoyed the whole experience, the sharing of information and experiences, listening to the excitement and motivation that existed within the group and the optimism that as an organisation and group of researchers we could move palliative care forward.

IV. What Types of Education and Training in Research are needed by Hospice Staff?

Following discussion with Terry McGee, at that time Head of Education and Research at Help the Hospices in Autumn 2007, it was decided that there was a need to explore the educational needs of hospice staff in relation to research. An exploratory study, jointly funded by CECo and Help the Hospices, was therefore conducted. This involved five focus groups in Manchester and London with 32 hospice educators in Autumn 2008. Participants were also provided with a master class on research opportunities linked to CECo. The focus groups and workshops were jointly facilitated by Dr Mary Turner (Lancaster University), with either Dr Sarah Brearley or Dr Ziv Amir (University of Manchester). The findings from the focus groups are presented in a report (available on the CECo website).

Briefly, they indicate a mixed picture with some good examples of research activity but also a worryingly poor level of knowledge about research, and few opportunities for staff to be supported or have access to expertise which has been more readily available to their NHS colleagues via NHS Research and Development Support Units and other initiatives since the 1990s. They also indicate that most research currently being undertaken appears to be in the form of small studies conducted as part of education course requirements such as Master's level dissertations. (A summary of the findings and recommendations are available in Appendix 1).

Building on this study, a team based in Lancaster have conducted a telephone survey of independent bedded hospices in the UK to map current research activity. The telephone survey was conducted in January and February 2009, and sought to identify research activity and infrastructure in hospices and establish where specific education and support for hospices could be focused. One hundred and eighteen responses were received, a response rate of 72%. Results show that whilst the majority of hospices reported being involved in some sort of research during the past year, it confirmed many of these were small scale (for example higher degrees), and only a quarter of hospices had initiated research projects of their own. A database of named people with research responsibilities within hospices has been created and further in-depth qualitative research is planned to establish their expertise, role, academic links, and training needs. There is a potential to establish a forum for this group as they appear to be largely unsupported and have unrealistic organisational expectations placed upon them. An open meeting has been arranged at the Help the Hospices conference in November 2009, where CECo will also be providing an introductory research workshop.

V. Master Class on Evaluation of Complex Symptoms:

A Research Master Class took place in June 2008 on the evaluation of complex interventions in palliative care. This workshop provided an opportunity for researchers and practitioners to explore the challenges of designing and conducting trials of complex interventions using the MRC framework. Speakers at the workshop included Professor Chris Todd (University of Manchester), Professor Julia Addington-Hall (University of Southampton), Professor Alex Molassiotis (University of Manchester), Dr Steve George (University of Southampton) and Dr Gunn Grande (University of Manchester).

VI. Primary Care and Palliative Care Conference

It is widely acknowledged more than 90% of last year of life is spent at home under care of the primary care team. In April, a Primary Palliative Care conference was organised by Professor Mari Lloyd-Williams and the APSCSG at the University of Liverpool on behalf of CECo, COMPASS and the Palliative Care Research Society. Over 120 delegates attended from all over the UK. Key note speakers included Professor Scott Murray (University of Edinburgh) and Professor Jane Seymour (University of Nottingham) along with workshops on topics such as user participation in primary palliative care research; longitudinal qualitative studies and how to conduct randomised controlled trials within a community setting.

VII. Leadership Development:

The Senior Executive and theme leaders participated in a 24 hour leadership skills training workshop provided by experts from Lancaster University Management School. The course strengthened the leadership skills and increased team working abilities of the participants.

6. Annual Scientific Meeting

The third CECo Annual Scientific meeting was organised by a team lead by Roger Wilson (CECo research partner leader) and Professor Sheila Payne (Lancaster University) ably assisted by Anne-Marie McDonald (CECo administrator). The meeting was held on 21-22 April 2009 at the Radisson Airport Hotel, Manchester. A key note talk on continuity of care was provided by Professor Alison Richardson (COMPASS co-director) and Professor Sean Morrison (USA) provided an excellent key note on his experiences of running a research centre in the USA focusing on end of life care for older people. Professor Morrison also emphasised the importance of social marketing methods in bringing about lasting change in care for seriously ill older adults. The varied programme consisted of presentations on new scientific projects by CECo researchers, research partners' accounts of their experiences collaborating on research, CECo scholars' reports on their research and 'meet-the-expert' sessions. The ASM attracted a wide group of researchers, research partners, policy makers, clinicians and representatives of advocacy groups. All participated in structured networking which quickly broke down barriers and formed the basis for a lively and engaging meeting.

7. User Involvement

Research Partners continue to be integrated throughout CECo's activities, from a strategic level (where Roger Wilson continues to be a member of the Executive Team and the Chair of the Advisory Committee) to acting as Advisors to research projects on a local level.

As outlined above in the Older People Theme (Section 3) the Collaborative continues to seek to be innovative in terms of user involvement. This is probably best developed at present by the work of the Lancaster Research Partners Forum. This is funded and supported by CECo, with members contributing to wider debates within CECo and lessons learnt within the Forum being disseminated and discussed within the Collaborative and elsewhere.

The Lancaster Research Partner Forum was initiated and developed by CECo supported researchers based at Lancaster University, in October 2007. The Research Partner Forum was established with two key aims: firstly, to create a way for research partners to become involved in research projects being developed through CECo, and secondly to develop and design studies on issues of relevance and importance to the research partners. Both aims have been met in this year.

Monthly research partner meetings continue to be held. Membership has increased to 12 members. Members of the forum are generally older and come with a range of backgrounds. All members except one are members of the public rather than health professionals, but many members have a previous background as health and or social care professionals. Many members have either lived with, or still live with cancer or other life limiting illnesses or have been carers of people with such illnesses and/or experienced close personal bereavements.

The Forum was consulted about eight proposals and their design during the year, of which three have been funded. It has also developed and submitted two grant applications itself: an application to the Macmillan User-led grant applications, "*Cancer experiences: the impact on friends*" was short listed but not funded this year although re-submission next year has been invited; an outline application was submitted to Dimpleby Cancer Care, but not short listed. A further grant application submitted with some members of the Forum, and other parties, to develop peer education about end of life issues in the Lancaster area has been funded by North Lancashire teaching PCT under their research bursary scheme. Two members attended the NCRI conference on consumer bursaries (see box below and Appendix 2),

and a poster about research partner work presented at the NCRI conference.

In-house training in research methods has begun at the Forum's monthly meetings. Participants have also been involved in further training.

In-house training has been commenced at monthly meetings. Further training has been attended (Cancer Voices (4 members); Macmillan's Getting Involved and Influencing Research Workshop (4 members); CECo's Introduction to Research in London in February 2009 (2 members)).

Box 5. Experiences from the Lancaster Research Partner Forum.

'A driving interest of mine is for people to be consulted, to have a voice and to help shape services without being merely passive recipients of a 'top down' approach to service delivery. I have an interest in older people, with creative solutions to ageing and planning for the support and care of older adults which takes their views into account. As I am now becoming 'an older person' I want to 'have a voice' and help to ensure other people's voices were heard. The Research Partners Forum is a group where I can be involved in this type of work. My experience has been positive. I am keen to increase my knowledge and skills by being involved in the initiatives of the group.'

Gail Capstick

'I am currently Director of Nursing for St John's Hospice, Lancaster University. I initially became involved with the research partners after one of its existing members – Norah (a volunteer at a Day Centre where I was at the time Lead Nurse), had told me the function of the group and suggested I sit in on a session. At the time I was researching how to set up a user group within the organisation. At the first meeting, I was impressed by the way the group from varying backgrounds had encompassed the importance and relevance of research for cancer patients, their relatives and friends. Since being involved in the group, although I have previously valued the importance of user involvement, the group has helped me to understand how these views can be taken forward through partnership with the University and local health facilities. I feel the group not only recognises the expertise of others and allows all involved to share their thoughts, views and opinions in a safe environment, but then works towards channelling this energy into areas such as research, review and audit. I do feel that my role within the group is justified as I can offer the link into clinical practice. I must say that I have found the whole experience to be worthwhile.'

Wendy Johnston

'Having been involved with the Cancer Network through 'user groups', I was very aware of the value of my experience and enthusiasm to relevant interested professionals. The Research Partners Forum presented me with a new opportunity to widen my interests in cancer services and general end of life issues. It has given me a chance to meet researchers, both within Lancaster University and the wider CECo network, and to contribute in a small way in the work they are undertaking. Through CECo training sessions, I started to gain a better understanding of the way that academic research sits alongside clinical research. Quite early on we discussed the possibility of doing a small research project of our own, and Katherine's introduction to us of the Macmillan User Lead Research Grant provided a possible opportunity. That has, so far, been a terrific experience. Helping to prepare the initial proposal and then going to the NCRI conference in Birmingham to submit it. Opening up another new world, and introducing me to another group of like minded people. Being short-listed for the Macmillan Grant feels to me like a great achievement, it makes what we're doing seem more real and valid. The prospect of being successful is also a bit scary, but very exciting. I'm sure that even if we aren't successful this time we will carry-on and eventually get funding to carry out our own small piece of research. I became involved with the Cancer Network, and ultimately with CECo, after my wife died of breast cancer. My aim was to put something back and make a difference, the Research Partners Forum is one vehicle that's helping me fulfil that aim.'

Paul Holroyd

8. International Activities

The model of research collaboration pioneered by CECo has attracted increasing international interest. It has been recognised that models of governance, leadership, collaborative research, research capacity and user involvement developed by the CECo team have wider applicability beyond the UK. We illustrate this with some examples:

- Within Ireland and Northern Ireland there are potential opportunities and funding for an all-Ireland Palliative Care Research Collaborative in which Professor David Clark (Lancaster University) has had a key role. Much of the thinking behind this initiative has been influenced by the success of CECo. Professor Sheila Payne (Lancaster University) has provided a seminar on developing a research collaboration (2008) and has been invited to advise on the forthcoming bid.
- Professor Julia Addington-Hall (University of Southampton) is the only European on the Scientific Advisory Board of the USA National Palliative Care Research Center, led by Professor Sean Morrison (New York). The Center shares a common mission with the UK collaboratives to improve the quality and quantity of palliative care research, to enable the field to compete for high status funding, and to encourage collaboration within a field which lacks critical mass. It currently offers competitive junior faculty and pilot study funding, hosts an annual retreat for funded junior faculty and senior investigators, and advocates for increased funding opportunities. Professor Addington-Hall participates in the Center's strategic decision-making and funding decisions, as well as in its annual retreats. There are considerable opportunities for mutual learning about how best to support and grow palliative care research, with the USA particularly interested in CECo's experience of building collaborative groups, something not yet tried in the USA.
- In the State of Victoria, Australia, the Victorian Cancer Agency is currently considering a bid to establish a State-wide Collaboration on Palliative Care influenced by the UK SuPaC experience. Professor Sheila Payne (Lancaster University) has provided detailed guidance on the bid and is a named partner on the proposal to provide international expertise and mentorship.
- Through our links with the EAPC, we are aware of considerable interest in the outcomes of the UK Collaboratives. We presented a workshop on building collaboratives at the EAPC Congress in Vienna in May 2009.

9. CECo Milestones – Year 3

- 9.1 Continue research training and mentorship activities**
√ milestone met: see Section 5
- 9.2 Appointment of CECo Scholars**
√ milestone met: see Section 5
- 9.3 Hold State of the Science and Annual Scientific Meetings**
√ milestone met: see Sections 2,3,6
- 9.4 Obtain three PhD/post-doctoral fellowship awards**
√ milestone met:
 - I. Dr Sorrell Burden was awarded a Macmillan post-doctoral fellowship at the University of Manchester.

2. Dr Katrina Lavelle was awarded a three year NIHR post-doctoral fellowship at the University of Manchester.
3. Dr Karen Gerard was awarded a three year NIHR Career Development Award at the University of Southampton.

9.5 Obtain peer-reviewed grants in each Theme area to sustain CECo fellow posts

√ milestone met: see Sections 2, 3, 11

9.6 At least three multi-centre grants in progress, using common ways of working

√ milestone met: see Sections 2, 3, 11

9.7 Advisory Group meeting

√ milestone met

The third meeting of the Advisory Group was held at the Annual Scientific Meeting, April 2009.

9.8 Partnership Group meetings

√ milestone adapted

Following discussion with research partners, a Partnership Group was not established with a research partner incorporated into (and Chair) of the Advisory Group.

10. CECo Milestones – Year 4

CECo co-applicants have identified the following milestones to measure the progress of the Collaborative in Year 4:

1. Continue research training and mentorship activities.
2. Appointment of CECo Scholars.
3. Hold State of the Science and Annual Scientific Meetings.
4. Obtain 3 PhD/post-doctoral fellowship awards.
5. Obtain peer-reviewed grants.
6. At least five multi-centre studies in progress, using common ways of working.
7. Advisory Group meeting.
8. Partnership Group meeting.

11. Research Grants

As in Year 2's Report, a distinction has been made in reporting grants and other outputs between those that have resulted directly from the work of CECo and those that have benefited from the work of the Collaborative.

Grants which have resulted directly from the work of CECo have usually been developed through the theme's protocol development activities, by theme members' responding jointly to a funding call, and/or are the work of CECo Fellows. These grants would not have existed without CECo.

Grants which have benefited from the work of CECo have changed or developed as a result of collaborations within or with CECo, but have not been initiated within the theme groups. These grant proposals may well have been written without CECo but would have had different applicants and/or would not have benefited from the academic debate and rigour of CECo.

Table 3 lists the grants directly resulting from the work of CECo, and Table 4 those which have benefited from the Collaborative's activities.

Table 3: Grants resulting directly from the work of the Collaborative, by year

Title	Research Team	Start/end date	Amount	Source of Funding
Year 3				
Comprehensive review of evidence base for the National Cancer Survivorship Initiative	A. Richardson (Kings College London), J. Addington-Hall (University of Southampton), M. Sharpe (University of Edinburgh), C. Foster (University of Southampton), Z. Amir (University of Manchester)	2009	£91,468	Joint grant awarded by Macmillan/ National Cancer Survivorship Initiative to CECO and COMPASS collaboratives
A prospective study to clarify the cluster of symptoms related to chemotherapy-induced nausea	S. Brearley , A. Molassiotis (University of Manchester), C. Farrell (The Christie NHS Foundation Trust)	2009-10	€30,000	EONS Major Research Grant
Development of a risk model for chemotherapy-related nausea and vomiting	A. Molassiotis (University of Manchester)	2009-10	£89,000	Merck, Sharp and Dohme
A non-pharmacological supportive care intervention for patients with lung cancer and their caregivers in the management of the respiratory distress symptoms cluster	A. Molassiotis (University of Manchester), M. Lloyd-Williams (University of Liverpool), C. Bailey (University of Southampton), P. Lorigan (Christie Hospital NHS Trust)	2009-10	£225,000	National Cancer Research Institute
Evaluation of end of life care tools in care homes	S. Payne , K. Froggatt , M. Turner (Lancaster University)	2008-09	£10,700	North Lancashire PCT
Improving public awareness of end of life issues among older people in North Lancashire: A peer education approach	K. Froggatt (Lancaster University), Lancaster Peer Education Group: J. Seymour (University of Nottingham)	2008-09	£9,986	North Lancashire PCT
Transitions between services at the end of life for older people – patient and provider perspectives	B. Hanratty (University of Liverpool), J. Addington-Hall (University of Southampton), M. Goldacre (University of Oxford), G. Grande (University of Manchester), S. Payne (Lancaster University), J. Seymour (University of Nottingham)	2009-12	£486,254	NIHR SDO programme
Transitions in palliative care within	M. Gott , C. Ingleton (University of Sheffield) (Joint	2009-11	£462,794	NIHR SDO

an acute hospital	PIs), J. Seymour (University of Nottingham), M. Bennett (Lancaster University), M. Cobb, B. Noble (University of Sheffield)			programme
Year 2				
Men as carers in multiple sclerosis: identifying their support needs and preferences	J. Addington-Hall, J. Brown (University of Southampton), S. Payne (Lancaster University)	2008-10	£95,157	Multiple Sclerosis Society
Perspectives of older people on end of life care	J. Seymour (University of Nottingham), J. Brown (University of Southampton), R. Deschepper (Brussels), B.D. Onwuteaka-Philipsen (Amsterdam), S. Payne (Lancaster University), S. Pleschberger (University of Klagenfurt, Austria)	2008	£9,300	Foundation for Sociology of Health and Illness
Acupressure for the management of chemotherapy-induced nausea	A. Molassiotis, S. Brearley , M. Campbell, T. Eden , M. Rogers, J. Valle (University of Manchester), J. Hughes, M. Lloyd-Williams (University of Liverpool), A. Garrow (University of Salford), C. Hulme (University of Leeds), P. Mackereth (University of Derby), J. Richardson (University of Plymouth), R. Wilson (User Representative)	2008-10	£497,419	NHS Health Technology Assessment Programme
A mixed methods investigation to develop a complex intervention to support the effective family-management of cancer cachexia related problems.	J. Hopkinson (University of Southampton)	2008-12	£177, 313	Macmillan Cancer Support Post-doctoral Fellowship
Older adults with advanced cancer living alone: an exploratory study	B. Hanratty (University of Liverpool), J. Addington-Hall (University of Southampton), A. Arthur (University of Nottingham), G. Grande (University of Manchester), S. Payne (Lancaster University), J. Seymour (University of Nottingham)	2008 – 2009	£70,205	Dimpleby Cancer Care Research Fund

Year 1				
Social and Psychological Aspects of Dying in Old Age (ESRC Seminar Series)	K. Froggatt (Lancaster University), J. Seymour (University of Nottingham), S. Payne (Lancaster University), J. Addington-Hall (University of Southampton)	2007-8	£15,151	Economic and Social Research Council
Predicting weight loss in patients with cancer: development and preliminary validation of a screening tool	V. Siddall (University of Nottingham), J. Addington-Hall (University of Southampton), D. Porock, A. Wilcock, S. Langley-Evans (University of Nottingham), J. Hopkinson (University of Southampton), A. Arthur (University of Nottingham)	2007-8	£73,019	NCRI SuPaC Capacity Building Grant
An investigation of the prevalence, impact and causes of joint aches, pains and muscle stiffness in women following primary treatment for breast cancer	D. Fenlon, J. Addington-Hall (University of Southampton), P. Simmons (Southampton University Hospitals NHS Trust), C. Sheppard (Portsmouth Hospitals NHS Trust)	2006-7	£79,983	NCRI SuPaC Capacity Building Grant
Older women's experiences of breast cancer alongside other health conditions	J. Addington-Hall, C. Foster (University of Southampton), S. Payne (Lancaster University), D. Fenlon (University of Southampton), J. Seymour (University of Nottingham), R. Stephens (user representative), B. Walsh (University of Southampton), P. Coleman (University of Southampton), P. Simmonds (University of Southampton)	2007-8	£48,488	Macmillan Cancer Support User-led Research Grant
End of life care in care homes for older people: understanding and mapping innovative solutions	J. Seymour (University of Nottingham), K. Froggatt (Lancaster University)	2007-8	£40,000	NHS End of Life Care Programme
Care at the end of life: experience and support needs of older family caregivers of people with advanced cancer	C. Bailey, J. Addington-Hall, J. Corner (University of Southampton), J. Seymour (University of Nottingham), C. Sanders (University of Manchester), R. Wilson (NCRI), C. Davis (Southampton University Hospitals Trust), M. Moore, G. Leydon, S. Duke (University of Southampton)	2007-9	£80,849	Dimbleby Cancer Care Research Fund

Table 4: Grants benefiting from the work of the Collaborative, by year

Title	Research Team	Start/end date	Amount	Source of Funding
Year 3				
The impact of variations in out of hours end of life care provision on patient experience, staff and health systems	J. Addington-Hall, V. Lattimer, G Leydon, K Gerard, M Moore , S. Brailsford (University of Southampton), C. Salisbury (University of Bristol), D. Heaney (University of Aberdeen), C. Todd (University of Manchester), M. Bennett (Lancaster University).	2010-13	£474,690	NIHR SDO Programme
A study to develop integrated working between primary health care services and care homes	C. Goodman, A. Dickenson, (University of Hertfordshire), K. Froggatt (Lancaster University), S. Illiffe (University College London), H. Gage (University of Surrey), C. Victor, W. Martin (University of Reading)	2009-2011	£432,711	NIHR SDO programme
Chronic pain management for older adults living in the community. ESRC Seminar Series	P. Schofield, G. Macfarlane, A. Clarke (University of Aberdeen)	2008-10	£11,799	ESRC
Evaluation of the Department of Health / King's Fund 'Environments for Care at the End of Life' Programme	A. Arthur, E. Wilson (University of Nottingham), A. Forsythe (Liverpool John Moores University)	2008-10	£46,000	King's Fund
A systematic literature review on public attitudes to death, dying and bereavement	J. Seymour, A. Arthur , K. Cox, W. Stanton and K. Pollock (University of Nottingham)	2008-09	£35,000	NHS London and National Council for Palliative Care
Non invasive ventilation (NIV) in motor neurone disease: Establishing current use, identifying obstacles and developing pathways for optimising care	C. McDermott, P. Shaw and S. Ahmedzai (University of Sheffield), A Clarke (University of Aberdeen), H. Nixon (University of Sheffield).	2009	£223,224	NIHR Research for Patient Benefit Programme
Patient and family carers' construction of quality in supportive and palliative district nursing care	C. Walshe, K. Luker (University of Manchester)	2009	£48,535	Dimbleby Cancer Care
Supporting older carers to design and lead research reflecting their	S. Kennedy, J. Seymour (University of Nottingham), K. Cox, L. Bird (University of Nottingham), A. Clarke	2010-11	£53,000	Macmillan Cancer Support

key concerns about caring for people with cancer approaching the end of life: Phase one of a research development project	(University of Aberdeen)			
Survivorship in cancer: A narrative study of experiences	K. Cox, J. Seymour (University of Nottingham), J. Elliott (Macmillan Cancer Support)	2009-12	Fees and stipend according to research council rates	Economic and Social Research Council (PhD scholarship: CASE scheme)
Exploring staff attitudes to undertaking Advanced Communication Skills training	S. Payne, M. Turner (Lancaster University)	2009	£20,000	Lancashire and South Cumbria Cancer Services Network
Evaluation of end of life care in prisons in Cumbria and Lancashire	S. Payne, M. Turner (Lancaster University)	2009	£15,000	Lancashire and South Cumbria Cancer Services Network
Patient and family carers' construction of quality in supportive and palliative district nursing care	C. Walshe, K. Luker (University of Manchester)	2009	£48,535	Dimbleby Cancer Care
EAPC Task Force for curriculum development for psychologists in palliative care in Europe	S. Payne (Lancaster University)	2009	£4,000	British Psychological Society
Year 2				
Evaluation of storytelling for and in end of life care	K. Froggatt, A. Bingley (Lancaster University), P. Smith (NHS West Midlands), M. Patel ('Bridges' Support Service, Birmingham)	2007-08	£8000	Murray Hall Community Trust (West Midlands) from The Arts Council
District nurses and their provision of palliative care	C. Walshe (Fellow) , K. Luker (mentor) (University of Manchester), S. Payne (mentor) (Lancaster University)	2007-12	£125,000	RCUK Fellowship
Workshop to develop international collaborative on family care giving research in palliative and end-of-life care	G. Grande (University of Manchester) K. Stadjuhar, S. Aoun, L. Kristjanson L (Curtin University, Perth, Western Australia), C. Toye (Edith Cowan University, Perth, Western Australia)	2008	£7499	British Academy
Developing a carer's assessment tool: pilot study	G. Ewing (University of Cambridge), G. Grande (University of Manchester), S. Payne (Lancaster	2007-8	£43,600	Burdett Trust

	University)			
A pilot study to explore the palliative care needs of older patients with chronic obstructive pulmonary disease (COPD)	M. Gott , S. Barnes S (University of Sheffield), S. Payne (Lancaster University), D. Seamark (University of Exeter), N. Small (University of Bradford), D. Halpin (Royal Devon and Exeter Hospital)	2007-8	£56,890	Dunhill Medical Trust
Advocacy for the End of Life Programme	A. Clarke (University of Sheffield), J. Seymour (Nottingham), K. Froggatt (Lancaster University)	2007-8	£65,000	Help the Aged
Survey of hospice and palliative care bereavement services in Australia	M. O'Connor (Monash University, Melbourne) S. Payne (Lancaster University)	2007-8	A\$47,084	Helen Macpherson Smith Trust
Measuring and demonstrating the impact of user involvement on health and social care services for cancer in the UK	S. Morris, P. Attree, S. Payne , C. Thomas (Lancaster University)	2008 (9 months)	£46,865	Macmillan Cancer Support
Evaluation of Dimpleby Cancer Care Information and Support Service	S. Payne (Lancaster University)	2007-8	£7000	Dimpleby Cancer Care
Need for palliative care in patients with dementia	M. Lloyd-Williams (University of Liverpool)	2008-9	£80,000	St Luke's Hospice, Winsford
Supporting carers: exploring family members' perspectives of sharing information about cancer within families, and the availability and value of resources to support them in doing this	C. Foster , D. Wright , J. Hopkinson , J. Addington-Hall (University of Southampton), S. Payne (Lancaster University)	2008-9	£61, 399	Macmillan Cancer Support User-led Research Grant
A cohort study of joint pain and stiffness in primary breast cancer	J. Addington-Hall , D. Fenlon (University of Southampton), P. Simmons (Southampton University Hospitals Trust), S. George (University of Southampton)	Tbc	£207,648	Breast Cancer Campaign
Developing a carer's assessment tool: phase 2	G. Ewing (University of Cambridge), G. Grande (University of Manchester), S. Payne (Lancaster University)	2008-9	£38,859	Dimpleby Cancer Care
Safety and harms of antidepressant drugs for older people: an analysis using a large primary care database	C. Coupland, J. Hippisley-Cox, A. Arthur , T. Sach (University of Nottingham)	2008-10	£95,969	NHS Health Technology Assessment Programme
The experiences and expectations of older people resident in care	C. Goodman (University of Hertfordshire), S. Barclay (University of Cambridge), P. Fenner (East of England	2008-10	£214,489	NIHR Research for Patient Benefit

homes, their carers and professionals of end of life care and symptom relief needs: a prospective study	SHA), S. Illiffe (University College London), K. Froggatt (Lancaster University), J. Manthorpe (King's College London), D. Thompson (University of Hertfordshire)			Programme
Year 1				
An exploratory study to determine the natural history of depression and demoralization in patients with advanced cancer	M. Lloyd-Williams (University of Liverpool), S. Payne (Lancaster University), J. Reeve (University of Liverpool)	2007-11	£368,142	Big Lottery Fund
A narrative approach to bereavement in adults	M. Lloyd-Williams (University of Liverpool)	2006-9	£149,214	The Clara Burgess Trust
A systematic review of the management of breathlessness in lung cancer	A. Molassiotis , B. Wilson , A. Caress (University of Manchester), C. Bailey (University of Southampton)	2007	£7000	Breathlessness Research Charitable Trust
Supportive care needs of patients with myeloma and their partners	A. Molassiotis (University of Manchester)	2007-8	£40,000	Myeloma UK
A peer education programme for end of life care education among older people in a range of nursing care contexts	J. Seymour (University of Nottingham), A. Clark (University of Sheffield), C. Sanders (University of Manchester), K. Froggatt (Lancaster University), M. Gott , M. Welton (University of Sheffield)	2007-8	£200,000	The Burdett Trust for Nursing
Ethnicity and life transitions: older people's perspectives on a diagnosis of cancer	S. Payne (Lancaster University), J. Seymour (University of Nottingham), M. Chung (University of Plymouth), K. Froggatt (Lancaster University), A. Chapman (Lancaster University), M. Gott (University of Sheffield)	2006-8	£106,706	Dimbleby Cancer Care Research Fund
A Study of the Provision of Care for Older People Dying in Acute and Community Hospitals and Nursing Homes in Ireland	E. O'Shea, P. Larkin, K. Murphy (National University of Ireland, Galway), S. Payne , K. Froggatt (Lancaster University), A. Murphy, D. Casey, M. Keys (National University of Ireland, Galway)	2006-7	€99,400	The Irish Hospice Foundation/National Council on Ageing and Older People
Dignity on the Ward Pocket Guide: Bereavement and Loss	S. Payne , K. Froggatt (Lancaster University)	2007	£6,000	Help the Aged
Dignity on the Ward Pocket Guide: Dying	S. Payne , K. Froggatt (Lancaster University), J. Hockley (University of Edinburgh)	2007	£7,000	Help the Aged

The effectiveness of acupuncture in the management of cancer-related fatigue in breast cancer patients: an RCT	A. Molassiotis (University of Manchester), A. Richardson (King's College London)	2007-10	£350,000	Breakthrough Breast Cancer
Maintaining dignity at the end of life in old age: a longitudinal qualitative study	L. Lloyd, M. Calnan, A. Cameron, R. Smith (University of Bristol), J. Seymour (University of Nottingham)	2007-10	£210,688	New Dynamics of Ageing Programme

12. Publications

Only publications resulting directly from CECo or which have clearly benefited from it are listed here.

A complete list of SuPaC publications from CECo members is presented in Appendix 4.

12.1 Year 3: Publications resulting *directly* from the work of the Collaborative

Journal Articles

Brearley SG, Clements C and **Molassiotis A.** (2008) A review of patient self-report tools for chemotherapy-induced nausea and vomiting. *Supportive Care in Cancer*, 16:1213-1228

Brown JB, Bingley, Payne SA (2008) The need for narrative research. The Cancer Experiences Collaborative (CECo). *End of Life Care*, 2(3): 62-64

Froggatt K and Heimerl K (2008) Palliative Care in Long-Term Care Settings for Older People: An International Perspective. *European Journal of Palliative Care*, 15(5): 244-247.

Froggatt K, Vaughan S, Bernard C and Wild, D. (2009) Advance Care Planning in Care Homes for Older People: An English Perspective. *Palliative Medicine*. 23:332-338

Grande G, Stajduhar K, Aoun S, Toye C, Funk L, **Addington-Hall J, Payne S** and **Todd C** (2009) Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*, 23: 339-344

Rolls E and **Payne S** (2008) Narrative Research in Palliative Care Nursing. *International Journal of Palliative Nursing*, 14 (12), 576-577.

Thomas C, Reeve J, Bingley A, Brown J, Payne S and Lynch T (2009) Narrative research methods in palliative care contexts: two case studies. *Journal of Pain and Symptom Management*, 37 (5): 788-796.

Turner M and **Payne S** (2008) Uncovering the hidden volunteers in palliative care: a survey of hospice trustees in the United Kingdom. *Palliative Medicine*, 22: 973-974.

Reports

Seymour JE, Froggatt K and Kumar A (2009) End of life care in care homes: Understanding and mapping innovative solutions. Final report to the National End of Life Care Programme.

Books and Book Chapters

Hughes JG and **Lloyd-Williams M** (2008) Psychosocial research. In: Walsh et al (Eds), *Textbook of Palliative Medicine*. Philadelphia: Saunders.

Rolls E, Payne S and **Brown J** (2009) Narrative Methods in Supportive and Palliative Care: An Annotated Bibliography. *Observatory Publications*. Lancaster.

12.2 Year 2: Publications resulting *directly* from the work of the Collaborative

Journal articles

Bingley AF, Thomas C, Brown J, Reeve J and Payne SA (2008) Developing narrative research in supportive and palliative care: the focus on illness narratives. *Palliative Medicine*, 22(5): 653-658.

Foster C, Brown J, Killen M and Brearley S (2007) The NCRI Cancer Experiences Collaborative: defining self-management. *European Journal of Oncology Nursing*, 11(4): 295-297.

Lloyd-Williams M and Hughes JG (2008) The management of anxiety in advanced disease. *Progress in Palliative Care*, 16(1): 47-50.

Payne S, Addington-Hall J, Richardson A and Sharpe M (2007) Supportive and palliative care research collaboratives in the United Kingdom: an unnatural experiment? *Palliative Medicine*, 21(8): 134-144.

12.3 Year 1: Publications resulting *directly* from the work of the Collaborative

Journal articles

Bailey C, Wilson R, Addington-Hall J, Payne S, Clark D, Lloyd-Williams M, Molassiotis A, and Seymour J (2006) The Cancer Experiences Research Collaborative: building research capacity in supportive and palliative care. *Progress in Palliative Care*, 14(6): 265-270.

Bailey C (2007) The Cancer Experiences Research Collaborative (CECo): enhancing quality and increasing capacity in supportive and palliative care research. *CRUK PBSC Newsletter*, June.

Bailey C (2007) Palliative care research takes a step forward. *MHLS Graduate School Newsletter*, July.

Payne S (2007) The research page: Supportive and Palliative Care – ‘Cancer Experiences’. *Hospice Bulletin*, 5(3): 3.

12.4 Year 3: Publications *benefiting* from the work of the Collaborative

Journal articles

Addington-Hall JM, O’Callaghan A. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine*. 2009;23:190-197

Bardy J, Slevin NJ, Mais KL, **Molassiotis A** (2008) A systematic review of honey uses and its potential value within oncology care. *J Clin Nurs*, 17(19):2604-23.

Clarke A, Sanders C, Seymour JE, Gott M, Welton M (2008) Evaluating a peer education programme for advance end-of-life care planning: peer educators' perspectives'. *International Journal on Disability and Human Development*, 8, 1, 33-41.

Cohen J, Bilsen J, **Addington-Hall J**, Löfmark R, Miccinesi G, Kaasa S, Onwuteaka-Philipsen B, Deliens L. Organisation of dying: population-based study of dying in hospital in six European countries. *Palliative Medicine*. 2008;22:702-710

Ellis J and Lloyd-Williams M (2008) Perspectives on the impact of early parent loss in adulthood in the UK: narratives provide the way forward. *Eur J Cancer Care (Engl)*. 17(4):317-8.

Elting LS, Keefe DM, Sonis ST, Garden AS, Spijkervet FK, Barasch A, Tishler RB, Canty TP, Kudrimoti MK, Vera-Llonch M (2008) Burden of Illness Head and Neck Writing Committee (incl. **Molassiotis A**). Patient-reported measurements of oral mucositis in head and neck cancer patients treated with radiotherapy with or without chemotherapy: demonstration of increased frequency, severity, resistance to palliation, and impact on quality of life. *Cancer*. 113(10):2704-13.

Foster C and Roffe E (2009) An exploration of the internet as a self management resource. *Journal of Research in Nursing*, 14(1), 13-24.

Foster C, Scott I, Addington-Hall J. Who visits mobile UK services providing cancer information and support in the community? *European Journal of Cancer Care*. DOI: 10.1111/j.1365-2354.2008.01007.x

Gott M, Small N, Barnes S, **Payne S**, Parker C, Seamark D, Gariballa S (2008) Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science and Medicine*, 67(7): 1113-1121.

Hanratty B, Goldacre M, Griffith M, Whitehead M and Capewell S (2008) Making the most of routine data in palliative care research – a case study analysis of linked hospital and mortality data on cancer and heart failure patients in Scotland and Oxford. *Palliative Medicine*, 22: 744-749.

Horne G, **Seymour JE** and Payne S (2009) Advance care planning: evidence and implications for practice. *End of Life Care*, 3(1): 58-65.

Innes S and **Payne S** (2009) Advanced cancer patients' prognostic preferences: a review. *Palliative Medicine*, 23 (1): 29-39.

Kennedy VL and **Lloyd-Williams M** (2009) How children cope when a parent has advanced cancer. *Psychooncology*. [Epub ahead of print].

Kennedy VL and **Lloyd-Williams M** (2009) Information and communication when a parent has advanced cancer. *J Affect Disord* 14:149-155.

Kennedy S, Seymour JE, Almack K and Cox K (2009) Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a National Evaluation. *Palliative Medicine*, 23: 283-294.

Lloyd-Williams M and **Reeve J** (2008) Real life ethics. *Br J Gen Pract.* 58(552):509

Lloyd-Williams M, Reeve J and Kissane, D. (2008) Distress in palliative care patients: Developing patient-centred approaches to clinical management. *European Journal of Cancer* epub ahead of publication.

Lloyd-Williams M, Shiels C, Taylor F, Dennis M (2009) Depression--an independent predictor of early death in patients with advanced cancer. *J Affect Disord.* 113(1-2):127-32.

Molassiotis A, Potrata B, Cheng KK (2009) A systematic review of the effectiveness of Chinese herbal medication in symptom management and improvement of quality of life in adult cancer patients. *Complement Ther Med*, 17(2):92-120.

Molassiotis A, Stricker CT, Eaby B, Velders L, Coventry PA (2008) Understanding the concept of chemotherapy-related nausea: the patient experience. *Eur J Cancer Care*, 17(5):444-53.

Murray S, Barclay S, Bennett MI, Kendall M, **Amir Z, Lloyd-Williams M** (2008) Palliative care research in the community: it is time to progress this emerging field. *Palliat Med*, 22(5):609-11.

O'Connor M, Abbott J, **Payne S** and Demmer C (2009) A comparison of bereavement services provided in hospice and palliative care settings in Australia, the UK and the USA. *Progress in Palliative Care*, 17 (2): 69-74.

Partington L, Langhorn H and **Froggatt K** (2008) Educational Needs: Palliative care link nurses in care homes. *End of Life Care*, 2(3): 65-70.

Payne S (2009) Life changing research. *Nursing Standard*, 23 (28) 19.

Payne S and Hudson P (2009) EAPC Task Force on Family Carers: aims and objectives. *European Journal of Palliative Care*, 16 (2): 77-81.

Payne S, Seymour J, Chapman A and Holloway M (2008) Older Chinese people's views on food: implications for supportive cancer care. *Ethnicity and Health*, 13(5):497-514.

Payne S, Ingleton C, Sargeant A and **Seymour J** (2009) The role of the nurse in palliative care settings in a global context. (Special feature invited paper). *Cancer Nursing Practice*, 8 (5): 23-28.

Reeve JL, Lloyd-Williams M and Dowrick C (2008) Revisiting depression in palliative care settings: the need to focus on clinical utility over validity. *Palliat Med*, 22(4):383-91.

Reeve J, Lloyd-Williams M, Payne S and Dowrick D. (2009) Towards a re-conceptualisation of the management of distress in palliative care patients: the self-integrity model. *Progress in Palliative Care*, 17 (2): 51-6

Walshe C, Caress A, Chew-Graham C and **Todd C** (2008) Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three Primary Care Trusts. *Palliative Medicine*, 22: 736 – 743.

Walshe C, Chew-Graham C and **Todd C**, Caress A (2008) What influences referrals within community palliative care services? A qualitative case study. *Social Science and Medicine*, 67: 1: 137-146.

Walshe C, Todd C, Caress A-L and Chew-Graham C (2008) Judgements about fellow professionals and the management of patients receiving palliative care in primary care: a qualitative study. *British Journal of General Practice*, Vol. 58, No. 549. p.264-272.

Walshe C, Todd C, Caress A, Chew-Graham C (2009) Patterns of access to community palliative care services: a literature review. *Journal of Pain and Symptom Management*. On-line.

In press:

Brearley SG, Craven O, Saunders M, Swindell R, **Molassiotis A**. Clinical features of oral chemotherapy: results of a longitudinal prospective study of breast and colorectal cancer patients receiving capecitabine in the UK. *European Journal of Cancer Care*. In press

Gott M, Ingleton C, Gardiner C, Ryan T, Noble B, **Seymour J**, Bennett M, and Cobb M. How can we improve end of life care for older people in acute hospitals? *Nursing Older People*. In press

Molassiotis A, Brearley SG, Saunders M, Craven O, Wardley A, Farrell C, Swindell R, Todd C, Luker K. The effectiveness of a home care nursing programme in the symptom management of patients with colorectal and breast cancer receiving oral chemotherapy: a randomised controlled trial. *Journal of Clinical Oncology* . In press

Molassiotis A, Wilson B, Brunton L, Chandler C. Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. *Eur J Cancer Care* 2009 In press

Books and Book Chapters

Davies S, **Froggatt K** and Meyer J (2009) Reflections on the Way Forward. In K Froggatt, S Davies S and J Meyer (eds) *Understanding Care Homes: A Research and Development Perspective*. Jessica Kingsley Press. London.

Fenlon D (2006) Hormone therapy in cancer care (chapter 17). In: *Nursing Patients with Cancer: Principles and Practice* eds. Kearney,N. and Richardson, A. Elsevier, Edinburgh.

Fenlon D (2008) Endocrine Therapies Chapter 14 in *Cancer Nursing: Care in Context* (2nd edition). Corner J.L. and Bailey C. (eds) Blackwell Publishing. London.

Foster C (2008) Symptoms, self management and self help. In J. Corner & C. Bailey (eds). *Cancer Nursing: Care in Context* (2nd edition). Blackwell Publishing. London.

Froggatt K, Davies S and Meyer J (2009) *Understanding Care Homes; A Research and Development Perspective*. Jessica Kingsley Press. London.

Froggatt K, Davies S and Meyer J (2009) Research and Development in Care Homes: Setting the Scene. In K Froggatt, S Davies S and J Meyer (eds) *Understanding Care Homes: A Research and Development Perspective*. Jessica Kingsley Press. London.

Froggatt KA and Turner M (2008) Practice Development in Palliative Care In S. Payne, J. Seymour and C. Ingleton (eds) *Palliative Care Nursing. Principles and Evidence for Practice*. 2nd Ed. McGraw Hill, Maidenhead.

Grinyer A (2008) The impact of cancer in parents of adolescents and young people. *Cancer Care for Adolescents and Young People* (Gibson F and Kelly D, Eds) Oxford: Blackwell: 44-58.

Hopkinson JB (2008) Change in eating habits. In J. Corner & C. Bailey (eds). *Cancer Nursing: Care in Context* (2nd edition). Blackwell Publishing. London.

Hudson P and **Payne S** (ed). (2008) *Family Carers in Palliative Care* Oxford University Press, Oxford.

Lloyd-Williams M and **Hughes JG** (2008) Emotions and cognitions: Psychological aspects of care, in Payne et al., *Palliative Care Nursing* (2nd edition) Maidenhead: Open University Press.

Lloyd-Williams M (2008) *Psychosocial Issues in Palliative Care* (2nd Edition) Oxford University Press.

Payne S and Hudson P (2008) *Family Carers In: D Walsh et al (eds) Palliative Medicine 1st Edition*. Elsevier: New York.

In Press:

Froggatt K and Parker D. Care homes and long-term care for people with dementia. In J Hughes, M Lloyd-Williams and G Sachs (eds) *Supportive Care of the Person with Dementia*. Oxford: Oxford University Press.

Seymour JE and Horne G. Advance care planning: an overview. In: Thomas K and Lobo B (eds) *Advance Care Planning in End of Life Care*. Oxford: Oxford: University Press.

Seymour JE. The principles and practice of palliative care . In: Bryne J, Macnamara P, Seymour J and McClinton P (eds) *Palliative Care in Neurological Disease – A Team Approach*. Radcliffe Press.

Seymour JE and Macnamara P. Palliative Care and end of life needs in long term neurological conditions – an overview. In: Bryne J, Macnamara P, Seymour J and McClinton P (eds) *Palliative Care in Neurological Disease – A Team Approach*. Radcliffe Press.

Reports

Cox K, **Seymour J**, Moghaddam N, **Almack K**, Porock D and Pollock K. (2008) Choice and decision-making in palliative care: a study of patients', carers' and health care professionals' experiences. Final report to the Mid Trent Cancer Network.

Kennedy S, Seymour J (2008). Facilitating success - the contribution of facilitators to the effectiveness of programmes. A Commissioned Review of the Literature. Final report to the National End of Life Care Programme.

Kumar A and Allcock N. (2008) Pain in older people, Reflections and experiences from an older person's experience. Nottingham University, Help the Aged and the Pain Society.

Seymour J, Arthur A, Cox K et al (2009) *Public attitudes to death, dying and bereavement: an interim report of a synthesis of the published UK literature*. Confidential report to the National Council for Palliative Care/ National End of Life Care Programme.

12.5 Year 2: Publications benefiting from the work of the Collaborative

Journal articles

Almack K (2007) Palliative care and end of life care for the non-heterosexual community. *End of Life Care for Nurses*, 1(2): 27-32.

Barclay S, **Arthur A** (2008) Place of death – how much does it matter? The priority is to improve end of life care in all settings. *British Journal of General Practice*, 58: 229-31.

Brown JB, Addington-Hall J (2007) Identifying how people with MND/ALS talk about living through their illness: a narrative study to enhance self-management. *Amyotrophic Lateral Sclerosis*, 8(1): 49.

Brown JB and **Addington-Hall J** (2008) How people with motor neurone disease talk about living with their illness: a narrative study. *Journal of Advanced Nursing*, 62(2): 200-208

Gott M, Barnes S, **Payne S**, Parker C, **Seamark D**, Gariballa S and **Small N** (2007) Patient views of social services provision for older people with advanced heart failure. *Health and Social Care in the Community*, 15(4): 333-342.

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12.6 Year I: Publications *benefiting* from the work of the Collaborative

Journal articles

Hagen NA, **Addington-Hall JM**, Sharpe M, Richardson A, Cleeland CS (2006) Proceedings of the Birmingham International Workshop on supportive, palliative and end of life care research. *Cancer*, 107: 874-881.

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Henry C and **Seymour J** (2007) *Advance care planning: a guide for health and social care professionals*. NHS End of Life Care Programme, Leicester.

Appendix I

Summary of findings from a focus group study about research in hospices funded by CECo and Help the Hospices (2008)

	Strengths	Weaknesses	Suggestions
Staffing issues	<p>Some unofficial “research champions” and research leads exist in hospices</p> <p>Many staff have a research remit in their roles</p>	<p>Many hospices without research leads or research “champions” - few staff have appropriate skills</p> <p>Funding and backfill issues</p>	<p>Job descriptions should highlight research</p> <p>Managers should encourage staff to take part in research education and projects</p> <p>Create Link Nurses between universities and hospices, it will keep staff in touch with a special interest area and may lead to research</p>
Attitudes to research	<p>Some hospices are already prepared to support and fund research</p> <p>The general enthusiasm of staff in hospices could be harnessed</p> <p>Clinical staff have ideas about the research that needs to be done to improve patient care</p> <p>Patients may be happy and willing to take part in research</p>	<p>Fear and a lack of understanding leads to a resistance to research in hospices</p> <p>Staff and ethics committees act as “gatekeepers”</p> <p>Lack of a research culture in hospices</p> <p>Perception that drug trials are not necessarily of benefit to patients.</p> <p>Nurses fear they may lose their identity if they become researchers</p> <p>Research can be seen as advancing careers rather than advancing patient care.</p>	<p>Tapping into areas of staff interest for projects can help to overcome fear of research</p> <p>Hospice staff need to get involved in research at different levels</p> <p>Journal clubs can capture people’s interest in research</p> <p>Research ideas should be “bottom up”</p> <p>Hospice managers, trustees and commissioners need to understand the need for research and be supportive of it</p> <p>There is a role for CECo and Help the Hospices in promoting research</p> <p>Encourage a research culture in hospices</p>
Links between hospices and universities	<p>There are already some strong links between hospices and universities</p> <p>Links are two way, clinical expertise can be exchanged for research expertise</p> <p>Inter-professional teams are established in hospices which may be a basis for multidisciplinary research</p>	<p>Tension between needs of hospices and universities</p> <p>Medical model of research is regarded as too academic, seen as only for doctors, only sometimes for nurses</p> <p>Generally only those undertaking degrees actually do any research.</p>	<p>Encourage partnerships between hospices and academics</p> <p>The differing roles and goals of academics and hospice staff should be identified from the start</p> <p>Meetings should alternate between universities and hospices to avoid elitism</p> <p>Clinical staff should be encouraged to lead research</p>

			<p>Academics should work alongside clinical staff in hospices</p> <p>Academic staff should be on site in hospices, even if only for short periods of time, to give advice</p>
Education and support	<p>Some hospices are collaborating with other local hospices to provide education about research.</p> <p>Education consortia already exists, so there is the potential to have research consortia as well.</p>	<p>Research training is variable from one hospice to another</p> <p>Poor completion rates for distance learning courses.</p>	<p><i>Staff need training and support in:</i></p> <ul style="list-style-type: none"> · Increasing knowledge and skills about research · Facilitating involvement in projects · Statistical support and advice · Turning ideas into good study design <p><i>Types of training:</i></p> <ul style="list-style-type: none"> · Mentorship or “buddying” – pairing clinical staff up with researchers from nearby academic departments · Short workshops on specific subjects at all levels · “Bite-sized chunks” not full-length courses · Simplify language; jargon a barrier to learning · Repeated courses - because of staff turnover · A dedicated education unit within the hospice <p>The role of CECo and Help the Hospices, who could provide:</p> <ul style="list-style-type: none"> · An online education resource · “Top tips” for helping hospice staff to do research · An accessible resource for disseminating results · A research training pack for hospice leaders to use with their staff <p>An ‘idiot’s guide’ to getting through the research process from idea to completed research project</p>
Patients	<p>Many patients want to be involved in research.</p> <p>Many enjoy taking part in research – the ‘<i>legacy theory</i>’ and rewards to the staff.</p>	<p>Clinical staff and ethics committees often ‘gatekeep’</p>	<p>Patient and carers groups can be consulted about their ideas for research.</p> <p>Complaints and clinical incidents may spark ideas for research.</p> <p>The best research ideas are likely to be clinically relevant.</p>
Time		<p>Providing clinical care is seen as a higher priority, staff are always very busy, it is hard for staff to ‘look</p>	<p>Dedicated time needs to be set aside for research</p> <p>Staff often want to see quick benefits</p>

		<p><i>above the parapet</i>’</p> <p>Research can be very labour intensive.</p> <p>Staff avoid attending research meetings in case they are given more work</p> <p>Many practitioners are full time and finding time for study leave is a problem</p> <p>Research applications are a long and difficult process, with little chance of success</p>	<p>to patients from research, so methods such as action research may be useful</p>
Funding and resources	<p>Some hospices are already prepared to support and fund research</p> <p>Research, particularly with pharmaceutical companies, can generate income.</p>	<p>Unsure of how or where to apply for funding</p> <p>Pressure on hospices to generate income; some did not have the resources to undertake research</p> <p>Tension between benefiting patients and generating income when doing research for pharma. Relationships with NHS reported to be complex</p> <p>Many hospices rely on charitable support, leaving them vulnerable in difficult economic climate</p>	<p>Researchers need help with ‘selling’ the idea of research to hospice managers, trustees and commissioners in terms of income generation.</p> <p>Researchers need help with applying for funding, how to key into the [respond appropriately to funding calls. how you target it to what they want]</p> <p>The role of CECo and Help the Hospices</p> <p>Help to raise awareness in hospices of funding sources for research and how to access them</p>
Ethics and research governance	<p>There were varying experiences of NHS research passports, some positive, others less so</p> <p>Some thought that indemnity/insurance and research passports were easier to obtain for those working in the NHS than independent hospices due to a more positive culture of research participation.</p>	<p>Applying for ethical approval is a barrier in end of life care. Paternalistic attitudes towards vulnerable patients</p> <p>Long complex procedures mean researchers give up and won’t try to do sensitive research again</p> <p>Researching family carers is difficult</p> <p>Balance between safeguards and putting people off research</p> <p>Timescales too short for students undertaking courses to get ethical approval</p>	<p>Hospice staff could sit on ethics committees and give palliative care input, but time is a barrier.</p> <p>Better information about NRES to explain these issues to hospices.</p> <p>Gaining ethical approval daunting for practitioners. They would benefit from having support from academics</p> <p>Undertaking research with staff or students in hospices may be more straightforward because ethical approval may not be required</p> <p>The role of CECo and Help the Hospices:</p> <p>Produce a guide to applying for ethical approval and research governance from an end of life perspective. This</p>

			could be part of the research guide mentioned above Provide mentor support
Networking	In some places, several hospices are working together on research projects. There were examples of research groups meeting regularly to share their research.	Some find it hard to get people to form groups to work together on projects. Research can be local – people work ‘in silos’. It is difficult to find the time and staff backfill to attend conferences and meetings.	Face to face contact is important. A local forum for staff linked to an established research group and existing national networks, e.g. primary care, cancer. Meetings should take place at lunchtime Informal mentoring would be useful Hospices could collaborate on larger projects A national association of palliative care researchers (Note: Interestingly the respondents seemed unaware of the Palliative Care Research Society which already exists) The role of CECo and Help the Hospices: Host a roadshow to get hospice staff together to think about research and try to identify research questions Promote the existing EAPC junior research group or develop a similar group in the UK An email group to bring together and develop researchers (A CECo website forum exists but is under-used)
Sharing information about hospice research	Hospices should build on the existing research infrastructure; there is a danger of ‘reinventing the wheel’	Little centralized information about hospice usage Lack of awareness about what research has already been done or is currently ongoing in other hospices	A database of research – to avoid duplication, linking to other national research databases Develop links with the RCN database The role of CECo and Help the Hospices: Information could be shared about what research is currently being done, both regionally and nationally through a virtual network Provide a directory of useful people and resources for research
Evidence based practice	Clinical staff are committed to finding ways to improve patient care	A barrier to research in hospices is the perception that it has a lower priority than patient care	There is a need to demonstrate how doing research can benefit directly patient care, how evidence based practice (EBP) works

	<p>Good supportive and palliative care has a research evidence base</p> <p>Hospice staff are familiar with the concept of evidence based practice (EBP)</p> <p>Hospices need to provide evidence of what they do</p> <p>Hospices are specialist units so research should be part of their remit</p>	<p>Staff may understand the relevance of research to practice but may not have the knowledge or skills to undertake their own research</p>	<p>Practitioners need the skills to access EBP and they should be rewarded for gaining these skills</p> <p>Hospices need to think about ways of demonstrating what they do</p>
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Appendix 2

Feedback on the 2008 NCRI Conference,

Jill Robinson, Research Partner, User Involvement Group, End of Life Observatory, Lancaster University

“ I was able to attend the whole of this conference thanks to a general Consumer Bursary from the NCRI which covered the whole cost of the conference plus accommodation, food and travel. I was interested in attending to increase my knowledge and understanding of research into cancer and also as the User Group I am involved in was putting in an application to Macmillan at the Conference for funding for a small piece of research we hope to undertake, as well as having a poster at one of the Poster Sessions.

I had not know quite what to expect but the conference was bigger than I had anticipated and very focussed on scientific and clinical research. However, there was a significant Consumer Group, of which I was one, with over 40 people in all. This apparently represented quite an increase on previous years and indicates NCRI's commitment to user participation.

I travelled to the conference with Dr Katherine Froggatt from the End of Life Observatory and, on arriving at the venue we registered, receiving a bag containing a large amount of information including the conference programme with 134 pages! There were numerous sessions to choose from during each of the days, but I found that the majority of these were of a very scientific or clinical nature and not of much interest to me.

After attending the opening **Public Seminar and Open Forum**, Katherine and I were at the **Poster Session** with our poster giving information about our group. There were a great number of posters and it was impossible to see them all in any detail, but I managed to find a few which I found very interesting and to talk with some of the people involved. We also visited the Macmillan stand regarding our research proposal and were informed that we needed to find someone to sign this off, which we managed to do.

Later, we attended a session on **Dying with Dignity – a Contemporary Challenge in Palliative Cancer Care**, given by Harvey Max Chochinov from Manitoba, Canada. Despite the title, this was a very amusing and interesting lecture. During the afternoon, we had also found time to go to our respective hotels to check in. I had been given a room at Jury's Inn, which was a short walk from the Conference Centre, and which was very comfortable with the usual facilities. Later that evening all of the Consumer Group was invited to dinner in an Italian restaurant, by NCRN (National Cancer Research Network). This was a very lively affair which gave people the opportunity to either renew previous acquaintances or to start getting to know other consumer delegates as well as to find out more about the various organisations involved. I found this a very enjoyable and very useful evening.

Paul Holroyd, another member of our User Group who had also received a consumer bursary, joined us on Monday morning and we all went to a session entitled **Living Beyond Cancer**. In many ways, I found this the most personally meaning session of the whole conference. In the afternoon, I attended a session entitled **Understanding Health Behaviours Relevant to Cancer**. During the day, we also spent a little time re-writing our research proposal and getting it signed before depositing it with Macmillan. There were a large number of stands from various organisations, of which Macmillan was one, but I found this part of the Conference a bit overwhelming so I only visited a few. Later in the evening, Katherine, Paul and I went out for a meal.

On Tuesday morning we all went to a session on **The Cost of Cancer Care** and in the afternoon, I attended a workshop on **How to Write an Effective Grant Proposal**, hoping that this will help us with future proposals, and later a session on **Improving the Effectiveness of Multi Disciplinary Team Working**. Paul and I had both been given tickets to the **Conference Dinner and Party**, which we attended that evening. Again, this was very interesting as it gave us an opportunity to meet more people although we didn't stay for the dancing as, although the band was very good, it was rather loud and made it too difficult to continue

conversations! The final session I attended was on Wednesday morning on **Increasing Public Awareness of Clinical Trials**.

Each of the sessions generally consisted of three lectures given by different speakers and then two papers were presented by other speakers, with Q&A sessions at the end, so they were quite intense. It was therefore important to choose sessions carefully, to pace yourself and not try to do too much as it was a lot of information to take in, much of which was very new to me. Morning coffee was provided between the early morning and later morning sessions, a buffet lunch was also provided and drinks were available in the afternoon, all of which gave time for a break and to chat to other people. The Consumer Group had a table allocated to one of the floors which was useful as a meeting place. We were also supposed to have a room allocated to meet in the early evening but this did not seem to work out.

Overall, I enjoyed the conference very much although the aspects I was most interested in were somewhat marginal as the main thrust was scientific and clinical. However, it was encouraging to see that the NCRI are sponsoring consumer involvement and many of the questions asked in Q&A sessions were from consumers. I did think that I was made very welcome at the conference and would particularly like to thank the NCRI for their generous bursary; Eileen Loucaides from the NCRI Secretariat and Derek Stewart and David Ardron, both of the NCRI Consumer Liaison Group, for their kindness.”

Appendix 3.

Complete List of CECo SuPaC Publications

Year 3.

Journal articles

Abbot J, O'Connor M and **Payne S.** (2008). An Australian survey of palliative care and hospice bereavement services. *Australian Journal of Cancer Nursing.* 9: 12-17

Addington-Hall JM, O'Callaghan A. (2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine.* 23:190-197

Ahmed N, Bestall JC, **Payne SA,** Noble B, **Clark D** and Ahmedzai SH. (2008) The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs. *Supportive Care in Cancer,* (published on-line 4th November 2008)

Bardy J, Slevin NJ, Mais KL, **Molassiotis A** (2008) A systematic review of honey uses and its potential value within oncology care. *J Clin Nurs.* 17(19):2604-23.

Brown JB, Bingley, Payne SA (2008) The need for narrative research. The Cancer Experiences Collaborative (CECo). *End of Life Care* 2(3): 62-64

Brown J, Bingley A and Payne S (2008) The need for narrative research. *End of Life Care,* 2(3): 62-63.

Burt J, Shipman C, **Addington-Hall JM,** White P. (2008) Nursing the dying within a generalist caseload: a focus group study of district nurses. *International Journal of Nursing Studies.* 45:1470-1478

Clarke A, Sanders C, Seymour JE, Gott M and Welton M (2008) Evaluating a peer education programme for advance end-of-life care planning: peer educators' perspectives'. *International Journal on Disability and Human Development,* 8, 1, 33-41.

Davis M and **Payne S** (2009) Nursing care, documentation and discourse (2009) *Progress in Palliative Care,* 17 (3): 109-110.

Dowrick C, Gask L, **Hughes J,** Towey M, Charles-Jones H, Peters, S, Salmon P, Rogers A and Morriss R (2008) General practitioners' views on reattribution for patients with medically unexplained symptoms: a questionnaire and qualitative study. *BMC Family Practice,* 9: 46.

Ellis, J, Lloyd-Williams, M (2008) Perspectives on the impact of early parent loss in adulthood in the UK: narratives provide the way forward. *Eur J Cancer Care (Engl).* 17(4):317-8.

Elting LS, Keefe DM, Sonis ST, Garden AS, Spijkervet FK, Barasch A, Tishler RB, Canty TP, Kudrimoti MK, Vera-Llonch M (2008) Burden of Illness Head and Neck Writing Committee (incl. **Molassiotis A**). Patient-reported measurements of oral mucositis in head and neck cancer patients treated with radiotherapy with or without chemotherapy: demonstration of increased frequency, severity, resistance to palliation, and impact on quality of life. *Cancer.* 113(10):2704-13.

Foster C and Roffe, E (2009) An exploration of the internet as a self management resource. *Journal of Research in Nursing,* 14(1), 13-24.

Foster C, Scott I, Addington-Hall J. Who visits mobile UK services providing cancer information and support in the community? *European Journal of Cancer Care.* DOI: 10.1111/j.1365-2354.2008.01007.x

- Foster C**, Wright D, Hill H, **Hopkinson J** and Roffe L (2009) Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care*, **18**, 223-247.
- Froggatt K** and Heimerl K (2008) Palliative Care in Long-Term Care Settings for Older People: An International Perspective. *European Journal of Palliative Care*. 15(5): 244-247.
- Gott M**, Small N, Barnes S, **Payne S**, Parker C, Seamark D, Gariballa S (2008) Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science and Medicine*, 67(7): 1113-1121.
- Grande G**, Stajduhar K, Aoun S, Toye C, Funk L, **Addington-Hall J**, **Payne S** and **Todd C** (2009) Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine*, 23: 339-344
- Hanratty B**, Goldacre M, Griffith M, Whitehead M and Capewell S (2008) Making the most of routine data in palliative care research – a case study analysis of linked hospital and mortality data on cancer and heart failure patients in Scotland and Oxford. *Palliative Medicine*, 22: 744-749.
- Hopkinson, JB** (2007) How people with advanced cancer manage changing eating habits. *Journal of Advanced Nursing*, 59(5):454-62.
- Horne G, **Seymour JE**, and Payne S (2009) Advance care planning: evidence and implications for practice. *End of Life Care*, 3(1): 58-65.
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- Lloyd-Williams, M, Reeve, J** (2008) Real life ethics. *Br J Gen Pract*. 58(552):509
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- Lloyd-Williams M**, Morton J and Peters S (2008) The End-of-Life Care Experiences of Relatives of Brain Dead Intensive Care Patients. *J Pain Symptom Manage*.
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Partington L, Langhorn H and **Froggatt K** (2008) Educational Needs: Palliative care link nurses in care homes. *End of Life Care*. 2(3): 65-70.

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