



# Creating a Momentum for Change

Five years of the  
**Cancer**  
**Experiences**  
Collaborative



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## Director's introduction

It has been an exciting five-year journey since we established CECo. We set out to create a collaborative to generate better research by better researchers in supportive and palliative care – and we believe we have achieved that.

We, who have worked to make CECo the success it is, marvel at the policy changes that have taken place since 2006 - in particular the Cancer Reform Strategy and the End of Life Strategy. These two documents alone demonstrate the change that has taken place in the climate of caring for the seriously ill and those facing the end of life, in shifting the place of supportive and palliative care more centrally onto the health-care policy agenda. We are also pleased to see the new Cancer Survivorship agenda emerging. In all these areas, people associated with CECo have taken an active part.

I am intensely proud of CECo's achievements. The fact that we have invested in building a culture of collaboration - which is in some senses against all the competitive instincts of academia - is alone something to shout about. We have also been successful in reaching out to clinicians and more junior colleagues to enrich their knowledge and appreciation of the role of supportive and palliative care research.

We have gone some way towards our aim of establishing successful research 'dream teams' to bring supportive and palliative care into the mainstream.

The way CECo has been able to reach out to patients and their families is a core success. We have been grateful for their involvement in helping to shape our research questions, refine our research methods and direct our attention to what matters most to patients and families. We have felt empowered by their contribution and we hope the 'research partners' groups will be a lasting legacy for CECo.

There remain many challenges and we are conscious that we are facing an uncertain future. The economic environment has changed greatly since the optimistic days of the early 2000s, when the vision of the research collaborative was first mooted.

However, the investments made by the consortium of funders - coordinated by the National Cancer Research Institute - are bearing fruit, as illustrated in our report. As research and development takes time to impact upon clinical change and patient benefit, we are confident that there is much more to come from the scientific advances and knowledge transfer that arise from the work of CECo.

Attitudes to palliative and supportive care can not be transformed overnight. This area still does not attract the funding it deserves, but CECo is proud to have set up a momentum for change. I only hope that the gains pioneered by CECo will be maintained.

**Sheila Payne**  
Director CECo  
(Cancer Experiences Collaborative)



# What is the Cancer Experiences Collaborative?

The Cancer Experiences Collaborative (CECo) is a pioneering initiative set up in 2006 to improve the quality and quantity of palliative and supportive care research. It follows the identification of a number of weaknesses in the UK's research base by the National Cancer Research Institute (NCRI) strategic review.

It was created as a five-year-long partnership between researchers at five UK universities, (Lancaster, Liverpool, Manchester, Nottingham, and Southampton), a number of clinical organisations (including the four largest hospices in England, leading cancer centres and Help the Hospices) and user representatives. Funding totalling £1.9 million was awarded to CECo by the NCRI to set up the infrastructure, but not to pay for research.

Since then, CECo's model of working has created a critical mass of experienced groups and researchers performing at an international level, and closely linked with users and the clinical community. It has also generated £5.5 million in new grants in its first four years. This has attracted increasing international interest.

## How it looked then

Back in 2003 the NCRI's strategic review of research into supportive and palliative care research identified the following problems:

- Limited resources, with only 4.3 percent of spending on cancer research (£11 million per year) being directed at supportive and palliative care research
- Small-scale and often poor-quality studies with little attention to patient needs
- Lack of involvement by patients and their carers
- Absence of a critical mass of experienced researchers with international level performance
- Poor integration with the wider research community and other disciplines
- Inadequate career pathways for post-doctoral researchers
- Lack of strong leadership.

## How CECo responded

CECo created a working platform consisting of five strands – all dedicated to increasing the quantity and quality of the research over its lifetime:

- Innovative approaches to complex symptoms
- Caring for older adults towards the end of life
- Developing research methodologies
- Building capacity
- User involvement.

## Our aims and objectives:

- Development of new approaches and methodologies to address clinical challenges in supportive and palliative care research, in particular meeting the needs of patients, families and carers
- Improvement of the quality of research
- Maintaining a clear focus on policy and practice
- Support for new researchers in a manner sustainable beyond the life of the collaborative.

## What has CECo achieved so far?

Since 2006, CECo has achieved a powerful momentum for change in the way that supportive and palliative care is viewed, delivered and researched.

- 1 Creating an innovative collaborative that has worked to improve the quality and quantity of palliative and supportive care research.
- 2 Generating significant amounts of new research income. CECo has generated a total grant income over the first four years, of approximately £5,565,000.
- 3 The establishment of an impressive research collaboration involving some 100 researchers and experts, plus around 20 patients and their families.
- 4 Employment of 12 research fellows and helping to develop their careers.
- 5 The support of 11 clinicians across a range of disciplines, each of whom was able to undertake a piece of research as a result of CECo's funding and mentorship.
- 6 More than 337 publications accepted by 2010, with more in preparation, plus 32 books and book chapters and nine reports.
- 7 Influencing the development of a number of international collaboratives, including the All Ireland Institute for Palliative Care and the Palliative Care Collaboration in Victoria, Australia, and setting up links with the National Palliative Care Research Centre in USA.
- 8 Developing UK policy, and influencing the national agenda, including the Cancer Reform Strategy and the End of Life Strategy and Cancer Survivorship Initiative.
- 9 Contributing to the first international conference on advance care planning in Melbourne, Australia in 2010, and to the establishment of the International Society for Advance Care Planning and End of Life Care.
- 10 Prestigious financial backers include the Medical Research Council, the Economic and Social Research Council, the National End of Life Care programme, the Department of Health/Health Technology Assessment, Dimbleby Cancer Care, the BUPA Foundation, Macmillan Cancer Support, and other charitable funders.
- 11 Cancer patient and leader of user involvement within CECo, Roger Wilson was awarded a CBE for his work in January 2011.





# Complex symptoms

Around two million people have cancer - or have had it in the past - and this figure is rising by more than three percent per year (Macmillan, 2008). During their cancer journey, people experience a range of different symptoms, not only because of the cancer itself, but also because of the treatment and the consequences of advanced disease. The problems caused by unrelieved symptoms, and their effect on how well people return to normal activity, has been well documented. We also know that inadequate support can lead to suffering for patients and families, long-term disability, costly hospital admissions, financial hardship and social isolation. With rising numbers of survivors, the need to understand how to support self management is becoming increasingly important for service planners and health policy makers. This has led to interest in non-pharmacological approaches to symptom management (including complementary treatments).

## Our aims

- Development of a body of evidence about how people affected by cancer avoid, or control symptoms, and treatment side effects
- Testing of non-pharmacological interventions, focusing on nausea and vomiting, depression, sleep disturbances and nutritional problems
- Establishment of a new theoretical basis for self-management interventions in cancer, alongside existing non-cancer models
- Exploration of innovative non-pharmacological and self-management interventions for symptoms, drawing on appropriate theoretical models and to assess their effectiveness via multi-centre, randomised controlled trials
- Development of programmes of research, making maximum use of the collaborative culture of CECo
- Nurturing of strong involvement from research partners.

## Our work in practice

**Funding established for a five-year, UK research programme to understand recovery following cancer treatment** and to develop self-management interventions for patients with cancer-related problems. This was led by the Macmillan Survivorship Research Group at the University of Southampton, with funding from Macmillan Cancer Support.

**Development and pilot study of an online, interactive, surgical decision aid for young women** newly diagnosed with early stage breast cancer, led by the University of Southampton with funding from the National Institute of Health Research (NCRI) Research for Patients' Benefit (RfPB) fund.

**A prospective study to clarify the cluster of symptoms related to chemotherapy-induced nausea** led by The Christie Hospital in Manchester, funded by a European Oncology Nursing Society major award.



**Development of a model to try to predict the risk of patients developing nausea and vomiting as a result of chemotherapy**, led by the University of Manchester, with funding from Merck.

## Key Achievements

**Studentships and career scientist fellowships** such as Dr Joanne Reeve from the University of Liverpool, who researched narratives and depression and Dr Jane Hopkinson, from the University of Southampton, who looked at support for families in managing problems of weight loss in advanced cancer.

**Publication of around 64 papers in a range of relevant and important journals**, such as the Journal of Clinical Oncology, in addition to non-cancer and palliative care publications, thereby reaching wider audiences in addition to mainstream supportive care journals.

**Four highly-successful 'state of the science' meetings** with audiences of nearly 300 participants and wide dissemination at oncology, palliative care and supportive care conferences regionally, nationally and internationally.

**An investigation of how to support families in managing problems of weight loss** related to advanced cancer, led by the University of Southampton with funding from a Macmillan Cancer Support post-doctoral fellowship.

**Work to develop a non-pharmacological, supportive care intervention for patients with lung cancer** and their care givers in the management of symptoms of respiratory distress. Researchers came from the universities of Nottingham, Manchester and Southampton, with funding from the NCRI Supportive and Palliative Care capacity building grant.

**An investigation of joint aches, pains and muscle stiffness in women following treatment for breast cancer.** It was a collaboration of researchers from the University of Southampton, Southampton University Hospitals NHS Trust and Portsmouth Hospitals NHS Trust, with funding from a NCRI Supportive and Palliative Care capacity building grant.

**A research project on older women's experiences of breast cancer**, alongside other health conditions, led by the universities of Southampton, Lancaster and Nottingham with funding from a Macmillan Cancer Support user-led research grant.

**Research on relatives' needs for information and support related to cancer**, led by the universities of Southampton and Lancaster, with input from service users. Funding came from a Macmillan Cancer Support user-led research grant.

**Pilot study of auricular therapy and acupressure for cancer-related insomnia** by researchers from the universities of Liverpool, Manchester and Belfast, funded by a CECo grant.

## Acupressure wristband trials

A £500,000 grant to CECo has enabled researchers from three universities to run a large trial demonstrating that acupressure bands can cut nausea caused by cancer treatment.

The trial, led by Professor Alex Molassiotis at the University of Manchester, involved experts equally from the universities of Liverpool, Manchester and Plymouth, as well as using several expert patients to draw up the protocol. They demonstrated not only that acupressure bands are effective in the management of chemotherapy-related acute and delayed nausea, but that this treatment is also cost effective.

Funding for this important collaborative study came from a very prestigious funding source – the NIHR Health Technology Assessment.

Nausea and vomiting are unpleasant and common side effects of chemotherapy, which have been addressed with a range of drugs over the years and occasionally with other non-drug treatments including acupressure.

Research studies have suggested that wearing a pair of these wristbands to apply pressure on known acupressure points, may alleviate chemotherapy-related nausea. The NHS however needs sufficient research to confirm that acupressure is a useful and cost-effective method of treatment in conjunction with traditional drug therapy.

This study recruited 500 patients from cancer clinics in Manchester, Liverpool and Plymouth. All patients were on conventional anti-sickness drugs and were then randomly assigned to three conditions – self-administered acupressure, sham bands that do not press on the acupressure point and a control group.

The results of the study will be published soon.

# Older adults

In the UK more than 80 percent of deaths and 75 percent of cancer deaths occur in people aged over 65, but little is known about older adults' views on end of life issues or what the best ways are to support them and their families. CECo has developed a comprehensive programme of research to support older adults facing death and their families and professional carers.

## Our aims

- Identification of older adults' own priorities in end of life care
- Examination of older adults' own preferences for engaging in decision making in end of life care
- To understand more about the contexts in which older adults express a preference about where they are cared for
- Exploration and evaluation of how older adults may be involved in the design of palliative care services
- Development of common approaches to research methods.



## Work we have done

**Collaborative research programmes** have been undertaken in a number of areas such as living alone in older age, end of life in care homes, older carers and public awareness around end of life.

**Development of national guidance** for health and social care professionals on best practice in advance care planning (see *case study*) and a related public education leaflet published by the National End of Life Care Programme and the National Council for Palliative Care. This has been distributed to all health trusts in England and Wales.

**Professor Merryn Gott** (formerly at the University of Sheffield) and Professor Christine Ingleton

(the University of Sheffield) have jointly led a study for the NHS Service Delivery and Organisation programme to improve care for older people at the end of life by examining the need for, and provision of, palliative care at two hospitals in England serving contrasting populations. This is in response to the national cancer director, Professor Sir Mike Richards' finding that 'a proportion of dying patients receive very poor care' in acute hospitals.

**Work to develop a family support needs assessment tool** which has attracted funding to evaluate its impact in Hospice at Home care and to pilot its use in palliative home care practice.

## case study

### Public awareness

A group of older adults aged from 58 to 85 have been key participants in the production of resources and a training manual to prepare volunteer educators, to raise awareness about advance care planning in their communities or workplaces.

Advance care planning allows patients and their carers to think ahead to a time when they may not be able to articulate their wishes for care and treatment. Its scope ranges from expressing a basic preference about their nutritional likes, to recording a formal decision to refuse medical treatment in certain circumstances.

The package - which is available from the National End of Life Programme ([www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)) and the Dying Matters Coalition ([www.dyingmatters.org](http://www.dyingmatters.org)) - is based on work led by Professor Jane Seymour at the University of Nottingham. It was undertaken by a team consisting of researchers from the universities of Lancaster, Aberdeen, Manchester and Nottingham.

Building on work started before the establishment of CECo, the Burdett Trust for Nursing (with additional support from Help the Aged) funded the two-year project. This enabled the training of 32 volunteer peer educators of whom 24 were older adults. Of these, about two thirds are still involved in peer education.

The volunteer peer educators adopted a range of different approaches to raising public awareness about advance care planning, from an individual giving talks to pensioner groups, to an advocacy group. One group obtained lottery funding to work with lesbian, gay and bisexual older people on these issues, whilst another put together a resource portfolio about advance care planning.



## Key Achievements

The establishment of an enthusiastically-received ESRC-funded seminar series entitled **Social and Psychological Aspects of Dying in Old Age**.

The attraction of 36 grants across the older people's theme, to a value of more than £3.46 million by 2010.

A book co-written by CECo researchers - **Living and Dying with Dementia: Dialogues about Palliative Care** by Small N, Froggatt KA and Downs M (2007) - was joint winner in the new non-clinical medical book category 2008 awarded by the Society of Authors and Royal Society of Medicine.

Direct contribution made into numerous policy areas including social attitudes to death, dying and bereavement, attitudes to end of life issues amongst health-care professionals, demographics of dying, environments of care, economics of end of life care, prognostication and advance care planning.

CECo researcher Dr Catherine Walshe at the University of Manchester received second prize in the inaugural EAPC Young Investigators Award 2009, for her work on referral decisions to palliative care services.



# Research methodologies

Research in supportive and palliative cancer care is methodologically challenging. Patients are often very unwell and they, and their families, may 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 taking part in studies. Whilst these factors are understandable, they cause methodological problems for researchers in this area, including difficulties in outcome assessment and study adherence. The methodology theme has been established to help address these challenges.

## Our aims

We want to study the suitability of methods used in supportive and palliative care research, and to provide evidence that helps to improve the research process and outcome. This has required us to develop a research programme which both compares research approaches, and analyses evidence about the benefits of different methods.

The scope of our work is broad and covers:

- 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 innovative methods or approaches.

## Continuing work

The entire theme originally developed from work on narratives, which recognises the power of stories in understanding how people make meaning from their lives. The aim of this group was to improve understanding of narrative methodology and to investigate the application of narrative methods in supportive and palliative care. During the two and a half years of its existence, it achieved remarkable successes including:

- Ten funded research studies from the Economic and Social Research Council, the MS Society, Macmillan Cancer Support, Dimbleby Cancer Care and other charitable organisations
- More than 32 papers, books and other publications
- Four protocol development meetings bringing together its 50 members in collaborative work on new research proposals, which helped to build capacity in more junior researchers and clinicians.

**A decision was made in 2009, to expand the work of this theme to take a wider approach to the challenges of developing appropriate methodology in supportive and palliative care.**

**Prognostication relates to the more familiar term ‘prognosis’** which is how a physician tries to work out the likely course of a disease or illness. The methodologies theme has been involved in two areas – the development of prognostic indicators for palliative care (see *case study*) and the organisation of a conference dedicated to it.

**MORECare (Methods of Researching End of Life and Palliative Care)** is an innovative collaboration with colleagues from the COMPASS collaborative, to develop guidance for developing and evaluating models of service delivery in end of life care. The End of Life Care Strategy in England 2008, says that research is too slow and expensive and frequently fails to produce results useful for policy makers and commissioners. This MORECare project is working to identify, evaluate and collect ‘best practice’ methods for the evaluation of end of life care, particularly focusing on complex service delivery and reconfigurations.

## Key Achievements

The group working to develop a PROM for use in gynaecological oncology has been successful in gaining a grant for £10,999 from the Rosemere Foundation to conduct a systematic review of the use of PROMs in gynaecological oncology.

**At least 21** published papers.

**Low recruitment in supportive and palliative care research** is an issue that has blighted progress in this field. Healthcare professionals sometimes block recruitment, because they feel it is inappropriate to ask patients to enter studies. However, research has demonstrated that most patients want to be given the opportunity to decide for themselves. The methodology theme has developed a collaboration across five universities (Manchester, Lancaster, Southampton, Cambridge and Loughborough) to carry out a systematic review of how health care professionals might help (or hinder) the recruitment of patients in palliative care.

**Patient reported outcome measures (PROMs) is an interest shared with the Complex Symptoms theme.** The main work has been focused on developing a measure of empowerment. The methodology theme jointly hosted a two-day conference on PROMs, out of which has developed a collaboration with clinical colleagues in gynaecological oncology and with other staff at Lancaster University, to develop a PROM for use in gynaecological oncology.

## Predicting a patient’s prognosis

Working out a patient’s prognosis is key to decision making in cancer care, with consequences on how and where an individual is cared for. The global repercussions following the Scottish government’s decision to release the Libyan Abdelbaset Mohmed Ali al-Megrahi convicted for the Lockerbie bombing, on the grounds that he had only three months to live, is a vivid demonstration of how inaccurate clinical judgement is.

CECo’s methodology team, led by Professor Chris Todd from The University of Manchester, has made an important advance in attempting to introduce more rigour into predicting prognosis (prognostication) by identifying the key five research questions that need to be asked.

The establishment of the five questions took place during a one-day conference on the topic, including presentations from international speakers. Participants went into four groups to discuss the talks and suggest research questions related to prognostication, using consensus techniques. These were written down and more were sought until there were no more suggestions. The questions were scored and given a ranking.

The top five emerged as:

- How valid are prognostic tools?
- Can we use prognostic criteria as entry criteria for research?
- How do we judge the impact of a prognostic score in clinical practice?
- What is the best way of presenting survival data to patients?
- What is the most user-friendly validated tool?

The findings from this study were written up for publication in the journal *Palliative Medicine* and attracted media attention.

The strongest priority to emerge from the consensus data concerned the validity of prognostic tools. Further research is essential to validate the clinical value of existing tools.

## Capacity building

The future of supportive and palliative care can only remain bright, if enough researchers of the highest calibre can be attracted into the field and retained within it. In response to the NCRI strategic review, CECo has put great emphasis on improving both the quality, and the quantity, of researchers by capacity building. It sees a specific need for doctors and other practitioners - particularly in the independent hospice area - to develop a basic understanding and appreciation of research. So we have dedicated time and resources to improving the research skills of people from novice to expert level. CECo has also committed itself to the achievement of these key drivers, by giving talented clinicians the opportunity to pursue short-term research projects under expert mentorship.

### What we do

Building capacity consists of any activity which increases the research knowledge or expertise of participants. It is integrated into the fabric of each of CECo's research theme groups through active working groups consisting of up to 20 academics, user representatives and clinicians from across the collaborative. Activities are planned and co-ordinated through regular meetings.

### Other activities

**Annual 24-hour State of the Science meetings** bringing together researchers, students, academics, service users, and clinicians from CECo and beyond, to review the year's activities and debate leading issues.

**Supporting the career development of new researchers** and their work, and providing informal mentorship. Protocol development meetings provide a valuable practical learning exercise, particularly for junior researchers, in designing realistic, feasible studies and writing convincing proposals.

**A series of highly-successful, one-day events to build capacity in supportive and palliative care, has specifically targeted hospice staff. Networks between participants have been set up to continue these events beyond the life of the collaborative. CECo produced a report on this in 2008, Exploring the Research Education Needs of Hospices: A focus group study conducted in Manchester and London by Payne S, Turner M, Kerr C, Amir Z, Brearley S.**

What we did

**Time and resources have been dedicated to working with Help the Hospices** towards the development of a more research-friendly environment in these settings, and to promoting care backed by evidence of its efficacy.

**Developing links between teams**, and opportunities for participation in research studies and other capacity building activities.

**Hosting a series of workshops** on research methods designed to address the needs of researchers with a range of different experience.

**Operating and funding a research scholarship scheme** offering competitive grants to clinicians, to develop their research and scholarship skills under the mentorship of senior research staff based in CECo universities.

**Involving the wider public** and user community.

case study

### Michele Wood, CECo Scholar 2008



My interest in research has grown over years of practising as an art therapist in mental health, hospice care and medical oncology. However, it was through my award of a CECo scholarship in 2008 that I have been able to undertake my own academic research in art therapy and cancer care.

During three intensive months I plunged myself into the world of research supported by my CECo mentors, carrying out a systematic review of all the research done on art therapy interventions with adults with cancer, predominantly for symptom management.

The financial support provided by CECo ensured that I could access the best resources and expertise, and gave me the opportunity to attend the Lancaster University Research Summer School. This was an invaluable experience, introducing me to a variety of research techniques and giving me confidence to develop my skills. I have presented my research findings at conferences in London and Vienna (both in 2009) and the systematic

review was published in *Psycho-Oncology* in March 2010, following a year of support from my CECo mentors whilst I wrote it up.

Since the scholarship finished, I have been building on the work I began with CECo as a Master's student at The University of Manchester in clinical health research. I work as an art therapist at the Marie Curie Hampstead Hospice and also teach on the MA in Art Psychotherapy at Roehampton University.

I very much want to continue to develop my career as a researcher within supportive and palliative care, and the CECo scholarship was instrumental in opening up opportunities for this.

### Key Achievements

Introduction to research workshops have now become so successful that they have been made available as an online resource called Introduction to Research for Hospice Staff, available for free on the CECo website.

PhD and post-doctoral workshops were set up in the form of 24-hour meetings, offering networking opportunities, support and seminars on successful NIHR doctoral and post-doctoral research.

A fellowship discussion group was set up on the CECo website following consultation with PhD/post-doctoral researchers, to enable further questions, discussions and advice.

Research scholarships have been awarded to 11 people by CECo which have enabled clinicians to achieve goals they would not otherwise have been able to reach and helped them towards a career in research.

A total of 12 papers have been published by CECo scholars in recognised journals - for many of them it was their first time. Three of them have gained funding to further their research careers by doing higher degrees.

State of Science meetings (12 in all) have attracted well-known speakers and delegates from abroad as well as the UK, to discuss subjects including perspectives on evaluation in palliative care and patient-reported outcome measures (PROMS). As a result of this success the journal *Palliative Medicine* will be dedicating a special issue to evaluation methodology.

Scholars have presented their work at national and international conferences, including at the European Association for Palliative Care (EAPC) Annual Congress.



# User involvement

No two people's experiences of serious and advanced illness are the same. They are shaped by a wide range of physical, psychological and social factors, from the way that clinicians have involved them in treatment decisions, to the kind of support available to them from friends, family and other carers. What is right for one person can be completely inappropriate for another. This is why CECo makes the patient and carer perspective of illness a key strategy in considering services for people suffering from advanced illness. Little research has been done to demonstrate the added value of user involvement, but CECo is committed to giving patients and carers a clear voice and the opportunity to develop and expand their role according to their individual needs and ambitions.

## Lancaster Research Partner Forum

This was established at Lancaster University in 2007, to enable users to become involved in research projects with CECo. The membership has ranged from four to 12 members. Monthly meetings are chaired by research partners, supported by researchers from the university. Researchers present proposals to the forum for review and comments. Individual users are also involved in specific research studies as members of advisory groups and as researchers, having received training in meetings and at external events. The forum is reviewed annually.

What we did



### How we work with users

Working with research partners with varying experiences of cancer and other life-limiting illnesses and caring responsibilities, to build relationships with CECo's five academic centres in Southampton, Lancaster, Nottingham, Liverpool and Manchester.

Users work to develop and advise on new projects, create links with other researchers and often help with training.

Once trained, they may act as advisors on the designs and direction of a research project.

## Key Achievements

Approaches have been made by 21 researchers from various universities and organisations asking for input on research proposals from a user perspective. Some wanted advice on designing patient information and consent forms, whilst others needed help on recruiting users.

Two studies have each had three users on their project advisory groups and as user researchers. In one study two research partners assisted researchers to recruit and support residents in a care home to take part in an interview study about the care they receive.

Three research proposals have been submitted by research partners for funding, of which one application was successful. Two others were shortlisted, but were eventually not funded.

One cancer patient – Roger Wilson – has served on the CECo Executive Group, helping to ensure that users' views are central to all CECo's strategies. He received a CBE on the 2011 New Year honours list for his contribution to user involvement.

Their personal experience and insight can often be invaluable to researchers developing a project.

They may help develop their own protocols, review others' protocols and contribute to the research project once funded by helping conduct interviews and analysing data.

Research ideas have been initiated by users from their own unique perspective and developed into research projects.

case study

Sue Kernaghan  
research  
partner



When I was diagnosed with breast cancer in 2002 my life changed forever, but through my work with CECo I am proud to have been able to use what happened to me to improve the lives and treatment experiences of people like me.

Then as a 50-year-old manager at Wirral PCT, I thought life would just fall back into place after surgery, chemotherapy and radiotherapy – but it did not. The experience had changed me and I was no longer able to cope with the work in the same way.

My relationship with my daughter underwent a major change as we struggled to come to terms with who was the 'parent' and who was the 'child' in this new situation.

I developed a passionate interest in the psychological aspects of the cancer journey – first as a patient representative with Merseyside and Cheshire Cancer Network, then with CECo in 2007. CECo allowed me to share my views on patient treatment with research groups three or four times a year.

Since then I was also diagnosed with a gastro intestinal stromal tumour (GIST) in 2009 and this has also helped inform my work with CECo.

The thing I am most proud of with CECo is the contribution I made to a study on depression in patients with advanced cancer. I attended meetings, gave ideas on how to devise the research and helped frame the questions to assess patients' psychological state. That research was published as a paper.

Researchers and clinicians need to broaden the way they look at cancer and serious illness and realise that when you help the carers, you help the patient too. I do not have an academic background but am really honoured to be involved and to have helped CECo formulate studies that will inevitably improve the patient journey.



## Looking to the future

The vibrant teams and newly-skilled researchers that CECo has helped to create, ensure that our vision will continue into the future. It has established a new dynamic of users, health-care professionals, politicians and researchers with an understanding of the importance of supportive and palliative care, and of the need for good-quality research.

CECo's work will continue. We will complete research that is already underway, to measure its impact since 2006 and to reflect this in high-quality publications.

The executive team will continue to push the boundaries of research in palliative and supportive care.

One option under consideration is to maintain the links CECo has built up, but in the form of a virtual network, available through its website.

The CECo executive team has aspirations to continue the work it has started on an international platform, because of the interest shown from researchers all over the world. It is currently seeking ways to achieve this in Europe, but clear decisions will not be made on this until summer 2011.

Changing the way people think about supportive and end of life care takes time.

We have been able to influence government policy on supportive and palliative care in the last few years, but we need to continue to gather the evidence to ensure that services are designed to allow people to live with serious disease, and ultimately to end their days, the way they want to do so.



What they say . . .

## What people say about CECo and its work

Here are some of the comments we have had from researchers, users and event participants about their experience of working with us.



Really interested in health promoting/ community education idea with palliative care. Would like to take this forward as a project with care homes.

Being part of the Forum has widened and informed my life and I hope that I have been of use to my fellow members.

... the chance to actually work on some of the projects the group discussed appealed to me as I could see that the research the group 'may' undertake 'might' improve services to the patient, their family and friends.

It was useful to have such a good introduction to an area of presentation of knowledge of which I had no previous experience.

Although I was pleased to be retired, I did feel that I would like to give something back to society and that it would be a challenge to become involved in research, an area of work which is unfamiliar to me albeit in a subject in which I have a great deal of interest.

*I became involved with the Cancer Network, and ultimately 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.*

Good opportunity to network. Excellent speakers who were relaxed and informed and friendly. Meeting people from Australia/Spain. High quality of speakers and information gained.

Very good speakers and content and longer discussion session worked well. Putting the flesh on the bones with details of studies essential and helpful and interesting.

I was glad for the opportunity to learn and think about a subject about which I know very little.

*Candid discussions of successes/failures/problems. Excellent overview of research methodologies.*

*As a group we make comments, based upon our own experiences which are wide ranging. This helps to create a more inclusive approach to research. We are also involved as co-applicants.*

I most enjoyed the different slant on the theme requiring thought to connect aspects up, which stimulated new ideas and a change of perspective in me.



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**Hundreds of thousands**  
of older people receive no care or support  
from either official sources  
or family and friends

**56%**  
of people  
die in  
hospital

**90%** of people  
spend time in  
hospital in their final  
year of life





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