

2nd Annual Scientific Meeting Showcases CECo Research



CECo Fellows Sarah Brearley and John Hughes at this year's Annual Scientific Meeting

CECo was established, with COMPASS, to improve the quality and quantity of supportive and palliative care research in the UK. Evidence of the contribution it is making was showcased at the 2nd CECo Annual Scientific Meeting in Manchester this February.

Participants representing the wide cross-section of groups that CECo brings together, including researchers, research partners, clinicians and practitioners, charitable organisations, CECo scholars and students heard Julia Addington-Hall, CECo Co-director, open the meeting by highlighting how far the Collaborative has come in its first year and a half—from a concept to an active Collaborative.

In the course of the day, participants heard presenters describe the collaborative work they are developing in CECo's three research theme groups—new approaches to complex symptoms, planning for the care of older adults towards the end of life, and narratives of cancer and other life-limiting illnesses.

Plenary sessions highlighted work being undertaken with older people on the priorities for care at the end of life, research into the prevalence, aetiology and natural history of depression and demoralisation in patients with advanced cancer, and the contribution of narrative research methods in palliative care contexts. CECo's NCRI capacity-building scheme projects—on joint

pain and stiffness in women following primary treatment for breast cancer and predicting weight loss in people with cancer—were the focus of the afternoon session, alongside the work of CECo's research fellows on studies of the support needs of older family caregivers of people with advanced cancer, living through motor neurone disease, CAM therapies in palliative care and a major RCT of the effectiveness of acupuncture for the control of chemotherapy-related nausea.

The Annual Scientific Meeting is a key opportunity to show how CECo is focusing on achieving its core objectives—next year's expanded two-day meeting promises to be just as busy as this year's!

CECo plans 2nd Master Class:

- Turn to the back page for news of CECo's next **Master Class on Evaluating Complex Interventions in Palliative Care**, to be held at **Southampton University** on **Thursday 19th June**.
- Slides from the **Master Class on Ethics** can be accessed from the **CECo website** (www.ceco.org.uk) in the **Research Capacity section**.

Manchester hosts Master Class on Ethics

CECo's first research Master Class was hosted by Manchester University on 4th December on ethical issues in supportive and palliative care. The morning sessions focused on theoretical aspects of ethics in researching vulnerable people; in the afternoon, discussion

turned to practical advice, including guidance on research governance, the role of ethics committees, and completing NRES documentation.

Attendance at the Master Class exceeded expectations, with representatives from medicine, nursing,

service users, and education taking part alongside researchers and research students. Feedback on the meeting has been very encouraging and our thanks go to Ziv Amir and the team at Manchester University for all their hard work in organising such a successful event.

CECo holds research methods workshop

“A great 2 days.

Well facilitated.

Lots of information

but didn't feel

rushed”

One of CECo's key aims is to develop research capacity by providing new learning and training opportunities for researchers, practitioners, service users, academics and others with an interest in developing their skills.

CECo's first research methods workshop, led by Dr Christine Ingleton of the University of Sheffield, was held in February at the Foresight Centre in Liverpool.

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.

Among the speakers taking part with Christine Ingleton were CECo Fellows Sarah Brearley (University of Manchester), John Hughes (University of Liverpool) and Chris Bailey (University of Southampton). The workshop was designed as an introduc-

tion for those wishing to learn more about research in supportive and palliative care and to develop their knowledge and skills.

The workshop will move to London in early 2009 and in the future events will also be held for those with greater research experience—more details soon!



Christine Ingleton

“This experience

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CECo's first two Scholars

In 2007 CECo awarded its first two Scholarships to Lorna Higgins, a graduate mental health worker in Liverpool and Anne Marie Lydon, a Research Associate in the Macmillan Research Unit at the University of Manchester. Here Lorna and Anne Marie describe life as a CECo Scholar...

Lorna writes: I am currently nearing the end of my part time CECo Scholarship at the University of Liverpool in the Academic Palliative and Supportive Care Studies Group (APSCSG) under the supervision of Professor Mari Lloyd-Williams and mentorship of Dr John Hughes. This experience has been a valuable insight into the world of research. It has allowed me to develop my understanding of research methods as well as spending time in a real research department! In my job as a mental health worker I designed a self-help guide for cancer patients which lead me to develop an interest in the

psychological needs of cancer patients. Before starting the Scholarship, although I had always had an interest in research, I hadn't had the opportunity to conduct much research. By attending CECo meetings and courses I have been able to meet with other researchers and find out more about what other research is being conducted. Currently I'm working on a proposal for a PhD which we are hopeful of getting funded—something I would not have had the opportunity to do without the Scholarship.

Although I am now nearing the end of my time on the Scholarship there is still much to look forward to with poster presentations at 2 conferences as well as a number of CECo meetings and conferences looming. Many thanks to all at CECo and the University of Liverpool, particularly everyone in the Academic Palliative and Supportive Care Studies Group for their help and support.

Anne Marie writes: I feel very honoured to have been awarded the CECo scholarship. The scholarship aims to help health care professionals develop their research ideas and submit an application for a research grant or PhD studentship award. With the support and guidance of experienced CECo researchers, I plan to write a research proposal with the aim of submitting an application for a PhD training studentship. The Scholarship is for 3 months and I am being mentored and supervised by Professor Kinta Beaver at the University of Manchester.

The PhD proposal will be based on preliminary work that I have undertaken. This exploratory work investigated patients' and clinicians' attitudes towards follow-up service provision following treatment for ovarian cancer with a specific focus on the acceptability of telephone follow-up by specialist nurses.

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CECo's first two Scholars (cont.)

The data generated from this study highlighted two very different perspectives regarding follow-up care. Clinicians felt that current follow-up procedures were not meeting the needs of the patient and welcomed the idea of nurse-led clinics and telephone consultations for asymptomatic patients. The patient group were divided in their views. Patients who were confident, well informed and supported, appeared to be less worried about a change in follow-up procedures than those who were not.

With clinical support from a regional cancer hospital and academic support from my mentor and the Macmillan Research Unit at the University of Manchester I plan to explore these issues further.

I hope to investigate whether different types of follow-up care are positively or negatively associated with self-care and quality of life, with a view to making recommendations for best practice in this important area of care.

If you would like further information about my experience as a CECo scholar, please

contact me at:

Anne.Lydon@manchester.ac.uk

“With the support of experienced CECo researchers, I plan to write a research proposal with the aim of submitting an application for a PhD”

More highlights from the year so far...

- **Palliative Care Research in the Community: Taking Stock—One day conference** hosted by University of Edinburgh Primary Palliative Care Research Group, organised by CECo, COMPASS and UK Palliative Research Society, 6th March 2008
- **The Value of Stories in Supportive & Palliative Care—2nd CECo Narrative Theme Conference, Southampton Solent University, 8-9th April**, with Arthur Frank & Tom Wengraf
- **2nd CECo Doctoral & Post-doctoral Researchers Meeting, Manchester, 3-4th March**
- **Ongoing programme of collaborative Protocol Development Meetings** hosted by CECo's three research theme groups

Innovative Approaches to Complex Symptoms: State of the Science

Claire Foster and Sarah Brearley report on critical debate on research on complex symptoms.

The second State of the Science Meeting of the CECo Complex Symptoms research theme group took place on 10th April, at the Foresight Centre, University of Liverpool. Over 55 delegates attended including research partners, researchers from across the UK, clinicians and representatives from primary, secondary and hospice care.

Four thought-provoking key note talks from eminent speakers from the UK and Europe set the scene. Prof. Leslie Walker, Chair of Cancer Rehabilitation and Clinical Lead for the Division of Cancer at the University of Hull, challenged the future direction of research into psychological distress. He argued that enough research had looked at the prevalence of distress and we should now

be looking at predicting, preventing and developing more effective interventions.

Professor Nicola Robinson, Professor of Complementary Medicine at Thames Valley University and Chair of the Research Council for Complementary Medicine Research, explored what we should be researching in Complementary and Alternative Medicine (CAM). She discussed issues facing CAM, including the lack of regulation, and made a plea for mixed methods research, indicating that the outcome measures used in CAM RCTs may not reflect the benefits reported by patients.

Professor Stein Kaasa, Chair of the European Association for Palliative Care Research Network and Professor in Palliative Medicine at the Norwegian University of Science and Technology, outlined ethical considerations that have been used as reasons for

not undertaking research in palliative care settings and argued that research is necessary to evaluate the effectiveness of interventions. Current research tends to be focused on surveys and descriptive studies with little attention given to RCTs. Prof. Kaasa argued that we need a systematic approach, evaluating the effectiveness of interventions, improving treatment of physical symptoms and psychological distress and evaluating models of service care delivery.

The final presentation of the day was given by Reverend Mark Cobb, Senior Chaplain and Clinical Director at Sheffield Teaching Hospitals NHS Foundation Trust. He raised the question “Should we be researching suffering?” and highlighted that whilst suffering can be a defining experience for many patients, re-

search in this areas is very limited. The lack of critical attention, despite its association with advanced cancer, means that suffering appears to have become another way of talking about pain and distressing symptoms. Reverend Cobb talked about the different types of research into suffering, including narrative research looking at the meaning of suffering, concepts of suffering, care needs and measurement. He concluded that there is a duty to prevent suffering. The meeting generated much discussion about new areas of research and these were taken forward in the Protocol Development Meeting that followed the next day.

Claire Foster and Sarah Brearley are part of the management group of CECo's Innovative Approaches to Complex Symptoms research theme group.

C.L.Foster@soton.ac.uk

sarah.brearley@manchester.ac.uk

Coming soon...

- Thursday 15th May— Social and Psychological Aspects of Dying in Old Age, ESRC Seminar Series 2007-8, Seminar 4: Planning for Older People Facing Death in Old Age, Queen Margaret University, Edinburgh (k.froggatt@lancaster.ac.uk)
- From the beginning of next month a new look CECo website! Watch this space...

Visit us at:
www.ceco.org.uk

Web queries and questions?

Contact Anthony Greenwood (web manager):

a.j.greenwood@lancaster.ac.uk



Master Class: Evaluating Complex Interventions in Palliative Care



Speakers include:

- ◆ Prof. Chris Todd, University of Manchester
- ◆ Dr Steve George, Clinical Trials Unit, University of Southampton
- ◆ Prof. Alex Molassiotis, University of Manchester
- ◆ Part of the NCRI Cancer Experiences Collaborative (CECo) programme of research capacity building
- ◆ Cost: £40
- ◆ Further information: Fabia Ward (02380 597868/ F.Ward@soton.ac.uk)

Date: Thursday 19th June 2008

Time: 9am-4pm

Place: University of Southampton, School of Nursing & Midwifery, Highfield, Southampton SO17 1BJ

- ◆ An opportunity for researchers and practitioners to explore the challenge of designing and conducting trials of complex interventions using the MRC framework
- ◆ Presentations from experts in the field
- ◆ Discussions and problem-solving workshops

Introducing ... Fabia Ward



Fabia ward, CECo Administrator

Fabia Ward, CECo Administrator, talks about her role in managing the work of the Collaborative. I joined the University of Southampton as full-time CECo Administrator in April 2007, and having graduated from the University itself in 2005, it is nice to be working in such familiar surroundings. One of my main responsibilities is to provide administrative support to the CECo group, both within Southampton and the other four universities of the Collaborative.

This includes working with the CECo Academic Coordinator on a daily basis, liaising with the theme groups, research partners and administrative staff. Another part of my role is to deal with the financial aspects of the Collaborative, including monitoring and updating the CECo budget. I also work closely with finance departments to produce regular budget updates and to aid the end of year financial accounting of CECo. As CECo grows and

activity increases, part of my time is spent providing events management support and arranging CECo research theme group and Executive Team meetings. I also contribute to the organising of conferences and seminars, where delegate numbers can range from 20 to 100 and deal with related enquiries. If you would like to get in touch regarding general CECo enquiries or conference and meeting details, then please email me at: F.Ward@soton.ac.uk.