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Reinforcing our aims: 'Better research by better researchers'

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This is a time of tremendous challenges and success as we mark the first complete year of the Cancer Experiences Collaborative (CECo). Our Collaborative was funded for 5 years by the National Cancer Research Institute in the United Kingdom, starting in May 2006. As co-directors, Professor Addington-Hall and I have taken time to reflect on the challenges and opportunities that this year has brought. Our aim has been to establish a 'virtual' research organisation to improve the quality and quantity of research in three areas:

- Complex symptom management
- End of life care for older people
- Narratives of illness and dying.

In addition, we are seeking to build the research capac-

ity of our junior researchers, clinicians and of course, ourselves by linking with academic and clinical colleagues in cognate disciplines. All our activities have been underpinned by the



Sheila Payne

central involvement of people affected by cancer (called research partners).

So in the last year what have we achieved? We have es-

tablished effective and responsive management structures in which all five universities (Lancaster, Liverpool, Nottingham, Manchester, Southampton) are represented. Each research theme has held 3-4 meetings to link researchers, develop research proposals and jointly prepare papers. We have listened to the needs of our PhD and post-doctoral researchers, and rejoiced in the successes of five or more new grants. All this information and much more can be found on our website (<http://www.ceco.org.uk>). We must continue to gather our evidence, develop our research plans, and mobilise the strengths of our research partners into the next year. We hope you will join us.

Professor Sheila Payne, CECo Co-Director

A nurse-led intervention for the follow-up of lung cancer patients



Lynn Calman

Lynn Calman, Research Associate, School of Nursing, Midwifery and Social Work, University of Manchester, talks about her MRC Training Fellowship.

I am delighted to have been awarded an MRC Special Research Training Fellowship in Health Services and

Health of the Public. The aim of the fellowship is to develop and test a nurse-led intervention for the follow-up of lung cancer patients.

The development of the intervention will be informed by the MRC framework for the design and evaluation of complex interventions. The intervention will be defined

during the fellowship and is likely to have a number of components including assessment, symptom management, an information package and psychosocial support. User involvement will be central to the development of the intervention and

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A nurse-led intervention for the follow-up of lung cancer patients

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stakeholder views will be sought in a number of ways including a consensus conference process to develop the definitive intervention.

The intervention will be tested in an exploratory trial to determine efficacy, feasibility and acceptability and to identify appropriate outcome measures and cost utility and to provide estimates of sample size and effect size for a definitive RCT. Funding for a definitive (phase III) trial will be sought after the period of the fellowship.

The fellowship has been awarded for four years and will give me the opportunity to have advanced training in health services research. It will be based at the University of Manchester.

Throughout the award I will be mentored and supervised by Dr Kinta Beaver, Senior Research Fellow, School of Nursing, Midwifery and Social Work, and Dr Chris Roberts, Senior Lecturer in Medical Statistics, Epidemiology and Health Sciences, School of Medicine.

As a member of CECo I am looking forward to the opportunity to collaborate with other researchers with an interest in lung cancer, complex symptoms and complex interventions. Please get in touch if you would like further information about the study or if you have an interest in the research area or methodology.

Contact Lynn at: lynn.calman@manchester.ac.uk

Venetia Franglen

We mourn the passing of a special and gracious friend. Venetia Franglen passed away in early May. She took on the challenge of being a CECo Research Partner with some relish. She had tackled the patient advocate role in just about every other area of cancer research and had made a significant mark in doing so. Venetia served on a number of NCRI groups, including the Board Sub-Group, which gave her an overview of the whole community. She also worked on individual research projects where her acute and analytical mind spotted gaps and made links where others did not see them. Her contribution in the early meetings of CECo has been immensely valuable and we will miss her wisdom, her calmness and her friendship.

Roger Wilson



Web Matters: Creating your CECo profile

Anthony Greenwood, CECo Web Manager, explains how to get the most out of the CECo website.

With just over a year in existence, the CECo website has grown from being a small collection of static pages to a larger ensemble of member profiles, a discussion board, events calendar and a repository for documents. I would

like to take the time each newsletter to briefly cover the advantages of each of these elements and how you might wish to further contribute to them. At present, CECo has a web-registered membership of 108 members. However, this number is only apparent if you either count the names on the now three pages of members in the "Memberlist"

or you are eagle-eyed enough to view the total in the "Who is Online" area at the bottom of the page once you have logged in. Where it is not apparent is within the selection named "CECo Profiles", that you will find either on a tab along the top of the page or as a selection down the left-hand column of each page.

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CECo doctoral researchers meeting

Nic Hughes, Macmillan Research Fellow/ Nursing Lecturer School of Healthcare University of Leeds reports on a the first 24-hour meeting for CECo doctoral researchers on 6-7th March.

Fifteen doctoral researchers met for 24 hours in Manchester with CECo co-directors Sheila Payne and Julia Addington-Hall, facilitated by Chris Bailey, CECo Academic Co-ordinator, and Ziv Amir, Director of the Manchester Macmillan Research Unit, who jointly lead a working group in CECo on building research capacity. Participants were enabled to begin forming a network of researchers with shared interests on which it is hoped to build over time to forge collaborative working research partnerships. CECo Directors gave talks about the background, purpose, activities and direction of the Collaborative. Guest speakers provided insights into the processes of getting the most out of your relationship with your research supervisor (Catherine Walshe); of forging research partnerships with people affected by cancer (John Belcher) and of seeking funding for post-doctoral research (Jim Elliott).

Participants spent time generating ideas and

discussing ways in which they could contribute to the capacity building work of CECo, as well as ways in which CECo could support them to pursue their research projects and develop their research careers. These ideas were documented for development and action by the CECo Management Team. Two members of the group, Kim Chivers (Southampton) and Gemma Bryan (Manchester), will represent doctoral researchers on the Building Research Capacity Working Group. Nic Hughes will co-ordinate informal 'fringe meetings' for doctoral researchers attending CECo events such as conferences, seminars, protocol generation and state-of-the-science meetings.

On a personal note, I found this to be an enjoyable and productive meeting from which I took a real feeling of being part of something substantial. I feel we have the opportunity, supported by CECo, to build relationships which can support our present research activities and help to develop our futures in supportive and palliative care research.

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“I found this to be an enjoyable and productive meeting from which I took a real feeling of being part of something substantial.”

What next after the PhD?

Catherine Walshe, Research Associate, School of Nursing, Midwifery and Social Work, University of Manchester, reflects on discussion at CECo's first 24-hour meeting for post-doctoral researchers.

What next after the PhD? That wasn't perhaps the first question on everyone's minds at the CECo post-doctoral researchers meeting in March 2007, but for someone who is a new recruit to the post-doc fold, it was certainly a question uppermost in my mind. I think I got an answer to this, and many other questions I hadn't even thought of asking at this thought provoking meeting. Perhaps the most fascinating, and useful, aspect of the meeting was starting to understand how different others' career paths have been. Because of this we all brought different insights when we started to explore our past professional and research biographies to inform our discussions on what we brought to CECo, how we could contribute to the success of CECo, and how CECo could help us

in our research and research careers. Our discussions on these aspects, and our own understanding of different topics, was informed by presentations by Jim Elliot on how Macmillan Cancer Support could support our post-doc careers, Alex Molassiotis giving us tips on grant writing success, and Roger Wilson on the benefits of working with research partners. Anthony Greenwood also gave us a guided tour of the workings of CECo e-technology, although I think most of us are still Luddites and are failing to exploit the benefits this could bring us! We left I think both having a clearer idea of how we could personally work to develop our research career, and also feeding back to CECo many ideas about how the post-doc community can contribute to the success of the collaborative, and how the collaborative can help us to succeed as researchers.

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“The most fascinating, and useful, aspect of the meeting was starting to understand how different others' career paths have been”

Web Matters: Creating your CECo profile

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There are hundreds of thousands of community web sites in existence which have a similar function to ours and each of these sites may well have a membership in the thousands. It is hoped that CECo too will attract a membership approaching at least a thousand but imagine how difficult it would be to find a person in a Memberlist that could stretch to hundreds of pages long!

With this in mind, it was considered from the outset that it would be easier to find like-minded individuals if we created a number of standard headings for information about CECo members. So you can find details of colleagues with shared interests under a theme, profession, workplace or photo in the “CECo Profiles” section. This is only possible, however, if you have both contributed to your profile page, sent me a photograph and notified me of your favoured theme when replying to my initial welcome message.

If you haven't done so already, creating a profile is a simple affair. Firstly, you must be a registered member. Once you have applied for membership it is my job to activate your account. At this point, I send out a welcome message, inviting you to detail your theme interests and to complete some further information about yourself by way of completing a profile page. To do this, you simply log in and select “CECo Profiles” from the list of options in the left-hand column. There is a confusing option named simply “Profile” and I am working to have this changed – ignore this for now. The next page will, if this is the first time you have selected this option, invite you to “Apply

for your CECo Profile”. Clicking this link will take you to an “Edit Personal Profile” page and invites you to complete as much or as little as you like. Aside from your actual name, all we ask is that you enter at least one tick against each of the “Profession” and “Work Setting” categories and that you put some text in the box marked “Description”. Once you have completed the bare minimum, then clicking the Submit button at the bottom of the form will go a long way to getting you more easily noticed.

The next step in the evolution of your profile is that I am told you have completed it. At this stage, I activate your profile and assign your name to the theme you specified as your major interest provided you replied to my welcome message. This puts you firmly on the CECo map and it is time to sit back and await messages from your many adoring fans!

When completing your profile, you may have noticed that there was space at the bottom of the form to include a photo. Because I am a control freak, I don't allow anyone to upload files onto the web, so I would ask you to ignore this. What would be very nice, however, is to receive a photo of your good self by email. Providing a photograph completes the methods by which someone could possibly find you.

There we are, then. Now you are a fully-fledged member of the CECo website, where you can search for other members, find them and perhaps start a collaboration that will last for eternity! Next time, I will discuss how to access resources on the CECo web.

Forthcoming events

- Thursday 31st - May Friday 1st June—Complex symptoms theme State of the Science meeting, Martin Luther King House, Manchester (Sarah.Brearley@christie-tr.nwest.nhs.uk)
- Thursday 5th July—Social and Psychological Aspects of Dying in Old Age ESRC Seminar Series 2007-2008: Processes of Dying in Old Age, Postgraduate Medical Centre, University of Nottingham (Jane.Seymour@nottingham.ac.uk)
- Please note that some dates are provisional and should be confirmed with named contact person.

Visit us at:
www.ceco.org.uk

Web queries
and questions?

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