



# Palliative Care Research Society

## Newsletter

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### Welcome from the new Chair

Dear members

I'd like to introduce myself to you as the new Chair of the Palliative Care Research Society having taken over from Professor Julia Addington-Hall last autumn. Julia's hard work and leadership will be missed but I'm keen that the PCRS remains an important player in the UK palliative care research scene.

One of my first tasks has been to develop a strategy with the executive committee that outlines the aims of the PCRS and the priorities for the next few years. This strategy is available on our website ([www.pcrs.org](http://www.pcrs.org)) and covers the important areas of our work, not least of which is communication. This new-look newsletter is the first in a series of regular updates and bulletins that we intend to send to you. We will also update the website, organise a membership survey to better understand your needs and hear your views, and review the size and scope of the executive committee. If you'd like to get in touch with me, please email [m.bennett@st-gemma.co.uk](mailto:m.bennett@st-gemma.co.uk), or phone 0113 218 5549.

I look forward to meeting you at our various meetings.

Mike Bennett, Chair of PCRS, St Gemma's Hospice, Leeds

### PCRS Annual Scientific Meeting

Our annual scientific meeting this year will focus on 'End-of-Life Research'. The meeting is being held at St Anne's College, Oxford on Thursday 13<sup>th</sup> September 2007. If you have

research you would like to present at the meeting then you can submit abstracts via the website ([www.pcrs.org.uk](http://www.pcrs.org.uk)) from Monday 2<sup>nd</sup> April until Friday 15<sup>th</sup> June.

### NCRI Primary Palliative Care Sub Group

This sub group was set up in 2006 and comprises of members of both the NCRI Primary Care Clinical Studies Group and the NCRI Palliative Care Clinical Studies Group. It is co-chaired by Stephen Barclay (Cambridge) and Scott Murray (Edinburgh) and its purpose is to encourage researchers to develop and submit studies relating to Primary Care or Palliative Care to donors such as the CRUK for funding. Should you be considering developing a project proposal in this area or in health services research more generally feel free to contact Stephen Barclay at [sigb2@medschl.cam.ac.uk](mailto:sigb2@medschl.cam.ac.uk) or Scott Murray at [Scott.Murray@ed.ac.uk](mailto:Scott.Murray@ed.ac.uk) to learn about how this group may help.

### Supportive and Palliative Care Collaboratives

In June 2006, UK palliative care research received a major boost from two grants to support supportive and palliative care research for cancer patients. The funding scheme was created by the National Cancer Research Institute (NCRI) in response to a report on "Supportive and Palliative Care Research in the UK" published in 2004, which identified the need for research in the field to be enhanced and more widely published in order to improve the quality of care for cancer patients. It recommended the setting up of a funding programme which could be specifically targeted to encourage collaborations of health and social care professionals to undertake appropriate research.

Two large collaborations of researchers from universities and health care settings, known as Cancer Experiences Collaborative (CECo) and Complex Interventions: Assessment, Trials and Implementation of Services (COMPASS), will each receive about £1.9 million over the next 5 years. In addition to these two major awards, a sum of £900,000 has been made available for a Capacity Building Grant Scheme to link in isolated or new investigators to broaden the work of the two collaboratives, and to develop a national network of researchers for the future. The first round of competition for this scheme was assessed in September 2006.

Organisations represented in COMPASS include University of Edinburgh, Kings College, London, and University of Leeds with their networks of NHS and voluntary sector partners; Worthing and Southlands NHS Trust; and 9 other associated universities. Organisations represented in CECo include University of Southampton; University of Manchester; Lancaster University; University of Nottingham, University of Liverpool; NCRI Consumer Liaison Group. Further details are available from:  
[http://www.mariecurie.org.uk/forhealthcareprofessionals/palliative\\_care\\_research/NCRISupportiveandPalliativeCareResearchCollaboratives/](http://www.mariecurie.org.uk/forhealthcareprofessionals/palliative_care_research/NCRISupportiveandPalliativeCareResearchCollaboratives/)

or the CECo website at [www.ceco.org.uk](http://www.ceco.org.uk) or for COMPASS at [susie.edwards@kcl.ac.uk](mailto:susie.edwards@kcl.ac.uk)

### The National Institute for Health Research

Major changes are taking place in NHS Research and Development. In July 2006, the Department of Health established the National Institute for Health Research (NIHR) to oversee the direction for publicly funded health research in England, with the aim of ensuring research funding is focused where it is needed, and provides both value for money and high

quality outputs. Funding for existing programmes is being expanded and new funding streams are being introduced. Perhaps of most interest to palliative care is the Research for Patient Benefit funding stream. This has the specific aim of commissioning research to improve the day to day practices in the NHS. Further details are available at:

<http://www.nihr-ccf.org.uk/site/programmes/rfpb/apply/default.cfm>

## Forthcoming conferences

### **The 10th EAPC Congress will be held in: Budapest, Hungary Thursday 7<sup>th</sup> June - Saturday 9<sup>th</sup> June 2007**

This biennial European palliative care conference is unique in being truly multi-professional in terms of delegates and scientific program. All palliative care professionals are welcome to this exciting combination of relevant research, evidence based knowledge, policy and public health issues. This is the first EAPC Congress in Eastern Europe, and is a great opportunity to update yourself on the evidence base of palliative care, get inspired in your clinical work, and research and meet and discuss with colleagues from all over Europe and the world.

Further details are available from: <http://www.eapcnet.org/Budapest2007/>  
Abstract submission is already closed

### **The 7th Palliative Care Congress will be held at: The Glasgow Royal Concert Hall Tuesday 29th April - Thursday 1st May 2008**

Full details including the Conference programme are available on the website at:

<http://www.pccongress.org.uk/>

Call for papers: Friday 25th May 2007, Closing date: Friday 12th October 2007

## Review of 2006 events

### **The 6th Palliative Care Congress was held at The University of Sheffield from 5<sup>th</sup> – 7<sup>th</sup> April 2006**

This very successful conference encompassed a wide range of clinical and research topics. Plenary presentations ranged from 'Mechanisms of pain' and 'Molecules in cachexia' to psychiatric issues, bereavement, and the development of multi-disciplinary research. Excellent free paper sessions covered medical education, services, non-cancer, children, primary care, symptom assessment and user involvement. There was also considerable attention to different aspects and innovations in research methodology, including qualitative research<sup>1</sup> cluster randomization<sup>2</sup>, delayed intervention RCT design<sup>3</sup>, and methodology to explore futility<sup>4</sup>, to give just a few examples. Perhaps the most memorable contributions were the presentation by Mark Cobb on 'Myths we grieve by' and the lively closing debate on physician assisted suicide. The abstracts are available in Palliative Medicine 20 (2), 2006 and at

<http://www.pccongress.org.uk/>

1. Fleming KA Use and potential role of qualitative data in evaluations of palliative care interventions. Pall Med, 2006; 20(6):137
2. Fowell A, Johnstone R, Russell I et al Cluster randomization or randomized consent as an appropriate methodology for trials in palliative care. Pall Med, 2006; 20(6):139
3. Edmonds P, Hart S, Burman R, Silber E, Higginson IJ. Evaluation of a novel palliative care service for patients severely affected by multiple sclerosis. Pall Med, 2006; 20(6):139
4. Feathers L, Baker I, Williams M, Faulk C. Evolving a vignette to explore the complex and sensitive issues of a yes/no choice. Pall Med, 2006; 20(6):137

**The 4th Research Forum of the EAPC  
was held in  
Venice  
from 26th – 28<sup>th</sup> May 2006**

This outstanding research conference demonstrated to us all that the quality and rigor of palliative care research is improving rapidly. Over 1000 delegates contributed to a dynamic and stimulating programme. A few highlights: Konrad Fassbender from Edmonton, Canada, outlined some of the demographic changes ahead – the ageing population across the developed world will profoundly alter the cost of health care provision, increasing the demand for health funding, while reducing revenue growth. We need to be well-informed and target measures to address this challenge. Marie Fallon presented the American Pain Society's recommendation that pain be adopted as 'a fifth vital sign', and Nathan Cherny led a shared session between palliative care and oncology. Chris Todd discussed the issues around use of RCTs in palliative care, (only 4 of 157 pieces of research presented at this conference met the criteria for an RCT) and elucidated how the MRC Framework for Evaluation of Complex Interventions might help.

Further details of the conference and the MRC Framework are available at:  
<http://www.eapcnet.org/congresses/Research2006.html>

Campbell M, Fitzpatrick R, Haines A et al. Framework for design and evaluation of complex interventions to improve health. BMJ, 2000, 321; 694-6.

**Joining the PCRS**

The society is easy to join, with full details and a downloadable form on the website at [www.pcrs.org.uk](http://www.pcrs.org.uk). Membership costs just £30 per year and benefits include:

- Reduced registration fees for some of the conferences organised, or jointly organised by the PCRS (note: individuals who are considering attending at least one such conference during the year will often find it economically advantageous to join the PCRS simply in order to benefit from the reduced conference fee). Note: this does not apply to every conference.
- Access to a list of members' contact details and research interests to facilitate multi-professional and multi-centre research initiatives.
- A newsletter twice per year
- Reduced subscription fees to the journal 'Mortality'.

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