

NEWSLETTER

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Welcome from the PCRS Chair Professor Julia Downing

Welcome to this edition of the Palliative Care Research Society Newsletter. It feels like a lot has happened since our last newsletter, both in terms of the Palliative Care Research Society, but also in the palliative care world generally, with the launch of the Lancet Commission on pain and palliative care¹, work towards Universal Health Coverage and the increase in the stakeholder voice within palliative care.



**Dedicated to promoting research
into all aspects of palliative care**

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The APM Supportive and Palliative Care/ Palliative Care Congress took place in Bournemouth in March and it was great to be able to launch our new website at the conference. Work continues to develop the website and to correct the initial technical hitches but we hope that our new website will provide a new platform for the work of the society. It is also great to have been joined by a few new members on the Palliative Care Research Society committee and we will have a focus on committee members in our next newsletter so you know who we all are! We are always looking for new members so if you are interested in getting more involved please do contact us. The conference in Bournemouth was a great opportunity to meet members, to network and to hear about ongoing developments in palliative care in the UK and we thank Erna for giving us a review of the conference in this newsletter. It is also encouraging to hear of the many palliative care PhD students across the country and to gain an insight into their work – we look forward to hearing more from these students in the future.

We would also like to be able to disseminate information about Palliative Care Research Society members' recent work – so if you have had anything published do please let us know so that we can highlight it in our next newsletter and on our website. We are keen to help disseminate research further so do please help us in this, and take this opportunity to share the work that you have been doing.

In this newsletter we also have a question and answer session with Prof. Scott Murray. Scott has been a Professor in Primary Palliative Care at the University of Edinburgh for many years and officially retired at the end of May. In his time at the University, and in his various roles before that, he has been a passionate advocate for the development of palliative care globally, particularly in relation to the provision of palliative care at the primary health care level. Alongside his many research projects looking at trajectories of palliative care in different conditions, his studies across different countries and his commitment to the Palliative Care Research Society, Scott was one of the founders of the Primary Palliative Care Research Network and also the Primary Palliative Care Task Force of the European Association of Palliative Care (EAPC). Whilst Scott is retiring, I am sure that he will continue to be linked in with palliative care and we will see him turning up regularly at future events, however in the meantime, we thank him for all he has done for the development of palliative care and wish him all the best for his retirement.

Prof. Julia Downing
Chair Palliative Care Research Society
June 2018

¹ Knaul FM, Farmer PE, Krakauer EL, et al, on behalf of the *Lancet Commission on Palliative Care and Pain Relief Study Group*. (2017) Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report. *The Lancet*. Published online October 12, 2017
[http://dx.doi.org/10.1016/S0140-6736\(17\)32513-8](http://dx.doi.org/10.1016/S0140-6736(17)32513-8)



Guest Q&A with Professor Scott Murray

Prof. Scott Murray held the St Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh, and retired in May 2018.

What have been the highlights and challenges of your career?

1. My wife Mary and I working as missionary doctors in Kenya for 7 years, bringing up a young family. There was great unmet need, with HIV arriving on the scene.
2. Working clinically as a GP near the Old Town in Edinburgh in very varied practice.
3. Starting a palliative care research group at Edinburgh University to promote generalist palliative care so that everyone might access palliative care when they get a life-threatening illness.

What experiences or which people have influenced your career the most?

Seeing inequalities in care and in quality of life at many levels- between countries, between care for different illnesses, between people in the community and hospices.

What advice has helped you in your career?

I remember being advised not to train as a GP, as I could do better than that. I was advised by sensible people not to be a missionary as that would waste my career. I did not take such advice from such well-meaning friends and mentors. So I have not taken much good or "safe" advice.

What advice would you give to someone contemplating following in your footsteps?

Do something that you are passionate about, something that makes a difference. Do not be conformed to current normal practices, but be adventurous and think big. Collaborate nationally and internationally. I was bold enough to start a Global group of enthusiasts in palliative care in the community as there was a gap. I did not seek permission to do that. Find a gap and mind it!

In your opinion, what are the top 3 issues affecting the provision of palliative care for all people approaching the end of life?

Lack of access to palliative care for people with multimorbidity and frailty due to the way hospices and palliative care are generally set up. Professionals still generally think palliative care is only appropriate when the person is actively dying. The persisting stigma that palliative care has with the public as associated closely with dying rather than living well up to the very point of death.

What changes in palliative care do you anticipate in the next few years?

Specialists and hospices spending more time and energy in training and supporting generalists in hospitals and the community, to render a palliative care approach integrated in their routine care. Much more end-of-life care happening at home or in next generation care homes.

Who would be on your ideal plenary panel at an international palliative care conference?

Important politicians, policymakers and innovative thinkers and service providers to think widely and creatively. They could discuss how ante-mortem care could be as reliably good as ante-natal care, and how people and communities could be more involved.

What do you enjoy doing when you are not working?

Time with our 7 grandchildren, church activities, and travelling. I am determined to get my golf handicap back down to single figures after I retire at the end of May!



Review of recent events

1. End of Life Care Catalyst Event at Edge Hill University

Stephen Mason gives a summary of the successful catalyst event supported by PCRS, which took place in April 2018

The PCRS recently sponsored an End of Life Care Catalyst Event, hosted by the Post Graduate Medical Institute (PGMI) at Edge Hill University and led by Professor Barbara Jack - Director Evidence-Based Practice Research Centre at Edge Hill, and Dr Susan Salt – Medical Director at Trinity Hospice and Palliative Care Services, Blackpool. The Catalyst event sought to provide a forum for clinicians and academics across the North West of England to explore research priorities and examine the potential for developing collaborative projects across the region.

Dr Sarah Russell – Head of research at Hospice UK, started the meeting with an overview of the work done by the charity to promote and facilitate research in the Hospice arena, and challenged the audience to explore how they can promote wider collaboration and action with the Hospice setting. Following this, the open space methodology for the meeting was presented by



Professor Sally Spencer from the PGMI and two rounds of small group discussion explored a range of topics including: Dementia and cognitive decline; Hospital based palliative and end of life care including in the Emergency Department; Technology/telemedicine/digital health; Advance Care Planning and Communication; Hydration.

Feedback from the discussion groups has been circulated to the delegates and discussions regarding collaborations and future catalysts events are ongoing.

2. APM's Annual Supportive and Palliative Care Conference in Association with the Palliative Care Congress and the PCRS



Erna Haraldsdottir attended the conference in Bournemouth back in March, and gives an overview of the key points from the sessions she attended and the workshop she held

The Opening Plenary: the hellomynameis Story, was presented by Chris Pointon who told the moving and inspiring story behind the hello my name is campaign. The Campaign was developed by Chris and his wife Kate who was a medical doctor and died of cancer. She believed that whether the experience of care would be good or bad was based on 3 things, Communication, 'The little things' and Person Centred Care. 'Hello my name is' is an example of worldwide innovation set up to remind health care staff how to start building a relationship with patients and their families based on person centred care.

Website: <https://hellomynameis.org.uk/>

Twitter: @PointonChris.

hello my name is...



Bereavement

A free paper session on Bereavement included presentation of 3 studies which all were thought provoking and led to good and interesting discussions between presenters and the audience. Loss of Relationship: A qualitative Study of Families and Caregivers after Home based Palliative Care Ends presented by Megan Vierhout and Jaymie Varenbut. This study highlighted that the relationship between the family and home care team ended very abruptly after the death of the person that the team was looking after. This was seen as a loss by both the family and the palliative care team. The research highlights the need to honour this relationship and find ways to end it in a way that reflects the value of the relationship.

The Role of primary care in providing bereavement support: perspective from a community sample (Stephen Barclay)

This study interestingly recruited persons who collected a death certificate of a loved one. Those who participated in the study were asked to identify what they needed from their GPs in order to cope with bereavement. The study highlighted the complexity of the current system in primary care to identify those who have lost a loved one who is registered in a different GP practice from their relative. In summary, all participants said they would favour contact from their GP, acknowledging the death and telling them they are there for them if they need to get in touch. The study highlighted a gap in the current system for those who may only need low level input which can though make a huge difference to wellbeing as supporting the persons grieving process. The study also highlighted lack of structure within primary care as to how this can be achieved.

A study on the medium-term effectiveness of a community based bereavement programme for vulnerable children and young people- Kalliopi Selioti. This study assessed the impact of Winston Wish programme which came favourable out in terms of reducing stress. The study used a measurement tool which might be useful in bereavement services: The Strength and Difficulties Questioner (SDQ) (Goodman et al 2000).

Palliative Care in the Community (Nikolaos Efstathiou)

Nikolaos Efstathiou presented his work using a realist evaluation to assess the impact of coordinated End of Life Care Service. He highlighted that this methodology has its limitations when used for evaluation of new services, as its main focus is to identify what works for whom and how, rather than identifying barriers and difficulties. This caused some issues for the research team, which they managed to resolve.

Research Ethics

I held a workshop in Ethical Issues in Palliative Care Research- adopting a person centred approach, whereby I highlighted the limitations of detached ethics for palliative care research in its current format, i.e. applying for local committee ethical approval prior to the study and anticipating all ethical issues in an abstract way. Situated ethics is an approach that is based on the relationship and context and needs to be applied to research with people in addition to the formal ethical approval gained from local ethical committee. I used examples from my own research practice to demonstrate this. Firstly, an observational study, which highlighted the need for moral judgement by the researcher based on relationship and care for participants. Secondly, interview based studies with vulnerable people such as people with dementia and people very close to death, to highlight how a

blanket approach to exclude this group from participation in research is unethical. Situated ethics and process consent is an approach that is needed to allow inclusion of this patients group in an ethical way.

Homeward Bound play (Lesley Goodburn)

It was a delight to watch the Homeward Bound play which is a 30 minute play telling the true story of Lesley and her husband Seth Goodburn. At 49 years old, Seth was diagnosed with pancreatic cancer following a short history of feeling unwell. He died just 33 days after diagnosis. This is a play, written by playwright Brian Daniels, to give people, especially health and social care professionals, the opportunity to reflect on the importance of compassionate person and family-centred care at the end of life and to help individuals to understand how little things mean a lot to the person who is dying and to their family. The play draws its content from a series of letters written by Lesley before and after Seth's untimely death. She articulates the journey from the first signs of his illness, through diagnosis, care and treatment and after his death at their local NHS Hospital. This has been developed into a teaching and learning resource. <http://www.ncpc.org.uk/homeward-bound>

An Evaluation of palliative care nurse prescribing: A mixed method study in Uganda (Julia Downing).

It was fascinating to listen to Julia Downing describe this research, which was a part of a leadership programme for nurses in Uganda. Nurse prescribing was implemented in Uganda and this has resulted in much better pain management of patients. Nurses already play a key role in relation to palliative care in Uganda and enabling them to prescribe morphine has increased their confidence and accountability.



PCRS Grant Award Winner – Dr Ros Scott

Congratulations to Dr Ros Scott who was awarded our recent PCRS grant to present her research at the European Association of Palliative Care Congress in Bern in May 2018. Ros explains the research presented in Bern.

I feel very privileged to have received a grant from PCRS to attend the 10th World EAPC Research Congress in Bern and to have the opportunity to share a number of projects with which I have been involved.

One study presented in Bern is “The voice of European volunteers: a qualitative analysis of accounts of volunteering in palliative care contexts” which explored what it means to be a volunteer in hospice and palliative care. Undertaken with colleagues from the EAPC Task Force on



Volunteering Professor Anne Goossensen (Netherlands) Professor Sheila Payne (UK) and Leena Pelttari (Austria) we invited stories from five volunteers from each of eight countries. Volunteers were involved in five main areas of support: directly with patients, families, bereavement and organisational, in addition to religious and faith activities. Their moving accounts gave significant insight into the rewards and challenges of volunteering in this context. Volunteers find significant meaning in their work and highlight the privilege of being permitted to accompany people at end of life.

A second volunteering project presented as a poster considers a qualitative evaluation of the impact of a volunteering pilot project offering support to families caring for a child with a life limiting/life threatening condition. Led by colleagues Lizzie Chambers and Katrina McNamara from Together for Short Lives, the evaluation explored the impact on families, volunteers and on the pilot organisations. It was clear from the evaluation that family wellbeing and quality of life improved as a result of the volunteer support. Volunteers reported the experience as rewarding, increasing their confidence and skills.

The third project, also presented as a poster, explores secondary school pupils understanding of loss and bereavement. Undertaken with colleagues Professor

Rebecca Wallace and Annie Audsley from Robert Gordon University Aberdeen this study involved pupils aged 11-18 years, parents and teachers from a large secondary school in Scotland. Pupils showed significant insight into their experiences of and their feelings around different experiences of loss and grief. Pupils mainly sought support from parents and peers and school mainly recognised as a source of support by teachers.

My future plans for research include further studies into the experiences of and training of volunteers, and to further test the applicability of my theoretical model of volunteering and hospice sustainability, beyond the UK.



PCRS PhD Students

Joanna Davies,
Dunhill Medical Trust PhD
Research Training Fellow at
the Cicely Saunders Institute,
gives an overview of her PhD
project



If you live in a deprived neighbourhood you're significantly less likely to die in a hospice than someone who lives in a less deprived neighbourhood, and this inequality has worsened in recent years; the gap between those living in the least and most deprived areas has grown by 25% between 1993-1997 and 2008-2012. This was the finding from a study I worked on in 2013/14 led by Dr Katherine Sleeman and Professor Irene Higginson at the Cicely Saunders Institute. It led me to want to investigate why people from more socioeconomically deprived backgrounds tend to have worse outcomes at the end of life, in terms of dying in hospital more rather than at home or in hospice, having more acute care admissions and receiving less specialist palliative care.

A first generation university student I studied undergraduate Sociology at the University of Liverpool and then a masters in research methods in Sociology at the University of Bristol. I was then fortunate to work with a team led by Professor Michael Noble at the University of Oxford helping to construct the Index of Multiple Deprivation, a small-area measure of deprivation that many researchers will be familiar with. This is where I became interested in large and routinely collected data and how research can be used to illuminate inequalities and potentially alleviate them as well.

I've been working with inspiring clinical and research colleagues at the Cicely Saunders Institute since 2012. The Dunhill Medical Trust (DMT) fund a diverse portfolio of research focused on improving care and quality of life for older people. In 2016 I won PhD fellowship funding from the DMT to investigate the social determinants of outcomes important to older people towards the end of life, supervised by Professor Fliss Murtagh, Dr Matthew Maddocks and Dr Katherine Sleeman. I'm now 18 months into my project using large existing datasets, including the English Longitudinal Study of Ageing, to explore the interrelationship between the health and social characteristics of older people in the last years of life.

Members' new research studies

BEACHeS aims to better support cancer patients with terminal illness. Anne Finucane gives an overview of the project

The University of Chester has been awarded funding by Macmillan Cancer Support for a new research study, to develop a psychological support intervention for cancer patients who have been referred into palliative care services. A team of researchers at the University of Chester and the University of Edinburgh have been awarded a £34,000 grant for the collaborative project, which will be run in partnership with terminal illness charity Marie Curie.

The funding will enable Acceptance and Commitment Therapy (ACT) based psychological therapy sessions to be delivered to people with cancer who are transitioning into specialist palliative care services. The shift from curative to palliative treatment can be accompanied by high levels of psychological distress and poor quality of life. The intervention being developed as part of this study is called BEACHeS which stands for Brief Engagement and Acceptance Coaching in Community and Hospice Settings.

Previous research led by the University of Chester has already shown that ACT may help cancer survivors to become more resilient to suffering and psychological distress (eg: <https://link.springer.com/article/10.1007/s00520-015-3050-9>). This pilot work aims to extend that research to patients receiving palliative care. ACT is a psychological therapy that aims to help people to get the most out of their lives, whatever their circumstances. As such the research team think this will be a complementary approach to mainstream palliative care.

The pilot study began in March 2018 and will run for a year. Participants (patients at Marie Curie Hospice Edinburgh and Marie Curie Hospice Liverpool) will have one-to-one therapy sessions with a psychologist over a six-week period and the researchers will test whether this short intervention has improved their psychological wellbeing. The research team hope that this will lead to a future trial and larger programme of work researching the benefits of ACT for people with cancer and other life-limiting conditions.



Photo: The BEACHeS Study Steering Group (left to right): Sue Millington, Jenny Strachan, David Gillanders, Brooke Swash, Juliet Spiller, Anne Finucane and Nick Hulbert-Williams.

Members' new publications

Boa S, Duncan E, Haraldsdottir E, and Wyke S. (2018) Patient-centred goal setting in a hospice: a comparative case study of how health practitioners understand and use goal setting in practice. *International Journal of Palliative Nursing*, 24(3), pp.115-122. <https://www.ncbi.nlm.nih.gov/pubmed/29608386>

Knighting K, Bray L, Downing J, Kirkcaldy AJ, Mitchell TK, O'Brien MR, Pilkington M, Hack BA. (2018) Meeting the needs of young adults with life-limiting conditions: A UK survey of current provision and future challenges for hospices. *Journal of Advanced Nursing*

Downing J, Boucher S, Daniels A, Nkosi B. (2018) Paediatric Palliative Care in Resource-Poor Countries. *Children* 5:27. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5835996/>

Knaul FM, Farmer PE, Krakauer EL, et al on behalf of the *Lancet Commission on Palliative Care and Pain Relief Study Group*. (2017) Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report. *The Lancet*. Published online October 12, 2017 [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)32513-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext)

Wakefield, D Bayly J, Selman L et al (2018) Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. *Palliative Medicine* <https://doi.org/10.1177/0269216318783919>

Kimbell B, Murray SA, Byrne H. et al. (2018) Palliative care for people with advanced liver disease: A feasibility trial of a supportive care liver nurse specialist. *Palliative Medicine* Volume: 32 issue: 5, page(s): 919-929 <https://doi.org/10.1177/0269216318760441>

Bristowe K, Hodson M, Wee B et al. (2018) Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliative Medicine*. Volume: 32 issue: 1, page(s): 23-35 <https://doi.org/10.1177/0269216317705102>

Finucane A, Carduff E, Lugton J. (2018) Palliative and end-of-life care research in Scotland 2006–2015: a systematic scoping review. *BMC Palliative Care*. 26;17(1):19. <https://www.ncbi.nlm.nih.gov/pubmed/29373964>

Brogan P, Hasson F, McIlpatrick S, et al. (2018) Shared decision-making at the end of life: A focus group study exploring the perceptions and experiences of multi-disciplinary healthcare professionals working in the home setting. *Palliative Medicine* Volume: 32 issue: 1, page(s): 123-132 <https://doi.org/10.1177/0269216317734434>

Ewing G, Austin A, Jones D. (2018) Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. *Palliative Medicine* Volume: 32 issue: 5, page(s): 939-949

<http://journals.sagepub.com/doi/abs/10.1177/0269216318756259>

Brighton L, Pask S, Benalia H et al (2018) Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research Members' new research studies. *Research Involvement and Engagement* 4:14

<https://doi.org/10.1186/s40900-018-0097-z>

Farquhar M (2018) Assessing carer needs in chronic obstructive pulmonary disease. *Chronic Respiratory Disease* Volume: 15 issue: 1, page(s): 26-35

<https://doi.org/10.1177/1479972317719086>

Sampson E, Candy B, Davis S et al (2018) Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliative Medicine*. Volume: 32 issue: 3, page(s): 668-681

<https://doi.org/10.1177/0269216317726443>

Yardley I, Yardley S, Williams H, (2018) Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents. *Palliative Medicine* (Article first published online: June 1, 2018)

<https://doi.org/10.1177/0269216318776846>

Nwosu A, Collins B, Mason S (2018) Big Data analysis to improve care for people living with serious illness: The potential to use new emerging technology in palliative care. *Letter in Palliative Medicine* Volume: 32 issue: 1, page(s): 164-166

<https://doi.org/10.1177/0269216317726250>

Pask S, Pinto C, Bristowe K (2018) A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative Medicine* Volume: 32 issue: 6, page(s): 1078-1090

<https://doi.org/10.1177/0269216318757622>

Johnston B, Patterson A, Bird L et al (2018) Impact of the Macmillan specialist Care at Home service: a mixed methods evaluation across six sites. *BMC Palliative Care* 17:36

<https://doi.org/10.1186/s12904-018-0281-9>

Upcoming events

25th July 2018

4-5pm Cicely Saunders Institute, King's College London, London

"Why missing data matter" seminar by Jamilla Hussein

14th September 2018

9am start, Trinity Hospice, London

"Too little too late" International research on Paediatric Palliative Care Conference.

27-28th September 2018

John McIntyre Conference Centre, Edinburgh

Strathcarron Hospice Conference "Challenge or conform: finding new consensus in an evolving speciality"

17th October 2018

Royal Society of Medicine, London

'From radical to real: implementing new models of care,' the annual Marie Curie Palliative Care Research Conference, open to organisations, academics, health and social care professionals as well as anyone with an interest in palliative and end of life care research.

If anyone would like to promote a seminar, workshop, conference or other event among PCRS members, please let us know at pcrs.research@gmail.com

Joining the PCRS

This society is easy to join, with full details and an online form on the website at www.pcrs.org.uk

Membership costs just **£48 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).
- ✓ Regional PCRS Masterclasses (contact us if you'd like to organize or host a masterclass)
- ✓ Access to a list of members' contact details and research interests to facilitate multi-professional and multi-center research initiatives.
- ✓ PCRS Newsletters

We want to hear from you!

We want to hear from members, about how we can better support members. Please do get in touch!



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