Welcome to this edition of the PCRS newsletter and we hope that you like our new branding! A lot has happened in the last year, much of which has been going on behind the scenes. This year the Palliative Care Research Society celebrated its 25 years anniversary. It has been interesting looking back over these 25 years and talking to different people involved from its inception, in particular Robert Twycross, who has written a small piece for this newsletter. Late 2016 we met as an executive committee to look at where we are at as the Society and where we think we should be going. Much has changed in palliative care research since those early days and yet we felt that there is still a place for the Palliative Care Research Society in today’s changing world.
In relooking at who we are we felt that the Palliative Care Research Society supports good quality palliative care research through:

1. Collaboration – linking with other organisations, researchers and clinicians with an interest in research in palliative care.
2. Networking – social media/ events/ conferences/ website news
3. Training – research skills workshops across the UK for all members
4. Information sharing – through email updates, newsletter, workshops, social media and our website.

We are still to finalise what this actually looks like and will be contacting all members to have an input into our strategy for the next few years, later in 2017. In order to be more responsive to our members and to be able to move the Society forward we have decided to appoint an administrator – working initially on a consultant basis. Kate Hockey is starting to work for us on the 1st November and she will be supporting us with the membership, newsletters, the website, social media and communications.

Another big change this year has been that of the Palliative Care Congress. Following a successful PCC in March 2016, the Association of Palliative Medicine (APM) approached us to say that due to financial reasons they wanted to change the existing PCC and they hope to run an annual ASP conference for their members. There was much discussion about this, what it would mean for the Palliative Care Research Society, but also for the future of conferences such as the PCC. As you will know, APM held their first ASP conference in Belfast in 2017 and the congress next year is a joint ASP/ PCC conference – after 2018 we do not know what will happen and this may be the last PCC. We have been working hard with APM to ensure that this coming conference is as multi-disciplinary as possible, with a variety of plenary speakers, and also there will be a research track running through all of the breakout sessions, as well as abstract sessions. We are aware that the branding for the conference focuses on ASP, but we do encourage members to attend, and as per usual, members will get a reduced registration rate.

As the Palliative Care Research Society we are also offering a grant which is open to all members. The aim is to offer an award to encourage and acknowledge good quality palliative care research and offer financial support to PCRS members to attend our national palliative care research conference or the EAPC research conference also being held in 2018. Whilst this has meant a lot of change over the
past year, the Palliative Care Research Society are looking at this as a way to explore and develop new partnerships e.g. with Hospice UK. If you are at the Hospice UK conference in November please do come and visit us at the Palliative Care Research Society stand.

Another big event of the year has been the process of rebranding – we decided that we needed a fresh look, and that our 25th anniversary was a good time to do this. You will have seen our new logo, and hopefully our new materials which were on display at EAPC in Madrid and you will see them again at the Hospice UK conference next week. The next step is to redesign the website and we hope that Kate will work with the developers on this in the next couple of months.

In this newsletter, we are honoured to have a Q & A section with Prof Fliss Murtagh from Hull York Medical School, an article from Dr Robert Twycross, as well as a feature on two PhD student members, an introduction to our new administrator and upcoming events. Please do share information for future newsletters and the website with us.

In conclusion, the past few months have continued to show the Palliative Care Research Society is a vibrant society. It is challenging but a privilege to be working with the Society and I am excited about the next steps and where we go from here. I would like to thank all members of the committee for their hard work and in particular I would like to thank Sonja McIlfatrick who has stepped down as Treasurer and Jo Bayly who has been our Communications Officer and has handed this role over to Anna Bone. We would also like to encourage new members to join the Executive Committee and help us shape the Palliative Care Research Society so that it is a robust society that continues to support quality palliative care research, so if you are interested do please let us know.

Prof Julia Downing
Chair PCRS
The Palliative Care Research Forum (as it was then called) was founded in 1991. It emerged from the Research Group at Sir Michael Sobell House, Oxford. This met for a working lunch every 1–2 months. The early 1990s were the heyday for research at Sobell House with, at one point, six members of staff working towards a doctorate. Much of the research being undertaken was qualitative, in contrast to the more traditional medical quantitative symptom management research. Indeed, then, many (possibly most) physicians suffered with tunnel vision and were largely disinterested in qualitative research.

However, the wealth of research being undertaken at Sobell House pointed to the need both to share the information with researchers elsewhere and to enlighten palliative care physicians to the potential and importance of qualitative methods. Of course, things have moved on dramatically, and there are now numerous opportunities to share palliative research, and medical tunnel vision in relation to research methods is largely a thing of the past. But 25 years ago the founding of the Palliative Care Research Forum was ground-breaking: multiprofessional from the start with parity between professions.

Ginny Dunn and I organized the inaugural half-day meeting of the Forum in Cardiff in the Autumn of 1991 on the eve of the AGM and annual clinical meeting of the Association of Palliative Medicine (APM). There were 29 participants. A year later, we organized a 2-day meeting in Glasgow attended by about 60 people, again on the eve of the AGM of APM. In 1993, over 130 people registered for the 2-day meeting in London.

The original twosome quickly grew into a committee of six: two doctors (me and Sam Ahmedzai) two nurses (Ginny Dunn and Jessica Corner), and two allied professionals (Marilyn Relf, bereavement, and Frances Sheldon, social work), and meetings were carefully structured so that no one profession dominated events.

In those early days, there was no major competition in terms of palliative care research meetings. In 1996, the Forum joined forces with APM and the RCN Palliative Care Interest Group to organize a biennial Palliative Care Congress. As readers will know, this has become a major event in the UK palliative care calendar, with the 11th Congress last year in Glasgow attended by several hundred people.
CHANGES TO PCRS

New administration support – welcome Kate Hockey!
“I am delighted to be working for the Palliative Care Research Society in an Administrative role. I have a wealth of experience in office management and administration working in Education and the NHS. More recently I helped set up a secondary Free School in Kent and after three years handed over the role to my successor last September. We then relocated to Cornwall and I undertake part time Administrative work whilst maintaining a work life balance! In my spare time I enjoy walks on the beach with my family and the odd cream tea at local tea rooms.”

New Committee members—goodbye to Sonja & Jo, hello to Anne, Stephen, Anna & Felicity

Dr. Anne Finucane – Membership Officer
Anne is the Research Lead at Marie Curie Hospice Edinburgh and an Honorary Fellow at the University of Edinburgh.

Dr Stephen Mason
Stephen is lead of the Research and Development Division of the Marie Curie Palliative Care Institute Liverpool at the University of Liverpool.

Anna Bone – Communications Officer
Anna is a Cicely Saunders International PhD Training Fellow at King’s College London.

Dr Felicity Hasson
Felicity is a Senior Lecturer at the Institute of Nursing Research, Ulster University.

A thank you to Sonja McIlfatrick and Jo Bayly for all their work as Treasurer and Communications Officer, and PCRS wishes them all the best for the future.

We are looking for a new Treasurer! Anyone interested in joining the Executive Committee, please do get in touch – pcrs.research@gmail.com
In March 2017, Fliss Murtagh began a Professorship at Hull York Medical School based in the new Wolfson Palliative Care Research Centre. We interviewed Fliss to learn more about her career and her thoughts about palliative care...

What have been the highlights and challenges of your career?

I think one of the highlights of my career was getting into the study of end stage kidney disease, because I like to listen to the people who don’t have a voice, and give them a voice. When I first went and did interviews with people who had end stage kidney disease they were mostly elderly. Some very elderly, 104 for example, but they hadn’t been heard by professionals when they should have been. I was then able to use some of that evidence and other work to illustrate the needs of that population, which was a big highlight for me. Challenges? Trying to fit everything into a 24 hour day!

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

There are lots of people really. I would say there are 2 people at the top of the list. When I worked in the Heart of Kent Hospice, there was a Consultant called Gordon Titmus, who was very impressive. He inspired me to really get interested in palliative medicine, because he did such a good job communicating with patients, families and staff. He always managed to get to the heart of whatever the issue was and communicate a way forward and that was quite impressive. So he was one big influence. And the other is Irene Higginson. Because I have learnt such a lot from her; she has achieved so much and is so very skilled in how she does it, and that has always been very impressive to me.

What are the top 3 issues affecting the provision of palliative care for all people approaching the end of life?

First, the fact that it is considered an added extra rather than an essential part of care. So ideally palliative and supportive care shouldn’t need to exist, it should be part of routine standard care for everyone with all types of illness. But it isn’t.
Secondly, the fact that there are so many competing priorities for resources - people, money and time. We live in a health system that prioritises acute disease-management interventions over caring interventions. Probably rightly. But it’s a shame that we don’t get the acute interventions and care both at the same time.

The third big challenge is the changing demographics and the rising numbers of people needing palliative care. We’ve only just begun to see that change. And over the next 10 years it will have a big impact.

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

There will be a much larger demand for palliative care and I think we won’t have the luxury of models of care that allow for long-term interventions or support. I think we’ll have to be much more focused in how palliative care is delivered. Both by specialist palliative care – short term interventions - but also we’ll have to do a lot more work to skill other people up to provide the general palliative care.

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

David Currow, because he’s nearly always got a good but slightly unexpected answer.

Irene Higginson because she’s got so much experience and expertise.

And then I’d go for someone else who is a bit more controversial for liveliness…I’m not going to name anyone!

**What do you enjoy doing when you are not working?**

Walking on the North York Moors!
Earlier this year, the PCRS ran a one-day masterclass focused on funding for palliative care research at Marie Curie Hospice Edinburgh. Seventeen people signed up for the event representing a mix of academics and clinicians with an interest in research.

Prof. Bridget Johnson gave the first talk on building research capacity in palliative care, and highlighted the usefulness of grant writing groups to start the grant application process. Next up was Dr Tom Barlow, Senior Research Officer at the Chief Scientist Office (CSO Scotland) and Dr Sabine Best, Head of Research at Marie Curie, who both gave excellent advice on developing grant applications from the funders’ perspective, and spoke about current research priorities. Dr Catherine Burns, Head of Strategic Research Development at the University of Edinburgh, spoke about the wider research funding environment, and opportunities for collaborations between universities, hospitals and hospices in applying for funding. Dr Connie Swenson, Speciality Doctor at Marie Curie Hospice Edinburgh, gave a comprehensive overview of funding opportunities for clinicians, and described the opportunities and well as the challenges of making time for research within a clinical role. Prof. Scott Murray, Chair of Primary Palliative Care at the University of Edinburgh, drawing on several years’ experience, gave advice on how to build a successful team.

Finally, Prof. Sonja McIlfatrick, Head of the School of Nursing at the University of Ulster outlined the perils, pitfalls and pearls of the research grant application process and emphasized that grant applications needed to fulfil four criteria: (i) important – ask an important question; (2) successful – be able to successfully answer the question; (3) value – show that the likely gain is worth the resources expended, and (4) competence – show that the applicants have the resources and expertise to carry out the research as planned.

The PCRS Committee would again like to thank all our speakers on the day, who gave their time freely to support this event. Presentations from the day are available. Please email Anne Finucane (anne.finucane@mariecurie.org.uk) if you would like a copy.
I am a PhD Training Fellow at Cicely Saunders Institute, King’s College London, and am in the final stages of writing up, for submission this Autumn.

I trained as an occupational therapist at the University of Cape Town, South Africa and for most of my career have worked in older adult mental health, with a special interest in dementia. On completion of an MSc in Mental Health Services Research at King’s College London in 2011, I wanted to continue to develop my research skills; and was therefore delighted to get the opportunity to do a PhD in my field of interest, palliative care for people with dementia, at Cicely Saunders Institute.

My PhD has involved the development and preliminary evaluation of a measure to improve the assessment and management of symptoms and concerns for people with dementia living in residential care homes. To do this, I adapted the Integrated Palliative care Outcome Scale (IPOS) for people with dementia in residential care homes (IPOS-Dem). This involved reviewing literature and qualitative work with family members, care home staff and health care professionals to ensure that IPOS-Dem is a comprehensive, relevant and acceptable measure for assessing symptoms and concerns in this population.

I then conducted a mixed-methods evaluation of IPOS-Dem used in the routine care of people with dementia living in care homes. This was to understand the likely mechanisms of action and potential benefit to people with dementia and their families, and the acceptability, feasibility and implementation requirements of IPOS-Dem.

The PhD outputs are IPOS-Dem, a measure which is acceptable and feasible for use in routine care of people with dementia to improve assessment and management of symptoms and concerns; and a theoretical model detailing its likely mechanisms of action and potential benefit; and implementation requirements in the care home context.
Zana Saunders  
PhD Student, Open University, Faculty of Wellbeing, Education and Language Studies

The Unique Case of Milton Keynes and its Hospice Provision

Milton Keynes is a unique new city which has grown rapidly into a thriving population of over 280,000 in 50 years. Despite values in equitable care, hospices fail to reach all sections of their local communities; with statistics and research confirming lower uptake of BME groups, homeless, incarcerated, lower socio-economic groups, and people with terminal conditions other than cancer. This is a national concern as population growth and diagnostic improvements cause an increased demand for end of life care. Milton Keynes hospice has an unusually high uptake of its inpatient services compared to other hospices in the UK, but has similar difficulties of inclusivity.

This research will investigate these issues by focusing on this hospice in an in-depth case study of people’s perspectives. How do people define hospice; who is it for; what do hospices do? Using a qualitative, in depth case study approach and a phenomenological, thematic analysis, the answers will get to the heart of the identity of Willen Hospice. It may elucidate why this hospice is preferred over dying at home, and why, like other hospices there are also issues of inclusion and diversity, from which solutions can then be developed.

Members’ recent publications:


Bereaved people often say that friends, family and colleagues avoid talking to them about their loss. Indeed, sometimes people will cross the road to avoid engaging with them. This project sought to understand why ordinary people come forward to volunteer to help those who have been bereaved and what this experience means to them. Stories gathered from eighteen volunteers at Cruse Scotland suggested that their own experience of bereavement was the main motivating factor and that volunteers found significant meaning and growth through involvement in this work.

http://dx.doi.org/10.1080/02682621.2017.1305052
UPCOMING EVENTS

- Hospice UK National Conference
  ACC, Liverpool. 22-24 November 2017

- ‘Palliative care beyond cancer: Redressing the balance’ by Marie Curie Northern Ireland
  Riddel Hall, Belfast. 27th November 9am – 2pm,

- Inaugural SPICT International
  2nd February 2018
  Conference Registration now open!

- APM ASP with PCC 2018
  Bournemouth, 15th-16th March 2018

- European Association of Palliative Care Congress – EAPC 2018,
  Bern Switzerland, 24-26th May 2018

- PhD Masterclass
  Nottingham Centre for the Study of Palliative, Supportive and End-of-Life Care (NCARE) supported by PCRS. March 2018 (date TBC)
  “Research in the field of supportive/palliative and end of life care: developing the next generation of researchers”

- Coming soon - PCRS supported events in Wales and Scotland. Details to be confirmed….

We are delighted to announce that the PCRS are offering a conference grant award of £500 for one PCRS member to attend a national or international palliative care conference. Applications are welcome from all PCRS members for this competitive award. The deadline for applications is 15th December 2017. Contact pcrs.research@gmail.com for more info.
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. We will send out a survey monkey to find out what you think about PCRS and how we can make improvements. Watch this space…!

Email for general enquiries and for items for the newsletter:

pcrs.research@gmail.com

Follow us on Twitter:

@PCRScommittee