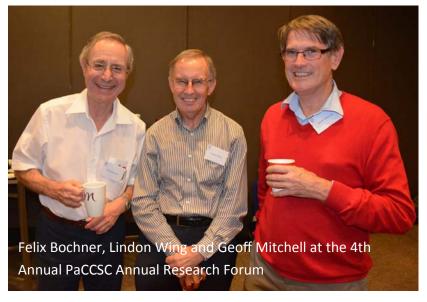


Newsletter May 2013 ISSUE 17

PaCCSC Research Forum and New Website Launch!





A major highlight on the PaCCSC annual calendar is the *PaCCSC Annual Research Forum* which was held in March. There was a range of attendees from participating PaCCSC sites, new members and individuals who contribute to the governance of our organisation. A complete wrap up of the events proceedings has been included in this issue of the newsletter.

The redesigned PaCCSC website was completed just in time to launch at the *Forum* and the enhanced features have been well received by our regular users. If you haven't visited the website

please take a moment

to have a look www.caresearch.com.au/Paccsc. I'd particularly like to take this opportunity to thank the Paccsc central coordinating office team for making these two significant items such a success.

Paccsc, under the funding agreement with the Commonwealth, is required to report progress against our deliverables. There are 10 reports required over the three year funding period and our sixth report was submitted and accepted in March, leaving only four reports remaining including our final report. This means there is considerable work to be done between now and June next year. Risperidone and megestrol studies are so close to reaching their respective target numbers we can almost hold our breath! MOP and sertraline still have a way to go and it would be great to see the numbers recruited to these studies increase at an increasing rate. However, this is also a time for some serious consideration regarding new studies and for this we look to direction from the trials management committee who operate at the cutting edge of palliative care clinical practice and who continually question what they do.

These are busy and interesting times in the life of the Collaborative, thank you to all our members for your ongoing contributions.

Linda Devilee National Manager

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In the Spotlight: Peter MacCallum Cancer Centre, VIC

This month we checked in with the team at Peter MacCallum Cancer Centre. If you would like to be showcased in our next edition please contact: stacey.williams@flinders.edu.au

Peter MacCallum Cancer Centre (PeterMac) in Melbourne and advance care planning, and most recently, under the is a public hospital solely dedicated to the treatment and leadership of Dr Natasha Michael, advance care planning in care of patients with cancer. It is a unique institution in patients with cancer. We have participated in the interna-Australia and has achieved international renown for the tional validation of the Edmonton Classification System for quality of its research in oncology and supportive care. The Cancer Pain and in the development of pain clinical indicacancer research group is reportedly the largest in Australia. tors for palliative care. PeterMac is undergoing major transition in that it will be relocated to Parkville, Melbourne and become part of a major health and research precinct which will include the We have had many research staff over the years who have

Royal Melbourne Hospital, Royal Women's hospital, University of Melbourne, and other research and health care institutions, with the aim of facilitating the exchange between clinicians and researchers, and the development and translation of research findings to clinical outcomes.

A few notes about our service achievements:

Palliative care services at PeterMac are predominantly consultative. In recent years, we have focussed on integrating palliative care into oncology care, through new service models which 'fit' into the tumour stream organisation of services at the hospital. Our Rapid Response Team provides daily ambulatory care clinics. Patients may be pre -booked or attend as urgent reviews on the day of their oncology review. This has led to a 40% increase in our outpatient activity over the past 12 months, making this the predominant setting of consultation for our team. Other distinguishing features of our service are the number of adolescent and young adult patients referred, as a result of our integration into the onTrac@petermac team and the large sarcoma oncology specialty practice at PeterMac, and the increasing number of referrals from haematological oncology.

Our department has developed a number of research interests over the years, broadly in the areas of pain and symptom (dyspnoea, nausea, delirium) management, the impact of team prognostication on clinical decision making

And now to introduce the PaCCSC team at PeterMac:

contributed greatly to our research agenda. Some of you

will remember Judi Greaves, Elaine Mills and Joy Williams. Our current staffing is



Odette has been director of the Department of Pain and Palliative Medicine, since 1997. Before this, she worked with Prof Norelle Lickiss in the Central Sydney Palliative Care Service, which was her orientation to palliative medicine in Australia. She had trained in this specialty at St Joseph's Hospice

in the east end of London, so the journey from free standing hospice to cancer centre consultation, has been an interesting one with many unexpected twists.

Not least has been the development of an active research program, stimulated by the strong research culture of Peter Mac, collaborations with colleagues in Australia and overseas and discovery of the enjoyment and satisfaction which comes from research practice.

Current signs of madness include:

- -embarking on a PhD Palliative Care, through the University of Lancaster, UK
- -working 7 days per week in 4 days
- -agreeing to organise a get together for parents of grade 6's at my 11 year old's school

Best recent occasion: walking the Abel Tasman track in Marlborough, New Zealand with my family. Put it on the bucket list!



Palliative Care Clinical Studies Collaborative

In the Spotlight: Peter Mac continued...





Courtney Bamford, Clinical Trial coordinator.

Courtney joined the department in June 2011. With a long history in oncology, Courtney has gradually made the change from laboratory science to clinical cancer research. Courtney brings a wealth of experience in scientific research to the team.

While Courtney has not had a chance to walk the Abel Tasman track in Marlborough, she does consider herself a connoisseur of the regions famous Sauvignon Blanc wine varietal!

An avid lover of music, even with two

young children to look after, Courtney managed to attend 4 live concerts in March, 1 in February and 1 in April. Her most memorable moment was performing an on-air interview with Keith Urban back in 2001, when she volunteered as a DJ on NuCountry radio station.

Indy Khera, Research Nurse

Indy joined the department in August 2010. She was new to research, coming from a palliative care nursing background. Indy had trained at Staffordshire University, UK, graduating in 2004. In 2011, Indy began her Masters in Public Health and is passing her assignments with flying colours. She is currently enjoying maternity leave, with her little bundle of joy due to arrive any day now!



Bamford applying their expertise to Lebanese cooking!

Japanese Delegation Visit

In March PaccSC welcomed a group of Japanese researchers who were interested to learn from our experience in establishing a clinical research collaborative including our governance structure and network of recruiting sites. The Japanese research team are developing a multi-centre collaborative study group, focusing on medical intervention, in Japan and they were keen to learn from the experiences of PaccSC.

On their way to Adelaide, the group made a stopover in Sydney and visited Calvary Heath Care Kogarah and were fortunate to spend time with Dr Christine Sanderson and her team. Following their Sydney site visit they visited the coordinating office and attended another PaCCSC site visit at SAPS. The Japanese team spent time meeting members of the central coordinating office, the team from Caresearch, Steve Quinn the PaCCSC Biostatistician, Nikki McCaffrey the PaCCSC Health Economist and Professor David Currow, and learnt more about the research

endeavours of the SAPS team under the leadership of Dr Peter Allcroft and Site Coordinator Aine Greene. PaCCSC would like to thank all those involved who assisted hosting the Japanese delegation and making the visit a success.



Standing L to R: Keisuke Ariyoshi, Zac Vandersman, Stacey Williams, Rhiannon Vince, Belinda Fazekas, Linda Devilee, Dr. Takuhiro Yamaguchi, Kota Kihara

Seated L to R: Dr. Masanori Mori, Dr. Natalie Cutri, Dr. Takashi Yamaguchi, Dr. Satou Iwase, Tempei Miyaji



In the Spotlight: Calvary Health Care, Sydney

This month we checked in with the team at Calvary Health Care. If you would like to be showcased in our next edition please contact: stacey.williams@flinders.edu.au



Calvary Health Care Sydney is a public health care facility operating within the South Eastern Sydney Local Health District providing palliative

care and aged care rehabilitation in both inpatient and community settings. Calvary Health Care Sydney is owned and operated by the Sisters of the Little Company of Mary (LCM), a religious order of the Catholic Church, which was founded by Mary Potter, in Nottingham, England in

1877. It is administered by LCM Health Care Services and is one of 15 health and aged care facilities.

The Palliative Care inpatient unit provides care for 38 patients; pain and symptom management, respite for patient and/or carer fatigue, palliative rehabilitation and terminal care. Patients, whilst having palliative radiotherapy or chemotherapy at acute hospitals within the area, are

also referred to the wide range of services offered by the organisation. The Community Palliative Care Team is a multidisciplinary team offering consultative and support services within the home environment. Symptom management and related procedures are also available on a day only basis in the inpatient unit. The service operates seven days a week with an on-call service available is after hours.

Research

Professor Liz Lobb is head of our Research Department; she is a Professor of Palliative Care at the Cunningham Centre for Palliative Care, and an Adjunct Professor for the School of Medicine at The University of Notre Dame. Liz has worked in psycho-oncology and palliative care research as a behavioural scientist since 1996 and has been a bereavement counsellor for 24 years. The unit is involved in a diverse range of both quantitative and qualitative research projects. Calvary Health Care Sydney joined PaCCSC in 2008. The current team includes: Dr Christine Sanderson



(Site Investigator), Lesley White (Site Coordinator) and Louise Bryce (Clinical Research Nurse). We are currently recruiting to five studies: Risperidone, MOP, Sertraline, Nausea 1 & 2. We will commence another two studies in the near future: PAX-1 & Dexamethasone/ Sleep. In August 2012 our team was awarded "The Mary Potter Team Recognition Award for Excellence" by Calvary Health Care Sydney. In March 2013 Dr Sanderson hosted a delegation

of leading palliative care clinicians from Japan who were keen to observe how a clinical trials unit operates

Team Profiles

Christine Sanderson works as a Staff Specialist in palliative medicine at Calvary Health Care, Sydney. She has a back-

> ground in sociology and public health, and got the research bug very badly when she was working with Prof David Currow in South Australia as a registrar. Unfortunately she is unlikely to ever recover fully from this. And as a result, she is now site investigator for the PaccSC studies at Calvary. She is inclined to be a bit opinionated about evidence based medicine, and is passionate about doing research in proper clinical trials with ethics approval – rather than on patients in daily prac-

tice, using medications without or in spite of good evidence - and has been known to get a little excited on this subject. Working on the PACCSC studies and the other clinical trials has been a fantastic experience – with a real focus on improving what we do every day. She works with a wonderful and quickly growing team at Calvary. As well as our research nurses, Lesley and Louise, others in the team have an interest in bereavement, and in patients' and caregivers' experiences, and how these can contribute to our understanding of the outcomes of palliative care.



Palliative Care Clinical Studies Collaborative

In the Spotlight: Calvary continued...

Chris is very excited to now be getting involved in a series of new qualitative and mixed method studies dealing with issues related to this topic, and so once again being able to put her sociology training to really good use. The rest of the time Chris hangs out on Dangar Island in the

Hawkesbury River – a car-free water access community full of quite eccentric people – where it has to be said she blends in perfectly! She is also the proud parent of four beautiful hens....the Dangar Island Egg-laying Cooperative.

Lesley White commenced at Calvary in Feb 2010 on the 'Uncertainty' study for Professor Liz Lobb; the first paper from

this study has recently been published. My role as Site Coordinator started on 15/2/11, I

have had a steep learning curve into the 'Art of

Clinical Trials' and have managed to maintain my sense of humour. My previous employment was in the acute care setting at Prince of Wales Hospital for 22 years; a CNS in Palliative Care for 12 years. I have Post Grad. Qualifications in Palliative Care, Oncology & Anaesthetic/
Recovery Room Nursing. I am a qualified Clinical Aromatherapist; Remedial Massage & Shiatsu Practitioner.
I am heading to Hawaii to celebrate my 50th Birthday, I love chocolate, enjoy shoe shopping, live with two cats and a Latino muso, and would live in Hawaii if I could obtain a green card



Potter Team Recognition Award for Excellence



Louise Bryce commenced the new graduate program as a registered nurse at Calvary Health Care Sydney in 2008. I have been working with PaCCSC since 2010. Throughout my time at PaCCSC I have found it to be challenging but have also learnt loads. I work with a fantastic

White. Dr Sanderson's passion for delirium has enabled us to recruit so fantastically to the Risperidone study. So many thanks to a great team. J As discussed over and over with the team we plan to keep our chins up and keep recruiting consistently. In my spare time I am attempting to organise to get married and have absolutely no idea what I am doing. I haven't even set a date yet!!! I have recently received a new addition to my family. A little bird (parrot) named Elvis. He is so

beautiful. Favourite TV show: well it was My
Kitchen Rules, but now the season has finished, I haven't
really got one. What will I be doing in 10 years time: Probably not too much different from now. Definite hope for
health and happiness..... and world peace.. LOL

NEWS FROM THE STUDY SITES

BARWON HEALTH

Lesley White and Louise

Bryce

Kirsty McKendrick has resigned from the trials team at Barwon Health to take up a position as an ANUM. We wish her all the best in her new role. Thank you Kirsty for all your hard work and dedication.

Anna Dowd - Site Coordinator

ROYAL MELBOURNE HOSPITAL

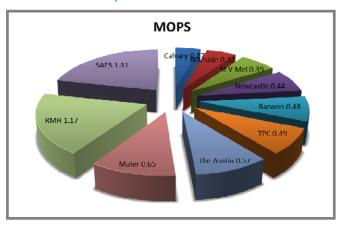
While Gillian focused on preparations for her sister's wedding James attended his first PaCCSC forum in Sydney this year. James arrived fashionably late to the GCP training day, after a lengthy wait on the plane in Melbourne, while the control tower was evacuated due to a fire alarm! James found it valuable meeting many of the site coordinators he's only heard via teleconferences and learning about the workings of PaC-CSC from different perspectives. With both James and Dr Le taking annual leave this month, its been a quieter month in the office, but starting the nausea one and two studies soon should liven things up a bit.

James Watt - Study Nurse

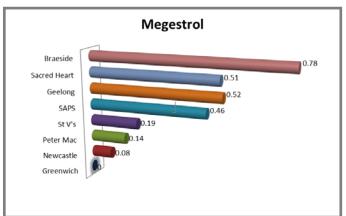
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Paccsc Studies update

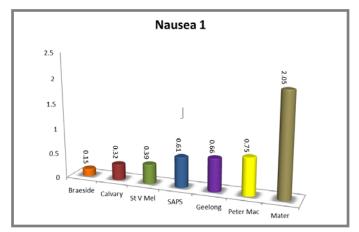
The below graphs show the randomisations obtained per month for each site since the individual site commenced recruitment to the study.



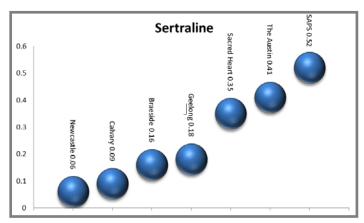
MOPS – SAPS leads RMH here: We must apologise for inaccuracies in the original graph here which did not include our leading site!



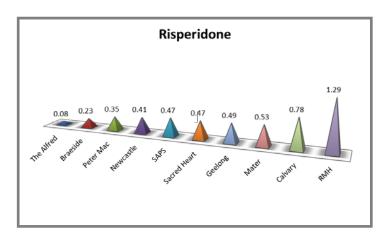
Megestrol – A slight drop from Braeside but they maintain their strong leading position as Barwon edges ahead of Sacred Heart by a whisker.



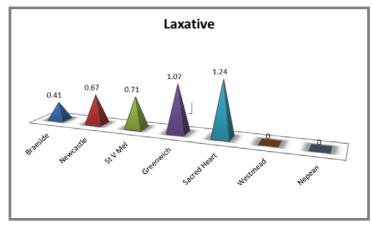
Nausea 1 – Can anyone challenge this lead? Strong results from the Mater mean they are the ones to beat in the Nausea 1.



Sertraline – Consistency here with SAPS holding onto the lead from The Austin in second place.



Risperidone – RMH and Calvary Kogarah maintain their strong 1st and 2nd places while the pack closes in to battle for 3rd and 4th place.



Constipation – Sacred Heart has a clear lead in the Constipation/laxative trial.



Paccsc NEWS

National Palliative Care Week 2013

The theme for National Palliative Care Week 2013 is **Palliative Care... everyone's business.** Palliative care is an issue that will affect all of us at some point in our lives, whether as a patient, carer, family member, neighbour or friend.

For this reason, Palliative Care Australia is calling 2013 the year to make palliative care *everyone's business*. To ensure that we all have quality care at the end of life, and are able to live and die well, we all need to take responsibility for making this happen.

National Palliative Care Week is 19th – 25th May 2013 and during this week we'll be reminding everyone in our communities about the importance of palliative care and asking them to think about how they can make it their own business. Palliative Care Australia has a list of organised events available on their website at:

http://www.palliativecare.org.au/ NationalPalliativeCareWeek.aspx

Or check out their campaign on YouTube at:

http://www.youtube.com/watch? v=Ebb0YWHw-Po&feature=player embedded

Fan Study News

Some of you may have seen the Chanel 9 News segment 'Breathing Easier' on Wednesday 1st May. If you missed it you can re-watch it on YouTube at:

http://www.youtube.com/watch?v=q0S baimM2Y

Mr. Dean Sherry and Dr. Peter Allcroft featured in the above pourne in April. report discussing the Fan study. For more information on Fan study please contact Jane Phillips at Sacred Heart.

The GCP Trainin

To read an interview with Mr. Dean Sherry about his participation in the Morphine Oxycodone Study please visit the Promotional Items Section under Governance on our website at:

www.caresearch.com.au/paccsc

Or follow the link below:

http://www.caresearch.com.au/caresearch/tabid/2494/ Default.aspx

The Prague Charter: Relieve Suffering!

The European Association for Palliative Care (EAPC), the International Association for Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch (HRW) are working together to advocate for access to palliative care as a human right.

The Prague Charter is urging governments to relieve suffering and recognize palliative care as a human right Go online to sign the petition today at:

http://www.avaaz.org/en/petition/
The Prague Charter Relieving suffering/?krRDHeb



PaccSC Coordinating Office New Assistant

Archie joined us in the PaCCSC Coordinating Office as Rhiannon's new assistant. His responsibilities include staff supervision, lunch time management and of course proof reading the latest newsletter issue. Unfortunately after only a day Archie elected to return to his former role as well loved pet but we hope to see a return visit from him soon!

Paccsc GCP Training

The PaCCSC central coordinating office en-

gaged the services of Minerva Medica to run two GCP Training Workshops this year. The first workshop was held in Sydney in March and the second took place in Melbourne in April.

The GCP Training was tailored specifically to the needs of PaCCSC site staff and helped participants to be able to identify and categorise the requirements of ICH GCP as adopted in Australia by the TGA and to empower participants to better manage the demands made of them by understanding.their roles and responsibility according to GCP.





4th PaCCSC Annual Research Forum 2013

The PaccSc Annual Research Forum was held on Wednesday 20th and Thursday 21st March at the Mercure Sydney Airport Hotel. Day 1 presentations were open to all members. The Forum was opened by invited speaker A/Professor Janet Vardy where she detailed her 'Experiences in clinical trials - the good, the bad and the ugly". The morning sessions showcased a range of new study proposals for further clinical research in palliative care being put forward by members of the Collaborative. In the afternoon a range of member presentations were delivered to showcase the various clinical research being conducted at PaCCSC sites across the country. The PaCCSC Management Advisory Board and Site Coordinator Meetings also took place. Day 2 saw a business skills workshop conducted for the benefit of the PaC-CSC site investigators and the Paccsc Trials Management Committee held an extended face to face meeting.



"The forum goes from strength to strength each year. It was excellent to see the exponential learnings across the clinical trials teams and the innovative research being undertaken. The most striking feature of the forum was the spirit of collaboration, lots of new faces and willingness to share ideas."

- Dr. Meera Agar



Dr Meera Agar

Reflections from a non-palliative care practitioner.

- Professor Felix Bochner

CSC was launched in 2007. The agenda for the Board Forum, and the first that I have attended. meetings always rightly contains items about the progress of ongoing studies, planned new studies, and reports from the Trial Management Committee, Scientific Committee and Data and Safety Monitoring Committee. Over the years, the magnitude of these items has grown significantly, and is a testament to the vigour of the organization. The Board is familiar with the scientific activities of the Collaborative, but only at an abstract level. This is because whilst these agenda items make critical and interesting reading, they cannot be replaced by the enthusiastic, robust, multidisciplinary and friendly person-to-person scientific dis-

I have chaired the Management Advisory Board since PaC- course that was evident at the Forum. This was the fourth

The day was logically divided into two parts. Following the invited speaker lecture, the morning session dealt with four new study proposals. These proposals were impressive as they had been rigorously considered with respect to rationale, objectives, outcome measures and interventions, recruitment, ethical and resource considerations. Each presentation was followed by wide-ranging discussion with many suggestions for possible enhancement of these studies. The level of discussion was at least as sophisticated as I have witnessed at many international conferences.

Reflections from a non-palliative care practitioner continued...

In the afternoon, there were 10 member presentations that described work in progress, (one presentation occurred before lunch). These offerings described the day-to-day joys and miseries that befall all patient-based research and I was reminded that research into palliative care is particularly challenging and difficult (the reason why there is so little scientifically based research in these patients). I particularly liked the questions in each presentation that asked, "what worked well/is working well" and "what did not work well/is not working well/is problematic". It became clear that many of the same obstacles occur in most of the collaborating groups; this is likely to be reassuring to site personnel and also an avenue to solve such problems. Successes, and how these were achieved, were also described. It is highly likely that everyone would be able to learn from these. As with the morning session, the discussion was of the highest calibre.



Dr John Primrose and Dr Natalie Cutri

"I thought that the PaCCSC Forum was an excellent opportunity to discuss the outcomes of the research undertaken by PaCCSC and future directions for the Collaborative."





Day 1 Presentations

participated in the Forum, and learnt a great deal. The Collaborative is now achieving impressive outcomes that were mere aspirations some years ago. This can be attributed to the enthusiasm, commitment to patient welfare, intellectual curiosity and collegiality that so strongly prevailed amongst the many people present.

One of the strengths of the collaborative is its multi-disciplinary membership that recognizes the unique contribution from each of the critically important groups of professionals whose choice it is to optimise the care for these patients, applying the best available evidence. It became clear to me by the end of the Forum why the model adopted by the Collaborative is attracting international attention, with other countries now starting to emulate what we do in Australia."

- Professor Felix Bochner

NOW AVAILABLE:

The daily programs, abstract booklet and selected PowerPoint slide presentations and recordings from the Forum are now available online under News, Events and Publications at the PaCCSC Website at www.caresearch.com.au/paccsc





Conferences, Events and Publications

Upcoming Conferences & Events

13th World Congress of the European Association of Palliative Care: 30 May—2 June 2013, Prague, Czech Republic

Supportive Care Coalition 2013 Congress: 2—4 June 2013, California, USA International Conference on Opioids: 9 – 11 June 2013, Boston, USA ANZAHPE 2013 Conference: 24—27 June 2013, Melbourne, Australia

International Symposium on Supportive Care in Cancer: 27—29 June 2013, Berlin, Germany

5th International Conference on Ageing and Spirituality: 7—10 July 2013, Edinburgh, Scotland

2013 Primary Health Care Research Conference: 10—12 July 2013, Sydney, Australia

New Age Workforce: Blending Professional and Digital Behaviour: 15 July 2013, Adelaide, Australia Inaugural National Palliative Care Research Colloquium: 18—19 July 2013, Melbourne, Australia Cancer Nurses Society of Australia 16th Winter Conference: 25—27 July 2013, Brisbane, Australia

12th Australian Palliative Care Conference 2013: 3-6 September 2013, Canberra, Australia

Recent Member Publications

If you have published a paper in the last three months, please write to us and let us know!

Clark K, Currow D. A pilot study to assess the feasibility of measuring the prevalence of slow colon transit or evacuation disorder in palliative care. J Palliat Med. 2013 April.

Allcroft P, Margitanovic V, Greene A, Agar MR, Clark K, Abernathy AP, Currow D. The Role of Benzodiazepines in Breathlessness: A Single Site, Open Label Pilot of Sustained Release Morphine Together with Clonazepam. J Palliat Med. 2013 April 18 Breaden K, Phillips J, Agar M, Grbich C, Abernethy AP, Currow D. The Clinical and Social Dimensions of Prescribing Palliative Home Oxygen for Refractory Dyspnea. J Palliat Med. 2013 March.

Burns CM, Abernethy AP, Dal Grande E, Currow D. Uncovering an invisible network of direct caregivers at the end of life: A population study. Palliat Med. 2013 April 15.

Dunning T, Duggan n, Savage S, Martin P. Diabetes and end of life: ethical and methodological issues in gathering evidence to guide care. Scand J Caring Sci. 2013 March

Goddard C, Speck P, Martin P, Hall S. Dignity Therapy for older people in care homes: a qualitative study of the views of residents and recipients of 'generativity' documents. J Adv Nurs. 2013 Jan.

Jelinek GA, Marck CH, Weiland TJ, Philip J, Boughey M, Weil J, Lane H. Caught in the middle: Tensions around the emergency department care of people with advanced cancer. Emerg Med Australas. 2013 April.

Michael N, O'Callaghan C, Clayton J, Pollard A, Stepanov N, Spruyt O, Michael M, Ball D. Understanding how cancer patients actualise, relinquish and reject advance care planning: implications for practice. Support Care Cancer. 2013 March 14.

Sanderson C, Hardy J, Spruyt O, Currow D. Placebo and Nocebo Effects in Randomized Controlled Trials: The Implications for Research and Practice. J Pain Symptom Manage. 2013 March 22.

Ritchie CS, Currow D, Abernethy AP, Kutner JS. Multisite studies offer a solution to recruitment challenges in palliative care studies. J Palliat Med. 213 March.





