

Research Report 2016



“ Research allows us to seek the best ways to provide for those in need . . . ”



Welcome

It is my great pleasure to introduce the 2016 Research Report for HammondCare. Research allows us to seek the best ways to provide for those in need, and in keeping with HammondCare's strengths the focus of the research is on palliative care; supporting people living with dementia; helping people to age well; better management of chronic pain; providing the best in rehabilitation care; and understanding and catering for the spiritual needs of our clients and patients.

Thirteen of the 76 projects were new in 2016, and the breadth of projects is impressive, ranging from evaluating the most appropriate medications for symptom control, to understanding and dealing with distress and planning for the future. The focus on the spiritual aspects of care highlights the mission of HammondCare.

I encourage you to particularly read the first section of the report, titled 'Translating research into better care'. In this section seven research projects from different areas are presented in more detail in an easy to read format. The research 'problem' is spelled out, followed by a description of what the research involved, and then the outcomes, or what was found and its importance. Case studies of people involved in the research are included.

This section of the report also describes HammondCare's involvement in the Cognitive Decline Partnership Centre (an initiative of the National Health and Medical Research Council), as well as a new research partnership HammondCare is building in the United Kingdom.

Finally, you will notice a short piece about the HammondCare Foundation. This section highlights how you too can be involved in HammondCare's exciting research strategy by partnering with us in a way that can truly improve the quality of people's lives.

Before I leave you with the Report, I would also like to highlight awards that were received by two of HammondCare's senior researchers – Professor Roderick Macleod (Member of the New Zealand Order of Merit) and Professor Phillip Siddall (Distinguished Member Award, Australian Pain Society).

Dr Annette Britton
Chair, HammondCare Research Committee

Contents

1	Introduction from Dr Annette Britton
3	Foreword by Professor Christopher J Poulos
	Translating research into better care
4	Improving Cancer Pain Management in Australia: Pat's story
6	Equipping Nurses in Advance Care Planning and Palliative Care: Beth's story
8	Supporting Palliative Care in the Home: John's story
10	Spirituality and its Relevance to Healthcare
12	Establishing Best Practice in Pain Management for People with Dementia
14	Showing the Way: Signage for People with Dementia
16	Understanding the Wellness Needs for Carers: Greg's story
18	Dealing with Cognitive and Related Functional Decline in Older People
20	The HammondCare Foundation: Facilitating Research that Changes Lives
22	Building a Research Infrastructure in the UK
	Research projects
26	Key Research Areas – Overview
28	Successful grant applications+statistics
30	Palliative Care
38	Dementia
43	Ageing, Restorative Care+Reablement
45	Rehabilitation
48	Pain Management
50	Advance Care Planning
52	Spiritual Aspects of Care
54	Teaching+academic professional activities
	Education, presentations+publications
60	Education – Higher Research Degrees
60	Education – Academic Degree Supervision
61	Education – Awards
62	Publications – Books+Chapters
62	Publications – Journal Articles
64	Publications – Technical+Other Reports
66	Publications – Industry+Magazine Articles
66	Presentations – Academic Conference+Industry Seminars
72	HammondCare Service locations map
74	Index

Foreword

HammondCare has a long history of supporting research. It is part of our organisational DNA and is what makes HammondCare a learning organisation. To that end I feel privileged to be writing this, my first introduction to a HammondCare Annual Research Report.

Without a culture of research we cannot expect to deliver fully on HammondCare's Mission and Mission in Action. For example, research allows us to build the knowledge and skills necessary to do our jobs well; it helps us to manage resources effectively and sustainably; to develop and improve care services, and encourage creativity and innovation.

Ultimately, research helps us to better serve people with complex health or aged care needs, regardless of their circumstances, with the aim of improving quality of life for people in need.

Research comes in many forms. At one end of the spectrum is novel research, or the testing of new approaches to care or drugs. At the other end is research that looks at the best way of applying existing knowledge into real life practice. Adding vital pieces to the puzzle, such as being a part of a multi-site trial, is another form of research, as is the systematic analysis of findings from a large number of published works to produce robust guidelines for care. Then there is research that evaluates the effectiveness, including the cost effectiveness, of service delivery models.

But in the end, research is of no use to our clients, residents, patients or staff if it doesn't make its way into routine care. This is why HammondCare makes sure that a large component of the research we do is translational (i.e., putting existing research findings into real world practice) and research that critically evaluates the outcomes of the services being delivered.

So how does HammondCare decide what research we will support? To do this we have developed a rigorous approach to research governance, overseen by our senior research staff, with input from service managers, clinicians and our enabling portfolios (such as finance, people services and legal). All research ideas need to be endorsed by a senior academic in the first instance, before going through a detailed project approval process. The research should generally sit within one of HammondCare's key research themes (described on pages 26 and 27), and clearly demonstrate how it will help us deliver on our Mission, and Mission in Action. It must also pass independent ethics review, and be monitored during its conduct, to make sure that it delivers on what was intended and meets ethical, financial and reporting requirements.

At the end of the project the research team needs to provide feedback on what was found, along with the implications for training, practice and public policy. We strongly support the publication of research findings in academic literature and the presentation of findings at scientific and industry conferences. And, because we believe that the outcomes of research should be disseminated widely, we look at ways in which 'plain English' versions of the outcomes can be made accessible, for example through the web and social media.

In all of this, it is important to acknowledge that research is not possible without the support of people willing to participate in a project. For many people, participating in a research project may not help them directly, but could have benefits for those who follow. So thank you to all those who have taken part in the projects listed in this Report. And thank you too to all the generous people who have donated through the HammondCare Foundation to support the research effort.



Professor Christopher Poulos MB BS (Hons) MSc PhD FAFRM (RACP)
Head of Research and Aged Care Clinical Services, HammondCare
Conjoint Professor, UNSW (School of Public Health and Community Medicine)

“... putting existing research findings into real world practice and care”



Improving Cancer Pain Management in Australia

The problem.

Up to three quarters of cancer patients experience pain; for many, the pain reaches moderate to severe levels. Despite ongoing advances in cancer treatments, the literature reports that cancer pain management remains inadequate for a significant proportion of people with cancer in Australia. This is due to barriers at all levels: patient, caregiver, health professional and the healthcare system.

The research.

Professor Melanie Lovell, Medical Director and Senior Staff Specialist at Greenwich Palliative and Supportive Care Services, has a long-term commitment to improving the pain outcomes of patients attending outpatient oncology and palliative care departments.

Knowing that clinical guidelines – if effectively embedded into oncology centres – can improve outcomes for people with cancer pain, Professor Lovell's team has created the Australian Cancer Pain Guidelines, currently being used in the Palliative Care Ward at Greenwich Hospital, and housed on the Cancer Council Australia online wiki page.

Supported by HammondCare, the team is now in the midst of a larger clinical trial evaluating the implementation of the guidelines across nine metropolitan, regional and rural outpatient oncology and palliative care sites throughout Australia. Called the Stop Cancer PAIN trial, this research uses evidence-based strategies – including health professional education, patient self-management tools, audits and feedback from trial participants – to support local site implementation of the guidelines.

Understanding the cancer patient's experience is a key component of the trial. Part of the study involved asking consented patients to take part in an extended interview about their experience with pain and pain management. These interviews have highlighted the importance of reassessing patient goals and non-pharmacological interventions. To better meet patient

needs, clinicians were provided with the patient-held booklet 'Managing cancer PAIN' during the intervention phase of the trial. In partnership with their health-care team, this booklet provides patients with a valuable resource that also helps them to set SMART goals (Specific, Measurable, Achievable, Relevant to the patient and Time-based) related to pain management; document regular and breakthrough pain relief they've received, as well as document other medications that relieve the symptoms of pain relief medications.

The outcome.

Professor Lovell and her team are currently one third of the way through the trial, with the final results – including the economic impacts of guideline implementation – expected in November, 2018.

Preliminary analysis of the work to date has shown there are both barriers and enablers to successful implementation of the Australian Cancer Pain guidelines and optimal cancer pain management. The research team is continuing to work closely with all sites to tailor its strategies, overcome any identified barriers and aim for successful implementation of the guidelines. So far, the trial is already seeing an impact on improving health professionals' knowledge of, and adherence to, the Australian Cancer Pain guidelines. This in turn is increasing the patient's capacity to be involved in their own pain management, which improves both pain and caregiver outcomes.



Case Study: Stop Cancer PAIN study

Pat is 80 years old and has advanced colorectal cancer. A former painter, she currently lives alone and, on most days, experiences pain with an above moderate rating of six out of ten.

Pat's participation in the Stop Cancer PAIN project through her local outpatient oncology department has provided valuable insights into how she manages her pain. During an in-depth interview with the project's researchers, Pat reported that turning to non-pharmacological forms of relief – for example, techniques such as relaxation, meditation, "thinking about my breathing, and prayer" – helped to a certain degree.

Pat has also adjusted her expectations when it comes to living with advanced cancer and the activities she enjoys. Although her ability to paint has been limited, she now finds some solace from pain in everyday tasks and simple pleasures like stroking her cat.

"I did drop a lot of major interests because I thought [having advanced cancer] would deplete me too much, which turned out to be right," she says. "The simple tasks of day-to-day living are more satisfying for me. Being at home and being responsible for simple tasks to immerse yourself in is quite helpful, the satisfaction to be able to get out in the garden a little bit – I'll do all those kinds of things. I think if you can do that, keep your mind focussed on the day, on the hour, [it helps with the pain]."

Having regular contact with other people, according to Pat, is also crucial for managing pain. "I had a good visit with my cousin in the nursing home recently," she says. "Those are the sort of things that can keep me buoyed up."

Through the experiences of cancer patients like Pat, the Stop Cancer PAIN project demonstrates the importance of reassessing goals and using non-pharmacological interventions when it comes to managing pain. The project continues throughout Australia until November, 2018.

Equipping Nurses in Advance Care Planning and Palliative Care

The problem.

There are many people in the Australian community with unmet palliative and supportive care needs. Evidence shows that, when done well, Advance Care Planning (ACP) helps older people and those with chronic illness to prepare and plan for their future medical treatment and care. It can also increase the likelihood of a person receiving end of life care in accordance with their wishes, and reduce stress and anxiety for surviving family members. Despite the potential benefits of having an ACP, there are often barriers to initiating the discussion. General Practitioners could help to fill this gap, but they often lack time and the confidence needed to begin these discussions and screen for patients' palliative and supportive care needs.

Case Study:

Beth Salleras is one of more than 500 general practice nurses across Australia who have so far registered to take part in The Advance Project training.

The regional Queensland-based nurse, who has been working in general practice for 18 years, believes nurses often develop a close relationship with patients they see regularly – especially if they're based in rural or remote areas. This puts general practice nurses in an ideal position to talk about dying, the future, and end of life care with patients. However, Beth Salleras says this can be a hard conversation to have.

"In my experience, health professionals can find it difficult to know what to say in these times," she says. "Some people may be in denial as they come to terms with what may be down the road for them. You need to gauge whether the patient is prepared to talk about it, and know how to go about it."

After completing the online training, Beth found The Advance Project was valuable in equipping

her to have those difficult discussions: providing helpful suggestions, advice and different options for broaching difficult topics such as death and end of life care with a patient.

"The training is a great approach because it helps nurses initiate this care as part of the process in conjunction with the General Practitioner, who does get very reliant on their nurses as GP practices can be really busy," she says. "It's wonderful that The Advance Project is looking to fill what is a real need: to create a structured approach to helping patients with advance care planning and their palliative care needs."

Beth also encourages other general practice nurses to "get in there", complete the training, and adopt it into their own practices. "We are known as nurses for being caring," she says. "To feel that you are providing more holistic care as opposed to purely delivering routine assessments and wound checks is satisfying. Nurses can and should be involved in that identification and planning, and this program provides the tools for that."

The research.

Pilot work completed by HammondCare suggests nurses in general practices are well placed to assist with ACP and supportive care assessments. To better support them in this role, Associate Professor Josephine Clayton, Specialist Physician in Palliative Medicine at Greenwich Hospital, and Associate Professor Joel Rhee, General Practitioner at Hammondville, received government funding to lead The Advance Project: a program designed to equip general practice nurses in initiating ACP and palliative care.

Led by HammondCare in collaboration with partner organisations and universities, The Advance Project enables general practice nurses to raise awareness of ACP among older people and those with chronic illness as part of their routine health assessments. In addition, the training equips nurses to identify people who are at risk of deteriorating health and dying, assess their symptoms; discuss important questions and concerns with these patients; evaluate the needs of their family caregivers, and identify patients who would benefit most from early referral to a specialist palliative care service.

To achieve this, The Advance Project team developed a unique, evidence-based toolkit and multimodal training package, informed by input from an expert advisory group and a literature review of the best available tools to support ACP and palliative care. Hosted on a dedicated website (www.caresearch.com.au/advance), the Advance Toolkit contains six screening and assessment tools that general practice nurses can incorporate into routine practice. The accompanying multimodal training program includes an online training module and face-to-face workshops, delivered in every state and territory across Australia by HammondCare nurse facilitators Jennifer Gavin and Jolan Stokes.

To ensure the program is sustainable, participating nurses also receive individual tele-mentoring from Ms Stokes – an experienced palliative care nurse educator – to further consolidate their learning, and to access a 'train the trainer' program. The entire package is available free of charge to nurses working in Australian general practice, with scholarships available for nurses from rural settings to assist with the cost of physically attending face-to-face workshops.

The outcome.

The training program has been endorsed by the Australian Primary Health Care Nurses Association and promoted locally around Australia by Primary

Health Networks. On the ground level, general practice nurses who have participated in the training say it has improved their practice in relation to ACP and palliative care. "The training is user friendly and the program provides you with the education to really make use of the resources it provides," says one participant. "It's extremely comprehensive, very thorough and compassionate."

We are still in the process of assessing the impact of the training on participants' knowledge, skills and confidence in using the assessment tools. An economic evaluation will also assess the cost of delivering The Advance Project toolkit and training – as well as the cost of using the screening and assessment tools as part of routine practice.

We expect the program will increase the confidence levels of general practice nurses when it comes to initiating conversations with patients and their carers about ACP and palliative care, enabling more Australians to have access to high quality care at the end of life.



Supporting Palliative Care in the Home

The problem.

Surveys indicate that many Australians would prefer to die at home, but relatively few are able to have this wish fulfilled. This is partly due to the reality that patients and their families may not have the support they need to enable end-of-life care in their own home.

The research.

Led by HammondCare, a consortium of not-for-profit aged and palliative care providers was funded by the New South Wales Ministry of Health to trial the Palliative Care Home Support Program (PCHSP). Existing multi-disciplinary community palliative care teams in local health districts, along with specialist supportive community care workers, were made available to family carers to provide assistance with non-clinical patient care – for example, domestic tasks, day or night respite, personal care and companionship.

Between October 2013 and February 2017, the PCHSP program delivered over 2,000 packages of care to around 1,800 patients across seven local health districts – all free of charge. Over 700 community care workers were trained using teaching material, adapted with permission, from a Hospice New Zealand program called Fundamentals of Palliative Care. The training program was delivered over two days by staff from the HammondCare Learning and Research Centre at sites across New South Wales.

The outcome.

To determine the extent of the PCHSP's benefit to patients and their families, an evaluation was undertaken by HammondCare staff and colleagues from the University of New South Wales.

Data from the 128 family carer surveys returned to the evaluation team suggest that community care workers effectively supported carers and patients by meeting their needs in a sensitive, caring and professional manner. Families made use of the support

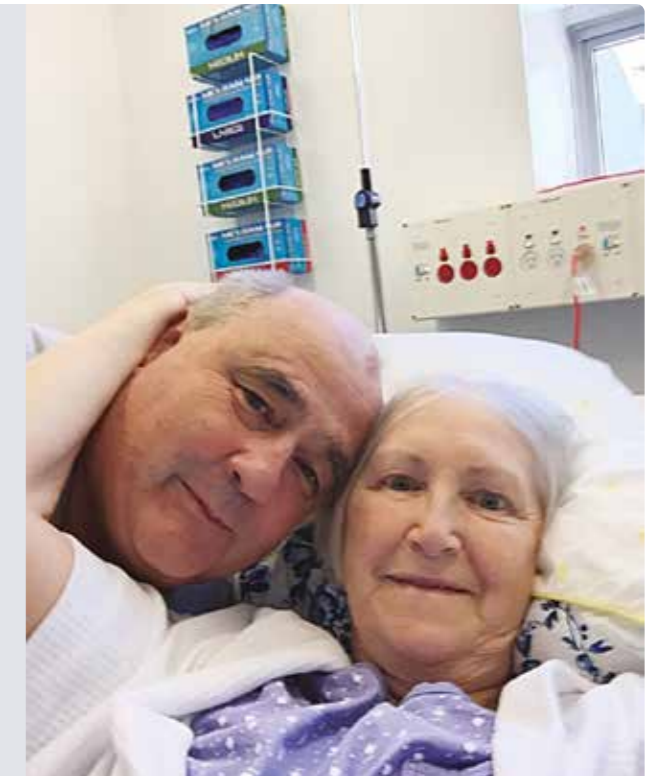
offered in multiple ways; these included receiving assistance with personal care (for example, washing and toileting), domestic tasks, overnight respite care, companionship, sitting with the patient, and even advice. Over three quarters of families who cared for a loved one at home with the support of the PCHSP would choose to participate in the program again.

Data from the family carer surveys – alongside telephone interviews conducted with 20 family carers – also found the support provided by community care workers was greatly appreciated; some carers even indicated that a home death would not have been possible without their support. Suggestions for service improvements centred on enabling more direct communication between family carers and the PCHSP central office, earlier engagement of services, and grief and counselling support for families.

From the PCHSP care team's perspective, community care workers, when surveyed, described their role as "rewarding", "satisfying", a "privilege", "meaningful" and, at times, "challenging". Our evaluation also found the training we provided prepared them well for the role. An interest in occasional refresher training to maintain or further develop skills (delivered either face-to-face or online) was expressed by some community care workers in post-workshop surveys, three month surveys, and in the qualitative interviews.

Overall, our evaluation suggests the Palliative Care Home Support Program is fulfilling its primary objective of supporting patients in their wish to die at home, and the families who care for them. Moreover, it appears the program is benefiting carers and patients who, without the assistance of the PCHSP, would not have been able to achieve their wish. We will continue to promote and deliver this valuable service to as many families as we can.

“The workers were professional, very knowledgeable and offered ideas and advice on how to make Sandy more comfortable and ease her pain.”



Case Study:

Throughout 37 years of marriage, John and his wife, Sandy, had only spent 30 days apart from each other.

The couple have lived through many experiences together: travelling, nurturing two successful careers in IT, skiing trips, mountain climbing, camping and most recently, retiring together on the far south coast of New South Wales. So when Sandy developed bowel cancer with a terminal prognosis in January last year – a cancer that later metastasised to her lungs, spine and liver – John was determined to keep her at home with him for as long as possible. “Sandy was my world,” he says. “I felt uncomfortable not being with her, but also uncomfortable about not being able to do all the things that needed to be done. Once Sandy deteriorated to be in a position where she needed more help, that’s where the team from HammondCare came in.”

In October, 2016, three palliative care health workers from HammondCare began to help John take care of Sandy's needs in their home. Working in conjunction with Sandy's local GP, oncologist team and local community care nurses, the workers created a roster and coordinated the tasks required to take care of Sandy. They did practical jobs: giving Sandy daily bed baths; physically moving her when needed; helping John clean her tumor wounds,

apply dressings, change bed linen and refresh her incontinence pads. They ensured Sandy didn't miss out on simple pleasures such as back massages, wearing perfume, having her nails done and having her hair shampooed. Towards the end of her life, when Sandy's health rapidly deteriorated and she lost the ability to swallow, all the workers continued to provide sensitive and dedicated care – from sponging the inside of Sandy's mouth in order to lessen her discomfort, to counseling John and cooking him meals after Sandy died in February this year. “They were absolute angels,” says John. “All three of them just made Sandy feel so comfortable when she was in this world of pain and discomfort.”

Apart from the physical tasks they performed, John also appreciated the emotional support all the workers offered Sandy by simply chatting to her, sharing their lives and offering her companionship. “When she saw them, her eyes would light up,” recalls John. “They did wonders for her mentally in lifting her spirits ... things like bringing flowers out of the garden for her, or because one of them was into craft, making her some beautiful butterflies out of paper.”

“The workers were professional, very knowledgeable and offered ideas and advice on how to make Sandy more comfortable and ease her pain,” says John. “I'm really thankful that the girls were here. They gave me the strength to carry on, and enriched both our lives.”

Spirituality and its Relevance to Healthcare

The opportunity.

Spirituality is becoming increasingly recognised as relevant to effective healthcare as we move towards a person-centred approach. There is growing evidence of positive associations between spirituality and health outcomes. For example, a large European multi-country study of issues in palliative care found spirituality to have equal importance to other dimensions of health. Others have concluded from a review of literature that patients with an enhanced sense of psycho-spiritual well-being are able to cope more effectively with a terminal illness and find meaning in the experience.

The research.

HammondCare implemented a cross-sectional survey to determine levels in understanding of patients' spiritual needs and spiritual care. This was conducted among clinical and non-clinical staff working with people with chronic and terminal conditions at HammondCare sites across New South Wales. In simple terms: What do staff truly understand by spiritual care, and how do they determine what a person's spiritual needs are?

We administered an adapted version of a survey which had previously been used online for the Royal College of Nursing in UK, the Spirituality and Spiritual Care Rating Scale (SSCRS), to hospital and community care staff. Respondents were given a list of possible meanings of spiritual care and asked to identify which they thought the most appropriate. We also asked staff how they identified spiritual need. Was it from the patients themselves, the family, talking to loved ones, health record documentation or by using a more formal spiritual needs assessment tool? Or was it reliance on their own observations, or those of the chaplain or other staff members?

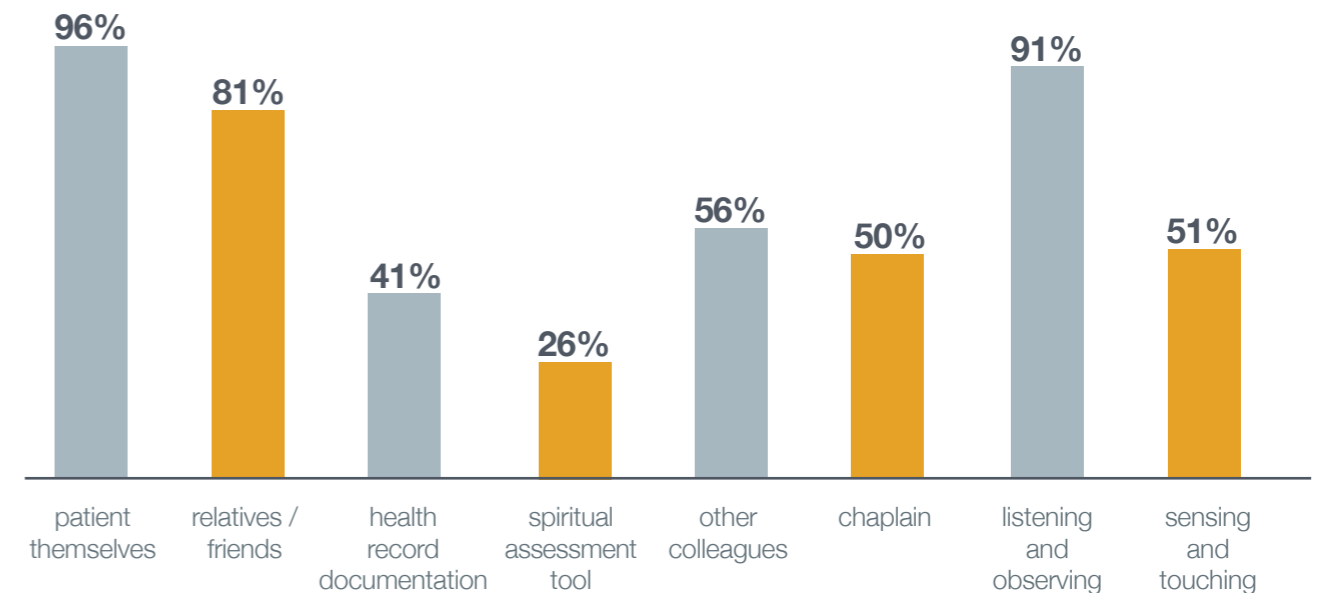
The outcome.

In total, 437 of 2,845 eligible staff (15%) responded to the survey. While this response rate is lower than anticipated, it is believed that the outcomes indicate the vital importance of spiritual care training for staff.

Most participants stated they would identify spiritual needs from the patients themselves (96%), through listening and observing patients (91%), and by talking to loved-ones (81%). However, between only 40% and 50% of participants used health records or discussion with colleagues, while only 26% of participants said they used spirituality assessment tools (refer to Figure 1).

Most participants agreed that spiritual care is fundamental to health care (88%), and that care-giving organisations should provide support for dealing with patients' spiritual needs (85%). Interestingly, dementia care staff encountered patient spiritual needs most often. While participants recognised patients' spiritual needs, only 51 (14%) stated they were always able to do so.

Figure 1 – HammondCare Staff Spirituality Survey 2016: 'How do you identify patient spiritual needs?' (345 respondents)



We suggest that this survey, although it has limitations because of the low response rate, shows that spiritual care training is needed for all staff having contact with people experiencing chronic or terminal conditions. While respondents can identify definitions of spiritual needs, their ability to recognise associated behaviours and meet these needs is uncertain.

For example, participants made unsolicited comments about their understanding of spirituality and spiritual care. Most stated that carers must show kindness, compassion and be respectful of individual patients' spiritual needs. Others suggested that staff must be consistently prepared to deliver spiritual care to those in need. Some suggested spiritual care guidelines are too prescriptive where patients are treated the same way regardless of beliefs.

Our findings show participants agree that spirituality and spiritual care are fundamental to healthcare and that hospital organisations should provide

guidance and support for staff dealing with patients' spiritual and religious issues. These results support recommendations for the benefit of routine spiritual care.

We believe this study provides support for further studies to develop an evidence-based model of spiritual care training, a project which is currently being planned. One excellent example of this type of work is the Foundations of Spiritual Care Program developed and delivered by Hospice New Zealand. Evaluations of that program show it positively influenced participants in two key areas: Personal influence in the sense of increased personal awareness and understanding of spirituality and spiritual care; and Professional influence in the sense of increased collegiality, increased health literacy and the development of new skills.

If we can develop a similar approach for staff at HammondCare we may go some way to improving this essential and perhaps undervalued aspect of healthcare.

The full results from the pilot study and the full study can be found at the journal references below:

Austin PD, MacLeod R, Siddall P, McSherry W, Egan R. 2016 The ability of hospital staff to recognise and meet patients' spiritual needs: a pilot study. *Journal for the Study of Spirituality* 6(1):20-37 DOI:10.1080/20440243.2016.1158453

Austin PD, MacLeod R, Siddall P, McSherry W, Egan R. 2017 Spiritual care training is needed for clinical and non-clinical staff to recognise and meet patients' spiritual needs. *Journal for the Study of Spirituality* 7:1, 1-13

Establishing Best Practice in Pain Management for People with Dementia

The problem.

More than a decade of research has shown that pain is largely unrecognised and frequently undertreated in people with dementia. In residential aged care there is often a gap between what is described as best practice in pain management for people living with dementia, and what is happening 'on the ground'.

The research.

In January 2016, the findings of a HammondCare pilot study (the Intervene Project) revealed persistent problems with the identification, assessment and management of pain in older people living in residential aged care. The findings from the original Intervene Project formed the basis of a successful funding application to the Cognitive Decline Partnership Centre for a second project – Intervene Two.

Intervene Two is an implementation project designed to lessen the gap between the pain management that occurs within an aged care facility, and 'best practice' pain management.

The project addresses barriers that reduce the ability of care staff to engage in pain management processes, as well as barriers to the development of a culture that supports best-practice pain management for people living with dementia in residential care.

To achieve this, Intervene Two researchers are working in partnership with multidisciplinary care teams established at four residential aged care sites around Australia, using a participatory action research approach. They will work with the teams to look at their current pain management practices, critique their approach, and identify areas for improvement.

The outcome.

Intervene Two commenced in the latter half of 2016 and will run for 24 months. The project has three stages, and there are three primary objectives. The first is to facilitate cultural change in residential aged care services – change that supports the translation of best practice pain management in residential aged care by working with multidisciplinary care teams and empowering personal care assistants in pain management processes. The second is to develop networks between the care teams at each location in order to decrease professional isolation, enhance the transfer of knowledge between services, and promote the robust implementation of best practice pain management strategies. The third is the development of a pain management model for use by multidisciplinary care teams in residential care services across Australia. Project findings and outcomes will be available in 2018.

The project will send a key message that 'pain is everyone's business'



Showing the Way: Signage for People with Dementia

The problem.

The physical environment has a profound effect on how people living with dementia function in day-to-day living. A critical element to help people navigate their surrounds is signage, yet there are no clear, dementia-specific guidelines about what constitutes the most useful types of signage for people living with dementia. Although the type and location of signage is frequently dictated by government regulations, these signs are potentially indecipherable to a person with dementia. For example, a toilet sign with the white stick figure on a blue background, usually beside the door to which it relates, often with braille and additional words indicating which side you approach if using a wheelchair, may cause confusion.

The research.

The Showing the Way research project was a collaboration between the Dementia Centre and the School of Health in Social Science at the University of Edinburgh, funded through a Dementia Collaborative Research Centre – Assessment and Better Care grant. Over 70 people with lived experience of dementia, family carers, experts in dementia and design, and those working in a caring environment participated in the project. Initial workshops held in both Australia and the United Kingdom explored the issues around the design, use and evaluation of signage. Three electronic surveys then refined the workshop themes into four key criteria, each supported by a series of statements that had reached consensus by participants as being essential for consideration when designing, using and evaluating signage for people with dementia.

The outcome.

The research project found the essential criteria to consider for signage that enables people living with dementia were factors relating to signs themselves: the use of words; realistic images and the volume of information presented; the environment in which signage was located, including the lighting levels and other distracting sensory information; the degree to which signage supported function of people with dementia; and ways in which the impact of signage and cues might be developed.

The next steps are to refine and test the research findings in order to confidently guide the design and use of signage to best support wayfinding and function of people with dementia.



Understanding the Wellness Needs of Carers of People Living with Dementia

The problem.

Carers report that supporting a loved one with dementia can be a rewarding experience. However, providing unpaid care and support can present many challenges. It can also have a significant impact on many aspects of a carer's own life, especially their health and wellbeing.

The research.

Undertaken in collaboration with the Dementia Collaborative Research Centre – Consumers and Carers, the Beyond Respite study seeks to explore the wellness needs of those caring for people with dementia.

As part of the study, 28 current and former carers of people living with dementia from the greater Sydney area participated in in-depth interviews to talk about their experiences. To measure their responses, researchers used Hettler's Six Dimensions of Wellness as an analytical framework. Within this model, a person's wellness is categorised into six key domains: the physical, emotional, social, intellectual, occupational and spiritual life of an individual. Carers of loved ones with dementia reported being impacted across many of these dimensions. They reported that their physical and emotional health had been negatively impacted by the caring role; as had their careers, social lives, hobbies, pastimes and ability to attend church. As a result, a number of carers reported feeling socially isolated and even unsupported by family members. In some cases, these circumstances had a damaging impact on carers – two of the 28 carers interviewed had contemplated whether life was worth continuing.

The Beyond Respite study also identified two types of carers, at opposite ends of the caring continuum: 'challenged' and 'resilient' carers. Challenged carers have limited family support (and in some instances, have to contend with family discord), as well as limited knowledge of dementia and how to care for a person with dementia. Some are 'sandwich' carers, juggling work or family commitments with caring responsibilities. Others neglect their own health and wellbeing needs – their care recipients take priority.

Resilient carers have been similarly impacted by their

caring role, but have taken on prudent advice from medical and other professionals, and feel they are coping reasonably well with the situation. They make it their responsibility to learn about dementia and what support is available to them, as well as to develop the skills needed for their caring role. They also tend to have supportive family networks, good medical support, and a more positive attitude to the situation – even though they admit that it is stressful at times. Importantly, they are proactive about their own health and wellbeing, scheduling in 'me' time, and developing coping skills such as meditation and going for regular walks. One carer talked about how their spiritual practice enables them to cope; another of how attending church not only allows her to practice her faith, but also gives her a rare opportunity to have social interaction.

The outcome.

As a result of the Beyond Respite study, an educational brochure has been developed to educate carers about the importance of looking after their own wellness needs. This resource includes advice on how to become a resilient carer, and is freely available on the DementiaKT hub website (<http://dementiakt.com.au/wp-content/uploads/2016/06/LookingAfterYourselfFlyer.pdf>).

The full report of Beyond Respite's findings is available on the Dementia Collaborative Research Centre's website (http://www.dementiaresearch.org.au/images/dcrc/output-files/1399-beyondrespitecarerstudy_final.pdf). It is intended that these findings will add to the body of knowledge on the wellness needs of carers, so that more effective interventions to support carers of people with dementia will be possible in the future.

A further study, currently in the process of being written up, has also been developed to explore how General Practitioners could better support carers of loved ones with dementia.

“The biggest mistake I made in the past as a carer is thinking, ‘I can do this,’ and ‘I can do that’, because that’s my job.”



Greg and Nolene dressed to celebrate Melbourne Cup

Case Study:

Greg had just retired from his career when he stepped up his role as a carer for his wife Nolene, who has Alzheimer's disease.

It's a full-time, unpaid job that has presented many trials over the years: challenging times such as when Nolene began to experience significant psychotic episodes; when she stopped eating and lost control of some of her faculties; she was admitted to HammondCare's Greenwich hospital for further care and monitoring of her medication; when she returned home Greg's role as a carer was significantly more hands on.

One of the major difficulties for Greg was not being able to talk to other people about the hardships he faced as a carer. "In the early stages of Alzheimer's, Nolene didn't present like she had problems," recalls Greg. "You can't talk to anybody about it, and it's the most frustrating thing because people don't believe you – that things are going on."

Greg was also suffering from the strain of trying to care for Nolene alone. His relationship with his daughter was negatively impacted as he was spending almost all his time with Nolene to the exclusion of his family; his health took a downhill turn; friends began to worry about his physical and mental wellbeing. Two people set him on a more sustainable path: a health worker Greg met through a local carers group, and later down the track, a geriatrician who urged Greg to take care of his own health. A team from Greenwich Hospital also played a large part

in caring for Greg by creating a management plan which admitted Nolene into respite care for a period, allowing him to take some time out, and successfully rebuild some communication bridges with his daughter and her family.

"The biggest mistake I made in the past as a carer is thinking, "I can do this," and "I can do that", because that's my job. The health care worker said to me one day, 'look, you're not Superman.' I started to realise that I can't be doing everything," says Greg.

Nolene has been living in residential care for the last five years – a move that has given Greg an opportunity to "get a bit of a breather" while still caring for his wife. To build up his resilience as a carer, Greg looks after his own health through diet and exercise, regularly takes time out, and ensures he stays informed, through attending seminars and conferences, about how to best care for people with Alzheimer's disease.

Most significantly, he spends quality time with his family and friends and attends carers groups (something he's always prioritised since the beginning of his caring journey) where he can find support from people who have been through similar experiences as a carer of someone with dementia.

"If you're caring for someone, try as best you can to maintain or retain your social links and your friends ... look after yourself, take some time out," he says. "I've been overwhelmed by the quality of the support services that are available for people like myself ... you've got to let them into your life; you can't just shut them out."

Dealing with Cognitive and Related Functional Decline in Older People: the Cognitive Decline Partnership Centre

The Cognitive Decline Partnership Centre (CDPC) was formed in 2013. It comprises the Australian Government's Department of Health and the National Health and Medical Research Council; consumer peak body, Alzheimer's Australia; and three major providers of aged care services in Australia – HammondCare, Helping Hand (in South Australia) and Brightwater (in Western Australia). The CDPC brings together a unique blend of consumers, carers, clinicians, service providers, policy makers and researchers. Together, they provide a platform for the exploration, examination and delivery of evidence-based health, supportive and social care to older Australians living with cognitive decline from a diverse range of perspectives.

Through collaborative effort, a work plan for the Centre has been developed based on eight key themes focussing on dementia and dementia care in Australia. The themes include: the nature of services offered; how people access and navigate services and plan for later life; culture and attitudes around dementia; how our health and aged care workforce is developed and educated; clinical guidelines to drive evidence-based care delivery; medication management and understanding and managing function decline in the presence of dementia. To date, the CDPC has supported 33 research activities reflecting these themes.

HammondCare is actively involved in the CDPC's activities and currently leads two activities that directly seek to improve the lives of people with dementia: 'Intervene', led by the Dementia Centre's Dr Sharon Andrews, supports the implementation of best-practice pain management for people living with dementia in residential aged care through the use of action research with multi-disciplinary teams; and Professor Chris Poulos leads research focussed on the development of evidence-based guidelines for reablement programs to improve function of people living with early to moderate dementia.

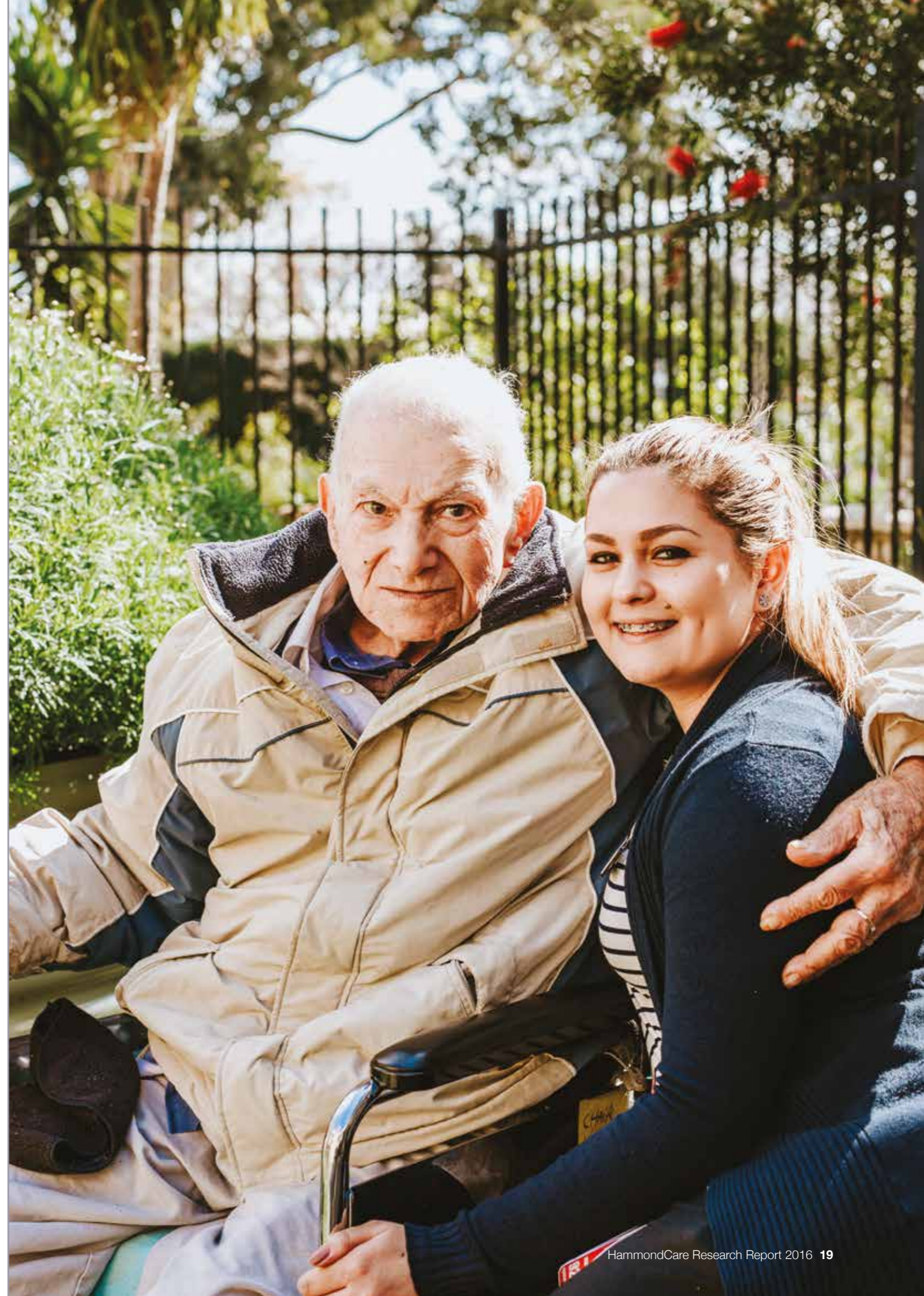
HammondCare supports an active group of senior staff in the role of Designated Systems Based

Investigators - DSBI. These staff members work with activities that support the development and conduct of the CDPC's research activities, and advise on the practical implementation of findings. To date, HammondCare DSBI's have been involved in over 16 of the 33 completed and current activities.

The CDPC is now at a stage of maturity where research results are ready to be considered for implementation by HammondCare sites around Australia.



Meredith Gresham and Marie Alford – Dementia Centre



The HammondCare Foundation:

Support Life Changing Research Through the HammondCare Foundation

The HammondCare Foundation was established to ensure HammondCare could continue improve our care for vulnerable and marginalised people for generations to come. Thanks to our generous supporters, we are able to help facilitate the fulfilment of our mission to improve the quality of life for people in need.

Research is a core focus of the Foundation's fundraising activities. This is because research and its translation into better care is the genesis of innovation that can transform people's lives. HammondCare is passionate about helping deliver new solutions to better care for people in need both in our services and sector wide.

None of our research projects are covered by ongoing funding. This means we rely heavily on grants and the generous donations of supporters. This support enables ground-breaking and varied research that changes people's lives. You can support any one of a range of critical areas of research that require funding to continue. Key focus areas for research donations include Palliative Care, Dementia, Ageing, Restorative Care and Reablement, Rehabilitation, Pain Management, Spiritual Care, and Advance Care Planning.

The Foundation is a small, dedicated team who raise funds through partnerships with philanthropists, trust and foundation grant funding, supporter appeals, 'in memory' gifts, bequests, and community fundraising. The focus of funding for research is on projects that will

have a practical outcome of improving quality of life for the patients, residents, and clients whom we serve.

In recent times, the most significant contribution from the Foundation to research projects has included the National Health and Medical Research Council Cognitive Decline Partnership Centre, and the Intervene Project: solving the hidden problem of pain in people with Dementia. These projects can be reviewed in this Research Report.

We are particularly grateful to the significant partnership with the Thomas Foundation, which has supported HammondCare's participation in the Cognitive Decline Partnership Centre for over five years.

The other areas the Foundation supports include provision of care for the most disadvantaged in our community through access to vital services, enabling innovative projects, facilitation of the expansion of HammondCare services, and improving the quality of care across our services through special training and equipment.

Should you wish to support the Foundation in enabling the important research projects that HammondCare is undertaking through a donation, you can contact us on 1300 426 666 or go to our website: www.hammond.com.au/about/support

We are very grateful for any support you can offer.



Building a Research Infrastructure in the UK

HammondCare's Dementia Centre has partnered with the Edinburgh Centre for Research on the Experience of Dementia at the University of Edinburgh to strengthen global understanding of the experiences of people living with dementia.

The Edinburgh Centre for Research on the Experience of Dementia (E-CRED) is an interdisciplinary group of researchers, practitioners, people with dementia and representatives from a range of organisations – all interested in developing theories, methods and impact around the experience of living with dementia. Throughout 2016, the Dementia Centre has been working closely with E-CRED to create international social research into dementia. The partnership has led to a research agenda focussed on the development of co-productive processes and outputs.

Today, the University of Edinburgh is the academic home within the United Kingdom of HammondCare's Dementia Centre. With its logos displayed on location and on E-CRED's website, the Dementia Centre has a visible presence within the University.

E-CRED currently hosts six Visiting Research Fellows from the Dementia Centre, while Senior Consultant, Mary Marshall, holds an honorary professorial appointment. The partnership between E-CRED and the Dementia Centre also contributes to the Dementia Centre's 'knowledge clusters' around Engagement, Models of Care, Design, Palliative Care and Understanding Behaviour.

Building an enabling environment for and with older people – and people living with dementia – requires vision, knowledge and commitment. The partnership will achieve this through innovations in research and knowledge exchange, and by combining co-production, research, design and practical modelling. By working with people who have dementia, families, care partners, practitioners, researchers, academics and thought leaders, the partnership intends to re-imagine care and support for people living with dementia around the world.

Key Partnership Research Outputs and Activities: 2016

Making an Impact

The impact of dementia activists was explored by sharing learning from several groups in the UK through a publication called 'Making an Impact'. The work was led by members of the Dementia Engagement and Empowerment Project: a network which brings together groups of people with dementia, supporting them to influence and change services, attitudes and policies. The booklet – written by, with and for people with dementia – aims to be a helpful resource for other groups.

Living with Dementia: Fostering Hope, Challenging Fear

This interactive exhibition of films, photographs and installations created by, with and for people with dementia, and participants, asked questions about dementia in a way that challenged assumptions about how we think about dementia, talk about dementia and relate to people with dementia. The exhibition ran in November, 2016, in Edinburgh.

Forthcoming Projects

There are a number of projects underway with reports expected in 2017. One example is a Scottish Universities collaboration entitled 'Widening choices for people with dementia'. This work addresses emerging issues identified by people who have been living with dementia for five years and over. The focus is on the availability of creative housing and support models, and what Scotland can learn from international partners in Australia and Japan.





Research projects

Key Research Areas – Overview

Palliative Care

Dementia

Ageing, Restorative Care+Reablement

Rehabilitation

Pain Management

Advance Care Planning

Spiritual Aspects of Care

Key Research Areas

Overview

Palliative Care

HammondCare is involved in many areas of research in palliative care. We are active partners in the Palliative Care Clinical Studies Collaborative (PaCCSC): a national research network that aims to generate high quality research evidence to support the use of medicines and other interventions at the end of life to better manage or alleviate symptoms such as pain, confusion, breathlessness, appetite loss, and gastrointestinal problems (for example, nausea, bowel obstruction and constipation). HammondCare is also conducting translational research projects to embed evidence in practice, including pain guidelines, an anxiety and depression pathway, and advance care planning. In addition, we are supervising PhD students' research in a number of areas, including collaboration in palliative care, investigating what helps make a 'good' rural death, and the experiences of dying away from one's country of birth.

Dementia

The Dementia Centre exists to improve the lives of people with dementia, their families and staff by providing training, consultancy and intervention based on sound research. We conduct our own research, which is currently concerned with technology use, environmental design and animal-assisted therapy. We also partner with national and international experts. With our HammondCare research colleagues, we focus research areas such as rehabilitation, palliative care, pain management, spirituality and music engagement on the unique issues and needs that dementia brings. As members of the National Health and Medical Research Council's Cognitive Decline Partnership Centre, we provide a practical viewpoint to make research implementable in the often complex world of aged care service provision.

Positioned at the intersection of research and operations within Australia's largest provider of dementia specific services, the Dementia Centre provides a working model of ongoing research knowledge translation and implementation.

As an important adjunct to our existing suite of research activities, we will be conducting a range of sponsored pharmaceutical trials of new, potentially disease-modifying medications for the treatment of Alzheimer's Disease commencing in 2017. These activities will not only complement the existing Dementia Centre research platform, but may provide hope for people living with dementia.

Ageing, Restorative Care+ Reablement

While population ageing means that, overall, people are living longer, it doesn't mean that everyone experiences good health, free of disabling conditions, as they age. HammondCare's research in ageing recognises this, and our focus is helping people gain the most from their ageing experience, taking a 'whole person' approach, and looking at ways that help maximise people's functional ability and wellbeing across multiple domains. The research is best described as translational – meaning that we take evidence of what works, and apply that 'in the field', through practical and sustainable service delivery models. Some specific areas of our research on ageing is caregiver wellness, helping people achieve positive ageing through active participation in the arts, community-based restorative care programs for older people with frailty and chronic disease, and reablement programs for people with dementia.

Rehabilitation

Research in the field of rehabilitation received a new impetus in 2016 with the establishment of a Cochrane Rehabilitation field – a collaboration in which HammondCare is also represented. This is very significant, as it will enhance the dissemination and translation of research into routine clinical practice. Within HammondCare itself, the need for research in rehabilitation is well established. A major achievement in our research last year was the conclusion of the first randomised controlled study comparing inpatient rehabilitation to a home program following elective total knee replacements.

Key Research Areas

Overview

This study was of sufficient interest to enable publication in the Journal of the American Medical Association. With the high quality work produced by our researchers, we continue to be one of the leaders in research in rehabilitation. Research is also being embedded into rehabilitation clinical practice, with one of our programs, Catch it Early, named 'runner-up' at the Clinical Excellence Commission's April Falls Month competition last year.

Pain Management

By nature, the problem of pain is multidimensional and reaches across many clinical conditions – involving and impacting people physically, emotionally and spiritually. In line with this, pain management research at HammondCare is looking at wide-ranging aspects of pain – from the physiology of brain and spinal cord pathways that help control pain, through to the existential and spiritual impact of pain on a person's sense of identity, meaning and purpose. Through collaborations with colleagues in different disciplines such as palliative care, rehabilitation and dementia care, these projects build on the existing strengths within HammondCare to help us contribute to the better management of pain, and to become recognised thought and practice leaders in our specialist areas of expertise.

Advance Care Planning

Sensitive and timely communication about end-of-life issues has been identified by patients and their families as one of the most important components of quality care at the end of life. Yet, communicating about death and dying is often difficult for patients, families and health professionals. Conversations in the form of advance care planning (ACP), well before the patient reaches the terminal phase of their illness, can help prepare the patient and family before a crisis situation occurs. HammondCare is leading and collaborating in a number of research projects aimed at improving ACP for people with a variety of health conditions and across various settings.

Our research explores ways to improve how ACP is conducted, how to best educate health care professionals about ACP, and how barriers to the wider adoption of ACP can be overcome.

Spiritual Aspects of Care

At HammondCare, we recognise that spirituality is a fundamental element of human experience. It encompasses each individual's search for meaning and purpose in life. When facing pain, rehabilitation, mental health issues, or disabling or a life-threatening illness, people often struggle to make sense of what is happening to them. Spirituality also encompasses the connections one makes: with other people, nature, the sacred, including – but not exclusively – connections made within traditional religions. Viewed in this way, spirituality can be a key factor in how people cope with illness. We are interested in how people express their spirituality and are keen to find ways to better provide care in this essential dimension of health.

Grants

Successful Grant Applications in 2016

Andrews S, Cunningham C, Poulos CJ, Siddall P, Fitzgerald A, Lorang C. *Intervene Phase 2 – Best practice pain management in residential aged care.* NHMRC Cognitive Decline Partnership Centre (CDPC). \$650,102. 2016 – 2018.

Andrews S, Cunningham C, Poulos CJ, Siddall P, Fitzgerald A & Lorang C. Cognitive Decline Partnership Centre, University of Sydney. *Intervene Phase 2 – Multi-disciplinary collaboration to support the implementation of best practice pain management for older people living with dementia: A participatory action research study in Australian Residential Aged Care Services.* Awarded \$591,002. 2016 - 2018.

Butow P, Newson A, **Best M**, Meiser B, Juraskova I, Goldstein D, Tucker K, Ballinger M, Gatto D, Schlub T. NHMRC Project Grant. *Cancer genomics; Psychosocial, behavioural and ethical issues and outcomes, two inter-related longitudinal studies.* Awarded \$506,654.30. 2017 - 2019.

Awarded to HammondCare as part of a consortium: **Clayton J** (Project Director) and **Rhee J** (from HammondCare - lead organisation), Tierman J (Caresearch), Detering K (Austin Hospital Advance Care Planning Department), Halcomb E (University of Wollongong), Mitchell G (University of Queensland), Phillips J (University of Technology, Sydney); Shaw T and Morton R (from University of Sydney). Australian Government, Department of Health National Palliative Care Project. *The Advance Project. Initiating palliative care and advance care planning: training and resources for General Practice Nurses.* Awarded \$1,400,000. 2016 - 2017.

Mowll J, Sanderson C, Lobb L, **MacLeod R**, Robertson M, Dufflou J, Cahill J, Fitzpatrick C. Australian Government Collaborative Research Network CRN funding. *'Mapping Grief' A mixed method longitudinal study to investigate and compare a group of palliative care and coronial deaths with regard to family members' experiences of their care, of the death, and their adjustment/recovery.* \$720,000. 2015 – 2017.

Naylor J, **Kohler F, Connolly C**, Harris I, **Buhagiar M**, Mills K, Xuan W. Medibank Private. *Investigating elements of post-operative rehabilitation for total hip replacements.* Awarded \$230,000 from 2017 – 2018.

Poulos CJ, Gresham M, Poulos RG, Corlis M, Seaman K, Clemson L, McGilton K, Cameron I. *Development of dementia reablement guidelines and programs.* NHMRC Cognitive Decline Partnership Centre (CDPC). \$246,337. 2017 – 2018.

Siddall P, Wrigley P, Australian and New Zealand College of Anaesthetists Grant, *Developing a pain modulation index in people with chronic pain: a pilot project.* Awarded \$49,458 from Jan 2016 for 12 months.

Zambrano S, Salis-Gross, C (PIs), Aslakson R, **MacLeod R**, Mitchell G (collaborators). Swiss National Science Foundation. *Determinants of end of life discussion in non-malignant*

illness; an international, multi-centre qualitative study to understand the key perspectives of bereaved families and medical specialists. \$57,602. 2016 – 2018.

Grants with continuing funding in 2016

Smith A, Karlawish J, Lee S, Moran P, **Clayton J** (Consultant), Sudore R (Consultant). *Enhancing Prognosis Communication with Disabled Elders. USA National Palliative Care Research Center Grant* (This project is based within the Department of Geriatrics, Palliative, and Extended Care, University of California, San Francisco (UCSF) Division of Geriatrics, Department of Medicine). Awarded \$140,000. 2015 -2017.

Butow P, Andrew G, Girgis A, Kelly B, Hack T, **Clayton J**, Price M, Beale P, Viney R, Kirsten L. Cancer Institute NSW Translational Program Grant. *A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients. Developing and evaluating components and testing implementation strategies.* Awarded \$3,643,992 (Y1 \$730,264; Yr2 \$717,465; Yr3 \$724,127; Yr 4 \$745,737; Yr 5 \$726,398). 2015 – 2020.

Currow D, Lintzeris N, Solowij N, Quinn S, McCaffrey N, Phillips J, Martin P, **Lovell M**, McGregor I, Martin J, Allsop D. NSW Health; *Evaluation of pharmaceutical cannabinoids and standardised botanical leaf cannabis for anorexia in advanced cancer: A pharmacokinetic and feasibility pilot Phase II study; and Phase III double-blind double-dummy multi-site parallel-arm randomised controlled trial.* Agar M, \$1,905,498. 2015 – 2018.

Duggleb, W(PI), Pesut B, Warner G, Fassbender K, Nekolaichuk C, Holroyd-Leduc J, Ghosh S, Hallstrom L, **MacLeod R**, Murphy S, Klein L, Antymnuik C, Clark G, Peterson-Fraser M, Woytkiw T & Laing R. Covenant Health Seniors Health and Wellness Innovation Fund. *Navigation Partnerships: Connecting, Accessing, Resourcing and Engaging (N-CARE) Older Persons, Families and Communities.* \$170,997. 2015 – 2017.

Lovell M (CI), Phillips J, Agar M, Boyle FM, Davidson PM, Luckett T, Currow DC, Ryan L, McCaffrey N, Shaw T. National Breast Cancer Foundation Grant. *Implementing a national clinical pathway for pain to ensure equitable, cost-effective, evidence-based, person-centred care for people with advanced breast and other cancers.* Awarded from NBCF \$939,139.00: Year 1: \$218,501.00 Year 2: \$242,694.00 Year 3: \$238,051.00 Year 4: \$239,893.00. 2014- 2018.

Lovell M (CI), Phillips J, Luckett T, Boyle F. Ritchie Foundation Grant. *Stop Cancer Pain*, (ongoing funding).

Poulos CJ, Poulos R, Rhee J, **Beilharz K** Commonwealth Government DSS Grant *Arts on Prescription.* Awarded \$876,238. 2015-2017.

Stancliffe R, **Clayton J**, Read S, Jettes G. *A toolkit to build the capacity of disability staff to assist adults with intellectual disability to understand and plan for their end of life.* Australian Research Council Linkage Grant, Project ID: LP130100300 Awarded \$226,000. 2013 – 2016.

Statistics

January 2016 to December 2016

76 Research Projects

13 New Projects and 63 Continuing Projects

30

Palliative Care.

14

Dementia.

6

Ageing, Restorative Care+Reablement.

11

Rehabilitation.

7

Pain Management.

6

Advance Care Planning.

2

Spiritual Aspects of Care.



Education, Grants+Awards

9

Successful Grant Applications.

5

Awards.

9

Higher Research Degrees.

15

Academic Degree Supervision.

125

Academic Conferences+ Industry Seminars.

8

Grants with continuing funding in 2016.



80 Publications

51

Journal Articles.

4

Book+Chapters.

14

Technical+Other Reports.

11

Industry+ Magazine Articles.

Palliative Care

New in 2016

Let's talk about it

Single-Site Research Project

Sexuality in palliative care is a very difficult topic for patients and health care workers to discuss, and yet there is a huge unmet need for these discussions to occur in this population.

A survey of staff will be conducted prior to intervention to discover the challenges in an inpatient palliative care ward. The participants will be asked to provide suggestions for interventions they think will be beneficial to enable staff to feel more comfortable to 'start the conversation' with their patients, and also to suggest ways of providing patients with privacy.

The researchers will then evaluate the findings. From this an educational program will be implemented as well as initiatives suggested by the staff survey to facilitate staff comfort and provide patients opportunities for privacy. After these interventions, a post intervention survey will be conducted to evaluate their success.

Researchers: Ms Brigitte Karle, Professor Rod Macleod, Ms Joo Ling Tan, Dr Sarah Thompson, Ms Michelle Griffiths

Site: Neringah Hospital
Duration: Aug 16 to Feb 17

Funding Source: Internally supported
Project Partners: Nil
Study Status: In Progress

New in 2016

Nausea Study 3

Multi-Site Clinical Trial

This study follows on from the previous two nausea studies, which HammondCare did not participate in. Patients with cancer and suffering from nausea will be invited to participate.

The project is looking at two cohorts - one will receive oral Methotrimeprazine and the other oral Haloperidol to manage their nausea. Assessments are over three days and there is a four week follow up period. The outcome is for improvement of nausea by 2 points on the nausea rating scale over the baseline reading.

Researchers: Ms Janet R Hardy, Queensland University of Technology; Professor Melanie Lovell & Dr Bridget Johnson, HammondCare

Site: Greenwich Hospital
Duration: Feb 16 to Jun 17

Funding Source: National Health and Medical Research Council
Project Partners: Flinders University of South Australia (sponsor), The Institute for Breathing and Sleep, University of Hull, Monash University, The University of Adelaide and University of Melbourne.
Study Status: In Progress

New in 2016

BEAMS: A pragmatic, phase III, multi-site, double-blind, placebo controlled, parallel arm, dose-increment randomised trial of regular low dose extended release morphine for chronic refractory breathlessness

Multi-Site Clinical Trial

Three hundred thousand Australians are breathless at rest or on minimal exertion despite optimal treatment of underlying cause. The aim of this study is to enhance the evidence base for the pharmacological treatment of chronic refractory breathlessness using potential therapies compared to placebo. The primary objective is to compare the difference of the net effect on chronic breathlessness in people with chronic obstructive pulmonary disease (COPD) and baseline breathlessness of 3-4 on a breathlessness scale for people taking once a day extended release morphine at two different doses when compared to placebo. The co-primary objective is to compare difference in steps per day measured using Fitbit between people taking once daily extended release oral morphine by dosing level.

This study will recruit people with optimally treated chronic breathlessness of 3 or 4 and COPD. Those recruited will use a diary to record the change of breathlessness over a 24 hour period each morning using an 11 point numerical rating scale.

The study will answer several practical questions including whether regular, low dose extended release oral morphine delivers a net benefit in people with COPD in reducing breathlessness on exertion in steady state.

Researchers: Professor David Currow, Flinders University; Professor Melanie Lovell & Dr Bridget Johnson, HammondCare
Site: Northern Sydney HammondAtHome
Duration: Jul 16 to Dec 21

Funding Source: In researchers' own time
Project Partners: Flinders University; Palliative Care Clinical Studies Collaborative
Study Status: In Progress

New in 2016

An observational study to document inter-observation in the reporting of plain radiographs of constipated palliative care patients

Palliative Care

Multi-Site Research Project

Constipation symptoms are commonly experienced by people with palliative and supportive care needs with laxatives being the most commonly prescribed of all medications for this cohort in Australia. Despite the fact that as many as 60% of palliative inpatients require treatment for constipation, there remains a lack of robust evidence in this population as to how the severity of this problem is best assessed.

Plain radiographs are commonly used in palliative care to assess constipation with the appearance of faecal loading used as a surrogate indicator of the severity of the issue. However, this has not been objectively confirmed as an effective practice and further investigations are required to ensure that this is not a low value intervention that should be discontinued.

The aims of this low risk study are to investigate whether:

1. Palliative care staff are reliably able to assign a faecal loading score to a plain radiograph;
2. Palliative care staff are able to predict patient's symptoms based on the appearance of a radiograph; and
3. If patient's self-reported symptoms correlate with the assigned faecal loading score.

Researchers: Professor Katherine Clark, Calvary Mater Newcastle; Professor Melanie Lovell & Dr Bridget Johnson, HammondCare
Site: Greenwich Hospital
Duration: May 16 to Jun 17

Funding Source: Internally supported
Project Partners: Calvary Mater Newcastle
Study Status: In Progress

New in 2016

Evaluating the sleep of adults caring for a person living with advanced cancer in the community: a mixed methods project

Multi-Site Thesis Project

This project aims to investigate the sleep patterns of informal caregivers of advanced cancer patients receiving community palliative care, and to identify whether Australian palliative care services need to initiate additional strategies to optimise caregivers' sleep.

The proposed outcomes are improved knowledge and understanding of sleep issues specific to caregivers of advanced cancer patients, the impact on caregivers' level of burden and depression, if and what patient related factors have an impact on caregivers' sleep and future directions needed to improve caregivers' sleep within the palliative care setting.

Researchers: Professor Jane Phillips, University of Technology Sydney; Professor Melanie Lovell,

HammondCare; Ms Kirstin Maltby, University of Notre Dame Australia; Professor Elizabeth Lobb, Calvary Healthcare Kogarah; A/Prof Christine Sanderson, University of Notre Dame Australia
Site: Greenwich Hospital
Duration: Aug 16 to Aug 17

Funding Source: Collaborative Research Network
Project Partners: University of Technology Sydney; University of Notre Dame Australia; Calvary Healthcare Kogarah; University of Notre Dame Australia
Study Status: In Progress

The impact of constipation on health related quality of life for advanced cancer patients

Multi-Site Clinical Trial

This study will help us understand the impact of constipation and more broadly will assist clinicians in a more holistic approach to management of this distressing symptom.

During 2016 a total of 60 respondents returned the survey and all but 11 participants came from the lead site. 29 respondents reported dissatisfaction with their bowel habits despite receiving laxatives, whereas only 15 respondents are satisfied without laxative intervention. The remaining 16 respondents were satisfied with laxative intervention.

Some preliminary data analysis has been undertaken and shows that the gender distribution is even and the most common age group is 70+. The youngest respondent is 28 and the eldest 89 years of age.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Jun 11 to Mar 17

Funding Source: DoHA & PaCCSC
Project Partners: PaCCSC
Duration: In Progress

A randomised double-blind multi-site parallel arm controlled trial to assess relief of refractory breathlessness comparing oral sertraline and placebo

Multi-Site Clinical Trial

Refractory breathlessness is one of the most distressing symptoms our patients face.

It is immensely frightening for caregivers, when faced with a loved one who cannot breathe. It affects the ability to sleep and function independently and is strongly correlated with

Palliative Care

sensations of panic and anxiety. Sertraline shows some promise as an agent to manage this symptom, where very few treatments are available.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Nov 10 to Jun 17

Funding Source: DOHA/ PaCCSC/NHMRC
Project Partners: PaCCSC
Study Status: This study is now closed to recruitment, results and publication pending

Carers' perspectives on, and expectations of, the use of long term home oxygen therapy for the treatment of refractory breathlessness

Multi-Site Study

The aim of this study is to understand caregiver factors that influence the prescribing of oxygen for those people who do not qualify for publically funded home oxygen.

HammondCare provides funding for home oxygen so understanding the caregiver experience will improve our prescribing practices. During 2016 HammondCare did not recruit any participants to this study.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Apr 14 to Jun 19

Funding Source: Flinders University
Project Partners: Flinders University
Study Status: In Progress

Randomised control trial of oral risperidone versus oral haloperidol versus oral placebo with rescue subcutaneous midazolam in the management of delirium in palliative care inpatients

Multi-Site Clinical Trial

Delirium occurs in over one third of patients admitted to palliative care, increasing to 80% in the days before death.

Delirium causes highly distressing symptoms including loss of cognition, behavioural disturbance and perceptual disturbances. Delirium is also predictive of risk of anxiety disorders in the caregiver who witnesses it in a loved one. There is currently no medication registered for delirium treatment.

This study puts HammondCare on the cutting edge of

delirium research internationally. The desired-for outcome is a potential treatment for delirium which has implications not only for palliative care but also in aged care where delirium is also highly prevalent.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Jun 11 to Feb 17

Funding Source: DoHA & PaCCSC
Project Partners: PaCCSC
Study Status: This randomised clinical trial is closed for recruitment, results and publication pending

Randomised, double blinded placebo controlled pilot phase II trial of oral melatonin for the prevention of delirium in hospital cancer patients

Multi-Site Clinical Trial

Delirium in patients admitted to palliative care is common and distressing.

This trial is studying a potential treatment for delirium prevention, which has implications for not only palliative care, but also aged care where delirium is also highly prevalent. If delirium can be prevented it also has a huge economic advantage, given it is highly costly to informal caregivers at home, and for Residential Aged Care Homes and health care systems once it occurs.

The researchers are currently awaiting the outcome of the funding proposal for a phase III trial.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: May 13 to Jul 17

Funding Source: Cancer Institute NSW, PaCCSC infrastructure support and ImPaCCT
Project Partners: University of Technology
Study Status: In Progress

Palliative care suite evaluation - Lavender Suite

This project was the initial evaluation of the Lavender Suite at Hammondville.

HammondCare is committed to evaluate the outcomes of this new model of palliative care delivered in a residential setting to ensure the outcomes expected are delivered and to allow feedback for ongoing improvement.

Palliative Care

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky

Site: Braeside Hospital
Duration: Jan 13 to Dec 16

Funding Source: Internally Supported
Project Partners: Nil
Study Status: Completed

Translational Outcomes:

The evaluation showed Lavender Suite is an innovative example of how specialist palliative care can be successfully delivered within an existing residential aged care setting. Residents and carers provided testimonies as to the quality of palliative care delivered to all residents. The success of the Lavender Suite Model can be attributed to the multidisciplinary approach, to the provision of palliative care and that the residents' designated GP remains intrinsically involved in their care. The unit established a good working relationship with the palliative care specialist who continued to mentor local GPs with an interest in palliative care. All staff working in Lavender Suite are skilled in palliative care and felt supported to provide palliative care.

A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients: Developing and evaluating components and testing implementation strategies

Multi-Site Study

This project will inform better and more streamlined psychosocial care of our patients.

During 2016 patient and health professional educational materials have been developed with stakeholder input. Educational materials are currently being piloted in a pre-post study. Online therapies (iCanAdapt) for early and advanced cancer have been developed and evaluated in a randomized control trial (RCT) and pre-post study. An online portal has been created to operationalise the pathway, and is currently being implemented at one pilot site. The study protocol for the multicentre cluster randomised controlled trial has been finalised and approved by ethics. Recruitment for the cluster randomised controlled trial will commence in June 2017.

Researchers: Professor Phyllis Butow (lead), Associate Professor Josephine Clayton (one of the Chief Investigators)
Site: Greenwich Hospital
Duration: Jun 15 to Jun 20

Funding Source: Funded by Cancer Institute NSW & funds administered by USyd

Project Partners: PoCoG, Sydney Catalyst; Centre for Medical Psychology and Evidence Based Decision Making, University of Sydney
Study Status: In Progress

Management of nausea in cancer patients - study 1

Multi-Site Clinical Trial

Nausea is a highly prevalent symptom in palliative care which causes poor quality of life and impacts caregivers because the patient does not feel like eating.

This study is aiming to find the most effective way to control nausea symptoms, in particular with medications that are accessible via Pharmaceutical Benefits Scheme (PBS), for community patients. It also acknowledges the importance of food beyond "nutrition" as an important aspect of life even when illness is advanced.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Sep 10 to Jun 16

Funding Source: NHMRC & PaCCSC
Project Partners: Queensland University of Technology
Study Status: This study is now closed to recruitment, results and publication pending

Randomised, double blind control of megestrol acetate, dexamethasone and placebo in the management of anorexia in people with advanced cancer

Multi-Site Clinical Trial

This study is exploring medication to improve appetite in people with advanced illness.

Megestrol acetate is not licensed or subsidised for this indication and if this study is positive, application to the Therapeutic Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC) will be pursued to ensure treatments to improve appetite are widely available. This study has been particularly important for the culturally and linguistically diverse population in South West Sydney, where great importance is placed on being able to eat and enjoy food by patients and caregivers in these communities.

During 2016, the results of this clinical trial were analysed and are now awaiting publication.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Mar 09 to May 17

Researchers: Associate Professor Melanie Lovell, Ms Alison Hession & Ms Bronwyn Raymond
Site: Greenwich Hospital
Duration: Jul 12 to May 17
Funding Source: DoHA
Project Partners: PaCCSC
Study Status: Closed to recruitment, analysis in progress

Palliative Care

Rapid report of pharmacovigilance program

Multi-Site Study

It is important clinicians monitor patients when they are started on a new medication, both for evidence that the medication is working and for side effects.

This program provides clinicians at HammondCare a point of care approach to monitoring medications which is time efficient. It also adds the benefit that data is pooled internationally giving more robust feedback on the actual effectiveness and side effects of the medications being used daily in our HammondCare facilities. This feedback improves prescribing to ensure patients are receiving medications with the maximum effect and minimal side effects.

During 2016 the following series were completed: Metoclopramide for nausea; Haloperidol for delirium; Gabapentin for neuropathic pain; Pregabalin for neuropathic pain; Dexamethasone for anorexia; Haloperidol for nausea.

The program continues to grow in the number of interventions being studied; the number of contributing sites; the gathering of real world data to inform clinical decision making; building of research capacity; and improvement of patient outcomes.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky

Site: Braeside Hospital
Duration: Jun 11 to Jun 19

Researchers: Associate Professor Melanie Lovell, Dr Bridget Johnson, Ms Alison Hession & Bronwyn Raymond

Site: Greenwich Hospital
Duration: May 11 to Jun 19
Funding Source: PaCCSC
Project Partners: PaCCSC
Study Status: In Progress

Improving quality of life at end of life: a randomised control trial of a doctor/nurse/patient intervention

Multi-Site Study

This multi-site study of a nurse facilitated communication support program aimed to assist incurable cancer patients discuss their prognosis and end-of-life care with their oncologists.

This study will inform our clinical practice for cancer patients and involves collaborations with researchers in the USA as well as across Sydney.

Researcher: Professor Phyllis Butow (lead), Associate Professor Josephine Clayton (one of the chief investigators)

Site: Greenwich Hospital
Duration: Jul 09 to Jul 16

Funding Source: Funded by NHMRC administered by USyd

Project Partners: External PhD supervision (Sydney University)

Study Status: Completed

Translational Outcomes:

110 patients participated in the study and the patients receiving the nurse-facilitated communication support program, which included a guided exploration of a question prompt list, revealed they wished to discuss their prognosis, end-of-life care and future care options during a follow up oncology consultation. However, they did not ask more questions about these issues and it remains unclear whether patient cues were noticed and responded to by oncologists during consultations. Nevertheless the intervention significantly increased patients' self-efficacy in knowing what questions to ask their clinician and satisfaction with the intervention was very high. Other aspects of communication self-efficacy were unaffected by the intervention, as was patients' health-related quality-of-life.

The addition of communication skills training for oncologists, further guidance for patients regarding advance care planning and the inclusion of the patient's caregiver in the intervention may be beneficial. The 'manualised' nature of the intervention, designed with existing clinical staff in mind, may make it suited for implementation in a clinical setting, though additional work is needed to identify why question asking was unaffected and establish its impact later in the illness trajectory.

This study has informed the design of a revised intervention which incorporates the key learnings. This revised intervention is now being trialled with people with advanced cancer and their caregivers.

Can death from chronic life-limiting illnesses be predicted in Australian general practice?

Multi-Site Study

This study will help to inform and support palliative care provision by primary care providers.

Supporting primary carers to provide palliative care is one of the important roles of specialist palliative care services. This study will also strengthen collaborations with key national researchers in primary palliative care.

Researchers: Dr Joel Rhee and Associate Professor Josephine Clayton

Site: Greenwich Hospital
Duration: Oct 11 to Jun 16

Funding Source: Primary Care Collaboration Cancer Clinical Trials Group, Royal Australian College of General Practitioners & funds administered by UNSW
Project Partners: UNSW; University of Queensland
Study Status: Completed

Translational Outcomes:

This mixed methods study showed that screening tools were better than intuition alone at predicting death in general

Palliative Care

practice settings. However, the prognostic screening tools had a higher false positive rate than intuition. Screening for possible death on its own is not likely to be the best option for initiating end of life planning in General Practice. Rather recognising the increased burden of illness and unmet supportive care needs is likely to be a better trigger. Qualitative findings emphasised the relational aspects and need for education in end-of-life care planning.

End Of Life in Northern Sydney Local Health District

Multi-Site Study

This study will assist in understanding the provision of end-of-life care in acute settings and any deficiencies.

Researcher: Professor Roderick MacLeod

Site: Greenwich Hospital

Duration: Mar 13 to Feb 18

Funding Source: Funded by NSW Health

Project Partners: None

Study Status: This project has been completed and papers are being prepared for publication. The findings highlight strengths and weaknesses of aspects of care in North Sydney hospitals compared with similar facilities in New Zealand. Overall there are many encouraging trends. The results have been fed back to relevant personnel in the hospitals.

The experience of dying away from birth country for transnationals

This study will assist in the provision of palliative care to transnationals in the HammondCare service.

Researcher: Professor Roderick MacLeod (PhD Supervision)

Site: Off-Site research

Duration: Aug 11 to Aug 16

Funding Source: Internally Supported

Project Partners: Nil

Study Status: Completed

Translational Outcomes:

Interpreting and understanding the experience from these stories generously shared by the migrants in this research is a strategic way to enable understanding of the deeper issues of migration and dying. It is a legacy for others in the same circumstances in the future. Phenomenology is never conclusive but demonstrates what can be gleaned from actual experience.

The implications of this research for practice include education to increase practitioner awareness of the issues discussed. The use of formal and informal life review could be of benefit for migrants grappling with dying away from homeland. Dignity therapy and the model of meaning-making could be utilised by practitioners to alleviate

dissonance experienced by migrants. Other strategies also include establishing community networks to invite migrant involvement as soon as they arrive in the country. Lastly, enhancing community support and work around mixed communities in activities that respect all cultural expressions can reduce any discord that can impact the end-of-life time.

ACCeRT Study: Auckland's Cancer Cachexia evaluating Resistance Training Study - A randomised feasibility study of EPA and Cox-2 inhibitor (Celebrex) versus EPA, Cox-2 inhibitor (Celebrex), Resistance Training followed by ingestion of essential amino acids high in leucine in NSCLC cachectic patients

This study will assist in the planning of clinics at HammondCare for the amelioration of effects of cancer cachexia which is the loss of skeletal muscle mass with or without loss of fat mass.

Researcher: Professor Roderick MacLeod (PhD Supervision)

Site: Off-Site research

Duration: Sept 11 to Mar 16

Funding Source: Internally Supported

Project Partners: Nil

Study Status: Completed

Translational Outcomes:

This is a pilot study with an outcome of minimal impact. Nonetheless the trends in efficacy in a number of cachexia markers, and the minimal toxicity support further evaluation of this study regimen within a larger phase II study. These data can serve as a baseline for future 'refractory cachexia' studies.

Collaborative practice in palliative care

This study will help HammondCare in understanding what collaborative practice actually means.

Researcher: Professor Roderick MacLeod (PhD Supervision)

Site: Off-Site research

Duration: Aug 11 to Mar 16

Funding Source: Internally Supported

Project Partners: Nil

Study Status: Completed

Palliative Care

Translational Outcomes:

There is the potential for improvements in collaboration within palliative care teams. The theory of 'Sharing Time' has potential value for all health professionals working in the area of palliative care as it facilitates collaboration and promotes further sharing. Collaboration and managing 'possessionship' promotes a safer work environment.

Understanding Care: The Volunteering experience in the space of Palliative Care

Single-Site Study

This project will aim to increase our understanding of the role of volunteers in enhancing patient quality of care in the palliative care setting.

Researcher: Ms Holi Birman (UNSW)

Sites: Greenwich, Braeside & Neringah Hospitals

Duration: Jun 14 to Mar 17

Funding Source: Administered by UNSW

Project Partners: Nil

Study Status: Data collection and analysis for this project is now complete and the final write-up for submission of PhD dissertation is currently underway.

Evaluating Community Palliative Care Teams

This evaluation will enable estimation of the value of the Community Palliative Care service to patients and families. It will also indicate how HammondCare's contribution to these people in need can be optimised.

Researchers: Associate Professor Roslyn Poulos (UNSW), Professor Rod MacLeod, Associate Professor Christopher Poulos, Associate Professor Andrew Cole, Ms Kristine Apitz & Mr Damian Harkin

Sites: Greenwich Hospital; Local Health Districts:

Central Coast, Far Western NSW, Murrumbidgee, Northern Sydney, South East Sydney, Southern NSW, Western NSW

Duration: Oct 14 to Jun 16

Funding Source: Ministry of Health

Project Partners: School of Public Health and Community Medicine, UNSW

Study Status: Completed

Translational Outcomes:

Data from the 128 family carer surveys returned to the evaluation team suggest that Community Care Workers were able to effectively support carers and patients by meeting their needs in a sensitive, caring and professional manner. Most families (77%) who cared for a loved one at home, now knowing what that entailed, would do it again. Families made use of the support that the community care workers offered in multiple ways. These included personal care (washing, toileting), assistance with domestic tasks, sitting with the patient, overnight respite care, companionship and even advice. Data from both the 128 family carer surveys

and the telephone interviews with 20 family carers found that the support provided by Community Care Workers was greatly appreciated and some indicated that a home-death would not have been possible without their support. Where suggestions for service improvement were made, these centred on enabling more direct communication between family carers and the Palliative Care Home Care Program Gateway Office, earlier engagement of services, and grief and counselling support.

The community care workers found the training prepared them well for the role. They found the role 'rewarding', 'satisfying', a 'privilege', 'meaningful' and at times 'challenging'. An interest in refresher training from time to time (either face to face or online) to maintain or further develop skills was expressed by some community care workers in post-workshop surveys, three month surveys, and in the qualitative interviews.

Community palliative care team interviews suggest that the Program is fulfilling its primary objective of supporting patients and their families in their wish to die at home. Moreover, it would appear that the program is benefiting carers and patients who, without the assistance of the Program, would not have been able to achieve this.

The role of Speech Pathologists in Palliative Care: Exploring the issues and reaching consensus

Single-Site Study

Development of a clear scope of practice and potential benchmarks for speech pathology service provision in palliative care will give HammondCare the opportunity to review its speech pathology palliative care service and ensure that it is optimally evidence based.

During 2016 the underpinning literature review was published in "Progress in Palliative Care" in 2016. In addition, questionnaire data has been collected that demonstrates the current activity of Speech-Language Pathologists in palliative care, and the way in which this differs from what they perceive to be ideal practice. This data has been presented at the annual meeting of the Multinational Association for Supportive Care in Cancer and the SWSLHD Research Showcase in 2016. It will also be presented at the Speech Pathology Australia annual conference in 2017, and a manuscript for publication will be written during 2017. Correspondingly, the best practice consensus statements have been developed and will be submitted to the Human Research Ethics Committee for approval to distribute by the end of February 2017, with the goal of doing so as soon as possible after approval is granted.

Researchers: Ms Katherine Kelly and Ms Kerry Gilsean

Site: Braeside Hospital

Duration: Jul 15 to Jun 17

Funding Source: Internally Supported

Project Partners: Nil

Study Status: In Progress

Palliative Care

Hope during a home death: family members' experiences

Multi-Site Study

This research project will inform HammondCare how best to serve family members/carers of palliative patients by understanding the spiritual, psychological and physical aspects of the hopes of families/carers in the context of a home death. This will benefit and support families by learning from them to develop innovative services in response to their views.

Researchers: Professor Roderick MacLeod, Dr Matra Robertson, Professor Wendy Duggleby and Ms Jenny Broadbent

Site: Greenwich Hospital; Neringah Hospital; Northern Beaches Clinic

Duration: Feb 15 to Dec 16

Funding Source: NSW Ministry of Health

Project Partners: NSW Ministry of Health; Northern Sydney Local Health District; University of Sydney

Study Status: Completed

Translational Outcomes:

Clarifying research challenges in research and learning from bereaved family caregivers where home support packages were in place, will inform interventions to sustain multidimensional factors that support the hopes of people who are dying and family caregivers.

The experiences of care, grief and adjustment for family members bereaved after a coronial or palliative care death: a mixed method longitudinal study

Multi-Site Study

This research will contribute to understanding the experiences and needs of relatives and family care givers of the care and death of their relative whilst in the care of a HammondCare facility. Such understanding will contribute towards service development and service delivery in the palliative and post death period.

Data collection is almost completed from the participants. Data analysis is ongoing and presentations are being prepared for international conferences and publication.

Researchers: Professor Roderick MacLeod, Dr Matra Robertson & Ms Christine Sanderson, Ms Jane Mowl Uni Notre Dame; Liz Lobb Calvary Health Care Kogarah; Johan Dufrou Department of Forensic Medicine

Site: Greenwich Hospital and Neringah Hospital

Duration: Dec 15 to Aug 17

Funding Source: University Of Notre Dame, Australia

Project Partners: Calvary Health Care Kogarah; Department of Forensic Medicine, Sydney

Study Status: In Progress

Stop Cancer PAIN

Multi-Site Study

The aim of this study is for improved pain outcomes for patients, improved staff knowledge and an improved international and national profile for HammondCare.

During 2016 the study began recruiting at the fourth site, completed at two sites completing the control arm at one site.

Researchers: Associate Professor Melanie Lovell, Ms Bronwyn Raymond, Ms Jane Phillips & Mr Tim Luckett UTS; Professor Fran Boyle USyd

Site: Off-site research

Duration: Nov 14 to Nov 18

Funding Source: National Breast Cancer Foundation

Project Partners: University of Technology Sydney and Sydney University

Study Status: In Progress

A randomised double-blind parallel-group placebo-controlled phase III study to assess the clinical benefit of three doses of PAX - 1 as adjunctive treatment for persistent cancer pain

Multi-Site Study

This study aims to assess the clinical benefit of PAX-1 medication on pain intensity, and also ensure it is not associated with adverse effects that outweigh its potential benefit.

A phase III trial would then be undertaken to confirm these results, to allow the agent to be available more widely in clinical practice. This project provides our clients' access to a novel agent for cancer pain. The management of cancer pain is core business for our palliative care services, and this project ensures the evaluation of new treatments which might allow us to better manage more complex cancer pain.

During 2016 the PAX-1 study was open for recruitment at eight sites across Australia.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky

Site: Braeside Hospital

Duration: Jun 15 to Apr 18

Funding Source: Flinders University

Project Partners: Bio and Gene

Study Status: In Progress

Palliative Care

Cannabis Survey

Multi-Site Study

This study will assist in leading to further knowledge in the area of cannabis use in advanced cancer patients and lead to evidence based practice with patients suffering with weight loss, appetite and taste loss. HammondCare's Greenwich Hospital participated in this multi-site study.

Researchers: Associate Professor Melanie Lovell, Ms Bronwyn Raymond, Dr Bridget Johnson, Professor Jane Phillips UTS; Dr Caitlin Sheehan Calvary Hospital; Dr Rajesh Aggarwal Liverpool Hospital; A/Prof Meera Agar Braeside Hospital; Dr David Allsop University of Sydney

Site: Greenwich Hospital

Duration: Aug 15 to Jun 16

Funding Source: Internally Supported
Project Partners: ImPaCCT & PaCCSC
Study Status: Completed

Translational Outcomes:

204 patients were surveyed about preferences, attitudes and beliefs in relation to participating in a clinical trial in cannabis. The results noted a preference for the oral route of delivery. The survey also looked at understanding the need for trials. The outcome is that this survey has assisted in the development of a further trial into the use of cannabis.

Communication strategies when discussing transfer of palliative care patients to nursing homes

Multi-Site Study

This project will inform palliative care clinicians regarding optimal ways to discuss nursing home placement with palliative care patients and families as well as strategies to ease this transition.

A set of recommendations for discussing transition to a nursing home from a palliative care unit will be developed based on this research. This will inform guidelines for communication strategies and highlight areas for future research.

This is a qualitative study, involving interviews with palliative care health professionals. Recruitment and data collection for the study is underway.

Researchers: Dr Hilary Stiel, Associate Professor Josephine Clayton and Dr Ben Foster

Site: Off-site research

Duration: Aug 15 to Jun 18

Funding Source: Internally Supported
Project Partners: Nil
Study Status: In Progress

Dementia

New in 2016

Optimising advance care planning in dementia through supported decision-making: An exploratory mixed methods study of community perceptions and law reform challenges in Australia

Multi-Site Research Project

This project brings together a multi-disciplinary team of clinicians, consumer representatives and researchers (psychology, medicine and law), to examine supported decision-making as a means of promoting participation in healthcare decisions among people with dementia. Supported decision-making aims to assist people with cognitive impairment to maintain involvement in decision-making, typically through provision of a 'support person' (or persons).

The Australian Law Reform Commission recommends that legislation should encourage supported decision-making, however little is known about community perceptions towards this approach, or practical factors associated with implementation.

This project investigates community perceptions towards supported decision-making in the context of cognitive impairment. People with dementia, family caregivers of people with dementia and key health provider groups will be interviewed and surveyed, to assess community perceptions and identify barriers to implementation. Working groups of clinicians, consumers and policy-makers in each state will meet to discuss the research data, identify areas of current best practice, and establish strategies for broader implementation in each state. The researchers will also study existing laws, court cases and tribunal hearings across three Australian states (New South Wales, Western Australia and South Australia), to identify areas for future law reform. Based on study findings, the investigators will develop educational materials and practical resources to assist community members and healthcare providers to support decision-making among people with cognitive impairment.

Researchers: Dr Craig Sinclair, University of Western Australia; A/Prof. Josephine Clayton, HammondCare; Prof. Sue Kurlle, University of Sydney; A/Prof. Meera Agar, University of Technology, Sydney; Sue Field, Western Sydney University; Kathy Williams, Alzheimer's Australia Consumer Dementia Research Network Representative
Site: Pallister House, Greenwich Hospital
Duration: Jan 16 to Dec 18

Funding Source: Cognitive Decline Partnership Centre
Project Partners: Cognitive Decline Partnership Centre
Study Status: In progress

Dementia

New in 2016

Evidence-based programs to improve the wellbeing of people with dementia and their carers: Implementing COPE in the Australian health context

Multi-Site Research Project

We will conduct implementation research to integrate an evidence-based intervention, Care of Older Persons with Dementia in their Environments (COPE), within existing health systems in Australia and determine strategies for implementation and sustainability to enable wider dissemination. COPE is a bio-behavioural program designed to improve function and has proven effective in reducing dependency and increasing engagement of the person with dementia and in improving carer wellbeing in a randomised trial in the US.

The program works at a very practical level using occupational therapy skills (e.g. problem solving such as poor toilet habits that result in stress and limited outings, environmental adaptations to facilitate safe behaviours and activity engagement, and joint problem solving with the carer to identify solutions and strategies) and complimentary nursing skills (e.g. educating carers concerning taking care of themselves and ways to manage incontinence, medication management, and hydration) and centres around the needs of both the carer and the person with dementia. This project will translate COPE to the Australian context within not for profit, private and government care systems. We will examine facilitators and barriers at therapist, organisation and policy levels, explore funding models and build in features of sustainability.

Outcomes of interest include dosage and feasibility, treatment fidelity to key features, acceptability of intervention to stakeholders, therapists and participants, engagement of champions, knowledge acquisition of staff providing the intervention, and cost utilisation. We shall employ a process evaluation using interviews, focus groups and observation.

Researchers: Professor Lindy Clemson, University of Sydney; Dr Kate Laver, Flinders University
Site(s): HammondCare At Home Western Sydney, South West Sydney, South East Sydney
Duration: Mar 16 to Dec 18

Funding Source: Internally supported
Project Partners: University of Sydney, Flinders University, Cognitive Decline Partnership Centre
Study Status: In progress

The experience of using a wash and dry toilet top bidet with frail older people and people living with dementia: clinical study

This study aimed to examine the acceptance of bidets in dementia specific care for residents and staff; the

ability of the bidet to clean and dry after voiding; the effects on management of incontinence and cost of continence pads. Eight bidets were installed and data collected on 14 residents.

Researcher: Ms Meredith Gresham
Sites: Benetas', Mornington Aged Care Facility and HammondCare's Tulip wing at North Turrumurra
Duration: Jun 11 to Sep 16

Funding Source: Dementia Collaborative Research Centre (Assessment and Better Care) University of NSW, HammondCare Foundation
Project Partners: Dementia Collaborative Research Centre
Study Status: In progress

A health economic model for the development and evaluation of innovations in aged care: an application to consumer directed care

This project aimed to develop health economics modelling about the cost of the new Consumer Directed Care (CDC) model, which is being rolled out as national policy.

HammondCare Liaison: Rebecca Forbes, with researchers based at Flinders University
Site: HammondCare At Home Central Coast & Hunter & South West Sydney.
Duration: Apr 12 to Dec 16

Funding Source: Australian Research Council Industry Linkage grant (including HammondCare contribution)
Project Partners: Flinders University, Resthaven, ACH Group, Catholic Community Services, Helping Hand Aged Care.
Study Status: Completed

Translational Outcomes:

The findings from our discrete choice experiment demonstrate the practicality and feasibility of this approach and its potential for wide applicability in providing a mechanism for systematically incorporating consumer preferences into new service innovations in aged care. We found that consumers exhibited strong preferences for a Consumer Directed Care (CDC) approach that allowed them to save unused funds from a home care package for future use; have support workers with the ability to be flexible in terms of changing activities within their home care plan and with the ability for consumer choice and continuity in relation to the support workers providing day-to-day care.

Investigation of health, quality of life and psychological wellbeing outcomes for older people and carers as a consequence of the transition to and the length of time exposed to CDC indicated the potential for quality of life improvements with CDC. Our cost analysis identified that the main cost drivers in the provision of CDC for older people are care services, administration and case-coordination. However, it will take some time for the full impact of CDC in relation to the key cost drivers and the key outcomes of health, quality of life and psychological wellbeing for older people and carers to be realised in practice.

Dementia

Going to stay at home

This project provided a 6 day intensive, comprehensive, residential carer education and support program designed to provide family carers with the tools to manage their journey with a family member with dementia.

Researchers: Ms Meredith Gresham, Mr Jason Li, Ms Deborah Moore, Ms Rebecca Forbes, Professor Henry Brodarty, Ms Megan Heffernan & Ms Ruby Tsang
Site: Now at evaluation stage
Duration: Aug 12 to Jun 16

Funding Source: Australian Government Department of Social Services
Project Partners: Dementia Collaborative Research Centre (Assessment and Better Care) University of NSW
Study Status: Completed

Translational Outcomes:

Going to Stay at Home (G TSAH) was a six day intensive and comprehensive residential carer training program. The family carer and person living with dementia 'lived-in' with the carer attending interactive education and skills development sessions and the person with dementia receiving an active respite experience.

G TSAH showed very positive results for carers and people with dementia. Most strikingly, carers felt more equipped to manage the needs of the person with dementia and themselves, even in the face of a deteriorating condition. When compared with a similar group of carers and people with dementia who used respite care, without the intensive carer training program at twelve months, 52.9% of these usual respite clients were in permanent aged care, compared to 17.6% of Going to Stay at Home participants.

G TSAH has now been replicated by an aged care provider in The Netherlands and is under consideration for implementation in the UK. HammondCare At Home is considering options for implementation and has commenced with a one-day introductory program for HammondCare At Home families in February 2017.

Functional & symptomatic outcomes of psychogeriatric patients in Riverglenn inpatient unit

Determination of contributions to better outcomes should result in more efficient and better care of psychogeriatric inpatients and reductions in length of stay.

During 2016 slow participant uptake has meant only 30 assessments have been completed (aiming for 100). However, preliminary results indicate that patients fall into two groups: rapid responders and treatment-resistant, the latter requiring much longer stays and skewing length of stay figures.

Researcher: Associate Professor Janine Stevenson
Sites: Greenwich Hospital
Duration: Apr 14 to Dec 17

Funding Source: Internally Supported
Project Partners: Nil
Study Status: In Progress

Exploring the value of overnight cottage respite

Multi-Site Study

To explore the cost effectiveness of Cottage model respite to carers (mostly carers of people with dementia), including the value of Cottage Respite in preventing or delaying permanent residential placement.

Researchers: Associate Professor Chris Poulos & Ms Mary-Rose Birch
Site: Lucinda Cottage & Woonona Cottage
Duration: May 15 to Jun 16

Funding Source: Internally Supported
Project Partners: Nil
Study Status: In Progress

Translational Outcomes:

The positive findings from the cottage respite project, in terms of cost effectiveness and client satisfaction, has given HammondCare the confidence to further develop the model, with a new 'multipurpose' respite cottage to open in South Eastern Sydney in 2017. The search for an innovative model of overnight respite care using modular building design for a cottage will bring cottage respite to new areas of HammondCare sooner than limited government Commonwealth Home Support Program (CHSP) funding might otherwise allow.

Understanding the real cost of long-term care models for older people with cognitive decline in residential settings

This project will benefit HammondCare by providing an opportunity to develop an understanding of the key determinants of a good residential aged care experience from the perspective of people with dementia and their family members, which will both benefit those providing and designing services at HammondCare, as well as providing this information for use across the sector.

In addition, this will provide an opportunity for staff at HammondCare to participate in research and gain capacity in conducting research, an important benefit given the need for research in the future to improve the care of those with dementia.

Stage 2 & 3 (in progress): This project aims to determine the outcomes (specifically in quality of life, quality of care, and utilisation of healthcare resources) and the costs to operate alternative ways of providing residential aged care for people with cognitive impairment and dementia. This will provide HammondCare with information on the outcomes provided by alternative ways of providing residential care for people with dementia.

Lead Investigator: Professor Maria Crotty, Flinders University
Designated System Based Investigators (DSBIs): Ms Meredith Gresham, Ms Angela Raguz, Associate Professor Colm Cunningham & Ms Rebecca Forbes

Dementia

Sites: Erina & Woy Woy Residential Care Homes
Duration: May 14 to Jun 17

Funding Source: Cognitive Decline Partnership Centre
Study Status: The researchers of this study took receipt of the health service utilisation data required for the INSPIRED study from all data custodians in December 2016. These data are being prepared for inclusion into the overall analysis and modelling. Collection of similar data in parallel from alternative sources where possible has allowed the researchers to evaluate the quality and completeness of some of these data and adjust for this in their analysis.

The Care of Confused Hospitalised Older Persons (CHOPS) Program Implementation

The CHOPS program is designed to enable staff to have the skills and knowledge to identify, treat and care for older people presenting to their hospitals with confusion. The CHOPS program built on a 12-month pilot study in five NSW acute hospitals.

Lead Investigator: Professor Susan Kurrle, University of Sydney
Designated System Based Investigator: Associate Professor Colm Cunningham, Dr Catriona Lorang & Ms Rebecca Forbes
Sites: Not applicable
Duration: Jul 13 to Jun 16

Funding Source: Cognitive Decline Partnership Centre
Study Status: Completed

Translational Outcomes:

Implementation occurred in 12 NSW Department of Health services including Prince of Wales Hospital, Broken Hill Base Hospital and Coffs Harbour Hospital. Formative evaluation results demonstrate that the model is able to be successfully adapted across a number of sites.

Systematic review and scoping study for the implementation of a national approach to dementia specific advance care planning

Advance care planning in cognitive decline is a critical area for the clients for whom HammondCare provides care.

This project will explore the implementation of advanced care planning specifically in the person who has expected cognitive decline, and also mechanisms to ensure such plans are communicated to, and also respected within, the health care systems.

During 2016 the researchers evaluated the evidence for advance care planning and identified what needed to be done to engage people with dementia in planning ahead. The project then worked with community partners to develop a range of resources to support and promote planning ahead for people with dementia in a community and home-care setting. Resources are now being housed on the Start2Talk

website (<http://www.start2talk.com.au> www.start2talk.com.au) to maximise reach to individuals with dementia and their caregivers.

Lead Investigator: Professor Meera Agar
Designated System Based Investigators: Ms Angela Raguz & Ms Catriona Lorang
Researchers: Ms Adele Kelly & Ms Gail Yapp
Sites: Not applicable
Duration: Oct 13 to Dec 18

Project Partners: Flinders University
Funding Source: Cognitive Decline Partnership Centre
Study Status: In Progress

The effects of regulation on aged care services for people with cognitive decline

This project will lead to greater understanding on how regulations such as rules, standards, guidelines, conventions and norms, influence and shape dementia care in different settings.

It is expected the outcomes will enhance the effective delivery of care, and prioritise the needs, desires and rights of people with dementia. A series of policy recommendations on aged and dementia care regulations will also result from this research.

Lead Investigator: Professor Simon Biggs, Melbourne University
Designated System Based Investigators: Ms Angela Raguz, Ms Meredith Gresham, Ms Rebecca Forbes & Ms Catriona Lorang
Sites: Dementia specific residential care homes: Erina, Hammondville, Horsley, Miranda, North Turramurra and Woy Woy
Duration: Feb 14 to Jun 17

Funding Source: Cognitive Decline Partnership Centre
Study Status: The researchers have completed all data collection for this project, and are currently working on disseminating key research findings, and developing policy and practice recommendations.

Optimising the quality use of medicines for people with cognitive and related functional decline

Stage 1 (focus groups): Investigation into the beliefs of older adults and carers towards deprescribing.

Stage 2 (questionnaire): Investigation into the beliefs of older adults and carers towards deprescribing: validation of the DeprescriBe (Deprescribing Beliefs)

This research project will generate new knowledge regarding how older adults and carers feel about the process of ceasing medications.

This may, in the future, lead to ways to better manage medications for people with and without dementia. This research will result in a validated questionnaire that will not only provide information in relation to beliefs about deprescribing but may be used as a tool to identify individuals who are more willing to deprescribe. The long term goal of this research is to

Dementia

develop a process that allows safe and effective cessation of medications that are no longer required and/or are high risk.

During 2016 development was completed on the “Goal-directed Medication review Electronic Decision Support System” (G-MEDSS, available at HYPERLINK “http://www.gmedss.com” www.gmedss.com). This tool aims to guide pharmacists and general practitioners and to provide clinical decision support for those receiving a medication review and to assist in meeting their goals and preferences. In order to validate the software interviews and focus groups are being held to ascertain the various participants perspectives on using the tool. The people being recruited for this include pharmacists, general practitioners, people with and without dementia. After completing the validation process G-MEDSS will be upgraded and trialled in a randomised controlled setting to evaluate the impact of the system as an intervention. In addition, Prof Sarah Hilmer and Dr Lisa Kouladjian O’Donnell are collaborating with the investigators on Activity 1 on a number of publications.

Lead Investigators: Professor Sarah Hilmer, University of Sydney and Associate Professor Simon Bell, Monash University

Designated System Based Investigators: Associate Professor Colm Cunningham, Ms Rebecca Forbes & Ms Catriona Lorang

Sites: Various HammondCare care homes.

Duration: Stage 1: Jun 14 to Aug 14 and Stage 2: Sept 14 to Dec 19

Funding Source: Cognitive Decline Partnership Centre Study Status: Stage 1: Completed Stage 2: In Progress

Showing the way: Developing an evaluation framework for signage for people living with dementia

Multi-Site Study

HammondCare has a significant interest in and a commitment to excellence in design for people living with dementia.

This project will develop ways to evaluate specific elements of the environment. The results will be used in Dementia Centre design consultancy for internal and external environment reviews. The project outcomes may lead to new ways of assessing the effectiveness of complex elements of the environment for people living with dementia.

Researchers: Ms Meredith Gresham, Dr Heather Wilkinson (Uni Edinburch); Danielle MacIntosh (HC); Ellen Skladzien (Alzheimers Aust); Liz Taylor (Uni Edinburgh); Associate Professor Colm Cunningham (HC)
Site: HammondCare, Kent Street Sydney
Duration: Mar 15 to Jun 16

Funding Source: Dementia Collaborative Research Centre Carers and Consumers
Project Partners: University Edinburgh & Alzheimers Australia
Study Status: Completed

Translational Outcomes:

This was a preliminary study. Translation should be guided by further validation. However the findings, as they stand, may be incorporated into environmental evaluation tools such as the Dementia Centre’s Design Smart Tool.

Quality Jobs and Quality Care: Improving work practices to deliver quality aged care jobs and aged care services for older Australians.

Multi-site research project

The Quality Jobs Quality Care Project was conducted over three years in a collaboration of researchers from three universities and partners from the aged care industry, including HammondCare. Its aim has been to develop innovative workplace tools, models and benchmarks to improve job quality and quality of services in aged care. The major focus has been on direct care workers, who provide 80% of front-line care in Australian aged care services.

Two innovative work practices were trialled with HammondCare. In 2015 a trial of Scheduled Working Hours for community care workers was undertaken to provide more consistency in working hours. In 2016 a trial of Specialised Care Mentors for community care workers was undertaken to provide more consistent and higher level care to clients with complex needs (especially dementia).

Researchers: Professor Sara Charlesworth, Associate Professor Debra King, Dr Natalie Skinner, Dr Sue Jarrad
Site: both interventions were based at HammondatHome in the south-west region of Sydney. Meetings were held at Hammondville
Duration: In total the project ran from June 2013 – Dec 2016. At HammondCare Intervention 1 was active from Sept 2014- June 2015; Intervention 2 was active from 7 Sep 2015-22 March 2016.

Funding Source: This project was funded by the Australian Government Department of Health under the Aged Care Service Improvement and Healthy Ageing Grants Fund.

Project Partners: Academic: University of South Australia, RMIT, Flinders University. Aged Care partners: HammondCare, Helping Hand, Brightwater Care, United Voice.
Study Status: Completed

Translational Outcomes: The development of benchmarks, innovative workplace trials, and contemporary research evidence has led to the development of the Quality Jobs Quality Care Toolkit. This resource is designed to assist aged care employers and managers to make small changes to work practices which will improve both job quality for care workers and the care quality that older Australians receive. Webinars provide an introduction to the area of job and care quality, and explain how to use the Toolkit. Worksheets, practical how-to advice and real-life case studies are included to support you along the way. The Toolkit is available at <http://www.qualityjobsqualitycare.com.au/toolkit.html>

Ageing, Restorative Care+Reablement

New in 2016

Investigating the implications of the aged care reforms, specifically care delivered in the home to older, low income rental tenants

Multi-Site Study

Housing is fundamental to the wellbeing of everyone, particularly older people. The number of lower income people aged 65 and over living in rental households, as home ownership falls, is projected to exceed the supply of the social housing system. The decline in public housing dwellings and tight targeting of housing assistance to those with complex needs, means demand on the private sector and social housing provision is considerable.

Council on the Ageing has identified that a lack of affordable, suitable accommodation for older people will result in a crisis in aged care support and will have a major impact on capacity of other support and care services. However, little attention has been paid to the consequences for older people with limited control over their home due to tenure. Rental tenants often have restricted rights to modify/adjust their accommodation, limited discretionary income and a restricted understanding of government programs.

This study will investigate these issues and develop both policy and program recommendations through review of the published and grey literature examining the relationship between consumer-directed aged care and tenure; focus groups with tenants; and interviews with service providers about the challenges they expect to face in providing care to tenants and how they expect to overcome these. The research will result in identification of strategies to enable aged care and housing providers to better meet the needs of tenants; identify more effective mechanisms for service delivery; and generate strategies for informing older tenants how to maximise use of aged care support.

Researchers: Ms Victoria Cornell, Centre for Housing, Urban and Regional Planning and University of Adelaide

Sites: HammondCare At Home Central Coast, Northern Sydney, Western Sydney, South West Sydney, South East Sydney
Duration: Apr 16 to Feb 18

Funding Source: University of Adelaide and the Australian Housing and Urban Research Institute
Project Partners: Nil
Study Status: In Progress

New in 2016

Best practice and the regulation of quality of care for older people

Single-Site Thesis Project

Governments have found it difficult to encourage providers of aged care to improve care quality.

Many approaches have been tried, but it is not clear which are the most effective. These approaches include conducting inspections, encouraging competition between companies and publishing performance data and star ratings. Many of these are used to make sure that providers deliver basic levels of care.

The purpose of this study is to look at what governments can do to encourage providers to deliver care which is better than just the basic level of quality. To do this, the research is comparing the approaches taken by the governments of England and Australia.

Part of this study is to conduct interviews with providers in both countries who are known for delivering quality over and above the minimum standards required. The aim of these interviews is to understand more about why and how providers exceed the quality standards. This includes for example, one or two facility managers, and staff who are engaged in specific roles associated with quality, such as Quality or Performance Improvement, Compliance or Learning and Development.

The aim of the study is to investigate how and why the approaches differ and to identify the advantages and disadvantages of each countrys’ approach. This information can then help future efforts to improve the design of regulation and ultimately the quality of the experiences of both residents and staff in aged care.

Researchers: Ms Lisa Trigg, London School of Economics and Political Science

Site: Hammondville

Duration: Apr 16 to Mar 17

Funding Source: National Institute of Health Research (England)

Project Partners: Nil

Study Status: In Progress

New in 2016

Arts on Prescription @ Home

Single-Site Research Project

The proposed participatory arts program (Arts on Prescription @ Home (AoP@home)) is a novel pilot project, focussing on supporting carers by providing new and meaningful methods of engagement between the carer, the person with dementia for whom they care, and those around them. It builds upon a growing evidence base showing the positive role of participatory arts in promoting the health and wellness of older people with a range of conditions, including people with dementia and their carers.

AoP@home will provide six dyads with an eight week arts program, of around two hours per week, delivered in the home by a professional artist. Between sessions, participants will be provided with materials and support to pursue their individually tailored program.

As the nature of the cultural arts is highly personal, the artistic endeavour to be undertaken by each dyad will be designed in collaboration with the participants. Shared experiences and lasting memories will be created, helping carers, family and

Ageing, Restorative Care+Reablement

friends deepen their understanding of their loved one, and nurture respect and dignity through new found achievement.

Researchers: A/Prof Chris Poulos & A/Professor Colm Cunningham, HammondCare; A/Prof Ros Poulos, University of NSW; Professor Elizabeth Beattie, Queensland University of Technology
Sites: HammondAtHome South West Sydney & South East Sydney

Duration: Feb 16 to Aug 16
Funding Source: Dementia Collaborative Research Centres-Consumers and Carers (Queensland University of Technology)
Project Partners: University of NSW & Queensland University of Technology
Study Status: In progress

Improving carer wellness

Helping carers focus on their own wellness needs. This is a guide for carers to help them understand their own wellness needs, how being a carer can adversely impact on wellness, and strategies for carers to take positive steps towards improved wellness.

During 2016 this project explored how the health and wellbeing of dementia carers is impacted by the caring role. It explored ways in which carers could be better supported, and asked them to identify gaps in service provision.

The health and wellbeing of many dementia carers is impacted by the caring role, with many experiencing social isolation and emotional stress, and having limited opportunity for education on how to better support themselves and their care recipients.

Researchers: Professor Christopher Poulos & Mr Damian Harkin
Site: Not applicable
Duration: Nov 15 to Jun 16

Funding Source: Dementia Collaborative Research Centre
Project Partners: University Queensland & Dementia Collaborative Research Centre
Study Status: Completed

Translational Outcomes:

A carer wellbeing guide was developed to inform and educate dementia carers. Further research was conducted with GPs to explore what challenges they face in supporting dementia dyads.

Arts on Prescription Evaluation

“Arts on Prescription” is a service delivery project that will provide participatory arts to community dwelling older people with unmet health and wellness needs who live in the Liverpool and Bankstown local government areas and in the local government areas surrounding North Turrumurra.

The Arts on Prescription project aims to improve the health and welfare of older people with complex health or aged care needs. And inasmuch as the project is classified as a service development project, the research component will aim to

provide an evaluation of the project suitable for dissemination within the aged care, academic and arts communities. It should also provide data for a scientific publication about the impact of an Arts on Prescription project for older people.

During 2016 Arts on Prescription continued to deliver programs to participants. Program evaluation continued, under the supervision of the UNSW evaluation team. The program will conclude in April 2017, with the final project and evaluation reports delivered by August 2017.

Researchers: Professor Christopher Poulos, Mr Damian Harkin & Ms Mary-Rose Birch
Site: Not applicable
Duration: Aug 15 to Jul 17

Funding Source: Department of Social Services
Project Partners: None
Study Status: In Progress

Food waste, dietary intake and nutritional status at Alfred Health: is there a link?

Single-Site Study

The aim of the project was to determine the risk of malnutrition of the residents at HammondCare Caulfield Care Homes, to measure the food and fluid intake, and wastage and to investigate the associations between malnutrition risk, food intake and food waste.

Researchers: Ms Sarah Ryan & Ms Indi Swan, Ms Kudzai Norah Nyamunduru
Site: Caulfield Residential Facility, Melbourne
Duration: Jun 15 to Jan 16

Funding Source: In researchers own time
Project Partners: Nil
Study Status: Completed

Translational Outcomes:

A total of 85 residents participated in the study. According to the Mini Nutrition Assessment, 20 (23.5%) residents were found to be at high risk of developing malnutrition, 49 (57.6%) were at moderate risk and 16 (18.8%) were at low risk. Overall, morning tea and lunch had the highest tray wastage of 10.6% and dinner and lunch had the highest food wastage of 43%.

The residents were provided with enough food to meet their daily energy and protein requirements. They consumed adequate amounts of energy to meet their estimated energy requirements and less protein than their estimated protein requirements.

Future research should consider conducting a similar study with longer audit days representative of food habits. And it is important to screen residents for malnutrition regularly to ensure that appropriate referrals and treatment are put in place before residents develop malnutrition.

Rehabilitation

New in 2016

Student-Led Outpatient Physiotherapy Rehabilitation Clinic

Multi-Site Research Project

The aim of this project is to evaluate a student-led outpatient rehabilitation physiotherapy clinic at Campbelltown and Camden Hospitals in terms of service delivery (wait time, occasions of service and discharge reason) as well as patient and student satisfaction. The objectives of this investigation are to increase service efficiency and activity with timely access to therapy services. The clinic aims to facilitate hospital transfer of care, optimise patient functional outcomes and reduce representation rates of patients in the target priority patient populations.

This project hopes to help evaluate if student run clinics provide an increased case load while maintaining the expected level of quality, satisfaction and efficiency of a NSW hospital department.

Researchers: Ms Renee Fortunato & Mr Paul Bowron, SWSLHD; Mr Mark Buhagiar, HammondCare; Professor Lucinda Chipchase & Mr Sascha Karunaratne, Western Sydney University
Site: Braeside Hospital
Duration: Feb 16 to Dec 16

Funding Source: In researcher's own time
Project Partners: Nil
Study Status: In progress

New in 2016

FIM item redundancy

Single-Site Research Project

The FIM is a commonly used assessment tool to assess functional status of patients in the rehabilitation setting. Out of the total 18 functional items measured in the FIM, there are three items to measure transfer functions. It is proposed, based on results from a previous study, that there is a high correlation between the three transfer items.

The aim of this study is to determine the agreement and correlation between the three transfer items indicating redundancy. A strong correlation of the transfer items will also affect the reliability and internal consistency of the whole FIM scale.

Researchers: A/Prof Friedbert Kohler, HammondCare; Professor Hugh Dickson, Liverpool Hospital
Site(s): Braeside Hospital
Duration: Jan 16 to Jun 17

Funding Source: In researcher's own time
Project Partners: Nil
Study Status: In progress

Is inpatient rehabilitation necessary after knee replacement? (HIHO study) which includes sub-study:- Determining clinically relevant change in 6-minute walk test (6MWT) following a total knee arthroplasty (TKA)

Main study

If inpatient rehabilitation is shown not to benefit patients following joint replacement, the resources could be redistributed to other patients.

Sub study: Exploring patient important improvement thresholds for the six minute walk test in a knee arthroplasty cohort. Description: This exploratory study aimed to identify 'minimal', 'moderate' and 'much better' improvement thresholds for the six-minute walk test (6MWT) in a knee arthroplasty cohort.

Researcher: Mr Mark Buhagiar
Site: Braeside Hospital
Duration: Jun 12 to Dec 16

Funding Source: HCF Foundation (sub study is internally supported)
Project Partners: South West Sydney (SWS) LHD, Ingham Institute UNSW
Study Status: Completed

Translational Outcomes:

The results of this project are being used to re-evaluate the effectiveness of current health practices in this area, particularly in the private sector, in the hope it will lead to increased efficiency of service delivery.

The feasibility of using an ICF based Mobility Assessment Tool to measure change in mobility of patients on a rehabilitation ward

To establish the practicability of using a free open access WHO classification system to demonstrate improvements in patient mobility in a rehabilitation setting.

To provide more cost-effective and affordable care to patients.

Researcher: Associate Professor Friedbert Kohler, Dr Jim Xu
Site: Braeside Hospital
Duration: Sept 10 to Dec 16

Funding Source: Internally Supported
Project Partners: Nil
Study Status: Completed

Translational Outcomes:

The outcome of this project found that it is feasible to use an ICF based mobility assessment tool to measure change of mobility in patients on a rehabilitation ward. Such a tool has now been developed and validated and is being validated for more widespread use as an international standard.

Rehabilitation

Validation and confirmation of reliability and sensitivity of the ICF brief core set in stroke patients as an outcome tool in sub-acute setting

The HammondCare unit, where this new assessment tool was tested, is at the leading edge of developing stroke assessment rehabilitation in the world.

This study will influence how stroke rehabilitation will be developed throughout the world. ICF is open access and does not cost. Use of the FIM incurs significant costs.

Researcher: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Jan 12 to Dec 16

Funding Source: In researcher's own time
Project Partners: Nil
Study Status: Completed

Translational Outcomes:

This study has enabled us to better understand the challenges of implementing the ICF, one of the family of International Classifications developed by the WHO in clinical practice. The ICF is very important as it is a detailed classification of human function and many disease processes, including stroke, affecting human functioning. Further work needs to be undertaken to facilitate better routine capture of the functional consequences of diseases and this study has been a significant step in this direction.

Sub-acute tools project. The development of an internationally valid ICF mobility outcome measure

Multi-Site Study

Developing, testing and validating an ICF based mobility assessment tool.

HammondCare at Braeside is the coordinating centre for a world-wide multi-centre group of rehabilitation professionals that are aiming to develop and test a generally usable mobility assessment tool for disabled people around the world.

During 2016 the assessment tool was developed and validated as a clinician rated tool, and is in the process of being published. As a follow on from this project the tool is now being validated as a patient reported outcome tool.

Researcher: Associate Professor Friedbert Kohler, Dr Seema Radhakrishnan
Site: Braeside Hospital
Duration: Dec 12 to Jun 17

Funding Source: Otto Bock Healthcare Products and Ossur
Project Partners: Multiple
Study Status: In Progress

Understanding consumer and clinician preferences for inpatient rehabilitation after joint replacement

Together with the findings of the related RCT, it is expected that this study will contribute to the redesign of the delivery of rehabilitation for total knee arthroplasty (TKA) recipients in particular, and especially in the private sector.

Redesign of extant rehabilitation models will enhance affordability and thus sustainability of TKA and total hip replacement (THR) procedures. Further, in the public sector, lower utilisation of inpatient beds by joint replacement recipients will release beds for patients who are more infirm, such as those who have suffered a stroke or hip fracture. Finally, more sustainable healthcare delivery benefits all Australians.

Researcher: Mr Mark Buhagiar
Site: Braeside Hospital
Duration: Feb 14 to Jun 16

Funding Source: HCF Foundation
Project Partners: SWSLHD Ingham Institute UNSW
Study Status: Completed

Translational Outcomes:

The outcome of this project was a better understanding of private patients' preferences for care post total knee arthroplasty leading to improved overall care.

Exercise self-management to improve long-term functioning & prevent falls after hip or pelvic fracture

The results of this study will be directly relevant to the care of older people recovering from fall-related fractures. We have designed a program that aims to enhance mobility and prevent falls in this high risk population.

The program involves home visits from a physiotherapist to teach a home exercise program as well as fall prevention strategies. This self-management approach has the potential to have a lasting impact on mobility and falls. If the intervention is found to be effective we will make program resources freely available so they can be implemented broadly. We will also undertake an economic evaluation so healthcare providers can decide whether any additional benefits from the program warrant the additional cost of providing it.

Researcher: Ms Constance Vogler
Site: Greenwich Hospital
Duration: Jan 09 to Dec 16

Funding Source: Administered by The George Institute for Global Health Australia
Project Partners: Nil
Study Status: Completed

Rehabilitation

Translational Outcomes:

This NHMRC-funded trial randomised 336 older adults to receive usual care or an additional home-based exercise and education program aimed at lessening disability and preventing falls. There was no significant between-group difference for the primary outcomes but important improvements on some of the secondary outcome measures and an indication of a greater impact in people who were more physically able at baseline.

The results have the potential to improve practice by encouraging prescription of ongoing home exercise and fall prevention advice in older people after fall-related fracture.

Using the ICF to explore mobility and the factors influencing mobility from the perspective of persons with an amputation

Sub-study of a multi-site study

It is essential to explore and understand the perspective of the individual with an amputation in provision of quality individualised care.

Exploring this perspective from an international sample facilitates inclusion of relevant and important cultural and geographical aspects of functioning in the development of the ICF mobility outcome measure.

Researcher: Associate Professor Friedbert Kohler, Dr Seema Radhakrishnan
Site: Braeside Hospital
Duration: Dec 12 to Jun16

Funding Source: Otto Bock Healthcare products & Ossur
Project Partners: Multiple
Study Status: Completed

Translational Outcomes:

This study has given us a much better understanding of the expectations of patients who have had an amputation. It is always important to take into account the expectations of patients and through this formal study we have been able to comprehensively explore the patients' expectations which will further enhance a balanced therapy program being given to the patients. In conjunction with the study on experts' expectations it has allowed us to gain an excellent understanding of differences between patient and professional expectations which in turn supports our endeavour to deliver the best possible patient focussed care.

Using the ICF to explore mobility and the factors influencing mobility of individuals with an amputation from the perspective of the professional

Sub-study of a multi-site study

It is essential to explore and understand the perspective of the professional who treats individuals with an amputation and the differences between the perspectives of professionals and individuals with an amputation.

Exploring this in a multinational setting is the basis for a broad understanding of relevant concepts in the functioning of individuals with an amputation to facilitate the development of the ICF mobility outcome measure.

Researcher: Associate Professor Friedbert Kohler, Dr Seema Radhakrishnan
Site: Braeside Hospital
Duration: Dec 12 to Jun16

Funding Source: Otto Bock Healthcare products & Ossur
Project Partners: Multiple
Study Status: Completed

Translational Outcomes:

This study has given us a better understanding of the expectations professionals have of individuals undergoing rehabilitation following an amputation in our own setting as well as in the international setting. Understanding professional expectations enables better planning and coordination of individualised rehabilitation programs as the professional biases can then be addressed to ensure optimal outcomes for the patients.

SNAP rehabilitation and AROC data accuracy

The Subacute Non-Acute Patient (SNAP) patient data collection and the Australasian Rehabilitation Outcome Centre (AROC) are instrument components of rehabilitation practice in Australia.

Funding and benchmarking are based on the data collection. This study explores the accuracy and reproducibility of part of the data collection.

Researcher: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Sep15 to Dec17

Funding Source: Internally supported
Project Partners: Nil
Study Status: The data for this project has been analysed and has been submitted to the Australasian Faculty of Rehabilitation Annual Scientific Meeting 2017 as an abstract for presentation.

Pain Management

Developing a community of practice for knowledge translation and practice improvement in spinal cord injury (SCI) and traumatic brain injury (TBI)

This project builds on the grant looking at a state-wide model of care by a wider project that takes it further to examine implementation and evaluation and brings in interstate and international contributors.

This increases the national and international exposure of the state wide model of care that we are developing and therefore the role of HammondCare in this area of service provision. It also means that we may have a role in delivering a model of care at a national and possibly international level.

Researcher: Professor Philip Siddall
Site: Off-Site research
Duration: Jun 13 to Dec 16

Funding Source: Internally Supported
Project Partners: Nil
Study Status: Completed

Translational Outcomes:

This project investigated the useability and uptake of web based resources that we had developed for GPs to assist in the assessment and treatment of pain following spinal cord injury. It was found that although very useful, GPs reported that some of the tools were too complicated for use in standard consultations and navigation was often not intuitive, discouraging regular use. To address these findings, Prof Philip Siddall and other investigators in the project are in the process of developing a new “Quicksteps” on-line tool which provides a streamlined, quickly accessible and easily navigable tool with the minimum required information. This will be accessible from a NSW Health website and provide GPs with a much more useable tool for spinal cord injury pain assessment and treatment. There is interest in the use of the tool in North America and we are considering collaborating with colleagues in the US and Canada to implement it in their setting.

Outpatient pain self-management program

This project aims to collect data from people attending HammondCare’s group pain program.

This is essential in disseminating the results of our program and establishing the value of the program, particularly as it takes a new approach. The very positive outcomes we have been achieving have already been noted by the Northern Sydney Local Health District and the NSW Agency for Clinical Innovation with Philip Siddall invited to present the data at a state wide meeting in November 2014. The results are crucial in validating our program.

During 2016 the researchers evaluated outcomes from over 100 people who completed the pain program. The results match or exceed results from other pain clinics including a

reduction in pain of over 30%. An unexpected but interesting finding was that one of the best predictors of a reduction in pain during the program was the person’s level of spiritual wellbeing.

Researchers: Professor Philip Siddall & Ms Rebecca McCabe
Site: Greenwich Hospital
Duration: May 11 to Dec 19

Funding Source: Internally Supported
Project Partners: Nil
Study Status: In Progress

Neurobiological, psychological and existential contributors to pain: an integrated approach

This grant has been awarded by the Australian & New Zealand College of Anaesthetists to support HammondCare in its development of an academic centre of excellence in pain medicine at HammondCare.

The award itself recognises HammondCare as a leading academic contributor to pain medicine and the funding will cover the salaries and associated costs of two researchers employed within HammondCare. The project itself aims to bring together the physical, psychological and spiritual contributors to pain. This emphasis particularly on the spiritual receives little attention within pain medicine and will help HammondCare in developing and disseminating an innovative approach to pain management that is in line with the HammondCare philosophy and ethos.

During 2016 the researchers have completed the collection of data from groups of people without pain, with chronic pain, with cancer and without pain and with cancer and pain. The results to date show that the level of existential and spiritual distress in people with pain is significantly higher than people without pain and as high as those with cancer.

Researchers: Professor Philip Siddall, Professor Melanie Lovell, Ms Mandy Corbett & Dr Phil Austin
Site: Greenwich Hospital
Duration: Feb 14 to Dec 17

Funding Source: Australian & NZ College of Anaesthetists
Project Partners: University of Sydney
Study Status: In Progress

The SCI Pain Course: Examining a low-intensity self-management program for chronic pain and emotional wellbeing among adults with spinal cord injuries

This project is a collaboration of key researchers in the field of pain management at Macquarie University and Sydney University and will aim to develop an on-line pain management program for people with pain following spinal cord injuries.

Pain Management

This project will have important implications for the treatment of people with pain following spinal cord injury, and complements the resources that are also being developed as part of our state wide service at Greenwich Hospital.

Researcher: Professor Philip Siddall
Site: Off-site research
Duration: May 14 to Dec 16

Funding Source: Lifetime Care and Support Authority
Project Partners: Macquarie University, University of Sydney, NSW Agency for Clinical Innovation
Study Status: Completed

Translational Outcomes:

The project aimed to develop an on-line pain management course to assist people living with pain following spinal cord injuries. The course has now been done by 58 people with spinal cord injury pain with pleasing results. People who completed the program reported modest improvements in pain intensity (15% on average) but substantial improvements in mood (average 33%) and very high satisfaction ratings (95%). So far the course has only been available as a trial and we are now looking at making it available more generally. We are also looking at the possibility of making the course available through collaborators in the US and Canada.

A clinically relevant tool for assessing pain modulatory pathways

This project will help us understand the contribution of several different mechanisms.

On completion of our research it is hoped we can provide a new and simple technique for the assessment of persistent pain. By doing so, it will enable us to identify potential targets for treatment.

During 2016 the researchers have developed and administered a new “Pain Modulation Index”, – a questionnaire that aims to measure peoples ability to block out pain. Results show a reasonable relationship with physiological tests however the researchers are looking to refine the questionnaire further to make it more accurate.

Researchers: Professor Philip Siddall & Dr Phil Austin
Site: Greenwich Hospital
Duration: Feb 14 to Dec 17

Funding Source: Australia & NZ College of Anaesthetists
Project Partners: University of Sydney
Study Status: In Progress

Changing the culture of pain management: Addressing the problem of pain for older Australians and people living with dementia (INTERVENE)

Intervene is a research project investigating pain experience and pain management practices in residential aged care (RAC) in Australia.

It has involved data collection across eight RAC sites in NSW, retrospective audit of resident notes, resident interviews, staff focus groups, staff knowledge questionnaires and monitoring DBMAS data.

Researchers: A/Prof Colm Cunningham, Dr William McClean, Professor Philip Siddall, Ms Juliet Kelly

Site: Residential and HammondCare At Home
Duration: Stage 1 Apr 2014 to Dec 2015, Stage 2 Nov 2016 to Oct 2018

Funding Source: John T Reid Trust & HammondCare Foundation and Cognitive Decline Partnership Centre
Project Partners: Nil
Study Status: Stage 1: Completed
Stage 2: In Progress

Translational Outcomes:

The INTERVENE project was completed in December 2015 and the final report was released in January 2016. The findings of this project revealed that pain management for older people in residential aged care continues to fall short of current best practice guidelines and that organisational culture is one of the key barriers to best practice in this area. Key findings from this project formed the basis for a successful funding application to the Cognitive Decline Partnership Centre for Intervene Phase 2, an implementation project.

Optimising the neurophysiological assessment of residual thermonociceptive sensation following spinal cord injury

Multi-Site Study

Researchers: Mr Paul Wrigley, University of Sydney, Professor Philip Siddall
Site: Off-site research
Duration: Jan 15 to Jun 16

Funding Source: Australian & New Zealand College of Anaesthetists
Project Partners: University of Sydney
Study Status: Completed

Translational Outcomes:

Specialised physiological tests show that even people with complete loss of sensation following a spinal cord injury still have messages that are getting through to the brain. It has been proposed that pain following a spinal cord injury may be due to these messages. If this is true, it has profound implications for the treatment of this type of pain because it would suggest identifying whether there are remaining pathways and then blocking any remaining messages going to the brain. We used functional brain imaging to show that 50% of paraplegics with no sensation below the level of injury still had brain activation when their toe was brushed indicating preserved pathways. However, pain was not more common in these people indicating that this is not the underlying cause of the pain.

Advance Care Planning

New in 2016

The Advance Project. Initiating palliative care and advance care planning: training and resources for General Practice Nurses

Single-Site Research Project

One of the biggest barriers to providing palliative care (PC) and implementing advance care planning (ACP) in primary care settings is general practitioners' time. We will develop a toolkit and training resource to enable nurses working in general practice to: efficiently and sensitively promote awareness of ACP using screening; identify patients who may benefit from a palliative approach; assess symptoms; and help patients to identify their most important questions and concerns regarding ACP/PC. This will enable GPs to address these issues more efficiently. Further, the tools will help identify patients who might most benefit from referral to specialist PC services.

During 2016 a toolkit was developed based on a literature review and input from our National and International advisory group. An online training resource is available from a project specific website www.caresearch.com.au/advance. In 2017 face to face training and individual tele-mentoring will be delivered nationally. Train-the-trainer materials have been developed and the program will be evaluated, using a mixed methods approach, to inform ongoing implementation.

Researchers: A/Prof Josephine Clayton & A/Prof Joel Rhee, HammondCare

Site: National Project with base at Greenwich Hospital
Duration: Feb 16 to Dec 17

Funding Source: Commonwealth Department of Health, National Palliative Care Project Grant
Project Partners: Caresearch (A/Prof Jennifer Tieman); Austin Health Department of Advance Care Planning (Dr Karen Detering); University of Queensland (Prof Geoffrey Mitchell); University of Technology Sydney (Prof Jane Phillips); University of Wollongong (Prof Elizabeth Halcomb); University of Sydney (A/Prof Rachael Morton and Prof Timothy Shaw).
Study Status: In progress

A toolkit to build the capacity of disability staff to assist adults with intellectual disability (ID) to understand and plan for their end of life

Multi-Site Study

This project will inform better end of life care and education about dying for people with intellectual disability and their caregivers.

It will strengthen ties with care providers in ID settings. This in turn will inform our palliative care services caring for people

with ID. This project involves international collaborations with an expert in palliative care for people with ID from the UK.

During 2016 the toolkit, including an award winning DVD partly filmed at Greenwich Hospital, and a training resource for care-workers was developed. This training resource aims to enable care-workers to assist adults with intellectual disability to better understand dying and death. The training was provided to care-workers, who then delivered the intervention to individual clients through discussion of end of life planning in everyday contexts. Data was collected using mixed methods to assess the impact of the training intervention on both staff and adults with intellectual disability. Feedback from both staff and clients has been very positive. The data from the formal evaluation will be analysed in 2017.

Researchers: Professor Roger Stancliffe (lead), Associate Professor Josephine Clayton (one of the Chief Investigators)

Site: Greenwich Hospital
Duration: Oct 13 to Jun 17

Funding Source: Funded by ARC administered by USyd
Project Partners: Department of Disability and Community, Faculty of Health Sciences, University of Sydney; Sunshine; Keele University, UK
Study Status: In Progress

Advance care planning in incurable cancer patients with disease progression on first line chemotherapy

Multi-Site Randomised Clinical Trial

This multi-centre project will evaluate an advance care planning intervention for people with incurable cancer.

During 2016 recruitment for the study was completed with 208 patient/family dyads participants. Data collection, including longitudinal follow up data for caregiver participants is continuing. Analysis of data will commence in 2017.

This could in turn help people with incurable cancer to be better prepared for their deaths, be able to participate in decisions about their care, enable their wishes for end of life care to be respected and reduce decision making burden for their loved ones. This will be a landmark study and involves collaborations with key researchers in this area across the country.

Researchers: Professor Martin Tattersall (lead), Associate Professor Josephine Clayton (one of the chief investigators)

Site: Greenwich Hospital
Duration: Jul 13 to Jun 17

Funding Source: Funded by NHMRC administered by USyd
Project Partners: Multiple including: Department of Cancer Medicine; USyd; Respecting Patient Choices Program, Austin Hospital Victoria; CeMPED USyd
Study Status: In Progress

Advance Care Planning

Investigating barriers and facilitators to advance care planning for dialysis and pre-dialysis patients

Multi-Site Study

This study will inform the development of advance care planning for people with end stage renal failure.

This will help people with renal failure to be prepared should their health deteriorate in the future, enable their wishes for end of life care to be respected and reduce decision making burden for their loved ones. As people with renal failure commonly develop cognitive decline it is important to start these conversations about advance care planning early in their disease trajectory. This is an area of clinical practice that has been highlighted as an important area of need, yet there are many barriers to implementation of ACP in this setting. This program of research will strengthen HammondCare's ties with non-cancer referrers to palliative care.

Researcher: Associate Professor Josephine Clayton (Supervision of PhD student)
Site: Greenwich Hospital
Duration: Jan 14 to Dec 16

Funding Source: Funded by Kidney Health Australia & administered by USyd
Project Partners: University of Sydney; Department of Renal Medicine, Royal North Shore Hospital; Respecting Patient Choices Program, Victoria; Improving Palliative Care through Clinical Trials (ImPaCCT)
Study Status: Completed

Translational Outcomes:

Qualitative interviews and a survey of renal clinicians across Australia highlighted that advance care planning can be rewarding for clinicians as it empowers patients and yet it can expose personal and professional vulnerabilities for clinicians. Renal clinicians believe that a more collaborative approach is needed, with increased efforts to identify the evolving and individualised needs and goals of chronic kidney disease patients. Models of ACP that address clinicians' personal and professional vulnerabilities when initiating ACP may foster greater confidence and cultural acceptance of ACP in the CKD setting. Survey results highlighted that ACP in nephrology needs support through education and chronic kidney disease specific resources as well as endorsement and leadership by nephrologists. Together these findings will inform the design, refinement and implementation of ACP education for renal clinicians and ACP programs for patients with chronic kidney disease in Australia.

Advance Care Planning: Ensuring your wishes are known and honoured

Multi-Site Study

This research will help to increase the awareness and knowledge of Advance Care Planning for elderly people in a primary care setting.

This will enable elderly people in the community to discuss their wishes for future medical care should they ever become too unwell to participate in decisions. We hypothesise that this will help normalise end of life discussions in the community and improve end of life care for elderly Australians, including people who are served by HammondCare.

Researchers: Associate Professor Josephine Clayton, Dr Abigail Franklin & Dr Joel Rhee
Site: Off-site research
Duration: Jan 15 to Dec 16

Funding Source: Internally Supported
Project Partners: Cremorne Medical Practise, Seaforth Medical Practice, GP Cremorne, Lynwood Medical & Natural Health Centre
Study Status: Completed

Translational Outcomes:

In this project we adapted and then piloted a nurse facilitated screening tool to initiate advance care planning conversations with elderly patients in general practice.

Twenty-four patients and six nurses participated in the study across four general practices in Sydney. All patients and nurses found the advance care planning tool to be useful and most patients felt it would encourage them to discuss their wishes further with their family and general practitioner. This nurse facilitated screening tool provides a simple, acceptable and feasible approach to introducing advance care planning to elderly general practice patients during routine health assessments. The screening tool has since been incorporated into a toolkit and training resource for general practice nurses, that is currently being evaluated nationally.

Advance Care Planning

A pilot study of a systematic patient-centred and practice nurse coordinated model of Advance Care Planning in Australian general practice

Multi-Site Study

The research project seeks to improve Advance Care Planning in the primary care setting.

This is important for HammondCare as many of its patients (e.g. dementia services, rehabilitation services, aged care services, palliative and supportive care services) require multidisciplinary care with primary care physicians and practices.

Researchers: Dr Joel Rhee and Associate Professor Josephine Clayton

Site: Off-site research

Duration: May 15 to Apr 16

Funding Source: Royal Australian College of GPs and HCF grant

Project Partners: University of NSW, University of Sydney, Prince of Wales Hospital

Study Status: Completed

Translational Outcomes:

This study has generated important supporting evidence to show that Australian general practices are ready to take a greater role in Advance Care Planning. We provided training to nurses and GPs in four general practices and encouraged them to have Advance Care Planning discussions with a selected number of patients. Five nurses and four GPs took up the training and education, and most found the education and training program to be useful and appropriate to their needs. The nurses felt comfortable in discussing Advance Care Planning with their patients, and felt that they had sufficient support from the GPs and the mentor nurse. The patients who took part in the study felt that the nurses provided them with an opportunity to work through important issues, and valued the therapeutic relationship that they had with the clinical team. The study shows that primary care nurse coordinated ACP is feasible, acceptable and useful.

The findings highlight that the primary health care sector, especially GPs and practice nurses, are important 'untapped resource' that should play a greater role in Advance Care Planning. These findings have informed the development of further training and resources as part of HammondCare's National Advance Project "Initiating palliative care and advance care planning: training and resources for General Practice Nurses"

Spiritual Aspects of Care

Spirituality and spiritual care in practice

This project will aim to understand what staff think and know about spirituality and spiritual care so they can provide more effective care and also to have a basis for professional development in this area.

Researchers: Professor Roderick MacLeod & Dr Phil Austin

Site: Greenwich Hospital

Duration: Mar 14 to Jun 16

Funding Source: Friends of Greenwich

Project Partners: Nil

Study Status: Completed

Translational Outcomes:

Findings from our studies do not immediately affect quality of life for people in care. More that our results suggest that training in spiritual care is required for all staff which will in turn help improve quality of life for hospital and community care patients.

If, as suggested by our findings, spiritual care training is developed and implemented for staff regardless of job description, they are more likely to recognise and act upon the spiritual needs of both patients and clients in the community. Indeed, previous work shows that by first understanding and second addressing spiritual needs, consideration can be given to the unique culture and spirituality of each individual.

Improving spiritual wellbeing in people who are chronically or terminally ill allows for more positive feelings especially with regard to meaning and purpose in life and therefore the quality of life for people in care.

Spiritual Aspects of Care

Levels and associations of existential distress in people with persistent pain

This project is examining levels of spiritual wellbeing in people with chronic pain.

The aims of the project around issues of spirituality are in line with the HammondCare ethos, as an innovative approach to pain management. The different emphasis on spirituality that is emerging from this research has gained interest and positive support from pain consumer groups.

During 2016 the researchers examined the levels of existential wellbeing in people with spinal cord injury and pain. People with pain in addition to a spinal cord injury had the lowest levels of existential wellbeing. In addition, a strong sense of meaning and purpose was protective in coping with pain and a spinal cord injury. With one exception, none of the people who had a strong sense of meaning and purpose developed depression even if they had a spinal cord injury and severe chronic pain. We are now in the process of developing a program to assist people with pain and disability build resilience through stronger sense of identity and purpose.

Researchers: Professor Philip Siddall, Dr Mandy Corbett & Associate Professor Melanie Lovell (Spiritual wellbeing in chronic and cancer pain), Ms Bronwyn Raymond & Ms Joan McClelland

Site: Greenwich Hospital

Duration: May 13 to Oct 17

Funding Source: Australian & NZ College of Anaesthetists

Project Partners: University of Sydney

Study Status: In Progress

Teaching+Academic Professional Activities

Professor Rod MacLeod MNZM

As the Director of the Greenwich Learning & Research Centre, Rod, has responsibility for developing research across the HammondCare palliative care sites. As well as supervising PhD students and undertaking research into varied aspects of palliative care, Rod has given many oral presentations to a wide variety of groups including the University of Sydney Medical Program, community palliative care workers across NSW and primary health care groups. He has also spoken at national and international conferences about our work.

One of his passions within HammondCare has been the development and growth of the Palliative Care Community Home Support Program which has provided support to over 2000 families across the districts we serve. In addition he has led development of the Palliative Care Bridge www.palliativecarebridge.com.au, an educational resource for health care professionals and families involved with end of life care.

He has reviewed research manuscripts for a number of academic journals and advised on research grant applications both in Australia and overseas.

Professor Philip Siddall

As well as his roles as Director of the Pain Management Service and Director of Medical Services at Greenwich and Neringah Hospitals, Phil is Conjoint Professor in Pain Medicine at the University of Sydney. He teaches in the Graduate Medical Program and Postgraduate Program in Pain Management as well as supervising a PhD candidate. In addition, he is involved in teaching trainees in anaesthesia, pain medicine and rehabilitation. During 2016, he presented lectures to doctors, nurse and allied health practitioners in general practice, anaesthesia, pain medicine and aged care.

In 2016, Phil also served as a member of a number of local, national and international committees including co-chair of the NSW Agency for Clinical Innovation Pain Management Network, the nomination committee of the International Association for the Study of Pain and the Court of Examiners for the Faculty of Pain Medicine of the Australian & New Zealand College of Anaesthetists.

Professor Melanie Lovell

As Medical Director of Palliative Care Services at Greenwich Hospital, Melanie is passionate about providing excellent care for people with life-limiting illness and their families. She has a strong track record of leading-edge collaborative translational research. Melanie holds a clinical academic appointment at the University of Sydney as Associate Professor and is an Adjunct Professor at the University of Technology Sydney (UTS). Her teaching roles include lectures and small group teaching for medical students and health science students in pain, symptom management and spirituality. She supervises two PhD students at UTS, and physician trainees through the College of Physicians.

Melanie's professional contributions include committee membership of the ImPaCCT (Improving Palliative Care through Clinical Trials) Management Advisory Committee, Palliative Care Clinical Studies Collaborative Trials (PaCCSC) management Committee and Publications Subcommittee. She continues to chair the Australian Cancer Pain Guideline Working Party which developed and updates the guideline on the Cancer Council Australia wiki platform.

She is a member of the ADAPT Measurement working group for implementation of the Anxiety and Depression Pathway for oncology patients nationally and the Cannabis Trials group. As lead investigator for the Stop Cancer PAIN trial, Melanie is involved in all the committees for that study. She is on the executive committee of Sydney Vital, the Northern Sydney Translational Cancer Centre and co-lead of its Supportive Care Pillar. Melanie is currently principal investigator of clinical trials run at Greenwich Hospital.

Teaching+Academic Professional Activities

Professor Christopher Poulos

Chris is HammondCare's Head of Research and Aged Care Clinical Services, having moved full-time to HammondCare in March 2016 from the position of Hammond Chair of Positive Ageing and Care, UNSW. He is Conjoint Professor in the School of Public Health and Community, Faculty of Medicine, UNSW and also Visiting Professorial Fellow with the University of Wollongong (Australian Health Services Research Institute).

Chris has an active teaching role in the areas of reablement and restorative care, and the role of arts in health and aged care. He contributes to the UNSW postgraduate and undergraduate teaching programs and has presented widely at national and international conferences.

As Chair of an international working group on reablement and older people, Chris presented on the topic of reablement in dementia at the inaugural International Federation on Ageing / DaneAge Copenhagen Summit in April 2016. He also consults to government on aspects of aged care.

Professor Kirsty Beilharz

Professor Kirsty Beilharz presented Music Engagement training through the Dementia Centre (Hammondville, Greenwich and Melbourne) for dementia care practitioners. This education developed carers' methods to support and relate to people living with dementia, using music to create engaging and meaningful experiences. It equipped carers with tools for tailoring music to the individual, and facilitating participatory (group) music-making and creative expression.

Professor Janine Stevenson

Janine is a supervisor and lecturer for the University of Sydney Master of Medicine post-graduate medical degree. She lectures, conducts tutorials, journal clubs and evidence-based medicine to undergraduates of Sydney University.

Post-graduate students in psychiatry receive lectures and workshops. As a member of faculty Janine is involved in exam setting and marking for undergraduates. She is on the RANZCP examination committee, the Board of the International Society for the study of Personality Disorders, the faculty of Psychiatry of Old Age of the RANZCP.

She is involved in research into psychotherapy and outcome of personality disordered adults across the age range, with treatment-resistant depression; the management of behavioural problems in dementia and effects on length of stay of psychiatry inpatients.

She has published articles on borderline personality disorders and on differentiating bipolar disorder from borderline disorder as well as the psychotherapeutic management of treatment-resistant depression.

Janine has presented her research findings at international conferences in Australia, China and the USA.

Dr Stephen Judd

Dr Judd has 30 years' experience in the healthcare and information technology industries and has been Chief Executive of HammondCare since 1995. When he began, HammondCare served fewer than 250 clients and had an annual revenue of \$8 million. Today, it provides care to more than 14,000 people each year, and FY17 revenue is estimated to be around \$250 million. Stephen has written and contributed to books on dementia care, aged care design and the role of charities in Australian society. He has served on numerous government and industry committees and is currently a member of the Advisory Council of the Australian Aged Care Quality Agency.

Teaching+Academic Professional Activities

Associate Professor Andrew Cole

As well as Andrew's substantive roles within HammondCare as Senior Staff Specialist (Rehabilitation) and Chief Medical Officer, he is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health & Community Medicine. He convenes the Aged Care & Rehabilitation teaching block in Phase 2 of the UNSW MD program, with regular teaching of medical students at Kensington, Hammondville and St George campuses. During 2016, he also presented lectures to doctors, nurses and allied health professionals in continuing education and training programs in rehabilitation, general practice, community health and aged care settings in Australia, China and Greece.

During 2016, Andrew served as a member of several national and international Rehabilitation Medicine peak bodies. He is President and Chair of Council of the Australasian Faculty of Rehabilitation Medicine (AFRM) of the Royal Australasian College of Physicians. In the first half of 2016, he was Oceania Representative and a member of the President's Executive of the International Society of Physical & Rehabilitation Medicine (ISPRM), and continues as a member of the Education Committee of that organisation.

Associate Professor Friedbert Kohler

Friedbert continues in his role as a senior academic in Rehabilitation Medicine within HammondCare. He is instrumental in encouraging the staff particularly in the rehabilitation unit at Braeside hospital to engage in research and supervises the registrars in their research projects.

In 2016 he was instrumental in leading a team to establish an Age and Ageing academic clinical stream as part of the Academic Health Science Partnership in southern Sydney which includes SWSLHD, SESLHD, SVPHN, UNSW, UTS and WSU as well as a number of research institutes. HammondCare is a partner to this stream with support from Professor Chris Poulos and Associate Professor Colm Cunningham. One of the aims of this clinical stream is to improve the timeframe for the translation of research into clinical practice.

Friedbert is active internationally in collaborations with the WHO, and the International Society of Prosthetics and Orthotics, where he is president-elect and multiple research partners.

Associate Professor Colm Cunningham

Director of the Dementia Centre, HammondCare, Colm leads an Australian and International team of over 200 staff involved in research, education and consultancy as well as the translation of this knowledge into accessible publications and tools to improve practice. The Centre's priorities are building design, life engagement, models of care, understanding behaviour and end of life care. Colm is an international expert with over 30 years' experience in older age care.

A general and intellectual disability nurse and social worker, Colm was the deputy director at the UK Dementia Centre, University of Stirling and has written extensively and undertaken research on a wide range of issues about dementia including design, pain care, hospital care, night time care and intellectual disability. Working across a range of faculties of education and research in HammondCare, Colm has significant expertise in supporting translational research and meaningful practice and culture change. Colm is an Associate Professor at the University of Salford Institute for Dementia and a Visiting Fellow in Dementia Design and Practice at the University of Edinburgh School of Health in Social Science. Colm is also a member of the Wicking Strategic Review Panel. Colm led national dementia behaviour response services, Dementia Support Australia, with the aim of reconsidering what it means to have a 'behaviour of concern'.

Associate Professor Stephen Macfarlane

Associate Professor Macfarlane is involved in undergraduate medical student teaching in Aged Psychiatry at Monash University, and is joint co-ordinator of the teaching program for Advanced Trainees in Aged Psychiatry in Victoria and Tasmania. He is Chair of the Victorian Branch of the Faculty of Old Age Psychiatry (RANZCP) and Secretary of the Binational Faculty (Australia/New Zealand). He remains heavily involved in Alzheimer's Disease clinical trials as a Principal Investigator at local, national and international levels.

Teaching+Academic Professional Activities

Associate Professor Josephine Clayton

Josephine is the Chair of the National and International Advisory Group and Project Director for HammondCare's Advance Project for initiating palliative care and advance care planning (ACP) in general practice (www.caresearch.com.au/advance). This project is funded by the Australian Government in a National Palliative Care Project and is being led by HammondCare in collaboration with various health organisations and universities across Australia. In 2016 she was the Clinical Lead for the NSW Clinical Excellence Commission's Communication Group for the Last days of Life Toolkit. She also chairs the patient resources working group and is a member of the steering committee for Cancer Institute NSW's ADAPT (Anxiety and Depression Pathways) Program. She chairs the expert advisory group for the Australian Research Council funded "enabling people with intellectual disability to understand dying" project and is a facilitator for the Australasian Chapter of Palliative Medicine Communication Skills training workshops. She is the co-pillar lead for Sydney Vital Translational Cancer Research Centre's pillar 4: Supportive care, end-stage tumours and end-of-life management. In 2016 she was a member of: the consensus panel for the American Society of Clinical Oncology Patient-Physician Communication Guidelines, the expert panel for the European Taskforce on ACP, the Primary Care Education Advisory Group and the Evaluation Advisory Group for the Australian Commonwealth funded Decision Assist Program (to improve palliative care and ACP in aged care, the NHMRC Cognitive Decline Partnership Centre advisory committee to implement a national approach to dementia-specific ACP, the management committee for ImPaCCT (Improving Palliative Care through Clinical Trials); and the Scientific Committee for the National ACP and end-of-life care conference held in Melbourne in November 2016.

Josephine coordinates palliative care teaching for medical students during the oncology block and for pre-interns at the Northern Clinical School, University of Sydney and contributes to teaching various health professionals about palliative care and ACP locally, nationally and internationally. She has a strong interest in teaching end-of-life communication skills.

Dr Megan Best

Megan holds a clinical academic appointment at the University of Sydney. Her teaching roles include lectures and small group teaching for medical students on spirituality and professional and personal development. She regularly teaches ethics in palliative care to physician trainees and to nursing staff pursuing professional education.

Megan's professional contributions include committee membership of the Australian and New Zealand Palliative Medicine Association working party for palliative sedation, the European Association of Palliative Care Spiritual Care Taskforce and The Global Network for Spirituality and Health (WHO). She reviews many manuscripts for medical publications on the topic of spirituality. She also speaks and writes widely on the topic of palliative care and euthanasia.

Mr Mark Buhagiar

Mark continues his role in the training of undergraduate and postgraduate physiotherapy students in the rehabilitation and palliative care specialties, and has had research in this area published throughout the past year. He also designs, coordinates and delivers placements within the rehabilitation setting for overseas trained physiotherapists seeking professional recognition of their qualifications in the Australian healthcare setting. In 2016/17 Mark maintained his role as an Adjunct Supervisor at Macquarie University.

In the past year Mark has presented aspects of his research at national and international conferences and meetings. He was a member of the organising committee for the 2016 SWSLHD Research and Innovation Showcase, and for the 2017 National Allied Health Conference. Mark has also continued with his regular contributions to the Ingham Institute and ACI research seminars, as well as to HammondCare and local district conferences, workshops and forums. He is in the final stages of submitting his PhD thesis on rehabilitation following joint arthroplasty, which he is completing through the University of New South Wales. This work has attracted significant industry interest along with further competitive funding, and formed the basis of a second research PhD (for another candidate).



Education, publications+ presentations

Higher Research Degrees

Academic Degree Supervision

Awards+Best Poster Presentation

Books+Chapters

Journal Articles

Technical+Other Reports

Industry+Magazine Articles

Academic Conference+Industry Seminars

Education

Higher Research Degrees

Student Name: Julie Bajic Smith
Degree: PhD under examination (December 2016)
University: Macquarie University
Thesis Title: Emotional and psychological wellbeing in home care workers – a multi-method study
Supervisors: Associate Professor Denise Jepsen and Professor Julie Fitness

Student Name: Dr Kirsty Beilharz
Degree: PhD candidate
University: Sydney College of Divinity
Thesis Title: Trinity & Metaphysics: Mystery, Given-ness and Mimesis – Interdisciplinary Analogy in Reasoning a Contemporary Epistemology
Supervisors: Rev. Dr. David Höhne and Prof. Dr. Philip Kariatlis

Student name: Dr Megan Best
Degree: PhD awarded 2016
University: University of Sydney
Thesis Title: Spiritual care of patients with advanced cancer and the role of the doctor
Supervisors: Professor Phyllis Butow and Professor Ian Olver

Student Name: Mr Mark Buhagiar
Degree: PhD candidate
University: University of New South Wales
Thesis Title: Investigating elements of post-operative rehabilitation for total knee replacement (TKR)
Supervisors: Justine Naylor, Ian Harris and Wei Xuan: All affiliated with both South West Sydney Clinical School, UNSW and Ingham Institute of Applied Medical Research

Student Name: Mr Michael Darragh
Degree: PhD candidate
University: University of Wollongong
Thesis Title: Effective Approaches to Leadership Skill Development
Supervisors: Professor Bourgeois and Dr Joyce-McCoach

Student Name: Ms Meredith Gresham
Degree: PhD candidate
University: The University of Sydney
Thesis Title: An investigation of the clinical utility of the electronic bidet for Australian nursing home residents and staff.
Supervisors: Professor Lindy Clemson and Associate Professor Lee-Fay Low

Student Name: Ms Bianca Kinnear
Degree: PhD candidate
University: University of Wollongong
Thesis Title: Physical Therapy as an adjunct to Botulinum toxin-A for treatment of spasticity in adults with neurological impairment.
Supervisors: Professor Anne Cusick (primary at University of Wollongong) & Associate Professor Natasha Lannin (secondary at LaTrobe University)

Student Name: Dr Martin Kennedy
Degree: PhD candidate
University: University of Lancaster, UK
Thesis Title: Junior hospital medical officers' experience of making clinical decisions regarding patients with advanced, irreversible, progressive and life limiting medical conditions
Supervisor: Dr Sarah Brearley and Dr Catherine Walshe

Academic Degree Supervision

Clayton J; Student Name: Adam Walczak, *PhD Thesis: Improving quality of life at the end-of-life*, University of Sydney, Sydney, commenced part-time candidature in 2009. PhD completed and awarded in 2016.

Clayton J; Student Name: Marcus Sellars, *PhD Thesis: Delivering patient-centred advance care planning in chronic kidney disease (CKD): the perspectives of patients, caregivers and healthcare providers*; University of Sydney, Sydney, commenced part-time candidature in July 2014. Awarded University of Sydney Postgraduate Award Scholarship in 2016.

Glasgow N, **MacLeod R;** et al. Student Name: Suzanne Rainsford, *PhD Thesis: A rural perspective on quality end of life care* ANU, Canberra 2014-2017.

Goodyear-Smith F, Wright-St Clair V, **MacLeod R;** Student Name: Yvonne Bray. *PhD Thesis: Transnationals' experience of end of life care in New Zealand*. University of Auckland 2010-2016.

Jones M, Healee D, **MacLeod R;** Student Name: Christine McDonald. DHSci, *PhD Thesis: Collaborative practice in the New Zealand palliative care environment* AUT Auckland, NZ 2011-2016.

Kohler F, and Dickson H. Student Name: Dr Seema Radhakrishnan, *Doctoral Thesis: Developing an ICF based Mobility Assessment Tool*; University of New South Wales, Sydney. 2013 – 2018.

Education

Academic Degree Supervision

Kohler F, and Dickson H. Student Name: Dr Jim Xu, *Thesis Title: Developing an ICF Core Set for persons with a lower limb amputation*; University of New South Wales, Sydney. 2010 – 2018.

Lovell M, Student Name: Dr Jessica Lee, *PhD Thesis: Improving outcomes for people living with complex cancer pain*. University of Technology Sydney. 2016 – 2019.

Lovell M, Clayton J Student Name: Celina Estacia. Honours Thesis: Exploring communication of symptoms meaning in palliative care. University of Sydney, Sydney. 2016.

Lovell M, Student Name: Ms Xiangfeng (Renee) Xu. *PhD Thesis: Developing a cultural specific education program for Chinese background cancer patients on pain management: a mixed methods study*, University of Technology Sydney. 2015 – 2019.

MacLeod R, Keogh J, Arroll, B et al – Elaine Rogers, *PhD Thesis: Does a multi-targeted approach of supportive care improve the cancer cachexia status in lung cancer patients?* University of Auckland 2009-2017.

Owens G, Huggard P, **MacLeod R,** Student Name: Sue Jacobi, *PhD Thesis: The nature of grief in family and professional carers of people with dementia*. University of Auckland 2010-2016.

Poulos CJ, Faux SG and Harris I (Supervisors). Student Name: Dr Jane Wu, *PhD Thesis: Early Rehabilitation in Trauma and Critical Illness*. Faculty of Medicine, The University of New South Wales. 2013-2019.

Siddall P, co-supervisors Wrigley P, Kellow J, Hush J. Student Name: Rosemary Chakiath, *Doctoral Thesis: Central sensitisation in visceral and somatic pain*, University of Sydney, Sydney, 2013-2017.

Stevenson J, co-supervisor Chui H. Student Name: Melissa Hulme, *Master of Psychology: Childhood trauma, social support, personality disorders and outcome on three inpatient psychiatric wards in Sydney*, University of Western Sydney, 2016-2018.

Awards

Buhagiar M, 3 Minute Thesis Competition Winner, SWSLHD Health Beyond Research and Innovation Showcase.

Best M, Sydney Catalyst Travel and Education Award, Sydney Catalyst.

Best M, Post-doctoral Fellowship, under media embargo.

MacLeod R, Member of the New Zealand Order of Merit.

Siddall P, Distinguished Member Award, Australian Pain Society.

Publications

Books+Chapters

Beilharz K. *Music Remembers Me.* Sydney, HammondCare Media, ISBN 978-0-9945461-1-1. Accepted, in press 2016.

Beilharz K. *Grace and Nurture: Connecting and Engaging through Music in Dementia Care* chapter in *Cambridge Scholars book: Well-Being, Personal Wholeness and the Social Fabric: An Interdisciplinary Approach.* Accepted, in press 2016.

Stevenson J. *Personality Disorders*, chapter in Handbook for medical students, Sydney (in print).

Walczak A, Butow B, **Clayton J.** *Communication at the end-of-life.* In Cooper N, Frain J (eds) ABC of Clinical Communication. Wiley Publishing, Chichester, UK, accepted December 2016.

Journal Articles

Austin PD, Macleod R, Siddall P, McSherry W *The ability of hospital staff to recognise and meet patients' spiritual needs: a pilot study.* Journal of the Study of Spirituality. 2016; 6 (1): 20-37. DOI:10.1080/20440243.2016.1158453.

Austin P, MacLeod R, Siddall P, McSherry W, Egan R. *Spiritual care training is needed for clinical and non-clinical staff to recognise and meet patients' spiritual needs.* Journal of the Study of Spirituality (accepted October 2016).

Austin P, MacLeod R, *Finding peace in clinical settings: a narrative review of concept and practice,* Palliative and Supportive Care doi:10.1017/S1478951516000924; 2016.

Best M, Butow P, Olver I (2016) *Why do We Find It so Hard to Discuss Spirituality? A Qualitative Exploration of Attitudinal Barriers,* J Clin Med: 5(9):77 doi:10.3390/jcm5090077.

Best, M (2016) *A good death.* Zadok Perspectives: 131: 9-11.

Best M, Butow P, Olver I (2016) *Palliative Care Specialists' beliefs about spiritual care, Support Care Cancer:* 24(8): 3295-3306.

Best M, Butow P, Olver I (2015) *Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality,* Palliat Support Care:10.1017/s1478951515001236.

Best M, Butow P, Olver I (2016) *Doctors discussing religion and spirituality: A systematic literature review,* Palliat Med:30(4):327-337.

Best M, Butow P, Olver I (2015) *Do patients want doctors to talk about spirituality? A systematic literature review,* Patient Educ Couns 98: 1320-1328.

Journal Articles

Best M, Aldridge L, Butow P, Olver I, Webster F (2015) *Conceptual Analysis of Suffering in Cancer: a systematic review,* Psychooncology 24: 977-986.

Best M, Aldridge L, Butow P, Olver I, Price MA, Webster F (2015) *Treatment of holistic suffering in cancer: A systematic literature review,* Palliat Med:29(10):885-98.

Cohen J, Beernaert B, Van den Block L, Morin L, Hunt K, Miccinesi G, Cardenas-Turanzas M, Onwuteaka-Philipsen B, **MacLeod R,** Ruiz-Ramos M, Wilson D, Loucka M, Csikós Á, Rhee Y-J, Ko W, Teno J, Deliens L. 2016 *Differences in place of death between lung cancer and COPD patients: A study in 14 countries using death certificate data.* npj Primary Care Respiratory Medicine (accepted October 2016).

Corbett M, **Lovell M, Siddall P.** *The role of spiritual factors in people living with chronic pain: A qualitative investigation.* Journal of the study of spirituality. [Accepted Dec 7, 2016].

Cummins, C, Kayes, NM, Reeve J, Smith, G, **MacLeod R,** McPherson KM. *Navigating physical activity management following a diagnosis of cancer: a qualitative exploration.* European Journal of Cancer Care DOI: 10.1111/ecc.12608, 2016.

Dong S, Butow P, Agar M, **Lovell M,** Boyle F, Stockler M, **Forster B,** Tong A. *Clinicians' Perspectives on Managing Symptom Clusters in Advanced Cancer: A Semistructured Interview Study.* Journal of Pain and Symptom Management. 2016; 51(4), 706-717.e5.

Dong S, Butow P, Tong A, Agar M, Boyle F, **Forster B,** Stockler M, **Lovell M.** *Patients' experiences and perspectives of multiple concurrent symptoms in advanced cancer: a semi-structured interview study.* Supportive Care in Cancer. 2016; 24(3), 1373-1386.

Egan R, **MacLeod R,** Jaye C, McGee R, Baxter J, Herbison P 2016 *Spiritual beliefs, practices and needs at end-of-life: results from a New Zealand study* Palliative and Supportive Care doi:10.1017/S147895151600064X.

Forster BC, Proskurin H, Kelly B, **Lovell M,** Ilchef R, **Clayton J.** *Psychiatry trainees' views and educational needs regarding the care of patients with life limiting illnesses.* Palliative and Supportive Care 2016 Jun 20:1-11. [Epub ahead of print] PMID: 27320847.

Franklin AE, Lovell M, Boyle FM. *A case of opioid toxicity on conversion from extended-release oxycodone and naloxone to extended-release oxycodone in a patient with liver dysfunction.* Journal of Pain and Symptom Management. 2016; Nov5. pii:S0885-3924(16)30767-9. doi:10.1016/j.jpainsymman.2016.10.354. [Epub ahead of print].

Publications

Journal Articles

Gill L, McCaffrey N, Cameron I, Ratcliffe J, Kaambwa B, Corilis M, Fiebig J, **Gresham M** (2016). *Consumer directed care in Australia: early perceptions and experiences of staff, clients and carers.* Health and Social Care in the Community 2016 Mar 2. DOI: 10.1111/hsc.12328. [Epub ahead of print].

Guy SD, Mehta S, Casalino A, Cote I, Kras-Dupuis A, Moulin DE, Parrent AG, Potter P, Short C, Teasell R, Bradbury CL, Bryce TN, Craven BC, Finnerup NB, Harvey D, Hitzig SL, Lau B, Middleton JW, O'Connell C, Orenczuk S, **Siddall P,** Townson A, Truchon C, Widerstrom-Noga E, Wolfe D, Loh E. *The CanPain SCI Clinical Practice Guidelines for Rehabilitation Management of Neuropathic Pain after Spinal Cord: Recommendations for treatment.* Spinal Cord. 2016; 54 Suppl 1: S14-23. doi: 10.1038/sc.2016.90.

Guy SD, Mehta S, Harvey D, Lau B, Middleton JW, O'Connell C, Townson A, Truchon C, Wolfe D, Bradbury CL, Bryce TN, Casalino A, Cote I, Craven BC, Finnerup NB, Hitzig SL, Kras-Dupuis A, Moulin DE, Orenczuk S, Parrent AG, Potter P, **Siddall P,** Short C, Teasell R, Widerstrom-Noga E, Loh E. *The CanPain SCI Clinical Practice Guideline for Rehabilitation Management of Neuropathic Pain after Spinal Cord: recommendations for model systems of care.* Spinal Cord. 2016; 54 Suppl 1: S24-7. doi: 10.1038/sc.2016.91.

Hatano Y, Moroni M, Wilcock A, Quinn S, Csikos A, Allan SG, Agar M, Clark K, **Clayton J,** Currow DC. *Pharmacovigilance in hospice/palliative care: the net immediate and short term effects of dexamethasone for anorexia.* BMJ Supportive & Palliative Care, BMJ Support Palliat Care. 2016 Sep;6(3):331-7. doi: 10.1136/bmjspcare-2015-001037. PMID: 27288400.

Johnson S, **Clayton J,** Butow P, Silvester W, Detering K, Hall J, Kiely B, Cebon J, Clarke S, Bell M, Stockler M, Beale P, Tattersall M. *Advance care planning in incurable cancer patients: a randomised controlled trial.* The study protocol. BMJ Open 2016 Dec 1;6(12):e012387. doi: 10.1136/bmjopen-2016-012387. PMID: 27909034.

Loh E, Guy SD, Mehta S, Moulin DE, Bryce TN, Middleton JW, **Siddall P,** Hitzig SL, Widerstrom-Noga E, Finnerup NB, Kras-Dupuis A, Casalino A, Craven BC, Lau B, Cote I, Harvey D, O'Connell C, Orenczuk S, Parrent AG, Potter P, Short C, Teasell R, Townson A, Truchon C, Bradbury CL, Wolfe D. *The CanPain SCI Clinical Practice Guidelines for Rehabilitation Management of Neuropathic Pain after Spinal Cord: introduction, methodology and recommendation overview.* Spinal Cord 2016; 54 Suppl 1: S1-6. doi: 10.1038/sc.2016.88.

Luckett T, Spencer L, Morton RL, Pollock CA, Lam L, Silvester W, Sellars M, Detering KM, Butow PN, Tong A, **Clayton J.** *Advance care planning in chronic kidney disease: a survey of current practice in Australia.* IN PRESS Nephrology, accepted February 2016.

Journal Articles

Luckett T, Phillips JL, Lintzeris N, Allsop D, Lee J, Solowij N, Martin J, Lam L, Aggarwal R, McCaffrey N, Currow D, Chye R, **Lovell M,** McGregor I, Agar M. *Clinical trials of medicinal cannabis for appetite-related symptoms from advanced cancer: A survey of preferences, attitudes and beliefs among patients willing to consider participation.* Internal Medical Journal 2016 Nov; 46(11):1269-1275. doi: 10.1111/imj.13224.

MacIntyre R, Menzies R, Kpozehouen E, Chapman M, Travaglia J, Woodward M, Jackson Pulver L, **Poulos CJ,** Gronow D, Adair T. *Equity in disease prevention: Vaccines for the older adults - a national workshop, Australia 2014.* Vaccine 34(46): 5463-5469.

MacLeod R, Crandall JM, Wilson DM, **Austin P.** *Death Anxiety among New Zealanders: The Predictive Role of Gender and Marital Status.* Mental Health, Religion & Culture doi 10.1080/13674676.2016.1187590. 2016.

MacLeod R. *The Palliative Care Bridge.* European Journal of Palliative Care 23(3); 150-151. 2016.

Mehta S, Guy SD, Bryce TN, Craven BC, Finnerup NB, Hitzig SL, Orenczuk S, **Siddall P,** Widerstrom-Noga E, Casalino A, Cote I, Harvey D, Kras-Dupuis A, Lau B, Middleton JW, Moulin DE, O'Connell C, Parrent AG, Potter P, Short C, Teasell R, Townson A, Truchon C, Wolfe D, Bradbury CL, Loh E. *The CanPain SCI Clinical Practice Guidelines for Rehabilitation Management of Neuropathic Pain after Spinal Cord: screening and diagnosis recommendations.* Spinal Cord. 2016; 54 Suppl 1: S7-13. doi: 10.1038/sc.2016.89.

Mitchell GK, Senior HE, **Rhee JJ,** Young S, Teo PCK, Murray S, Boy K, **Clayton J.** *Using intuition or a formal palliative care needs assessment screening pathway in general practice to predict death within twelve months: a randomised controlled trial.* IN PRESS Palliative Medicine, accepted December 2016.

Michael N, O'Callaghan C, **Clayton J.** *Exploring the utility of the vignette technique in promoting advance care planning discussions with cancer patients and caregivers.* Patient Education and Counseling, 2016 Aug;99(8):1406-12. doi: 10.1016/j.pec.2016.03.021.PMID: 27021780.

Morin L, Aubry R, Frova L, **MacLeod R,** Wilson DM, Loucka M, Csikos A, Ruiz-Ramos M, Cardenas-Touranzas M, Rhee YJ, Teno J, Öhlén J, Deliens L, Houtekker D, Cohen J. *Estimating the need for palliative care at the population level: a cross national study in 12 countries.* Palliative Medicine. doi:10.1177/0269216316671280. 2016.

Naylor JM, Mills K, **Buhagiar M,** Fortunato R, Wright R. *Minimal important improvement thresholds for the six-minute walk test in a knee arthroplasty cohort: triangulation of anchor- and distribution-based methods.* BMC Musculoskeletal Disorders. 2016; 17:390.

Publications

Journal Articles

Radhakrishnan S, **Kohler F**, Gutenbrunner C, Jayaraman A, Li J, Pieber K, Schiappacasse C. *The use of the International Classification of Functioning, Disability and Health, to classify the factors influencing mobility reported by persons with an amputation: An international study*. Prosthetics and Orthotics International. Epub 2016 Jul 1:0309364616652016.

Rainsford S, **MacLeod R**, Glasgow NJ, Wilson DM, Phillips CB, Wiles RB *Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review*. Palliative Medicine (accepted November 2016).

Rainsford S, **MacLeod R**, Glasgow NJ, Wilson DM, Phillips CB, Wiles RB. *Rural residents' perspectives on the rural "good death": a scoping review*. Health and Social Care in the Community doi: 10.1111/hsc.12385. 2016.

Rainsford S, **MacLeod R**, Glasgow NJ. *Place of death in rural palliative care: A systematic review*. Palliative Medicine 30(8) 745-763 DOI: 10.1177/0269216316628779. 2016.

Sanderson C, Quinn SJ, Agar M, Chye R, Clark K, Doogue M, Fazekas B, Lee J, **Lovell M**, Rowett D, Spruyt O, Currow DC. *Pharmacovigilance in hospice/palliative care: net effect of pregabalin for neuropathic pain*. BMJ Support Palliat Care 2016; 6:323-330 doi:10.1136/bmjspcare-2014-000825.

Sellers M, Tong A, Luckett T, Morton RL, Pollock CA, Spencer L, Silvester W, **Clayton J**. *Clinicians' Perspectives on Advance Care Planning for Patients With CKD in Australia: An Interview Study*. IN PRESS American Journal of Kidney Disease, accepted December 2016.

Shaw J, Price M, **Clayton J**, Grimison P, Shaw T, Rankin N, Butow P. *Developing a clinical pathway for the identification and management of anxiety and depression in adult cancer patients: an online Delphi consensus process*. Supportive Care in Cancer 2016 Jan; 24(1):33-41. doi: 10.1007/s00520-015-2742-5. Epub 2015 Apr 23 PMID: 25903929.

Siddall P, McIndoe L, **Austin P**, Wrigley PJ. *The impact of pain on spiritual well-being in people with a spinal cord injury*. Spinal Cord 2016; doi:10.1038/sc.2016.75 Epub, 2016 May 31.

Standcliffe RJ, Wiese MY, Read S, Jettes G, **Clayton J**. *Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?* Research in Developmental Disabilities 2016 Feb-Mar;49-50:47-59. doi: 10.1016/j.ridd.2015.11.016. PMID: 26658384.

Walczak A, Butow PN, Tattersall MHN, Davidson PM, Young J, Epstein RM, Costa DJ, **Clayton J**. *Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication*

Journal Articles

support program for patients and caregivers. International Journal of Nursing Studies 2016 Oct 21; 67:31-40. doi: 10.1016/j.ijnurstu.2016.10.008 PMID: 27912108.

Walczak A, Butow PN, Bu S, **Clayton J**. *A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?* Patient Education and Counselling 2016 Jan;99 (1):3-16. doi: 10.1016/j.pec.2015.08.017. Review. PMID: 26404055.

Widerstrom-Noga E, Biering-Sorensen F, Bryce TN, Cardenas DD, Finnerup NB, Jensen MP, Richards JS, Richardson EJ, **Siddall P**. *The International Spinal Cord Injury Pain Extended Data Set (Version 1.0)*. Spinal Cord, 2016; 54: 1036-46. doi: 10.1038/sc.2016.51.

Wilson DM, Dhanji N, Playfair R, Nayak SS, Pupilampu G, **MacLeod R**. *A scoping review of bereavement service outcomes*. Palliative and Supportive Care 1-18, 2016, doi:10.1017/S147895151600047X. 2016.

Wu J, Faux SG, Harris I, **Poulos CJ**, Stevermuer T. *Record linkage is feasible with non-identifiable trauma and rehabilitation datasets*. ANZJPH. 2016 40(3): 245-9.

Wu J, Faux SG, Harris I, **Poulos CJ**. *Integration of trauma and rehabilitation services is the answer to more cost-effective care*. ANZJSurg. 2016 86(11): 900-904.

Zdenkowski N, Tesson S, Lombard J, **Lovell M**, Hayes S, Francis PA, Dhillon HM, Boyle FM. *Supportive care of women with breast cancer: key concerns and practical solutions*. Medical Journal of Australia. 2016 Nov 21; 205(10):471-475.

Technical+Other Reports

Clayton J. *Now there is specialised support and training for Australian GP nurses to provide better care at a very difficult time*. Caresearch Palliative Perspectives. www.caresearch.com.au/blog 2nd December 2016

Authors include **Clayton J, Gavin J, Rhee J** on behalf of The Advance Project National and International Advisory Group www.caresearch.com.au/Advance *The Advance Toolkit: Initiating palliative care and advance care planning in General Practice*. Endorsed by the Australian Primary Health Care Nurses Association and officially recognized as an accepted clinical resource by the Royal Australasian College of General Practitioners in 2016.

Authors include **Clayton J, Gavin J, Rhee J** on behalf of The Advance Project National and International Advisory Group www.caresearch.com.au/Advance *The Advance Guide: a model for implementing six screening and assessment tools for initiating palliative care and advance care planning in General Practice*. Endorsed by

Publications

Technical+Other Reports

the Australian Primary Health Care Nurses Association and officially recognized as an accepted clinical resource by the Royal Australasian College of General Practitioners in 2016.

Authors include **Clayton J, Gavin J, Rhee J** on behalf of the Advance National and International Advisory Group www.caresearch.com.au/Advance *Advance Care Planning Screening Interview. A structured interview for initiating conversations about advance care planning into routine health assessments in Australian General Practice*. Endorsed by the Australian Primary Health Care Nurses Association and officially recognized as an accepted clinical resource by the Royal Australasian College of General Practitioners in 2016.

Authors include **Clayton J, Gavin J, Rhee J** on behalf of the Advance National and International Advisory Group www.caresearch.com.au/Advance *The Advance Referral Triage Tool. A tool to evaluate the supportive and palliative care needs of patients and their families in General Practice*. Endorsed by the Australian Primary Health Care Nurses Association and officially recognized as an accepted clinical resource by the Royal Australasian College of General Practitioners in 2016.

Authors include **Clayton J, Gavin J, Rhee J** on behalf of the Advance National and International Advisory Group in collaboration with the Pam McLean Communication Centre www.caresearch.com.au/Advance *The Advance Project Video Suite. A series of 12 practical training videos that present insights, case studies, and conversations between patients, families, nurses and general practitioners to illustrate how to initiate advance care planning and supportive care assessments into everyday general practice*. Endorsed by the Australian Primary Health Care Nurses Association and officially recognized as an accepted clinical resource by the Royal Australasian College of General Practitioners in 2016.

Clayton J. *HammondCare Why talking about end of life care matters*. HammondCare Health & Aged Care blog 18th May 2016 <http://www.hammond.com.au/health-and-aged-care/why-talking-about-end-of-life-care-matters>

Ftanou M, Michael N, Pollard A, **Clayton J**. *What is the role of psychological support and interventions in the treatment of lung cancer?* Updated April 2016, http://wiki.cancer.org.au/australia/Clinical_question:What_is_the_role_of_psychological_support_and_interventions_in_the_treatment_of_lung_cancer%3F. In: Cancer Council Australia Lung Cancer Guidelines Working Party. Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia. Available from: http://wiki.cancer.org.au/australia/Guidelines:Lung_cancer

Gresham M, Taylor L, Keyes S, Wilkinson H, **McIntosh D**. *Showing the Way: Developing an evaluation framework for signage for people living with dementia*. A Dementia Centre and University of Edinburgh collaboration.

Technical+Other Reports

Dementia Collaborative Research Centre – Carers and Consumers, Qld University of Technology, 2016.

MacLeod R, Flood J, **Dixon T** 2016 End of life care policy and position statement: <https://hammondcare.sharepoint.com/Pages/Policy%20and%20Planning%20Office.aspx> HammondCare, Sydney

MacLeod R 2016 Submission "NZ Parliament Health Select Committee: Petition of Hon. Maryan Street and 8,974 others".

MacLeod R 2016 What matters most in the end: <http://www.hammond.com.au/health-and-aged-care/what-matters-most-in-the-end>

Parker G, Bayes A, McClure G, Roman Ruiz del Moral Y, **Stevenson J**. *Clinical Status of comorbid bipolar disorder and borderline personality disorder*. The British Journal of Psychiatry Jun 2016,bjp.bp. 115.177998; DOI: 10.1192/bjp.bp.115.177998

Smith T, **Clayton J**. *What is the role of advance care planning and timing of referral for patients with lung cancer*. In: Cancer Council Australia Lung Cancer Guidelines Working Party. Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia. Updated June 2016, Available from: http://wiki.cancer.org.au/australia/Clinical_question:What_is_the_role_of_advance_care_planning_and_timing_of_referral_for_patients_with_lung_cancer%3F In: Cancer Council Australia Lung Cancer Guidelines Working Party. Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia. Available from: http://wiki.cancer.org.au/australia/Guidelines:Lung_cancer

Publications

Industry+Magazine Articles

Best M. *The truth about dying.* Solas, Summer:28-31. 2016. ISSN: 2058-9859.

Beilharz K, *Singing from the same sheet, Australian Ageing Agenda, February, 2016. pp. 44-45.*

Beilharz K, 'Engaging and connecting through music: enablement in practice' in *Australian Journal of Dementia Care*, Vol. 5 No.1 February/March, 2016. pp. 21-25.

Macfarlane SR, *When is a Delusion Not a Delusion?* Australian Ageing Agenda. July-Aug 2016. p47.

Stevenson J, *Borderline Personality Disorder: the difficult patient.* Medicine Today vol 16 no 3, 2016 p65-70

Clayton J. (interviewee) "New Training Program Helps Nurses Talk About Death And Dying", article in Huffington Post 22/11/16, http://www.huffingtonpost.com.au/2016/11/21/new-training-program-helps-nurses-talk-about-death-and-dying/?utm_hp_ref=au-refresh

Clayton J. (interviewee) "HammondCare rolls out practice nurse training on advance care planning", article in the Australian Ageing Agenda 24/11/16, <http://www.australianageingagenda.com.au/2016/11/24/hammondcare-rolls-practice-nurse-training-advance-care-planning/>

Clayton J. (interviewee) "Advance care and palliative care planning for general practice nurses", article in HealthTimes 15/11/16, <https://healthtimes.com.au/hub/practice-nursing/67/practice/kk1/advance-care-and-palliative-care-planning-for-general-practice-nurses/2102/>

Clayton J. (interviewee) "General Practice nurses encouraged to talk about death", article in Talking Aged Care 17/11/16 <https://www.agedcareguide.com.au/talking-aged-care/general-practice-nurses-encouraged-to-talk-about-death>

Clayton J. (interviewee) "Nurses will train to discuss death, dying in general practices", article in Aged Care Insite 17/11/16 <http://www.agedcareinsite.com.au/2016/11/nurses-to-be-trained-to-discuss-death-dying-in-general-practices/>

Clayton J. (interviewee) "Training offered to help nurses discuss death and dying", article in Nursing Review 17/11/16 <http://www.nursingreview.com.au/2016/11/training-offered-to-help-nurses-discuss-death-and-dying/>

Presentations

Academic Conference+ Industry Seminars

Alford M, Macfarlane SR. *Younger onset dementia and Australia's Severe Behaviour Response Teams.* Grand Designs International Dementia Conference. Sydney Australia, 16 June 2016.

Allison K, Shepherd H, **Clayton J,** Girgis A, Lindsay T, Orr F. *Development and evaluation of patient resources to explain screening for anxiety and depression as a routine part of cancer care.* Cancer Institute NSW Innovations in Cancer Treatment and Care Conference, September 2016, Sydney.

Anderzhon J, **Judd S.** *International Aged Care Environments.* Environments for Aging Conference. Austin, Texas. USA. 11 April.

Andrews S, Gilholme A, **Duggan N & Makin T.** *Enhancing the capacity of acute sector staff to deliver and support evidence based care for people with dementia in hospital settings.* Grand Designs: Are we there yet? 2016 International Dementia Conference. Sydney, Australia, 17th June 2016.

Ansell J, James L, **MacLeod R.** *Outcomes of the pilot Next Steps cancer rehabilitation programme.* COSA Conference, Gold Coast, November, 2016.

Ansell J, James L, **MacLeod R.** *The Next Steps cancer rehabilitation programme: results of a pilot survey.* New Zealand Psychological Society Annual Conference. Wellington, NZ. September 2016.

Austin P, Siddall P. *The Pain Modulation Index: A novel self-reporting questionnaire to determine levels of endogenous pain modulation in people with chronic pain,* World Pain Congress, Yokohama, Japan, 28 Sept 2016.

Beilharz K. *Music...the Food of Love: Connecting and Engaging in Dementia Care,* Grand Designs International Dementia Conference, (Plenary Speaker), Sydney Australia, 16 June 2016.

Best M. *Matters of life and death.* Charles Sturt University Annual Forum, Port Macquarie campus, November 2016.

Best M. *Should euthanasia be legalized? A consideration of the ethics involved.* Burwood Christian Union, Deakin University, Geelong, September 2016.

Best M. Butow P, Olver I. *Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality.* EACH conference, Heidelberg Germany, September 2016.

Best M. *Euthanasia,* Freedom 16 Conference, Freedom for Faith, Sydney Australia August 2016.

Best M. *Safeguarding our patients from the euthanasia debate.* 2016 Annual Scientific Meeting, Medical Oncology Group of Australia. Gold Coast Australia, August 2016.

Best M. Butow P, Olver I. *Comparing palliative care and supportive care specialist beliefs about spiritual care.*

Presentations

Academic Conference+Industry Seminars

MASCC International Conference, Adelaide Australia, June 2016.

Best M. Butow P, Olver I. *Helping dying patients with cancer find peace: a qualitative study examining the role of the doctor.* MASCC International Conference, Adelaide Australia, June 2016.

Best M. *Euthanasia.* SMA, University of Western Australia. Perth Australia, May 2016.

Buhagiar M, Naylor JM, **Kohler F,** Harris, IA, Xuan W, Wright R, Fortunato R. *Hospital Inpatient versus Home-based rehabilitation after knee arthroplasty (The HIHO study): A randomised controlled trial.* 2016 American Academy of Orthopedic Surgeons Annual Meeting: Florida USA, 3 March 2016.

Buhagiar M, Naylor JM, **Kohler F,** Harris, IA, Xuan W, Wright R, Fortunato R. *Hospital Inpatient versus Home-based rehabilitation after knee arthroplasty (The HIHO study): A randomised controlled trial.* 10th World Congress of the International Society of Physical and Medical Rehabilitation: Kuala Lumpur Malaysia, 17 May 2016.

Buhagiar M, Naylor JM, **Kohler F,** Harris, IA, Xuan W, Wright R, Fortunato R. *Hospital Inpatient versus Home-based rehabilitation after knee arthroplasty (The HIHO study): A randomised controlled trial.* SWSLHD Health Beyond Research and Innovation Showcase: Sydney Australia, 18 October 2016.

Buhagiar M, Naylor JM, **Kohler F,** Harris, IA, Xuan W, Wright R, Fortunato R. *Hospital Inpatient versus Home-based rehabilitation after knee arthroplasty (The HIHO study): A randomised controlled trial.* ACI Musculoskeletal Network Forum: Sydney Australia, 28 October 2016.

Clayton J, Gavin J, Rhee J, Tierman J, Detering K, Phillips J, Halcomb E, Morton R, Shaw T, Mitchell G. *The Advance Project. Initiating palliative care and advance care planning: training and resources for General Practice Nurses.* National Advance Care Planning Conference, Melbourne, November 2016.

Clayton J. *Initiating palliative care and advance care planning: training and resources for General Practice Nurses,* Sydney North Primary Health Network End of life co-design workshop, 5th December 2016.

Clayton J. *Involving students and junior doctors in your research in a meaningful way,* Inaugural ImPaCCT (Improving palliative care through clinical trials) Early Career Researcher Leadership Forum, Concord Medical Education Centre, 1st December 2016.

Clayton J. Invited Chair for session on *Advance Care Planning in Acute Health Settings* at the National Advance Care Planning Conference, 6th November 2016.

Clayton J. Presentation on The Advance Project *"Initiating palliative care and advance care planning in General Practice"* at the Australian Government Department of Health, Canberra 9th June 2016.

Clayton J. *Palliative care and advance care planning: a training package for General Practice Nurses,* Improving Palliative Care through Clinical Trials (ImPaCCT), Concept Development Workshop, May 3rd 2016.

Clayton J. *Palliative care and advance care planning: a training package for General Practice Nurses,* Sydney Catalyst, Concept Development Workshop, April 15th 2016.

Clayton J. Presenter and lead facilitator for the *Decision Assist, Living longer, dying better workshop,* for the Sydney North Health Network, Sydney 10th May 2016.

Clayton J. *The Advance Project: Initiating palliative care and advance care planning in General Practice,* Palliative Care Australia's National Palliative Care Grant Recipients Forum, Canberra, 7th April 2016.

Cole A. *Acute Confusion and Delirium in Older People and Medical Futility in Aged Care,* Thirty-sixth Annual CMDA-CMDE International Conference, Marathon, Greece, April 8th 2016.

Cole A. *Frailty, Falls and Complications in Older People,* Eighth Biennial Chickendocs Meeting, Shanghai, China, April 22nd 2016.

Cole A. *Driving and Travelling with a Brain Tumour,* COGNO + Asian Society for Neuro-Oncology Joint Meeting, Sydney, NSW, September 13th 2016.

Crandall J, **MacLeod R,** Wilson D. Testing a relationship between hospice palliative care awareness and death anxiety: Findings from a New Zealand Survey. *"Putting the pieces together: Collaborating for Quality Hospice Palliative Care in Ontario"* Annual Hospice Palliative Care Ontario Conference, Toronto, Ontario, Canada. April, 2016.

Dhanji N, Wilson D, Playfair R, Nayak S S, Ptoplampu G, **MacLeod R.** *A scoping review of bereavement outcomes.* 8th Annual Dr. Olive Yonge Teaching and Learning Scholarship Day. Edmonton, Alberta, March, 2016. (poster)

Franklin A, Rhee J, Clayton J. Enhancing primary palliative care and Advance Care Planning, HammondCare Palliative and Supportive Care Research Seminar, Greenwich Hospital, Tuesday 8th November 2016.

Gavin J, Phillips J, **Rhee J,** Tierman J, Mitchell G, Halcomb E, Detering K, Morton R, Shaw T, Cooper K, Dong S, **Clayton J.** *The Advance Project. Initiating palliative care and advance care planning: training and resources for General Practice Nurses.* Palliative Care Nurses Australia conference Canberra, September 2016.

Presentations

Academic Conference+Industry Seminars

Gresham M.D. *Dangerous Design: Understanding how people with dementia see the world.* Grand Designs: Are we there yet? International Dementia Conference, Sydney, Australia, 16 June 2016.

Halovic S, Korner A, McLean L, Chapman CL, **Stevenson J** et al. *Conversation in the making of mind. The art and science of psychotherapy.* Conference presentation 2016.

Halovic S, Korner A, McLean L, Meares R, **Stevenson J** et al. *Development of the CMAS: Adherence Scales.* Conference presentation, Jan 2016.

Halovic S, Korner A, McLean L, **Stevenson J**, et al. *Using the CMAS to measure adherence to the Conversational Model: how expertise influences CMAS ratings.* Conference presentation, Dec 2016.

Johnson S, Vaccaro LD, Butow P, Kiely BE, Silvester W, Detering K, **Clayton J**, Clarke S, Tattersall M. *Advance care planning increases communication between cancer patients, their oncologists and their family: an RCT.* Clinical Oncology Society of Australia Annual Meeting, Goldcoast, November 2016.

Judd S. *C-D-C does not spell quality.* COTA Criterion Conference: Quality in Aged Care. Sydney. 8 March 2016.

Judd S. *Aged Care and Superannuation.* Christians in Super Breakfast Event. Adelaide. 18 March.

Judd S. *Making change happen.* Dementia Centre International Dementia Design School. Leeds. UK. 15 April.

Judd S. *A sustained focus on dementia.* Alzheimer Scotland Lecture, the University of Edinburgh. Edinburgh. UK. 18 April.

Judd S. *The three myths of aged care.* Morgan Stanley Aged Care & Retirement Seminar. Sydney. 26 May.

Judd S. *Mad, bad and dangerous to know.* International Dementia Conference. Sydney. 16 June.

Judd S. *Making good dementia care the norm.* COTA Criterion Conference: Strategic Thinking for Choice and Control. Sydney. 6 July.

Judd S. *Flourishing or floundering in 2017 and beyond?* Aged & Community Services Australia National Summit. Hobart. 7 September.

Judd S. *How can dementia be core business?* COTA & Alzheimer's Australia Criterion Conference: Strengthening Dementia Services. Melbourne. 10 October.

Keall R, Clayton J, Butow P. *Therapeutic life review in palliative care: a systematic review of quantitative evaluations.* Palliative Care Nurses Australia conference Canberra, September 2016.

Kohler F. *Outline of the process of developing the ICF based Mobility Assessment Tool (IBMAT).* OT WORLD, Leipzig Germany, 2-6 May 2016.

Kohler F, Chow J, Knight A, Gonzalez-Arce V. *Retrospective Analysis of Telemonitoring in South West Sydney (RATE).* SWSLHD Health Beyond Research and Innovation Showcase: Sydney Australia, 18-19 October 2016.

Kohler F, Gonzalez-Arce V. *How to Integrate Healthcare Delivery?* (Our Journey). SWSLHD Health Beyond Research and Innovation Showcase: Sydney Australia, 18-19 October 2016.

Kohler F, Chow J, Knight A, Gonzalez-Arce V. *Retrospective Analysis of Telemonitoring in South West Sydney (RATE).* Wollondilly Health Alliance, Wollondilly Shire Council, Australia, 16 November 2016.

Kohler F, Chow J, Knight A, Gonzalez-Arce V. *Retrospective Analysis of Telemonitoring in South West Sydney (RATE).* 4th World Congress on Integrated Care, Wellington New Zealand, 23-25 November 2016.

Lovell M. Australian Cancer Pain Guideline. *Joint 2016 COSA & ANZBCTG Annual Scientific Meeting,* Gold Coast Convention Centre, Nov 15-17, 2016.

Lovell M. *Achieving improved care of palliative care patients through clinical studies to inform the quality use of medicines.* PaCCSC (Palliative Care Clinical Studies Collaborative). Hospice New Zealand, Auckland 14-16 September, 2016.

Lovell M. *'Touching the Void': Bridging the chasm between clinical guideline development and local site implementation.* Hospice New Zealand, Auckland 14-16 September, 2016.

Lovell M. *Palliative care in breast cancer.* Clinical Oncology Society of Australia Trainees Weekend. Gold Coast. November 13, 2016.

Lovell M. *Supportive Care in Melanoma: how we can do better.* Australasian Melanoma Conference, Sydney, October 28- 29, 2016.

Lovell M. *Evidence based management of cancer pain in the general population and patients with end-stage kidney disease.* Renal Supportive Care symposium. St George Hospital, July 30, 2016.

Lovell M, Lockett T, Davidson P, Stubbs J, Agar M, Boyle F, Forster B, Marie N, Spruyt O, Hosie A, **Birch M-R,** Phillips J. *Implementation Strategies for Cancer Management Guidelines.* EAPC Dublin, Jun, 2016. (poster)

Lovell M, Lockett T, Phillips J, Agar M, Ryan L, Lam L, McCaffrey N, Boyle F, Shaw T, Currow D, Hosie A,

Presentations

Academic Conference+Industry Seminars

Davidson P. *Clinical trial protocol - Implementing clinical practice guidelines for cancer pain in adults to ensure equitable, cost-effective, evidence-based, person-centred care: A phase III pragmatic stepped wedge cluster randomised controlled trial of guidelines and screening with implementation strategies versus guidelines and screening alone to improve pain in adults with cancer attending outpatients oncology and palliative care centres.* EPAC Dublin June, 2016. (poster)

Lovell M, Forster B, Hosie A, Lockett T, Phillips J, Agar M, Boyle F, Shaw T. *Patient and carer experiences of pain care in a regional Australian comprehensive cancer care setting: A qualitative sub-study of the Stop Cancer PAIN Trial.* MASCC/ISOO Annual Meeting in Supportive Care in Cancer, Adelaide, Australia, 23-25th June 2016. (poster)

Lockett L, Davidson PM, Green A, Marie N, **Birch MR,** Stubbs J, Phillips J, Agar M, Boyle F, **Lovell M.** *Development of patient-held resources to overcome barriers to cancer pain assessment and management.* EAPC, Dublin, June, 2016. (poster)

Macfarlane SR. *9-Months and 12-Months Safety and Exploratory Efficacy Data of ANAVEX 2-73 in a Phase 2a Study in Mild-to-Moderate Alzheimer's Disease Patients.* Clinical Trials in Alzheimer's Disease (CTAD) Conference. San Diego USA, 10 December 2016.

Macfarlane SR, Alford M. *Dignity in Care – Supporting the Unique Needs of Behavioural & Psychological Symptoms of Dementia.* Annual Scientific Meeting of the Australian and New Zealand Society of Geriatric Medicine. Adelaide South Australia, 23 October 2016.

Macfarlane SR. *Disease-Modifying Treatments in Alzheimer's Disease.* Victorian Branch Meeting of the Royal Australian and New Zealand College of Psychiatrists. Lorne Australia, 21 October 2016.

Macfarlane SR. *Dignity in Care – Supporting the Unique Needs of BPSD.* Dementia With Dignity CDAMS Conference. Melbourne Australia, 19 October 2016.

Macfarlane SR. *Severe Behaviour Response Teams – What's the story?* Grand Designs International Dementia Conference. Sydney Australia, 17 June 2016.

MacLeod R, Egan R, Moeke-Maxwell T, Crombie R. *Foundations of spiritual care: evaluation of a New Zealand hospice spiritual care programme.* 21st International Palliative Congress, Montreal, Canada, October, 2016.

MacLeod R, Johnson C, Kemp G, Pieper V. *A bridge to the community.* 21st International Palliative Congress, Montreal, Canada, October, 2016 (with poster).

MacLeod R. *Are you at peace?* Goodfellow Symposium. Auckland, March, 2016.

MacLeod R. *HammondCare Palliative Care Seminar.* Teaching, education and learning. Sydney, June 2016.

McLean L, Korner A, Haliburn J, **Stevenson J,** Crisante S, Halovic S. *Teaching local clinicians the Conversational Model: Process and early outcomes of the "Scholarship Program" and "Walking the Talk".* Conference Paper. ANZJP May 2016.

Middleton J, **Siddall P,** Katte L. *How to manage chronic pain,* Spinal Cord Injuries Australia Independence Expo, Sydney, Australia 16 April 2016.

Mowll J, Sanderson C, **MacLeod R, Robertson M,** Lam L, Lobb E. *Complexities in grieving after a palliative or coronial death: preliminary findings of a longitudinal study.* 21st International Palliative Congress, Montreal, Canada, October, 2016.

Mowll J, Sanderson C, **MacLeod R, Robertson M,** Lobb E. *Understanding the impact of the death event for bereaved relatives: preliminary findings from a longitudinal study.* Australian Grief & Bereavement Conference, Melbourne, May, 2016.

Parmegiani J, Macfarlane SR. *Stereotypes to Aging.* Annual Scientific Meeting of the Faculty of Old Age Psychiatry (RANZCP). Melbourne Australia, 3 November 2016.

Poulos R, **MacLeod R, Harkin D, Cole A, Poulos CJ.** *A palliative care home support program in New South Wales (NSW), Australia – design and evaluation.* 21st International Palliative Congress, Montreal, Canada, October, 2016.

Poulos CJ. (Invited speaker). *Learning the 3 R's – Reablement, Restorative care and Rehabilitation.* Aged Care and Rehabilitation Conference, South Western Sydney Local Health District. Sydney. 13th December 2016.

Poulos CJ. *Rehabilitation and the Macro Environment* (Invited speaker). Health Roundtable Subacute Meeting. Brisbane. 23rd November 2016.

Poulos CJ. *'Reablement', 'Restorative Care' and 'Rehabilitation' – What does it all mean?* Australasian Rehabilitation Outcomes Centre (AROC) Management Advisory Group meeting. Sydney. 16th November 2016.

Poulos RG, **Poulos CJ.** *'Arts on Prescription' - participatory arts to improve the health and wellbeing of older people.* Canadian Association of Gerontology 25th Annual Scientific Meeting. Montreal. Canada. October 20th – 22nd 2016.

Poulos CJ. (Invited speaker). *Reablement, restorative care and rehabilitation – getting back to basics.* Toronto Rehabilitation Institute. Toronto. Canada. 13th October 2016.

Presentations

Academic Conference+Industry Seminars

Poulos CJ, Poulos RG. *The 3 R's to achieving active ageing for challenged older people: Reablement, Restorative Care and Rehabilitation*. New Zealand Association of Gerontology. Wellington. New Zealand. 15th – 17th September 2016.

Poulos RG, **Poulos CJ**. *Making active ageing a reality through participatory art: The 'Arts on Prescription' model*. New Zealand Association of Gerontology. Wellington. New Zealand 15th – 17th September 2016.

Poulos CJ, Poulos RG, Marwood S, **Rhee J**, **Beilharz K**, **Robertson M**, **Cole AMD**. *Arts on Prescription*. International Dementia Conference. Sydney. 16th – 17th June 2016.

Poulos CJ. *The case for Reablement*. International Federation on Ageing and DaneAge Copenhagen Summit. Copenhagen. Denmark. 18th – 19th April 2016.

Poulos CJ. Saleability of the Reablement Approach. International Federation on Ageing and DaneAge Copenhagen Summit. Copenhagen. Denmark. 18th – 19th April 2016.

Poulos CJ, Poulos RG. *Reablement is the new black – the changing focus of community care provision in Australia*. Canadian Association of Gerontology 25th Annual Scientific Meeting, Montreal, Canada. October 20th – 22nd 2016 (poster).

Radhakrishnan S, **Kohler F**, Schiappacasse C, Gutenbrunner C, Li J, Fialka-Moser V, Jayaraman A. *Validation of an ICF based mobility assessment tool Step 2 Sensitivity*; 10th World Congress of the International Society of Physical and Medical Rehabilitation: Kuala Lumpur Malaysia, 30 May – 2 June 2016.

Radhakrishnan S, **Kohler F**. *The development of an ICF based mobility assessment tool*. SWSLHD Health Beyond Research and Innovation Showcase: Sydney Australia, 18-19 October 2016.

Raguz A. *How HammondCare manages risk in a risk averse world*. Risk Management Excellence Forum. Sydney. 24 February.

Rainsford S, **MacLeod R**, Glasgow N. *Does dying at home matter most?* 22nd Hospice NZ Palliative Care Conference, Auckland, New Zealand, September 2016.

Read S, Wiese MY, Stancliffe RJ, Jeltos G, **Clayton J**. *Dying to talk: Exploring dying and death*. IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities) 15th World Congress August 2016, Melbourne, Australia. Published abstract in Journal of Intellectual Disability Research, 60 (7/8): 806.

Robertson M, **MacLeod R**, Duggleby W. *Hope during a home death*. Palliative Care NSW State Conference, Broken Hill, September, 2016.

Robertson M, **MacLeod R**, Duggleby W. *What can we learn from family caregivers about hope during a home death?* Palliative Care New South Wales Biennial State Conference. Broken Hill, Australia, 13-15th October, 2016.

Robertson M, **MacLeod R**, Duggleby W. *Learning from bereaved caregivers about their experience of home death*, 21st International Palliative Congress, Montreal, Canada, October, 2016. (poster)

Robertson M, **MacLeod R**, Duggleby W. *What are the hopes of palliative care patients and their families during a home death?* 22nd Hospice New Zealand Palliative Care Conference. Auckland, New Zealand, 14-16 September, 2016 (plus poster).

Sellers M, Tong A, Luckett T, Morton RL, Pollock CA, Spencer L, Silvester W, **Clayton J**. *"Paradoxically rewarding": Clinician's perspectives on advance care planning for patients with chronic kidney disease*. National Advance Care Planning Conference, Melbourne, November 2016.

Shepherd H, Allison K, **Clayton J**, Girsig A, Lindsay T, Orr F, Butow P, Price M, Shaw J. *Development and evaluation of patient resources to explain screening for anxiety and depression in cancer care*. Clinical Oncology Society of Australia Annual Meeting, Goldcoast, November 2016.

Siddall P, **Austin P**, McIndoe L, **McCabe R**, Wrigley P. *Meaning as a protective factor in people with spinal cord injury and pain*, Australian Pain Society Annual Scientific Meeting, Perth, Australia, 15 March 2016.

Siddall P. *NSW Pain Management Model of Care: Where are we up to?* Annual Pain Management Workshop NSW ACl, Sydney, Australia, 6 April 2016.

Siddall P. *Pain and the older person*, Departmental Seminar, Department of Geriatrics, Concord Hospital, Sydney, Australia, 9 May 2016.

Siddall P. *Living well with neuropathic pain: from medications to meaning*, National Pain Week Conference, Sydney, Australia, 29 July 2016.

Siddall P. *Pain following injuries to the spine*, Injuries To The Spine Seminar, Australian Technology Park, Redfern Australia, 29 October 2016.

Stancliffe RJ, Wiese MY, Read S, Jeltos G, **Clayton J**. *Knowing, planning for, and fearing death: Findings from adults with intellectual disability and disability staff*. IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities) 15th World

Presentations

Academic Conference+Industry Seminars

Congress August 2016, Melbourne, Australia. Published abstract in Journal of Intellectual Disability Research, 60 (7/8): 741.

Stevenson J. *Conversational Model therapy and preliminary outcome in 40 participants*. Westmead conference on developmental trauma. Sydney, Australia May 2016.

Stevenson J. *Stigma and how to manage it*, Chickendocs conference, Shanghai, China April, 2016.

Stevenson J. *Obsessive-compulsive disorder*, Christian Counselling Conference, Shanghai, China, Dec 2016.

Stevenson J. *Anxiety Management*, Christian Counselling Conference. Shanghai, China. Dec 2016.

Stevenson J. *Depression and the Chinese perspective*, Christian Counselling conference, Shanghai, China, Dec. 2016.

Stevenson J. *Coping strategies for inpatients with and without personality disorders*. International Psychogeriatric Association Regional Meeting. Taiwan Dec 2016.

Stokes J, **Gavin J**, **Clayton J**. *Facilitators for the inaugural Advance practical workshops across Australia for the National Advance Project "Initiating palliative care and advance care planning in General Practice"* www.caresearch.com.au/advance

Vaccaro LD, Johnson S, Kiely BE, **Clayton J**, Clarke S, Beale P, Detering K, Silvester W, Butow P, Tattersall MHN for the ACP Study Investigators. *Acceptability of tailored life-expectancy information in patients with advanced cancer participating in an Australian nurse-led ACP RCT*. Clinical Oncology Society of Australia annual Scientific Meeting, Goldcoast November 2016.

Walczak A, Butow P N, Tattersall MHN, Davidson PM, Young J, Epstein RM, Costa DSJ, **Clayton J**. *Encouraging Prognosis and End-of-Life Care Discussions: An RCT of a Communication Support Program*. 14th International Conference on Communication in Healthcare, September 2016, Heidelberg, Germany.

Walczak A, Butow PN, Bu S, **Clayton J**. *Targets, Structure and Efficacy of End-of-Life Communication Interventions: A Systematic Review*. 14th International Conference on Communication in Healthcare, September 2016, Heidelberg, Germany.

Wiese MY, Stancliffe R, Read S, Jeltos G, **Clayton J**. *Assessing knowledge, planning for and fear of death*. IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities) 15th World Congress August 2016, Melbourne, Australia. Published abstract in Journal of Intellectual Disability Research, 60 (7/8): 762.

Wilson DM, Houttekier D, Cohen J, **MacLeod R**. *Population-based bereavement incidence and other findings for needed developments*. EuroSciCon AGEING Conference, London England, February, 2016.

Wilson DM, Houttekier D, Cohen J, **MacLeod R**. *Does quality dying matter after death? A population-based study of bereaved people*. 9th World Research Congress of the European Association for Palliative Care (EAPC), Dublin, Ireland. June 2016.

Xiangfeng X, Phillips J, Luckett T, **Lovell M**, Wang YA. *Cancer pain management needs and perspectives of patients from Chinese backgrounds: a systematic review of the Chinese and English literatures*. Palliative Care Nurses Association meeting, Dubbo, September 2016.

Xu X, Phillips J, Luckett T, **Lovell M**, Wang YA. *Cultural Influence on Chinese Background Cancer Patients' Pain Management Beliefs, Needs and Practices: A Systematic Review*. EAPC, Dublin, June, 2016 (poster).

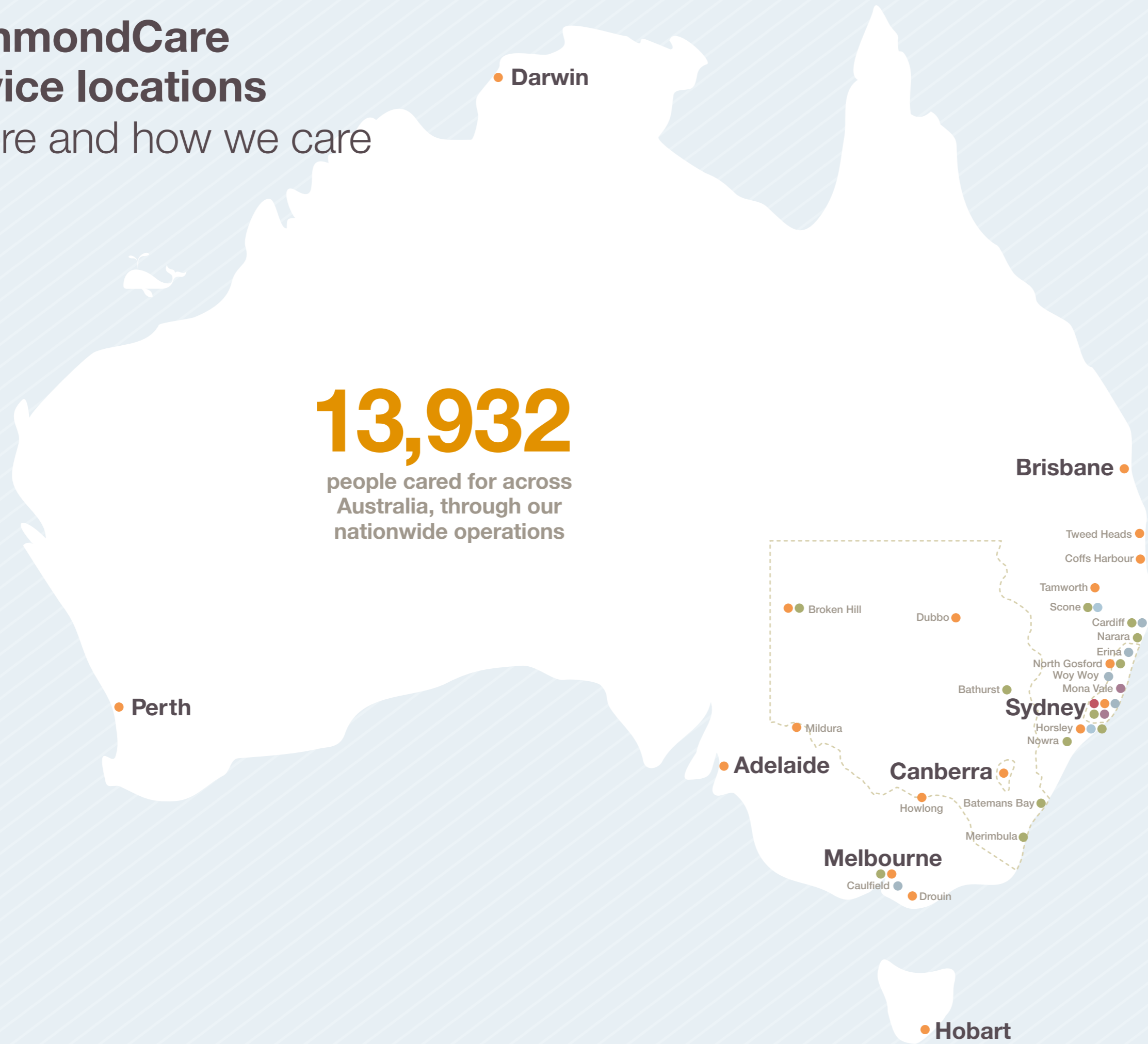
Xu X, Luckett T, Wang YA, **Lovell M**, Phillips J. *Cultural influences on pain-related perspectives, beliefs & needs of cancer patients from Chinese Backgrounds: a systematic review of Chinese & English language research literature*. CNSA 2016 (poster).

HammondCare service locations

Where and how we care

13,932

people cared for across Australia, through our nationwide operations



Residential Care

- Cardiff
- Caulfield
- Erina
- Horsley
- Hammondville
- Miranda
- North Turramurra
- Scone
- Wahroonga
- Woy Woy

Health+Hospitals

- Braeside
- Greenwich
- Mona Vale
- Wahroonga

HammondCare At Home

- Batemans Bay
- Bathurst
- Baulkham Hills
- Broken Hill
- Cardiff
- Hammondville
- Horsley
- Lindfield
- Manly
- Melbourne
- Miranda
- Merimbula
- Narara
- North Gosford
- North Turramurra
- Nowra
- Scone
- Wahroonga

Research+Education

- Braeside
- Greenwich
- Hammondville

Dementia Support Australia (DSA)

- Adelaide
- Brisbane
- Broken Hill
- Canberra
- Coffs Harbour
- Darwin (ARRCS)
- Drouin
- Dubbo
- Hobart
- Horsley
- Howlong
- Melbourne
- Mildura
- North Gosford
- Perth
- Sydney
- Tamworth
- Tweed Heads

Palliative Care Home Support Packages

311 rural and remote towns within NSW

Index

Acute 66, 67, 69
Advance Care Plan, 38, 41, 50, 51, 52, 63, 64, 65, 66, 67, 68, 70, 71
Aged Care 66, 67, 68
Ageing 69, 70
Alzheimer's 69
Amputation 47, 64
Anorexia 33, 63
Anxiety 33, 63, 64, 66, 70, 71
Arts 43, 44, 69, 70
Assessment tool 45, 46, 49, 68, 70
Bereavement 37, 64, 67, 69, 70, 71
Bipolar 65
Brain injury 48
Brain tumour 67
Breathlessness 30, 31, 32
Cancer 31, 33, 35, 37, 50, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71
Cannabis 38, 63
Caregiver 44, 63, 64, 70
Chemotherapy 50
Cognitive decline 40, 41
Community 69, 70
Communication 38, 62, 64, 68, 69, 71
Confusion 41
Constipation 30, 31
Consumer Directed Care 39, 63, 68
Cottage-Respite 40
Data accuracy 47
Death 34, 35, 37, 62, 63, 64, 66, 67, 69, 70, 71
Delirium 32, 67
Delusion, 66
Dementia 38, 39, 41, 42, 49, 62, 64, 65, 66, 68, 69
Depression, 33, 66, 70, 71
Dialysis 51
Dignity 69
Disability 64, 70
End-of-Life 34, 35, 37, 50, 64, 65, 71
Environment 66
Euthanasia 66, 67

Exercise 46
Existential distress 53
Falls 46, 67
Food 44
Fracture 46
Frailty 39, 67
General Practice 34, 50, 52, 63, 64, 65, 66, 67, 71
Grief 37, 69
Healthcare delivery 68
Home 40, 43, 69, 70
Hope 37, 70
Hospice 67
Intellectual disability 50, 64, 70
Junior doctors 67
Kidney disease 63, 68, 70
Knee replacement 45, 63, 67
Liver dysfunction 62
Long-term care models 40
Low income 43
Melanoma 68
Mobility 45, 47
Model of Care 63
Morphine 30
Music 62, 66
Nausea 30, 33
Nurse 50, 52, 64, 66, 67, 71
Nutrition 44
Obsessive-compulsive 71
Opioid 62
Outpatient 48
Oxycodone 62
Pain 37, 48, 49, 53, 62, 63, 64, 66, 68, 69, 70, 71
Palliative Care 30, 32, 35, 36, 63, 64, 67, 68, 69, 70, 71
Peace 62, 67, 69
Personality Disorder 62, 65, 66, 71
Pharmacovigilance 34, 63, 64
Physiotherapy 45
Prescribing 44, 69
Psychiatry 62, 65
Psychogeriatric 40

Psychotherapy 68
Quality of care 43
Reablement 69, 70
Regulation 43
Rehabilitation 45, 46, 47, 63, 64, 66, 67, 69, 70
Rental tenant 43
Respite 40
Risk 70
Rural & regional 64, 69
Severe Behaviour Response Team 69
Sexuality 30
Signage 42, 65
Sleep 31
Speech Pathologists 36
Spinal cord 48, 49, 63, 64, 70
Spirituality 52, 62, 64, 66, 69
Stigma 71
Stroke patients 46
Students 67
Superannuation 68
Tele-monitoring 68
Toilet-bidet 39
Toolkit 50, 64
Trauma 64
Vaccines 63
Volunteering 36
Wellbeing 39, 44, 48, 64
Work practices 43
Younger onset dementia 66

HammondCare has a long history of supporting research. It is part of our organisational DNA and is what makes HammondCare a learning organisation.

Professor Christopher Poulos
Head of Research and Aged Care Clinical Services, HammondCare





HammondCare

An independent Christian charity

To support the HammondCare Foundation by donating to vital life changing research, you can contact us on:

1300 426 666

or go to our website:

www.hammond.com.au/about/support

We are grateful for any support you can give.

Stay connected:



Catch up on Facebook

www.facebook.com/hammondcare



Follow us on Twitter

www.twitter.com/hammondcare



Watch us on YouTube

www.youtube.com/user/hammondcare

Level 2, 447 Kent Street, Sydney NSW 2000
Phone 1300 426 666 www.hammond.com.au

Front cover:
Professor Melanie Lovell and Ted Moors
HammondCare is an independent Christian charity
ABN 48 000 026 219