

# RESEARCH REPORT 2015



The involvement in teaching by HammondCare staff highlights the commitment of our staff to ensure all involved in providing people with needs in the physical, mental, psychological and spiritual domains are well informed and skilled to meet these needs.

**It is with great pleasure I introduce you to the HammondCare 2015 Research Report. We gain insight into how our staff are working to improve the lives of those who receive care through our organisation.**

The research at HammondCare is organized within seven priority areas that have specific benefit to the care foci of the organization. These priorities are Palliative Care; Dementia and Mental Health; Ageing, Restorative Care and Reablement; Rehabilitation; Pain Management including pain in spinal cord injury; The Spiritual Dimension and Advance Care Planning.

The stories of real people and their needs, in the first section, demonstrate how research is able to improve the care of a wide variety of people.

Usha's story and Ann's story - Chronic pain and spinal cord injury

Susan's story - Pain and spiritual distress

Brian's story and David's story – Dementia

The bidet story - Ageing and reablement

Stephen's story - Rehabilitation

There is a wide range of research projects. Of the 80 reported, eight have been completed and are now being published and are providing information for care, policies or resources across the sector. This should bring new people with different stories in future reports. A further four are in the analysis stage and there are 67 ongoing projects.

The involvement in teaching by HammondCare staff highlights the commitment of our staff to ensure all involved in providing people with needs in the physical, mental, psychological and spiritual domains are well informed and skilled to meet these needs.

This report should encourage us all to continue our involvement in HammondCare and prayerfully support those we seek to serve.



Annette Britton  
Chair, Hammond Research Committee



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How will this research translate into better care for people?



## Research – are we there yet?

**Most researchers can answer this quite easily, at individual project level. Once funding is received, completing the cycle of sending in ethics approval, finding the staff to run the project, gathering the research data, collating results, publicising findings and acquitting the budget, means we can say at the end of each research project, yes, we are there.**

In HammondCare, it is equally important for us then to ask of each project, both at planning and at completion – how will this research translate into better care for people? In mainstream practice, translation from research to practice may vary between eight and fifteen years, especially for introducing new medications. Thankfully in HammondCare we can and do compress this somewhat.

Overall, looking back to the start of the formal organising of our learning and research efforts in 2008, we now see careful governance of all of research undertaken, within seven defined priority areas. For each project, we test capacity to undertake and project relevance before work starts. All projects are regularly monitored, to ensure steady progress to final completion and reporting, and an integrated database will underpin all this in 2016.

With more than \$5 million in government funding, two new Learning & Research Centres have been established at Greenwich and Hammondville, and our research staff has increased in numbers, experience and seniority. In 2008, I was the only HammondCare staff member holding a conjoint academic appointment above the level of Senior Lecturer. As this is being written, we have four staff conjointly appointed at the level of Professor, and six at the level of Associate Professor. We now teach medical, nursing and allied health students across multiple disciplines, from more than a dozen Universities.

Despite increasingly lean times in research funding, HammondCare's ability to attract new research funding has consistently run at well more than \$1 million per annum, and 2015 was no exception. Right at the end of 2015, we received advice of success in significant funding for a landmark project to look at end-of-life care discussions in general practice settings.

Clearly, we shall never arrive at the definitive answer for everything, as there is always room for another set of questions to be asked to improve the care we provide for those in need. As Robert Louis Stephenson once famously observed "to travel hopefully is a better thing than to arrive" and that is certainly true in research.

I commend this report to you, as I now hand oversight of our learning and research portfolio to Professor Chris Poulos, HammondCare's new Head of Research.

Associate Professor Andrew M Cole,  
Chief Medical Officer & Head of Research (2008-2015)

## At last: help for people who have suffered chronic pain that would not respond to medication.

### The problem.

Around 50% of people with spinal cord injury develop additional pain. It's a tragic bind. They lose sensation, and are left with no feeling from the waist down, wheel chair bound. But at the same time, they develop significant new pain - nerve pain. And the worst thing is, this pain just doesn't respond to traditional pain killers like paracetamol, or even morphine. As a result, many people in this position fall between the tracks, and suffer long term, chronic pain.



### The research.

The aim of our research grant was to address this problem, to try to find help for people suffering intense and chronic nerve pain as a result of spinal cord injury.

We began by assembling a working team, who would sift through the existing evidence that would help us understand and treat this problem. The team spent two years getting hold of all the raw data and information, and translating it into conclusions that would help people. So eventually, we discovered that there really was hope. That the right medication, exercise, and other support, could actually lead to a reduction in pain levels.

#### From there, we wanted to do two things. First – develop some resources.

Our goal was to synthesize that information into some resources that would help those suffering as well as clinicians. And then, we wanted to develop a program that would allow us to deliver the care that would ultimately improve people's lives.

So we published a book - The Spinal Cord Injury Pain Book, which is now in wide use in many hospitals and clinics throughout Australia.

We also developed a website. So that clinicians such as GPs, will no longer ask – “what do I do? Where do I go for help?” This meant that online, answers were now available for people world wide, and help was able to be found.

Over the last 12 months, we have had around 3,500 users and nearly 33,000 page views - 69% from USA, 14% from Australia, 12% from UK and the other 5% from Japan, Canada, NZ and

French and Spanish speaking countries. So we are confident that we have been able to translate our research into practical help for people in need, on a wide basis, and through different channels.

#### And next, we wanted to develop a program.

This had to be developed specifically around the needs of the people suffering the pain. It had to allow us to deliver the care that would ultimately improve people's lives. It is a multidisciplinary treatment plan. Doctors are needed to help with medication plans. Physiotherapists are needed to help with things like stretching and exercise, clinical psychologists help with support around relaxation and meditation. All together, it's a combined approach, targeted to the individual, that really works.

But there was another problem we had to address. The evidence also told us that by definition, accessibility is a big problem for people with spinal cord injury. So we needed a plan specifically tailored to address that. For people with spinal cord injury, the traditional weekly or three week program just won't work.

So we developed a tele-health model of care that takes the treatment to the person. This has been very effective and people across NSW have received vital care from our team at Greenwich Hospital in Sydney, remaining in the comfort of their own homes.

### The outcome.

Overall, it's been very satisfying to have been able to help a group of people who have suffered greatly, and see a long term change in their lives. And to see that made available extensively.

### Case study: Usha's story

When Usha came to HammondCare for help, he had experienced severe pain for around 2 years. As a result, he had developed a dependence on very large amounts of pain medication. That was on top of the severe spinal cord injury that confined him permanently to a wheel chair.

The team at the Pain Clinic commenced a plan to both reduce his medication and reduce his pain. The program involved a diverse range of treatments, including sports, exercise, meditation, relaxation, distraction therapy and others.

It's completely changed Usha's life - he's been able to almost completely cease all his medication. It's very satisfying for us to have been able to help Usha and see this remarkable change.



## “It’s an area we’ve completely ignored in pain medicine... until now”: pain and spiritual distress.

### The problem.

Spiritual distress is what happens when a person is unable to find sources of meaning, hope, love, peace, comfort, strength, and connection in life. Due to the existential distress it causes, it’s well known to contribute to the suffering of people who are dying. And yet, it is an issue that has been almost completely ignored in people experiencing chronic pain. That’s despite many of the issues facing people at the end of life also confronting people with persistent pain.



### The research.

HammondCare runs an 8-week group Pain Management Program for people experiencing chronic pain. 17 people with referrals to take part in the Program at Greenwich Hospital were recruited for a research study into spiritual distress by Rebecca McCabe and the team at the HammondCare Pain Clinic.

We wanted to measure the level of spiritual distress in a group of people with chronic pain so that we could work towards building awareness around the issue of spiritual distress and look at further research and treatment options.

Before starting the Pain Management Program, the individuals filled in a questionnaire to assess their pain, as well as a questionnaire to assess their spiritual wellbeing. The same scale that is used to measure spiritual distress among palliative care patients was applied to this group of people.

The scores were then compared to those from people with HIV/AIDS and advanced cancer. The findings were both interesting and disturbing. What we discovered is that people with chronic pain suffer from higher levels of spiritual distress than those with HIV/AIDS and cancer.

People with chronic physical pain often face grief and existential suffering as they lose their meaning and purpose in life. It’s a similar sort of suffering as experienced by those facing end of life.

“Until now, pain medicine has been quite slow to look at these issues even though there has been increasing interest both in the community and the health profession in addressing existential issues as a component of health care,” says Rebecca.

“The plan is to use this research to develop a new course to address these deeper issues as a component of treatment for people living with pain.”

As to why people with chronic pain suffer from higher levels of spiritual or existential distress, we don’t yet know. The participants from the original study are currently being followed up as part of a qualitative study that forms part two of the research. They will be asked to share more about their experience of spiritual distress so we can better understand what causes their suffering.

But Rebecca McCabe says having worked with many people in chronic pain she can understand why they might feel so hopeless.

“My guess is that for people with chronic pain, many feel there’s no end in sight. By definition chronic pain has no cure. People living with ongoing pain often say that the pain has crushed their spirit and they are fearful of what the future will bring: a wheelchair, loss of independence or something worse.”

“Some people say, ‘I used to walk and get in touch with nature and look at the trees and I can’t do that anymore.’ Life becomes very mechanical for people with chronic pain: take the next tablets, go to the next physiotherapy session, get the next X-ray. A lot of time is spent in waiting rooms.”

### The next steps.

No one knows quite how to treat spiritual distress in patients with chronic pain and that’s the next challenge for Rebecca and the team. The good news is, the conversation has begun.

### Case study: Susan’s story

Susan suffers from full body rheumatoid arthritis that was triggered by trauma at work. As a result she can’t walk for more than 200 metres and is in chronic pain.

Currently, she works as a director of not-for-profit group Dragon Claw, advocating for and supporting individuals suffering from rheumatoid disease and Lupus.

Susan recently participated in HammondCare’s Pain Management Program, an 8-week program that addresses different aspects of chronic pain, including spirituality, something she’s very interested in.

Susan’s had two hip replacements, her marriage has ended, and she has a son with schizophrenia. To say she was faced with a number of challenges around the time of her diagnosis is an understatement. In her own words, she “was not a very well person spiritually, mentally, physically.” Spiritual distress has been a very real thing for Susan.

“For me it manifests itself in worrying about everything, panicking, operating on only a few feeling buttons — angry and scared.”

She says she was pleased the HammondCare Pain Management Program touched on spirituality.

Part of her journey prior to attending HammondCare’s Pain Program had been attending a 12-step program that addresses addiction and pain from a spiritual perspective.

“I needed a program, guidance and support from others who were in the same boat as me, but had reached the

other side of the minefield,” she says. “I needed to see the way out from the frozenness, fear and anger, guilt, all the negative emotions, a lack of hope, insensitivity towards others and a lack of tolerance that I was experiencing. I needed to see people on the other side and how they had found happiness.”

Susan says for her, keeping spiritually afloat is crucial to her overall wellbeing.

“It’s been learning to wear my skin like a lovely, loose cashmere coat. That’s spirituality for me. It’s about feeling really warm and good in myself. Spirituality is the journey I’ve been on to develop a relationship with myself and a power greater than myself. What’s a power greater than myself? I don’t know but I do know it’s putting off my ego and having humility.”

Susan says the Serenity Prayer is an anchor for her:

God grant me the serenity to accept the things I cannot change;

Courage to change the things I can; and wisdom to know the difference.

“I cannot change my son from being schizophrenic. I cannot change myself from being in pain with rheumatoid disease. But my spirituality gives me the courage to accept and to change the things I can change and to not worry about things I can’t.”

She says she’s looking forward to participating in any future programs run by HammondCare targeting spiritual distress.

## Raising the national standard: creating Australia's National Cancer Pain Management Guidelines.

### The problem.

More than half of people living with cancer experience pain. That increases as their cancer advances, so that up to three quarters of people experience pain, and of those, many experience moderate to severe pain. At the same time, we also know that many cancer patients aren't given enough medication to treat their pain. It's a tragedy, because evidence shows almost all cancer pain can be controlled with appropriate analgesia.



### The research.

As a Palliative Care Consultant Physician, Associate Professor Melanie Lovell has had a long-term interest in the management of cancer pain.

But it was during the National Pain Summit in Canberra six years ago when she was chairing a working group on Cancer Pain and Palliative Care, that the need for a national guideline for managing cancer pain was identified as a key priority for Australia.

To this end, a group was convened to work towards creating these new national guidelines. A/Prof Lovell took on the role of Chair of the Working Party which developed the Australian Cancer Pain Guidelines.

To create the Guidelines, she and her team carefully assessed all the existing international pain management guidelines, and then adapted them to come up with a draft Cancer Pain Management Guidelines for Australia. That document was then open to submissions from health professionals nationally. During the consultation period, the working group received over 1500 submissions to the Guidelines.

Once finalised, the Guidelines were hosted online to equip health professionals to appropriately treat pain in cancer patients in a person-centred, safe and effective manner.

In November 2014 A/Prof Lovell and her team started a very large research project, to find the most effective ways to implement the Guidelines nationally. The research is aimed at developing a national clinical pathway for pain to ensure equitable, cost-effective, evidence-based, person-centred care for people with advanced breast and other cancers.

### The outcome.

The pilot study took place at HammondCare's Greenwich Hospital and the Mater Hospital in Sydney, the results of which are already changing lives. The tools that were developed via that pilot study are in current practise in the Palliative Care Ward at Greenwich Hospital.

Following the pilot study, a large randomised controlled trial was launched at another site, and is currently on track to be completed in 2018.

In the meantime, all patients in the Palliative Care Ward at Greenwich Hospital are treated according to the Cancer Pain Management Guidelines which Dr Lovell's team developed and which can be accessed online via the Cancer Council Australia website.

### Case study: Ann's story

Ann is 80 years old and lives at home with end stage endometrial cancer.

She experiences significant pain as a result of her disease, so the doctors at HammondCare arranged to have her provided with a strong painkiller that's administered by a patch on the skin.

The patches need to be changed every 3 days. But this is a timing that Ann was finding difficult to remember while living at home by herself.

Because she wasn't managing her pain well at home, Ann was recently admitted to hospital. During her stay, Ann has received treatment according to the Cancer Pain Management Guidelines published by HammondCare's A/Prof Dr Lovell and her team.

During this time, Ann's pain has been regularly assessed, and she has been put onto a higher strength painkiller, as well as a complementary pain killer, and she has also received breakthrough analgesia when needed.

The Guidelines specify for health professionals the most effective combinations of drugs to effectively treat pain, and also discuss when to use breakthrough analgesia, all of which doctors considered in Ann's case.

According to the Guidelines, doctors should provide individualised treatment, and avoid taking a one-size-fits-all approach. Because of her problems with some oral pain killers giving her unwanted side effects, Ann had been receiving pain treatment through patches. And to help her with managing the patches at home, Ann's doctor has come up with a plan to have a community nurse visit her at home when she's discharged, to change the patches every three days.

Ann says she's very happy to have been cared for under the Cancer Pain Guidelines at Greenwich Hospital.

"You know that cancer brings pain and that you are going to get weaker, but you've got to keep on top of the pain, that's the answer I've discovered. The doctors here have been fantastic. I couldn't be more happy."

## Now there's a pathway for caring for loved ones living at home with dementia: *Going to Stay At Home*.

### The problem.

In our society we are seeing the rise of chronic diseases. Navigating the course of chronic disease is often complex. Health services have developed care pathways as guides to know when, where and how to seek help as diseases progress. Dementia can last up to two decades, but unlike other conditions there is often a long gap between diagnosis and the time when professional care is sought. And there is insufficient support for carers.



### The research.

We need a program to give people living with dementia and their families a well sign-posted pathway to follow – to support them in caring for loved ones at home as long as possible, and through the many challenges of the dementia experience.

Meredith Gresham, Senior Consultant with the Dementia Centre received funding to update and replicate a successful family-carer training program, originally run in the 1980's. The program was a 7-day residential program for people with dementia and their family carers, specifically designed to enable carers to better understand and navigate the journey ahead of them.

The program, called *Going to Stay at Home* was designed to enable people to care for the person with dementia at home for longer, by equipping them with the skills and knowledge they needed to care for themselves, as well as the person in their care.

*Going to Stay at Home* was held in an 8 bedroom residential cottage at HammondCare Miranda. To test the portability of the program, one stream was held in serviced apartments in Tamworth. 19 groups of between 3 and 5 couples participated in the program, involving a total of 180 people.

Carer training sessions during the week were aimed at reducing the psychological impacts of caring, educating carers about the progression of dementia, imparting practical nursing skills, techniques for relating to the person with dementia, and explaining how to access support and plan for the future.

The program was carefully structured. It started with the carer, helping them consider whether they've come to terms with the diagnosis, and then aimed to help carers discover they're not alone, and what commonalities they had with the group and to understand that caring for yourself was paramount.

The program then turned to how to care for someone with dementia, commencing with gaining an understanding of the disease and its effects, and other topics such as how to communicate, how to organise your day and your home, and where to apply for professional help and government support, before moving on to more challenging topics such as nursing care, managing incontinence and end of life care.

The pairs that participated in *Going to Stay At Home (G TSAH)* were followed up over a 12-month period after the course as part of independent evaluation conducted by Professor Henry Brodaty at the Dementia Collaborative Research Centre at UNSW. A number of positive findings emerged that powerfully underline the significance of this program:

1. As dementia progresses, we expect to see an increase in scores on carer burden scales as carers have more to cope with.

For the carers in the program there was no associated increase in carer burden or distress over the 12 months, even though people's dementia worsened and their ability to carry out activities of daily living declined over the 12 months.

2. Before attending *G TSAH*:

- 76.7% of carers said they didn't have adequate information on managing behaviours that challenge. After 12 months, that had dropped to 15.4%

- 57.6% of carers said they didn't have the knowledge they needed to look after the person in their care. After 12 months that had dropped to 7.8%

- 40.3% of carers said they didn't have the information and instructions on how to carry out practical tasks for the person with dementia. After 12 months, that had dropped to 2.7%.

3. After 12 months, 82% of participants with dementia were still living at home.

4. Compared with a similar group of people who had received usual residential respite care, over the same 12 month period 52.9% of residential respite users at HammondCare had entered permanent care, while only 17.6% of *G TSAH* participants had been moved out of home and into permanent care.

### The outcome.

The research demonstrates that the knowledge, coping skills and capacity of family carers can be significantly increased through a pathway program like this. As a result, there can be less carer stress, and a significantly better provision of care. And best of all, the person living with dementia may be able to stay at home for much longer.

### Case study: Brian's story

Brian Johnson was a much-loved Rugby League player, who began his career with the St George Dragons in the 1980s, before moving to the UK to play for Warrington.

Much to the dismay of Brian and his wife Karen, when they returned to Australia, Brian was diagnosed with Younger Onset Dementia at the age of 54, in 2010. Sadly, he passed away from Alzheimer's Disease in January 2016, age 59.

Three years ago, Karen and Brian took part in *Going to Stay At Home* as part of a Younger Onset group. Below she shares her experience:

"The main benefit to me from the program is that it existed. It made my role as carer for Brian seem real and recognised as worthwhile, not just the next stage in being his wife. Instead of fumbling through the changes in his personality, abilities and behaviour it showed me what to expect and gave me strategies for dealing with the changes. I particularly liked the practical advice from the nurse that spoke to us. I was not aware of what to expect in regards to his diminishing ability to get in and out of bed, chairs, the car – even doors...I thought he would

carry on as usual but just forget who I was.

From *G TSAH* I learnt where to get help, which government department to contact for what. I also learned a great deal from living in for 7 days with other couples in the same position. It was comforting to share our problems, solutions and experiences. It really helped knowing we were not alone and that we could spend very normal happy times with other people, despite coping with challenges.

By the end of the course I felt empowered to take on the challenges of caring for Brian at home. I am sure that if I had not done the course I would have listened to all the people telling me it would be too hard.

I cannot imagine how hard life would have been for both of us if I had placed him in a home, gone back to work and tried to visit him every day. I would have had to sell our house to pay the fees, I would have missed him terribly and he would have been miserable. I feel now that I did everything I could physically and emotionally to look after Brian. I am so grateful for learning that I did not have to place him – that life is easier on the path we chose".





## “What we did was basically show that rehabilitating cancer patients works”.

### The problem.

As their disease progresses, many cancer patients lose the ability to do everyday tasks independently. From showering, to walking, to getting into cars, to going up and down stairs, to swallowing, cancer patients can develop new and frustrating disabilities. For a long time, cancer patients weren't offered rehabilitation therapy, because many thought they might not have more than a few years or months to live, making an investment in therapy time and effort not worthwhile. Research has challenged this view.



### The research.

In the mid-1990's, HammondCare's Chief Medical Officer and Rehabilitation Specialist A/Prof Andrew Cole became unsatisfied with the care of cancer patients with disability, while he was working in east Asia.

“One of the ladies I went to see lived in a very small farmhouse. I was there to see her for palliative care after treatment for cancer. But I thought, ‘no, this lady is not yet needing palliative care, she needs rehabilitation’. So I made recommendations about her bedding, bowel and bladder management, wheelchair access to her home, and a few other things – I gave her a basic rehab program.”

A/Prof Cole then looked up what research had been done in the area of cancer rehabilitation, only to find very little. The following year, in 1996, after returning to work in Sydney, A/Prof Cole and other staff began providing rehab for cancer patients at Sydney's Braeside Hospital, and researching the effectiveness of cancer rehabilitation.

They recruited enough patients with and without cancer to do a case-control study. The outcomes for patients with various types of cancer disability were compared with patients without cancer experiencing similar disabilities.

For example, the outcomes of rehabilitation of patients with brain tumours was compared with those of rehabilitation of stroke patients, patients with spinal tumours compared with

patients with disc injuries, patients experiencing muscle wasting from chemotherapy and prolonged bed rest were compared with frail aged patients and so on.

Over 10 years, they recruited 180 cancer patients and matched them to “benign” patients, measuring their rehabilitation outcomes.

The research clearly showed that both groups of patients stayed in hospital for about the same length of time, their ability and “functional status” improvements were not significantly different, and about as many people went back home successfully, as needed to go to nursing home care.

### The outcome.

20 years on, and Australasia's first ever specifically-dedicated cancer rehabilitation ward, The Jacaranda Ward, has just opened at HammondCare's Greenwich Hospital.

“What we did was basically show that rehabilitating cancer patients works,” says A/Prof Cole.

He says it's been immensely satisfying 20 years on, after dreaming of such a thing in 1995. “It feels wonderful to know that there is a need being fulfilled. And to have College trainees in rehabilitation-related disciplines coming up through the ranks actually asking to be allocated to a term that includes work in a ward like Jacaranda, is very exciting.”

### Case study: Stephen's story

Stephen lives on a farm near the Snowy Mountains in NSW. In his late 50s, he was diagnosed with prostate cancer after a routine check-up at the GP.

If that wasn't enough, soon after his cancer diagnosis, Stephen started to lose function in his legs. “I noticed they were getting weaker and weaker. I just thought my legs were being a bit lazy, and we'd get them going. But they just kept getting worse.”

Stephen was diagnosed with Cauda Equina Syndrome, a condition where the nerve bundle at the base of the spine is damaged, interrupting signals from the brain to the legs. The neurological problem was somehow linked to the cancer. Stephen found it difficult coming to terms with being paralysed from the waist down.

“My legs are what drive me insane. I've never been incapacitated in my life. It's just unbelievable. To do anything off the farm we have to go 80kms or 100kms, so to not be able to drive is really hard.”

Stephen was the first patient to be admitted to HammondCare's Jacaranda Ward on the day it opened, September 1, 2015.

While at Jacaranda, every day Stephen was wheeled up to the rehabilitation gym where a physiotherapist

had him using a tilt-table to help bring muscle strength back to his legs. And every day he was taken up the road to another hospital for radiation therapy.

As it's a multi-disciplinary ward, he was also seen by a dietician and other allied health staff, as well as a range of specialist physicians.

A/Prof Cole says accessing rehabilitation has significantly improved Stephen's quality of life.

“What we were able to do for him was to get him to the point where he was able to get himself on and off his wheelchair, on and off the bed, in and out of the shower and to the point that he could go back to his farm.”

“He went from thinking ‘What am I going to do?’ to being able to live with his disability in his chosen situation. And that is what we aim to achieve.”

Stephen couldn't be happier.

“It's a winner. We were stumped about what we were going to do and then we found Jacaranda Ward. I'm very lucky. How could you get better? You couldn't get better. Everything's here that you need.”

## The value of cottage respite: better care, more choice and major cost benefits.

### The problem.

Respite for home-based carers provides vital support. It gives them a much-needed break from their caring role, knowing that the person they care for is being well looked after. But overnight cottage respite is an expensive form of respite, largely funded by the Federal Government. We wanted to know: is it worth the expense? Is it cost effective? Does it prevent or delay permanent residential placement?



### The research.

HammondCare provides respite through two purpose-built cottages that can accommodate a maximum of five people each, for up to ten days at a time. Because of the small scale and individual care provided in the cottages, this kind of cottage respite is more expensive than respite in nursing homes.

The Cottage Respite Study, led by Associate Professor Chris Poulos, Hammond Chair of Positive Ageing at the University of NSW, contacted people who had used a HammondCare respite cottage on two or more occasions over a two year period (October 2012 to September 2014). The study sought information from carers on their perceptions of the cottage model of respite care, the value it was to them, and whether it had enabled the person living with dementia they cared for to stay at home for longer.

#### The study was conducted in 2015.

136 carers were interviewed by phone using a specially designed survey. This represented an excellent response rate of about 80%. Five of these carers also participated in an in-depth telephone interview.

One of the main findings of the study was that, on average, the carers reported that their use of cottage respite delayed placement in residential care by about a year. While that was the average, responses varied greatly, with some carers reporting that it delayed placement by years.

A key insight that emerged was that the people who use this service really like using it. They like the fact that it's small, and that we offer individualised care and they don't feel that there is any detrimental effect on those using the respite. About half

of the people who used the cottages had also used respite in a nursing home, so we were able to ask them to compare the two types of respite.

#### We also conducted an economic analysis to try and put a 'dollar value' on the benefits of cottage respite.

The cost of permanent nursing home placement to the Government for someone in high care is about \$70,000 per year. Taking this figure, and then factoring in the cost of a Commonwealth funded home care package, as well as the cost of cottage respite, our economic analysis showed that the saving to Government is still around \$27,000 per respite cottage user.

Looking at the economics of cottage respite another way, for a government outlay of \$2.5 million dollars on cottage respite, plus community care, the Government saves around \$4.0 million in nursing home care, resulting in a net saving to Government of around \$1.5 million dollars.

The above savings were based on the current occupancy rate of the two respite cottages of 65%. Strategies that increase the occupancy rate would result in even greater savings to government.

### The outcome.

"Basically, we found that cottage respite delays placement into permanent care, saves the Government money in the process, and, importantly, people like it and it gives them more choice in the type of care available," says Assoc Prof Poulos.

"And even though cottage respite is an expensive model of care, it seems very effective in helping people to be cared for at home and is still very cost-effective."

### Case study: David's story

Jenny and David are 68-years-old, and live in Sydney's North. David has younger onset dementia and Jenny cares for him at home.

She also works 3 days a week as a music teacher at a primary school, juggling work, caring for David and co-ordinating his care when she can't be there.

To give herself a break from her carer's role, Jenny has been using HammondCare's Lucinda and Woonona respite cottages since 2014.

"It's my sanity, and David loves it," she says. "Most of the time I feel like a rubber band that is completely stretched. Work is great, but stressful, and caring for David is a full-time job in itself. But when he goes to Lucinda Cottage it gives him a lovely environment, he's happy, and I don't have to do anything for him, I can fully relax."

Jenny says having access to cottage respite has enabled her to keep David at home for longer.

"I live from respite to respite. I would've cracked long

ago had it not been for respite, and I would've looked for full time care options a lot earlier."

She says the style and size of HammondCare's cottage respite is appealing to her and David, as it's more homely.

"We have a joke actually that it's nicer than home. We talk about it being David's motel or his 'heritage home'. He loves the pool table at Lucinda, because he used to play snooker, and it's good for him to be standing because he has a catheter and leg bag that make it uncomfortable for him to sit."

"Last weekend we turned up to drop David off and there were three men sitting around the kitchen bench making jokes, and I thought, this is a much more stimulating environment for David than being at home. He doesn't get this kind of social life at home."

"I wish we had 10 Woonona or Lucinda cottages. We need more of them. I know others in my situation and we all rely heavily on it."

A man with a beard, wearing a dark jacket and pants, is sitting in a wheelchair on a green lawn. He is looking directly at the camera. In the background, there is a modern multi-story building with balconies, several palm trees, and a clear sky with some clouds. The lighting suggests it might be late afternoon or early morning.

# Research projects

Palliative Care

Dementia+ Mental Health

Ageing, Restorative Care

+ Reablement

Rehabilitation

Pain+ Spinal Cord Injury

Advanced Care Planning

Spiritual Dimension

## Management of constipation in palliative care *Can less be better?* study

Multi-Site Clinical Trial

**Constipation is a highly prevalent symptom in palliative care and residential aged care, and associated with significant distress for patients and caregivers.**

It is also a leading cause of avoidable hospital presentations. Better management of constipation will improve quality of life, but will also allow more efficient use of health care resources.

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

**Site:** Braeside Hospital

**Researchers:** Associate Professor Melanie Lovell, Ms Alison Hession & Ms Bronwyn Raymond

**Site:** Greenwich Hospital

**Duration:** Nov 12 to Jun 16

**Funding Source:** Department of Health & Ageing (DoHA)

**Project Partners:** Palliative Care Clinical Studies Collaborative (PaCCSC)

**Study Status:** Closed to recruitment, analysis 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.**

**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 fixed doses of morphine, oxycodone and placebo

Multi-Site Clinical Trial

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

It affects the ability to sleep and function independently and is strongly correlated with sensations of panic and anxiety. This study is designed to provide data to support registration of opioids for a dyspnoea indication. HammondCare cares for patients with refractory dyspnoea in Residential Aged Care Homes, Community and Inpatient settings and often bears the cost of providing medication when there are no other avenues for access. A registered medication will ensure timely access for our residents and patients with dyspnea.

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

**Site:** Braeside Hospital

**Duration:** Jan 10 to Jun 16

**Funding Source:** DoHA & PaCCSC

**Project Partners:** PaCCSC

**Study Status:** 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 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:** In Progress

## 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.

**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 hoped-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:** In Progress

## 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.**

It 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.

**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

## Improving palliative care for people with advanced dementia living in residential aged care

Multi-Site Study

**Care for people with advanced dementia requires an evidence-based, multi-disciplinary palliative approach that is targeted to specific issues which occur as dementia progresses and tailored to the needs of each individual and his/her family.**

Facilitated case conferencing (FCC) has improved outcomes in other palliative settings but evidence is lacking for Residential Aged Care residents with advanced dementia. This study aims to gain this evidence so as to be armed with data which can inform funding models and policy.

**Researchers:** Professor Meera Agar,

**Ms Julie Wilcock &**

**Ms Natalie Ohrynowsky**

**Site:** Jacaranda Unit, Hammondville

**Duration:** May 12 to Dec 15

**Funding Source:** DoHA

**Project Partners:** None

**Study Status:** Closed

**Translational Outcomes:**

This project has resulted in national resources to guide case conferences for people with advanced dementia that ensure shared decision making and the best care outcomes for the person with dementia and their families. The resources are free and can be found at: [www.caresearch.com.au/DementiaCaseConferencing](http://www.caresearch.com.au/DementiaCaseConferencing)

## 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.

**Researchers:** Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky  
**Site:** Braeside Hospital  
**Duration:** Jan 13 to Nov 17

**Funding Source:** Internally Supported  
**Project Partners:** None  
**Study Status:** In Progress

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.**

**Researchers:** 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

Exploring the role of clinical psychology in community palliative care: Identifying patients' psychological needs through 'real-world' clinical data

**Results of the study will identify the most common patient issues encountered by a clinical psychologist working in community palliative care.**

This will be used to clarify the role of clinical psychologists in these services and identify priority areas for professional development.

**Researcher:** Mr Geoffrey Lyons (University of Wollongong)  
**Sites:** Greenwich & Neringah Hospitals  
**Duration:** Jul 13 to Dec 16

**Funding Source:** Administered by University of Wollongong  
**Project Partners:** Not Applicable  
**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:** National Health & Medical Research Council (NHMRC) & PaCCSC

**Project Partners:** Queensland University of Technology  
**Study Status:** Closed to recruitment, analysis in progress

## 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 TGA and 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.

**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

## 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 programme 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.

**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 is a multi-site study of a nurse facilitated intervention to improve end of life care for patients with cancer.**

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

**Researcher:** Associate Professor Josephine Clayton  
**Site:** Greenwich Hospital  
**Duration:** Jul 09 to Jul 16

**Funding Source:** Funded by NHMRC administered by USyd  
**Project Partners:** External PhD supervision (Sydney University) & NHMRC grant with various collaborators  
**Study Status:** In Progress

## 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:** University of NSW; University of Queensland  
**Study Status:** In Progress

## 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 16

**Funding Source:** Funded by NSW Health  
**Project Partners:** None  
**Study Status:** In Progress

## 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:** None  
**Study Status:** In Progress

## 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:** None  
**Study Status:** In Progress

## 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:** None  
**Study Status:** In Progress

## 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 Aug 16

**Funding Source:** Administered by UNSW  
**Project Partners:** Not Applicable  
**Study Status:** In Progress

## 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:** In Progress

## Decision Assist Training Program

**This education project will aim to improve palliative care skills and advice by staff in aged care facilities, and advance care planning.**

**Team Members:** Ms Margaret Brown, Ms Pauline Luttrell, Ms Cheryl Johnson & Associate Professor Josephine Clayton  
**Sites:** Various  
**Duration:** Sept 14 to Dec 15

**Funding Source:** DoHA (Austin Health)  
**Project Partners:** Respecting Patient Choices Program (Austin Health)  
**Status:** Completed

**Training Outcomes:**

The level of promotion and marketing of workshops led to a smaller number of participants than expected, and cancellation of some workshops. This was evidenced most strongly in the community sector. And the ability of Residential Aged Care Facilities and Community Service Providers to release sufficient staff to attend the workshops was problematic.

## 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.**

**Researchers:** Ms Katherine Kelly and Ms Kerry Gilsenan  
**Site:** Braeside Hospital  
**Duration:** Jul 15 to Jun 16

**Funding Source:** Internally Supported  
**Project Partners:** None  
**Study Status:** In Progress

## An exploration of patient experiences of multiple symptoms in palliative care

Multi-Site Study

**It is well recognised that patients receiving palliative care often have multiple symptoms which may interact in a multiplicative rather than additive fashion.**

This study aimed to understand the patient experience of multiple symptoms in order to lead to better assessment, management and care.

**Researchers:** Associate Professor Melanie Lovell, Ms Skye Dong and Professor Phyllis Butow  
**Site:** Greenwich Hospital  
**Duration:** Dec 14 to Jul 15

**Funding Source:** Internally Supported  
**Project Partners:** University of Sydney  
**Study Status:** Completed

**Translational Outcome:**

This research sheds light into the multiple symptom experience for patients and health professionals managing them, which will hopefully improve symptom management pathways and integrated, co-ordinated care. Clinical implications in the assessment and management of both symptom clusters and psychosocial issues are outlined in our papers.

## 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:** In Progress

## Stop Cancer Pain

Multi-Site Study

**Improved pain outcomes for patients and improved staff knowledge and improved international and national profile for HammondCare.**

**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

## 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.**

**Researchers:** Professor Roderick MacLeod, Dr Matra Robertson & Ms Christine Sanderson, Ms Jane Mowl  
**Uni Notre Dame;** Liz Lobb Calvary Health Care Kogarah; Johan Duflou 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

## 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 on pain intensity, and also ensure it isn't 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.

**Researchers:** Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynovsky  
**Site:** Braeside Hospital  
**Duration:** Jun 15 to Dec 16

**Funding Source:** Flinders University  
**Project Partners:** Bio and Gene  
**Study Status:** In Progress

## 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.**

Data will be added to a larger sample from other sites and analysed. Findings will at this stage lead to a larger study that will answer questions about the usefulness of cannabis in the proposed setting.

**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:** Closed to recruitment, analysis in progress

## 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.

**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:** None  
**Study Status:** In Progress

(including the Cognitive Decline Partnership Centre)

## The experience of using a wash and dry toilet top bidet with frail older people and people living with dementia: a feasibility 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  
**Site:** Woy Woy  
**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:** The feasibility study is completed and a larger clinical study commenced Nov 2014

**Translational Outcome:**  
Overall, the bidets were well accepted. They cleaned adequately and saved money on continence products. The positive outcome of this feasibility study has prompted a larger controlled clinical utility study.

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

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

Secondly, in order to build these models, the researchers are conducting in-depth workshops (including with HammondAtHome clients) on the priorities of clients. Finally, the research is of interest to the relevant administrators within the Department of Social Services and benefits the industry through a cooperative research partnership by partnering in the research with Catholic Community Services, Helping Hand Aged Care and ACH Group.

**HammondCare Liaison:** Rebecca Forbes, with Researchers based at Flinders University  
**Site:** HammondAtHome Central Coast & Hunter & South West Sydney.  
**Duration:** Apr 12 to Jun 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:** In Progress

## Going to stay at home

**This project is providing 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.**

The program provides a working example of an innovative way of utilising capital resources such as residential cottages, respite cottages now and in the future. This model could be adopted as part of Consumer Directed Care offerings. The going-to-stay-at-home model has significant potential to form a basis for management of long-term chronic conditions in the community.

This program is being replicated as a Randomised Controlled Trial in Rotterdam, The Netherlands led by Dr Betty Birkinhager, an elder care physician from Laurens. Dr Birkenhager and psychologist Jannet van Klauwren spent time in Australia speaking with staff and former participants of the program to support their trial commencing in May 2016.

**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:** In Progress

## The nature of grief in family and professional caregivers of people with dementia

**This study will inform HammondCare about aspects of grief in carers in dementia units.**

**Researcher:** Professor Roderick MacLeod (PhD Supervision)  
**Site:** Off-Site research  
**Duration:** Aug 11 to Jun 16

**Funding Source:** Internally Supported  
**Project Partners:** None  
**Study Status:** Suspended

## 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.**

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

**Funding Source:** Internally Supported  
**Project Partners:** None  
**Study Status:** In Progress

## The Social Orientation of Care In Aged Living (SOCIAL) Study

Single-Site Study

**This project will allow HammondCare to understand the ways in which the social professional networks of those**

(including the Cognitive Decline Partnership Centre)

**policy makers and consumers who have a wide range of expertise in working with older people with cognitive and related functional decline.**  
**HammondCare partners in providing collaborators and staff as Designated Systems Based Investigators (DSBIs) to bring their knowledge and experience to facilitate research activities and the translation of outcomes into practice within our services and around Australia. Since 2014 there has been involvement in twenty five activities across the themes of service model options, pathways and navigation, planning for later life, attitude and culture, functional decline, clinical guidelines, medication management and workforce development and education.**

**who provide care to residents with dementia, in the unit / wing selected, influence the care provided to these residents.**

This information can inform future management practices and policy, potentially leading to economic benefits of less use of antipsychotics as well as better motivated staff and less staff turnover.

**Researchers:** Professor Henry Brodarty, Ms Janet Mitchell & Professor Jeffrey Braithwaite  
**Site:** Waldegrave House North Turramurra  
**Duration:** Mar 15 to Mar 16

**Funding Source:** In researchers own time  
**Project Partners:** Not applicable  
**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:** Not applicable  
**Study Status:** In Progress

## Cognitive Decline Partnership Centre (CDPC)

**Director and Chief Investigator:** Professor Susan Kurrle

**The National Health and Medical Research Council (NHRMC) Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, or Cognitive Decline Partnership Centre (CDPC)**

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.

Stage 4 (completed) determination of facility level costs.

**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.

**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  
**Sites:** Erina & Woy Woy Residential Care Homes  
**Duration:** May 14 to Jun 16  
**Study Status:** In Progress

## 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 builds on a 12-month pilot study in five NSW acute hospitals.**

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

Stage 1 (completed): Incorporating consumer opinions into dementia care in residential aged care service configurations: what is important to people with dementia and their family members? 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.

*(including the Cognitive Decline Partnership Centre)*

**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  
**Study Status:** In Progress

**Investigators:** Ms Angela Raguz & Ms Catriona Lorang  
**Researchers:** Ms Adele Kelly & Ms Gail Yapp  
**Sites:** No specific site  
**Duration:** Oct 13 to Dec 18  
**Project Partners:** Flinders University  
**Study Status:** In Progress

**University of Bangor, Wales Designated System Based Investigators:** Ms Meredith Gresham  
**Sites:** Not Applicable  
**Duration:** Mar 14 to Jun 15  
**Study Status:** In Progress

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

**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 16

**Study Status:** Stage 1: Completed and Stage 2: 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 Turrumurra and Woy Woy  
**Duration:** Feb 14 to Jan 17  
**Study Status:** Literature review & planning stage

## Improving quality of residential dementia care and promoting change by supporting and caring for staff

**Literature review. This project is examining the relationships between variables involving staff and the quality of care delivered in aged care homes.**

**Lead Investigator:** Dr Mike Bird,

## Evaluating the Dementia Key Worker Role

**An evaluation of the dementia key-worker role commenced with a systematic review of the literature on key worker models/role in Australia and internationally.**

Together with the literature from the review the researchers and working group developed a framework to evaluate current Australian key worker models. The evaluation of these current roles will be used to develop recommendations to inform policy change and shape implementation of future key worker models/roles.

**HammondCare Liaison:** Ms Jo Luhr  
**Sites:** No specific sites  
**Duration:** Mar 14 to Dec 15  
**Study Status:** Completed

## 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.

**Lead Investigator:** Professor Meera Agar  
**Designated System Based**

## Opportunities for improvement in aged care service delivery by Information & Communication Technology (ICT)

**This study aims to identify opportunities for improvement in residential aged care service delivery by ICT.**

This research study fits in an ongoing program at HammondCare that aims to streamline clinical and financial processes with an ICT solution.

**Researchers:** Professor Christopher Poulos & Mr Junhua Li  
**Sites:** Pines, Southwood, Bond House & HammondGrove Independent Living Units, Hammondville  
**Duration:** Jan 14 to Apr 15

**Funding Source:** Internally Supported  
**Project Partners:** School of Public Health, UNSW  
**Study Status:** Completed

**Translational Outcome:**

At HammondCare, information and communication technologies have been identified as a possibility for residential aged care facilities to streamline clinical and financial processes. To initiate any organisational innovation, it is critical to identify challenges in present practices or circumstances or significant enhancement opportunities. In this project, participant observations and interviews were conducted with key stakeholders to identify the challenges and opportunities in 8 areas such as care coordination and medication management. With the project findings, business and stakeholders' requirements will be elicited and specified in a near future for a new residential care management system.

## Real Cases, Real Time (TRACS): Teaching and Research Aged Care Services

**This study introduced a new teaching model for staff in Residential Aged Care Homes and HammondAtHome settings, using distance education and case method teaching methods.**

The outcome is that there will be a direct benefit to HammondCare staff learning and thus to care of residents. TRACS is a ten session education project run in two streams. Stream 1 is for professionally registered staff and Stream 2 is for the care worker staff. The project, using case studies, provides education, which constantly reminds staff to consider the patient and/or client in the context as a whole person.

**Researchers:** Associate Professor Andrew Cole, Professor Christopher Poulos & Ms Anne Loupis  
**Sites:** Bond House, The Meadows, The Pines, Southwood (Hammondville); Leighton House, Princess Julianna Lodge and Waldegrave House (North Turrumurra); HammondCare Woy Woy;  
**HammondCare Horsley**  
**Duration:** Jun 12 to Mar 15

**Funding Source:** Commonwealth Department of Health and Ageing  
**Project Partners:** School of Public Health and Community Medicine, UNSW  
**Study Status:** Completed

## 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.**

**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:** In Progress

## 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.

**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



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: In Progress**

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**  
**Site: Braeside Hospital**  
**Duration: Sept 10 to Dec 16**

**Funding Source: Internally Supported**  
**Project Partners: None**  
**Study Status: In Progress**

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 is 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: None**  
**Study Status: In Progress**

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.

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

**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: In Progress**

The Out-And-About trial: Occupational Therapists & Physiotherapists providing outdoor journey sessions to stroke patients

Multi-Site Study

**The Out-and-About behaviour change intervention did not change team**

**behaviour or increase outdoor sessions provided to stroke participants, compared to control teams.**

Stroke participants seen by the experimental teams also did not go out more often than participants treated by control teams. Therefore, the publication of results will explore possible reasons for the absence of change, what has been learned about stroke rehabilitation teams and practice for use in future implementation research, and strengths and limitations of the study.

**Researchers: Ms Annie McCluskey & Ms Sia Karageorge**  
**Sites: Braeside Hospital**  
**Duration: Jan 10 to Jan 15**

**Funding Source: Administered by University of Sydney**  
**Project Partners: Not Applicable**  
**Study Status: Completed**

**Translational Outcome:**

Although differences were recorded for key outcomes between experimental and control teams, the absolute differences were small (i.e. not clinically significant), nor were the differences statistically significant. The behavior change or implementation intervention had no clinically or statistically significant effect on therapists' provision of outdoor mobility training to stroke patients. In addition, the intervention had no significant effect on the number of outings taken by stroke patients six months post-intervention, although there were changes in the type and purpose of their outings. The implementation intervention cannot, therefore, be recommended for use in practice. A process evaluation (focus group interviews and analysis of audit data) will be completed during 2016 with the four rehabilitation teams that demonstrated the largest change in practice (including two control teams). This process evaluation will help to inform future implementation projects by exploring characteristics of, and systems used by, the 'successful' teams.

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 15**

**Funding Source: Administered by The George Institute for Global Health Australia**  
**Project Partners: Not Applicable**  
**Study Status: In Progress**

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**  
**Site: Braeside Hospital**  
**Duration: Dec 12 to Jun16**

**Funding Source: Otto Bock Healthcare products and Ossur**  
**Project Partners: Multiple**  
**Study Status: Paper submitted**

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 treat 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**  
**Site: Braeside Hospital**  
**Duration: Dec 12 to Jun16**

**Funding Source: Otto Bock Healthcare products and Ossur**  
**Project Partners: Multiple**  
**Study Status: Paper being finalised for submission**

Redundancy of transfer items in the Functional Independence Measure (FIM)

**The FIM is an outcome measure used in routine rehabilitation practice and as part of the funding classification in rehabilitation.**

It includes three transfer items which measure similar tasks. The purpose of this study is to determine how closely related the three items are statistically. This is relevant as any data collection requires time and the collection of three items which are similar should be justified.

**Researcher:** Associate Professor Friedbert Kohler  
**Site:** Braeside Hospital  
**Duration:** June 15 to Jun17

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

## 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:** In Progress

## Thalamic neuroplasticity and pain following spinal cord injury

**This project is at the forefront of research investigating the underlying mechanisms of pain following spinal cord injury. Pain following spinal cord injury is common, debilitating and resistant to currently available treatments.**

**Researcher:** Professor Philip Siddall  
**Site:** Off-Site research  
**Duration:** Jun 12 to May 17

**Funding Source:** Internally Supported  
**Project Partners:** None  
**Study Status:** Completed

### Translational Outcome:

Better understanding of the mechanisms underlying this condition, drawing on promising new insights from neuroplasticity research, is leading to exploration of innovative new methods of treatment that target brain plasticity as a novel and potentially effective new approach to treating this type of pain (also refer to publications listing).

## 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:** None  
**Study Status:** In Progress

## 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.

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

**Funding Source:** Internally Supported  
**Project Partners:** None  
**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.

**Researchers:** Professor Philip Siddall, 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 involves key researchers in the field of pain management at Macquarie University and Sydney University and aims to develop an on-line pain management program for people with pain following spinal cord injuries.**

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 Sydney, NSW Agency for Clinical Innovation  
**Study Status:** In Progress

## 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.

**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 8 RAC sites in NSW, HC and non HC, retrospective audit of resident notes, resident interviews, staff focus groups, staff knowledge questionnaires and monitoring DBMAS data. Findings show that pain assessment and management for older people falls short of best practice guidelines and is limiting quality of life. Intervene stage 2 is currently seeking funding to improve organisational culture, knowledge and skills in residential aged care.

**Researchers:** A/Prof Colm Cunningham, Dr William McClean, Prof Philip Siddal, Ms Juliet Kelly  
**Site:** Residential and HammondAtHome  
**Duration:** Stage 1 Apr 2014 to Sept 2015, Stage 2 June 2016 to June 2018

**Funding Source:** John T Reid Trust & HammondCare Foundation  
**Project Partners:** None  
**Study Status:** In Progress

## Optimising the neurophysiological assessment of residual thermnociceptive 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:** In Progress

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

Single-Site Study

**This project is investigating the wastage of food and fluid in order to assist in developing strategies to help improve dietary intake of inpatients across Alfred Health.**

**Researchers:** Ms Sarah Ryan & Ms Indi Swan, Ms Kudzai Norah Nyamunduru  
**Site:** Caulfield Residential Facility, Melbourne

**Duration:** Jun 15 to Jun 16  
**Funding Source:** In researchers own time  
**Project Partners:** Not applicable  
**Study Status:** 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 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:** 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.

**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.**

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

## 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:** In Progress

## 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 Jan 17

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

## 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:** In Progress

## Spirituality and spiritual care in practice

**To understand what staff think and know about spirituality and spiritual care in order that we 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:** None  
**Study Status:** In Progress

## 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, is 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.

**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 Dec 16

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

# Education, presentations+ publications

Teaching+ Academic  
Professional Activities  
Higher Research Degrees  
Academic Degree Supervision  
Books+ Chapters  
Journal Articles  
Technical+ Other Reports  
Industry+ Magazine Articles  
Academic Conference+ Industry Seminars



## Teaching+Academic Professional Activities

### Professor Roderick MacLeod

As well as being a Senior Staff Specialist with HammondCare Rod is Conjoint Professor in Palliative Care with the University of Sydney. He is committed to teaching and learning about palliative and end of life care and to this end he is involved with teaching medical students at all stages of their career. He has also taught care workers across New South Wales and delivered teaching to GPs. He supervises research students many of whom will complete their PhD studies this year. He continues to be closely involved with the Palliative Care Bridge which provides easy access to professionals and the public to education on many aspects of end of life care - [HYPERLINK "http://www.palliativecarebridge.com"](http://www.palliativecarebridge.com) www.palliativecarebridge.com He also published an anthology *The Unknown Sea* (Steele Roberts Publishing, Wellington, NZ) in 2015.

Rod continued to review manuscripts for many medical publications and collaborates with international research partners on a number of projects. He continues as International Advisor to Hospice New Zealand. He was appointed a Member of the New Zealand Order of Merit by HM Queen in the NZ Queen's Birthday Honours in 2015.

### Professor Philip Siddall

Phil has a conjoint professorial position at the University of Sydney and is involved in teaching in the Graduate Medical Program and students enrolled in the 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 2015, he presented lectures to doctors, nurses and allied health practitioners in general practice, anaesthesia, pain medicine, palliative care and rehabilitation.

In 2015, Phil 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, research committees of the Australian & New Zealand College of Anaesthetists and several committees 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 Christopher Poulos

As Foundation Hammond Chair of Positive Ageing and Care, UNSW, Chris has had a number of teaching roles during 2015, including undergraduate teaching within the UNSW Medical Faculty and postgraduate teaching in the Master of Public Health / Master of Health Management programs and Health Policy course. Chris was also invited to teach on ambulatory rehabilitation models and the rehabilitation patient journey at the Hong Kong Hospital Authority Annual Convention in May 2015.

In 2015 Chris was invited to chair an international working party on reablement in dementia for the International Federation on Ageing and DaneAge. This involved two meetings in Copenhagen (the Global Think Tank on Ageing) and will culminate in a further meeting, the Copenhagen Summit, in April 2016. It is hoped that this collaboration will firmly place reablement strategies for older people, and those with chronic disease, on the global policy agenda.

Through a large arts in health grant for the Commonwealth government Chris has also taught artists on the role of the arts in improving the health and wellbeing of older people, as well as providing community education on ageing and dementia.

Chris is a Visiting Principal Fellow, Australian Health Services Research Institute, University of Wollongong and during 2015 continued in the role of Immediate Past President of the Australasian Faculty of Rehabilitation Medicine, Royal Australasian College of Physicians.

### Associate Professor Andrew Cole

As well as Andrew's substantive roles with HammondCare as Chief Medical Officer and Head of Research, 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, St George and Hammondville campuses. During 2015, 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, Thailand and Japan. During 2015, Andrew served as a member of several national and international committees, including as President-Elect and Chair of the Policy & Advocacy Committee of the Australasian Faculty of Rehabilitation Medicine (AFRM) of the RACP, and as a member of the Education Committee and the President's Executive of the International Society of Physical & Rehabilitation Medicine (ISPRM).

### Professor Meera Agar

As a clinical academic at University of Technology Sydney, University of NSW and Flinders University, Meera holds a combination of teaching and supervisory roles including: lecturing, coordinating, tutoring and examining undergraduate and postgraduate medical students.

In 2014/15 Meera served as a Member of a number of committees: Guidelines Adaptation Committee Australian National Clinical Guidelines for Dementia NHMRC Partnership Centre for Cognitive Decline; Scientific Advisory Committee Psycho-oncology Cooperative Research Group (PoCOG); Ingham Cancer Research Steering Committee of the Ingham Institute of Applied Medical Research; and Cooperative trials group Neuro-oncology (COGNO) Scientific Advisory Committee, and Management Executive.

In an ongoing capacity Meera also chairs the NSW Palliative Care Clinical Studies Collaborative for Improving Palliative Care through Clinical trials (IMPACT). Meera is the Lead Fellow (Assessment) of the Palliative Medicine Education Committee Royal Australasian College of Physicians. She also contributes to her profession as a member of various committees: Palliative care clinical trials collaborative (PaCCSC) Risperidone trial management committee; Choosing Wisely Australia Advisory Committee; and is a Board Member of the European Delirium Association.

### Associate Professor Friedbert Kohler

As well as Friedbert's numerous administrative roles in SW Sydney LHD and clinical direction of rehabilitation services at Braeside, Liverpool and Fairfield Hospitals, he is a Conjoint Associate Professor with the University of New South Wales, teaching in their medical student program, and involved with graduate student supervision.

In Lyon 2015 Friedbert was instated to the position of president-elect of the International Society of Prosthetics and Orthotics. He is a member of the WHO standards development group, for the development of Standards for prosthetic and orthotic services.

### Associate Professor Josephine Clayton

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 advance care planning (ACP) locally, nationally and internationally. She has a strong interest in teaching end-of-life (EOL) communication skills.

Examples of Josephine's professional contributions in 2015 include serving on: NSW Ministry of Health reference group to develop a training framework to support health professionals across public health facilities in ACP/EOL conversations; NSW Health Education and Training Institute subject matter expert group for the blended learning solution called "SHAPE End of life conversations" (an elearning module and workshop for clinicians), National Decision Assist project (to improve palliative care and ACP in aged care) evaluation advisory group; and the NHMRC Cognitive Decline Partnership Centre advisory committee to implement a national approach to dementia specific ACP. In 2015 Josephine was the Clinical Lead for the Clinical Excellence Commission's Communication Group for the Last days of Life Toolkit. She Chaired the patient resources working group and was a member of the steering committee for Cancer Institute NSW's ADAPT (Anxiety and Depression Pathways) Program. She Chaired the expert advisory group for Australian Research Council funded "enabling people with intellectual disability to understand dying" project and was a facilitator for the Australasian Chapter of Palliative Medicine Communication Skills training workshop. She is a Pillar lead for Sydney Vital Translational Cancer Research Centre's pillar 4: Supportive care, end-stage tumours and end-of-life management, a member of the management committee for ImPaCCT (improving palliative care through clinical trials) and was a member of the Scientific Committee for the National ACP & EOL Care conference held in Melbourne in November 2015. She was an invited speaker and workshop Chair at the International ACP & EOL Care conference held in Germany in September 2015 and an invited speaker and guest at the Cecily Saunders Institute, Kings College London in September 2015.

## Teaching+Academic Professional Activities

### Associate Professor Melanie Lovell

Melanie holds a clinical academic appointment at University of Sydney and as an affiliate at University of Technology Sydney. Her teaching roles include lectures and small group teaching for medical students and health science students in pain, symptom management and spirituality. She supervises 2 PhD students at University, and physician trainees through the College of Physicians.

Melanie's professional contributions include committee membership of the ImPaCCT (NSW Palliative Care Trials group) Management Advisory Committee, Palliative Care Clinical Studies Collaborative Trials (PaCCSC) Management Committee and Publications Subcommittee, Caresearch Knowledge Network Management Committee. 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 Co-lead of the Supportive Care Pillar of Sydney Vital, the Northern Sydney translational cancer centre.

### Associate Professor Janine Stevenson

Janine is a supervisor and lecturer for the Sydney University 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 behavioral 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 Kirsty Beilharz

At the University of Edinburgh UK, and the University of Salford UK, Kirsty presented public lectures and seminars on music engagement in dementia care. Kirsty is a Visiting Fellow (Music) at the University of Edinburgh. At UNSW Art and Design, Kirsty (on behalf of the HammondCare Dementia Centre) with academic staff of the Master of Interaction Design Degree collaborated on the design instruction of specialist age-appropriate musical instruments and interfaces for people living with dementia. HammondCare provided training in perceptual and interactive experiences of people with dementia, language for developing dementia design, and residents of Leighton Lodge North Turramurra participated in the user-centred design process. This teaching activity contributes to our understanding of active and creative music making, which is part of the music engagement pilot project.

### Dr Matra Robertson

As well as being a Clinical Senior Lecturer at the University of Sydney, Matra is the Allied Health Academic, for HammondCare. She is dedicated to research in end of life care addressing the social, spiritual and psychological factors that support vulnerable people and also research on the use of the arts to promote health and healthy ageing. During 2015 she lectured Medical students, Advanced Studies Nursing students and contributed to the Death, Dying and Mourning program for Masters Social Work students. Matra continued in 2015 to support Postgraduate students individually and promote professional activities.

Matra's academic professional activities include serving her professional peers internationally through consultation, collaboration and Life membership of the Social Work and Hospice and Palliative Care Network of the United States of America. During 2015 Matra was Chair of the Palliative Care Education Committee, HammondCare. She continued to review of manuscripts for local and international academic publications.

### Mr Mark Buhagiar

Mark continues his role in the training of undergraduate and postgraduate physiotherapy students, from different universities across NSW, in the rehabilitation and palliative care specialties. 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 2015/16 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 has also continued with his regular contributions to the Ingham Institute research seminars, as well as to HammondCare and local district conferences, workshops and forums, and is a member of the organising committee for the 2016 SWSLHD Research Showcase. In the coming year Mark hopes to finalise and submit his PhD thesis on rehabilitation following joint arthroplasty, which he is completing through the University of New South Wales.

### Ms Meredith Gresham

Meredith Gresham is a Designated Systems Based investigator of the NHMRC Partnership Centre for Cognitive and Related Function Decline in Older People and was the inaugural Chair of this Enabling Sub Unit of the Centre.

She is an Associate Editor of the journal International Psychogeriatrics and edits the occupational therapy section of the International Psychogeriatric Association Newsletter. She is a member of the Australian Association of Occupational Therapists and the Australian Association of Gerontology.

## Higher Research Degrees

**Student Name: Dr Phil Austin**

**Degree: PhD completed 2015**

**University: University of Edinburgh**

**Supervisors: Dr Gordon Drummond and Dr Sarah Henderson**

**Thesis title: An international Delphi study to assess the need for multiaxial criteria in the diagnosis and management of functional gastrointestinal disorders**

**Student Name: Dr Megan Best**

**Degree: PhD candidate**

**University: University of Sydney, Medical Faculty**

**Supervisors: Professor Phyllis Butow and Professor Ian Olver**

**Thesis Title: The spiritual needs of cancer patients and the role of the doctor in meeting them**

**Student Name: Mr Mark Buhagiar**

**Degree: PhD candidate**

**University: University of New South Wales**

**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**

**Thesis Title: Investigating elements of post-operative rehabilitation for total knee replacement (TKR)**

**Student Name: Mr Michael Darragh**

**Degree: PhD candidate**

**University: University of Wollongong**

**Supervisors: Professor Bourgeois and Dr Joyce-McCoach**

**Thesis Title: Effective approaches to leadership skill development**

**Student Name: Ms Meredith Gresham**

**Degree: PhD candidate**

**University: University of Sydney**

**Supervisors: Professor Lindy Clemson and Associate Professor Lee-Fay Low.**

**Thesis Title: An investigation of the clinical utility of the electronic bidet for Australian nursing home residents and staff**

**Student Name: Ms Bianca Kinnear**

**Degree: PhD candidate**

**University: University of Wollongong**

**Supervisors: Professor Anne Cusick (primary at UoW) & Associate Professor Natasha Lannin (secondary at LaTrobe University)**

**Thesis Title: Physical Therapy as an adjunct to Botulinum toxin-A for treatment of spasticity in adults with neurological impairment**

**Student Name: Dr Martin Kennedy**

**Degree: PhD candidate**

**University: University of Lancaster, UK**

**Supervisor: Dr Sarah Brearley and Dr Catherine Walshe**

**Thesis Title: Junior hospital medical officers' experience of making clinical decisions regarding patients with advanced, irreversible, progressive and life limiting medical conditions when on-call after-hours.**

## Academic Degree Supervision

**Agar M;** Student Name: Megan Jeon, Doctoral Thesis: *Sleep disturbance in brain tumours*, University of NSW, Sydney, 2015

**Buhagiar M,** Adjunct Supervisor, School of Physiotherapy, Macquarie University, Sydney.

**Clayton J;** Butow PN; 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

**Clayton J;** Tong A; 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.

Goodyear-Smith F, Butow S, **MacLeod RD.** PhD (advisor) Student Name: Yvonne Bray, PhD Thesis: *Transnationals' experience of end of life care in New Zealand*. University of Auckland, Auckland 2011-6

**Lovell M;** Butow PN, Agar M, Tong A. Student Name: Skye Dong, PhD Thesis: *Symptom clusters in cancer patients*, University of Sydney

**Lovell M,** Phillips J, Luckett T. Student Name: Ms Xiangfeng (Renee) Xu. PhD Thesis: *Cultural Issues in Cancer Pain Management in Chinese nationals*. University of Technology Sydney.

**MacLeod RD,** Glasgow NP. PhD. Student Name: Suzanne Rainsford, PhD Thesis: *A rural perspective on quality end of life care* ANU, Canberra, 2014-7

**MacLeod RD,** Jones M, Healee D. DHSc. Student Name: Christine McDonald, PhD Thesis: *Collaborative practice in the New Zealand palliative care environment*. AUT University, Auckland. 2011-5

**MacLeod RD,** Sasidharan R, Keogh J, Arroll B, Stewart J. Student Name: Elaine Rogers, PhD Thesis: *Does a multi-targeted approach of supportive care improve the cancer cachexia status in lung cancer patients?*, University of Auckland, Auckland. 2008-16

Owens G, Huggard P, **MacLeod RD.** Student Name: Sue Jacobi, PhD Thesis: *The nature of grief in family and professional carers of people with dementia*, University of Auckland, Auckland. 2011-16

**Poulos CJ.** Student Name: Dr Jane Wu. PhD Thesis: *Early Rehabilitation in Trauma and Critical Illness*. Faculty of Medicine, The University of NSW.

**Siddall PJ,** 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

## Awards

**Professor Roderick Duncan MacLeod,** Member of the New Zealand Order of Merit, Her Majesty the Queen

**Professor Philip Siddall,** ANZCA/Pfizer Research Award, Australian & New Zealand College of Anaesthetists

## Best Poster Presentation

**Agar M,** Lawlor P, Quinn S, Draper B, Caplan G, Hill M, Rowett D, Sanderson C, Hardy J, Le B, Eckermann S, McCaffrey N, Devilee L, Fazekas B, and Currow D. *Phase III randomized double-blind controlled trial of oral risperidone, haloperidol or placebo with rescue subcutaneous midazolam for delirium management in palliative care*. American Geriatric Society Annual Meeting, National Harbor USA, Poster presentation May 2015. Journal of the American Geriatrics Society. 63: S99-S99. 1/4/2015

**Gresham M,** Shute J. *The electronic toilet top bidet in residential aged care: A potential improvement in clinical care*. 14th National Conference of Emerging Researchers in Ageing, Melbourne, Australia. December, 2015.

Sellars M, Tong A, Silvester W, Pollock C, Luckett T, Morton RL, Detering KM, Spencer L, **Clayton JM.** *Delivering advance care planning in chronic kidney disease (CKD): the perspectives of healthcare providers*. 5th International Advance Care Planning and End-of-life Care conference, Munich September 2015.

 Books+Chapters

## Books:

1. **Lovell MR**, Boyle FM. *Overcoming Cancer Pain, Sydney Australia*, Cancer Council Australia, September, 2015, ISBN 978-1-925136-66-1.

2. **MacLeod RD**, Vella-Brincat J, Macleod AD. *The Palliative Care Handbook. (8th Edition)* Sydney, Hammond Press (also available as an e-book) ISBN 978-0-9875828-7-4

3. **MacLeod RD**. *The Unknown Sea – an anthology of poems on living and dying*. Wellington, Steele Roberts. ISBN 978-1-927242667

## Book Chapters:

1. **Beilharz K**, *Grace and Nurture: Connecting and Engaging through Music in Dementia* Care in Harrison J, Costache D, Kariatlis P (Eds) *Wellbeing, Personal Wholeness, and the Social Fabric*, Cambridge (forthcoming).

2. **Lovell MR**, Boyle FM. Optimising pain control. In: *Handbook of Communication in Oncology and Palliative Care*. David W Kissane, Barry D Bultz, Phyllis N Butow and Ilora Finlay editors, Oxford University Press, Oxford 2010. ISBN 978-0-19-923836-1. P 315-326. Updated 2015.

3. Urban K, **Clayton JM**, Kissane D. *Communication about transitioning patients to palliative care*. In Kissane D, Bultz B, Butow P, Finlay I (eds) 2nd edition *IN PRESS Handbook of Communication in Oncology and Palliative Care*, Oxford, Oxford University Press, accepted August 2015

4. Glare P, Sinclair C, Downing M, **Clayton J**. *Predicting survival in patients with advanced disease*. In Nathan Cherny, Marie Fallon, Stein Kaasa, Russell K. Portenoy, David C. Currow (eds). 5th Edition, *Oxford Textbook of Palliative Medicine*, ISBN 978-0-19-965609-7, 2015, Oxford University Press, UK, pages 65-76.

5. **Clayton JM**, Tattersall MHN. *Communication in Palliative Care*. In Bruera E, Higginson I, von Gunten C, Morita T(eds). 2nd Edition, *Textbook of Palliative Medicine and Supportive Care*, ISBN 13:978-1-4441-3526-8, 2015, CRC Press, London, UK, pages 1047 to 1053.

6. Phillips J, Ingham JM, **MacLeod RD**. *The development of palliative care in Australia and New Zealand*. In Bruera E, Higginson I, Ripamonti C & von Gunten C (Eds.) *Textbook of Palliative Medicine and Supportive Care*. Hodder Arnold. pp59-70 ISBN 978-1-444135251

7. **Siddall PJ**, Middleton JW (2015) *Pain following spinal cord injury*, In: Chhabra HS (ed.) *ISCoS Textbook on Comprehensive Management of Spinal Cord Injuries*, ISBN: 9351294404, 9789351294405, 2015, Wolters Kluwer, New Delhi, pp 825-848.

 Journal Articles

1. **Agar M**, Koh E, Gibbs E, Barnes E, Hovey E, Livingstone A, Sawkins K, Chye R, **Lovell MR**, Clark K, Vardy J, King M. *Validating self-report and proxy reports of Dexamethasone Symptom Questionnaire for the evaluation of longer-term corticosteroid toxicity*. Supportive Care in Cancer [Epub ahead of print. Aug 21, 2015. DOI 10.1007/s00520-015-2897-0]

2. **Agar M**, Luckett T, and Phillips J. *Role of palliative care in survivorship*. Cancer Forum. July 2015. <http://cancerforum.org.au/forum/2015/july/role-of-palliative-care-in-survivorship/>

3. **Austin PD, MacLeod R, Siddall PJ**, McSherry W, Egan R. *The ability of hospital staff to recognise and meet patients' spiritual needs: a pilot study*. Journal for the Study of Spirituality (accepted November 2015)

4. Badger S, **MacLeod RD**, Honey A *"It's not about treatment, it's how to improve your life": the lived experience of Occupational Therapy in palliative care*. Palliative and Supportive Care doi. 10.1017/S1478951515000826

5. **Beilharz K**, *Engaging and connecting through music: enablement in practice*. Australian Journal of Dementia Care. 2015 February-March. Vol 5 No 1 pp.21-25

6. Butow P, Price M, Shaw J, **Clayton JM**, Grimison P, Rankin N, Kirsten L. *Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines*. Psycho-Oncology 2015; 24 (9): 987-1001

7. Chakiath RJ, **Siddall PJ**, Kellow JE, Hush JM, Jones MP, Marcuzzi A, Wrigley PJ. *Descending pain modulation in irritable bowel syndrome (IBS): a systematic review and meta-analysis*. Systematic Reviews. 2015 Dec 10; 4(1):175. doi: 10.1186/s13643-015-0162-8

8. Cheang F, **Clayton JM**. In reply to 'When paperwork does not represent the patient's wishes for surrogate decision-making' (letter to editor). Internal Medicine Journal 2015; 45 (11): 1200 -1201

9. Chow J, Waldon P, Lubiana A, Williams R, Loy G, Lim K, Larkin A, **Kohler F**. *The establishment of the Triple I (Hub), an intake, information and intervention hub*. Contemporary Nurse 2015: 50:227-237, doi:10.1080/10376178.2015.1116371

10. Clark K, Quinn SJ, Doogue M, **Lovell M**, Sanderson C, Currow DC. *Routine prescribing of gabapentin or pregabalin in supportive and palliative care: What are the comparative performances of the medications in a palliative care population?* Supportive Care in Cancer. 2015;5(3):273-280. [Epub ahead of print 2015 DOI 10.1007/s00520-015-2837-z.]

11. Currow DC, Clark K, Kamal A, Collier A, **Agar MA, Lovell MR**, Phillips J, Ritchie C. *The population burden of symptoms and comorbidities that pre-date the diagnosis of a life-limiting illness*. Journal of Palliative Medicine . 2015;18(6) [Epub ahead of print 2015 April 10.]

12. Dong ST, Butow PN, **Agar M, Lovell MR**, Stockler M, Boyle F, Tong, A. *Clinicians' perspectives on managing*

 Journal Articles

*multiple symptoms in advanced cancer: a semi-structured interview study*. Submitted to Journal of Pain and Symptom Management Accepted 9 November, 2015

13. Dong ST, Butow PN, Tong, A, **Agar M**, Boyle F, Forster BC, Stockler M, **Lovell MR**. *Patients' experiences and perspectives of multiple concurrent symptoms in advanced cancer: a semi-structured interview study*. Supportive Care in Cancer. 2015. Accepted 08 August, 2015

14. Dong S, Costa DSJ, Butow PN, **Lovell MR, Agar M**, Velikova G, Teckle P, Tong A, Tebbutt NC, Clarke SJ, van der Hoek K, King M, and Fayers PM *Symptom clusters in advanced cancer patients: an empirical comparison of statistical methods and the impact on quality of life*. Journal of Pain and Symptom Management. (accepted August 2015)

15. Duggleby W, Robinson C, Kassalainen S, Pesut B, Nekolaichuk C, **MacLeod R**, Keating N., Santos Salas A, Hallstrom L, Fraser K, Williams A, Swindle J & Struthers-Montford K. *Which way from here? Navigation for the Care of Older Rural Adults with Terminal Illness*. Canadian Journal on Aging (accepted July 2015)

16. Duggleby W, Kuchera S, **MacLeod R**, Holyoke P, Scott T, Holtslander L, Letendre A, & Moeke-Maxwell T. *Indigenous Peoples' Experiences at the End of Life*. Palliative and Supportive Care. 13, 1721-1733

17. Egan R, Wood S, **MacLeod RD**, Walker R. *Spirituality in renal supportive care: a thematic review*. Healthcare 3(4), 1174-1193

18. Faux SG, **Kohler F**, Mozer R, Klein LA, Courtenay S, D'Amours SK, Chapman J, Estell J. *The ROARI project – Road Accident Acute Rehabilitation Initiative: A randomised clinical trial of two targeted early interventions for road related trauma*. Clinical Rehabilitation, Clin Rehabil July 2015 29: 639-652, doi:10.1177/0269215514552083

19. Finnerup NB, Attal N, Haroutounian S, McNicol E, Baron R, Dworkin RH, Gilron I, Haanpaa M, Hansson P, Jensen TS, Kamerman PR, Lund K, Moore A, Raja SN, Rice ASC, Rowbotham M, Sena E, **Siddall P**, Smith BH, Wallace M. *Pharmacotherapy for neuropathic pain in adults: systematic review, meta-analysis and NeuPSIG recommendations*, Lancet Neurology. 2015 Feb; 14(2):162-73. doi: 10.1016/S1474-4422(14)70251-0

20. Hosie A, Lobb L, **Agar M**, Davidson PM, Chye R, and Phillips J. *Nurses perceptions of the Nursing Delirium Screening Scale in two palliative care inpatient units: a focus group study*. Journal of Clinical Nursing. Accepted 23/5/2015

21. **Keall R, Clayton JM**, Butow PN. *Therapeutic life review in palliative care: a systematic review of quantitative evaluations*. Journal of Pain and Symptom Management, 2015 Apr; 49(4):747-61. doi: 10.1016/j.jpainsymman.2014.08.015

22. **Kelly J and Papadopoulos C**; *Prevalence and management of pain in people with dementia*. Australian Journal of Dementia Care; August/September 2015 Vol4 No 4, pg44-47

23. **Lovell MR**, Luckett T, Boyle F, Stubbs J, Phillips J, Davidson PM, Olver I, Von Dincklage J, **Agar M**. *Adaptation of international guidelines on assessment and management of cancer pain for the Australian context*. Asia-Pacific Journal of Clinical Oncology 04/2015 11(2):170-177.

24. **Lovell M**, Phillips J, Luckett T, and **Agar M**. *Improving the system for managing cancer pain*. Internal Medicine Journal. 45 (3). 361-362

25. Luckett T, Bhattarai P, Phillip J, **Agar M**, Currow D, Krustev Y, Davidson P. In press. *Advance care planning in 21st Century Australia: A systematic review and appraisal of online advance care directive templates using the National Framework*. Australian Health Review. Accepted 22nd March 2015

26. **MacLeod RD** *Assisted dying is not part of good medical practice*. Australian Medical Student Journal (accepted September 2015)

27. **MacLeod RD** *How good do you have to be?* Journal of Palliative Care and Medicine 5(5): 134 doi: 10.4172/2165-7386.1000e134

28. **MacLeod RD** *Dying at home – can it be done?* Journal of Palliative Care and Medicine doi: 10.4172/2165-7386.1000e133

29. **MacLeod RD**, Johnson C, Yule S. *Making it easier to die at home*. European Journal of Palliative Care 22(1); 26-9

30. Marston C, Brown T and **Agar M**. *Patients and carers perceptions of occupational therapy and adapting to discharge home from an inpatient palliative care setting*. British Journal of Occupational Therapy. 2015. 78 (11). DOI:10.1177/0308022615586417

31. McCaffrey N, Hardy J, Fazekas B, **Agar M**, Devilee L, Rowett D and Currow D. *Potential economic impact on hospitalisations of the Palliative Care Clinical Studies Collaborative (PaCCSC) ketamine randomised controlled trial*. Australian Health Review. Accepted for publication 20th April 2015

32. McCaffrey N, **Agar M**, Harlum J, Katnon J, Currow D, and Eckermann S. *Better informed decision making with multiple outcomes cost-effectiveness analysis under uncertainty in cost-disutility*. PLOS-one. 2015. 10(3) e0115544

33. Michael N, O'Callaghan C, Baird A, Gough K, Krishnasamy M, Hiscock N, **Clayton J**. *A mixed method feasibility study of a patient- and family-centered advance care planning intervention for cancer patients*. BMC Palliative Care 2015, 14:27, DOI: 10.1186/s12904-015-0023-1 URL: <http://www.biomedcentral.com/1472-684X/14/27>

34. Mowll J, Lobb E, Lane L, Lacey J, Chochinov HM, Kelly B, **Agar M**, Links M, Kearsley JH, *A pilot study of an intervention to facilitate communication between couples in advanced cancer*. Palliative & Supportive Care. 2015. 1-10

35. Morgan A, **MacLeod RD**, Schumacher M. *Providing palliative care education to staff in elderly care settings in New Zealand*. European Journal of Palliative Care 22(6), 296-299



## Journal Articles

36. Morgan A, **MacLeod RD**, Schumacher M, Egan R. *Delivering spiritual care: a resource to train hospice staff in New Zealand*. European Journal of Palliative Care 22(3); 130-132

37. Nikles J, Mitchell G, Hardy J, **Agar M**, Senior H, Carmont S, Schluter P, Good P, Vora R, and Currow D. *Testing pilocarpine drops for dry mouth in advanced cancer using n-of-1 trials: a feasibility study*. Palliative Medicine. Accepted 7th April 2015.

38. Phillips JL, Lovell M, Luckett T, **Agar M**, Green A, and Davidson P. *Australian survey of current practice and guideline use in adult cancer pain assessment and management*. The community nurse perspective. Collegian. 2015; 22 (1). 33 – 41

39. **Radhakrishnan S, Kohler F**, Schiappacasse C, Fialka-Moser V, Li J, Gutenbrunner C, Jayaraman A. *Mobility post amputation from the patient's perspective: An International comparison using the International Classification of Functioning, Disability and Health (ICF)*. ISPO World Congress, 22-25 June 2015, Lyon, France, Book of abstracts p651

40. Shaw J, Price M, **Clayton JM**, 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 2015 April 23 doi: 10.1007/s00520-015-2742-5. (Epub ahead of print) PMID: 25903929

41. Selb M, **Kohler F**, Robinson Nicol MM, Riberto, Stucki G, Kennedy C, Ustun B. *ICD-11: A comprehensive picture of health, an update on the ICD-ICF joint use initiative*. J Rehabil Med 2015; 47:2-8. IF 1.895

42. **Siddall PJ**, Middleton JW. *Spinal cord injury-induced pain: mechanisms and treatments*. Pain Management. 2015 Nov;5(6):493-507. doi: 10.2217/pmt.15.47

43. **Siddall PJ**, Middleton JM. *Assessing and managing chronic pain after spinal cord injury*. Pain Management Today. 2015; 2:26-28

44. **Siddall PJ, Lovell M, MacLeod R**. *Spirituality: What is its role in pain medicine?* Pain Medicine. 2015 Jan; 16(1):51-60. doi: 10.1111/pme.12511

45. Stancliffe RJ, Wiese MY, Read S, Jettes G, **Clayton JM**. *Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?* Research in Developmental Disabilities 2015 Dec 1;49-50:47-59. doi: 10.1016/j.ridd.2015.11.016. [Epub ahead of print] PMID: 26658384

46. Walczak A, Butow PN, Bu S, **Clayton JM**. *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 Counseling 2015 Aug 17. pii: S0738-3991(15)30054-9. doi: 10.1016/j.pec.2015.08.017. [Epub ahead of print] PMID: 26404055

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50. Yong Joo R, Houttekier D, **MacLeod R**, Wilson DM, Cardenas-Turanzas M, Aubrey R, Teno J, Roh S, Deliens L, Cohen J. *International comparisons of death place for suicides: a population-level eight country death certificate study*. Social Psychiatry and Psychiatric Epidemiology doi 10.1007/s00127-015-1148-5

## Technical+Other Reports

1. Report from the NHMRC Cognitive Decline Partnership Centre (University of Sydney) and HammondCare 2015. *Future care planning for individuals with cognitive decline: why advance care planning needs to be different for people with cognitive decline*. **Agar M** (Chair), Advisory Committee: **Clayton J**, Field S, Kinsella P, **Lorang C, Forbes R, Rhee J**, Shanley C, Sinclair C, Van Eden J, Williams K, Project officers: **Kelly A, Yapp G, Ohrynowsky N**. <http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php>

2. **Beilharz K**, *Walking with God for All Our Days: Personhood in Dementia* Fixing Her Eyes, invited online article, 17 September 2015 <http://www.fixinghereyes.org/#!Walking-with-God-for-All-Our-Days-Personhood-in-Dementia/x8n1k/55fa01020cf219accd9945b1>

3. **Beilharz K**, *Where Words Fail ... Connecting through Music*, invited online article, 7 October 2014 <http://www.adisl.org.au/blog-webapp/where-words-fail-connecting-through-music?A=WebApp&CCID=17479&Page=4&Items=20>

4. DVD produced by Centre for Disability Research and Policy and Sunshine (**Clayton JM** was Chair of the Advisory group, member of the script writing team, and chief investigator for the project, the DVD was partly filmed at Greenwich Hospital, **Mears D** was a member of the advisory group) 2015. *Dying to Talk: Helping people with intellectual disability to understand dying and death*. Winner of the 2015 Australian Writers Guild Award (recipient Peter Flynn: script writer and director) <http://www.awg.com.au/news-18/latest-news/741-2015-awgie-winners-by-category.html>

5. **Gresham M D**, Clemson L. *Summary Report - Improving the toileting experience for older people in nursing homes*.

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Dementia Collaborative Research Centre – Assessment and Better Care. The University of NSW. 2015

6. **Cunningham C, McIntosh D**, Thorne, D, **Gresham M**. *Design Smart. The rating tool for environments that work for people with dementia*. HammondCare Media, 2015, ISBN: 978-09875828-5-0

7. **MacLeod RD**, Moeke-Maxwell T, Egan R, Crombie R 2015 *Foundations of Spiritual Care Evaluation Report: Findings from Surveys and Post Programme Reflections*. Wellington, Hospice NZ

8. **MacLeod RD** 2015 *Affidavit in the High Court of New Zealand - Seales v Attorney General under the Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990 CIV-2015-485-235*

9. **Poulos CJ**, Beattie E, **Gresham M, Harkin D**. *Beyond Respite: Designing Effective Wellness Programs for Carers*. Final Report. Dementia Collaborative Research Centres. 2015. <http://www.dementiaresearch.org.au/reports-cc.html?view=dcrc&layout=outputs>

## Industry+Magazine Articles

1. **Beilharz K**, *Singing from the same sheet*, Australian Ageing Agenda. September-October 2015, p44.

2. **Cunningham C & Beilharz K**, *Music that engages and endures*, Australian Ageing Agenda. Jan-Feb 2015, p 46 & 47

3. **Cunningham C & Marshall M**, *When is a door not a door*, Australian Ageing Agenda. March-April 2015, p 46 & 47

4. **Cunningham C**, *What is the story with dementia-friendly communities?*, Australian Ageing Agenda, May-June 2015, p46 & 47

5. **Gresham M**. *Promoting dignity in care: using a combined toilet-seat bidet and mobile shower chair shows promise in reducing carer strain and improving dignity for the user*. Australian Journal of Dementia Care 4 (6) December, 2015

## Academic Conference+ Industry Seminars

1. **Agar M**, Lawlor P, Le B, Martin P, Chye R, Clark K, Caplan G, Ely W, Lam L, de Souza P, Nikles J, McCaffrey N, Bush S, Draper B, Sanderson C, Luckett T, Rowett D, Lee J, Phillips J, Currow D. *Randomised double blind placebo controlled pilot phase II trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer. Oral presentation*. 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015.

2. **Agar MR**, Luckett T, Phillips J, Chenoweth L, Mitchell G, Beattie E, Pond D, Luscombe G, Goodall S, Davidson PM. *Implementing facilitated case conferencing for residents*

*with advanced dementia in aged care – development of the palliative care planning coordinator role*. Oral presentation 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015

3. **Agar M**, Lawlor P, Quinn S, Draper B, Caplan G, Hill M, Rowett D, Sanderson C, Hardy J, Le B, Eckermann S, McCaffrey N, Devilee L, Fazekas B, and Currow D. *Phase III randomized double-blind controlled trial of oral risperidone, haloperidol or placebo with rescue subcutaneous midazolam for delirium management in palliative care*. (Australian and New Zealand Society for Geriatric Medicine Annual Scientific Meeting. Oral presentation, Perth May 2015.) Australasian Journal on Ageing. 34. 33 – 33 1/5/2015

4. **Agar M**, Lawlor P, Quinn S, Draper B, Caplan G, Hill M, Rowett D, Sanderson C, Hardy J, Le B, Eckermann S, McCaffrey N, Devilee L, Fazekas B, and Currow D. *Phase III randomized double-blind controlled trial of oral risperidone, haloperidol or placebo with rescue subcutaneous midazolam for delirium management in palliative care*. American Geriatric Society Annual Meeting, National Harbor USA, Poster presentation May 2015. Journal of the American Geriatrics Society. 63: S99-S99. 1/4/2015

5. **Alpert K**, *“Why Not*, Montessori Ageing Support Services 2015 Conference, We are talking about a revolution. Coogee NSW Australia, 10th November 2015

6. **Beilharz K**, *Grace and Nurture: Connecting and Engaging through Music in Dementia Care*. Sydney College of Divinity Conference: Wellbeing, Personal Wholeness, and the Social Fabric. Sydney Australia, 28 September 2015

7. **Beilharz K**, *Embedded Music Engagement in Dementia & Aged Care*. Arts and Health Australia 7th Annual Art of Good Health and Wellbeing International Arts and Health Conference. Melbourne, 13 November 2014


8. **Beilharz K**, *Sustainable Practice Music Engagement in Dementia Care*. Arts Health Institute Play Up Convention. Sydney, 25 November 2014

9. **Birch MR**, Luckett T, Boyle F, Davidson PM, Stubbs J, Phillips J, **Agar M** and **Lovell M**. *Electronic screening for cancer pain and other symptoms: fit for the future?* Oral presentation. Oral presentation 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015

10. **Birch MR**, Luckett T, Boyle F, Davidson PM, Phillips J, Stubbs J, **Agar M, Lovell MR**. *Electronic screening for cancer pain and other symptoms: fit for the future?* Australian Palliative Care Conference, Melbourne 1-4 September 2015

11. **Buhagiar M**, *The HIHO RCT*, UNSW Dean's Seminar, Sydney Australia, 25 February 2015

12. **Buhagiar M**, *Understanding clinician preferences for inpatient rehabilitation after joint arthroplasty*, Ingham Institute Lunchtime Seminar. Sydney Australia, 5 May 2015

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13. **Buhagiar MA**, Naylor JM, Mills K, **Kohler F**, Harris IA, Xuan W. *Determining clinically relevant change in 6-minute walk test (6MWT) following a total knee arthroplasty (TKA): a preliminary analysis*. ISPRM 9th World Congress, June 19-23 2015, Berlin, Germany. J Rehabil Med Supp 54, June 2015 p147.

14. **Buhagiar MA**, Naylor JM, **Kohler F**, Harris IA, Simpson G. *Understanding consumer and clinician preferences for inpatient rehabilitation after joint arthroplasty*. ISPRM 9th World Congress, June 19-23 2015, Berlin, Germany. J Rehabil Med Supp 54, June 2015 p147.

15. **Buhagiar M**, *Meandering along the path of PhD undertaking, trial management, job juggling and family: a fantasised, uncontrolled trail?*, 9th World Congress of the International Society of Physical and Medical Rehabilitation. Berlin Germany, 20 June 2015

16. **Buhagiar M**, Naylor J, Simpson G, Harris I, **Kohler F**, Xuan W. *Understanding patient and carer preferences for inpatient rehabilitation after joint arthroplasty*, 9th World Congress of the International Society of Physical and Medical Rehabilitation. Berlin Germany, 19 June 2015

17. **Buhagiar M**, Naylor J, Mills K, *Determining moderately important change in 6-minute walk test (6MWT) following a total knee arthroplasty (TKA)*, 9th World Congress of the International Society of Physical and Medical Rehabilitation. Berlin Germany, 19 June 2015

18. **Buhagiar M**, Downes J, Shaik A, *Enhancing student comfort and critical conversations at the end of life*, 2015 Oncology Social Work Australia Conference. Sydney Australia, 12 September 2015.

19. **Buhagiar M**, Naylor J, Simpson G, Harris I, **Kohler F**, Xuan W. *Understanding clinician, patient and carer preferences for inpatient rehabilitation after joint arthroplasty*, Australian Orthopaedic Association: 75th Annual Scientific Meeting. Brisbane Australia, 11 October 2015

20. **Buhagiar M**, Naylor J, Simpson G, Harris I, Kohler F. *Consumer and clinician preferences for inpatient rehabilitation after joint replacement*. 23rd ASM, AFRM, 14-16 October 2015, Wellington, New Zealand.

21. **Buhagiar M**, Naylor J, Harris I, **Kohler F**, Xuan W, Wright R, Fortunato R, *Hospital inpatient versus home-based rehabilitation post total knee arthroplasty (the HIHO study): preliminary results of a randomised controlled trial*, 2015 AFRM/NZRA Combined Rehabilitation Meeting. Wellington New Zealand, 18 October 2015

22. **Buhagiar M**, Naylor J, Simpson G, Harris I, **Kohler F**, Xuan W. *Understanding clinician and consumer preferences for inpatient rehabilitation after joint arthroplasty*, 2015 AFRM/NZRA Combined Rehabilitation Meeting. Wellington New Zealand, 18 October 2015

23. **Buhagiar M**, Naylor J, Harris I, **Kohler F**, Xuan W, Wright R, Fortunato R, *Hospital inpatient versus home-based rehabilitation*

*post total knee arthroplasty (the HIHO study): preliminary results of a randomised controlled trial*, National Allied Health Conference. Melbourne Australia, 11 November 2015

24. **Buhagiar M**, Naylor J, Simpson G, Harris I, **Kohler F**, Xuan W. *Understanding clinician and consumer preferences for inpatient rehabilitation after joint arthroplasty*, National Allied Health Conference. Melbourne Australia, 11 November 2015

25. **Buhagiar M**, Naylor J, Harris I, **Kohler F**, Xuan W, Wright R, Fortunato R, *Hospital inpatient versus home-based rehabilitation post total knee arthroplasty (the HIHO study): a randomised controlled trial*, Ingham Institute Research Showcase. Sydney Australia, 27 November 2015

26. **Buhagiar M**, Naylor J, Simpson G, Harris I, **Kohler F**, Xuan W. *Understanding clinician and consumer preferences for inpatient rehabilitation after joint arthroplasty*, Ingham Institute Research Showcase. Sydney Australia, 27 November 2015

27. Bush S, Marchington K, **Agar M**, Davis D, Sikora L, and Tsang T. *Getting the best advice: A systematic appraisal of delirium clinical practice guidelines*. European Association for Palliative Care, Copenhagen, poster presentation, May 2015

28. **Clayton JM** (invited keynote speaker), *Advance Care Planning in Chronic Kidney Disease – results of recent research*. Cicely Saunders Institute Seminar Series, Kings College, London, UK, 14th September 2015

29. **Clayton JM** (invited speaker), Luckett T, Morton R, Spencer L, Silvester W, Sellars M, Detering K, Tong A, Butow P, Pollock C. *Current practice and barriers to advance care planning in the Australian and New Zealand nephrology setting: a national survey*. 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, Germany, 11th September 2015


30. **Clayton JM** (invited research workshop chair and facilitator) Houben CHM, Gilisen J, van der Heide A, Tattersall MHN. *The challenge of conducting randomised controlled trials to study ACP effectiveness. Practical insights from 4 current RCTs*, 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, 9th September 2015

31. **Clayton JM** (invited poster session chair), *Poster Group 2 Session*, 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, 11th September 2015

32. **Clayton JM** (invited speaker), *Advance care planning in Chronic Kidney Disease – results of recent research*, Renal Supportive Care Symposium, St George Hospital, Sydney, Australia, 21st August 2015

33. **Clayton JM**, *Communication about advance care planning in general practice*, Advance Care Planning workshop for General Practice Nurses, University of New South Wales, Sydney, Australia, 16th July 2015

34. **Clayton JM**, Meller A. *Advance Care Planning. End of life and people with intellectual disability seminar*, University of Sydney, Sydney, Australia, 30th June 2015

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35. **Cole AM, Poulos CJ**, Loupis AK, Poulos RG, Travaglia J. *Case Method Teaching by internet videoconference – Real Cases, Real Time*. (oral poster presentation). Ninth World Congress of the ISPRM. Berlin, Germany, 19-23 June 2015.

36. Cummins C, Kayes, N, Reeve J, Smith G, **MacLeod R**, McPherson K *Put back out into the world and left hung out to dry a bit: A place for rehabilitation service provision following a diagnosis of cancer*. AFRM/NZRA Combined Rehabilitation Meeting, Wellington, NZ. October, 2015.

37. **Cunningham C**, *Dementia Friendly Design*, Palliative Care Lecture Series 2015, Hospice New Zealand, Webinar, 5 March 2015

38. **Cunningham C**, *Exploring palliative care for people with dementia*, NICON 2015 Conference & Exhibition, Belfast, Ireland, 22-23 April 2015

39. **Cunningham C**, *Hearing and engaging people with dementia*, Ridley College Later Life Pastoral Seminar, Melbourne, Australia, 4 May 2015

40. **Cunningham C**, *Sex, drugs & rock'n'roll – addressing the negative perceptions around dementia in aged care*, Changing Minds 2015 Conference, Te Omanga Hospice, Wellington, New Zealand, 4 September 2015

41. **Cunningham C**, *Less race and more grace*, 10th Annual Conference on Dementia and End of Life Care, The National Council for Palliative Care, London, United Kingdom, 1 December 2015

42. Currow D, Clark K, Kamal A, Collier A, **Agar M**, Lovell M, Phillips J and Ritchie C. *The population burden of chronic symptoms that substantially pre-date the diagnosis of a life-limiting illness*. Journal of Palliative Medicine. Accepted 19/2/2015

43. Faux S, **Kohler F**, Mozer R, Klein L, Courtenay S, D'Amours S, Chapman J, Estell J. *The ROARI Project – Road Accident Acute habitation Initiative – a Randomised Clinical Trial of Two Targeted Early Interventions for Road-Related Trauma*; ISPRM 9th World Congress, June 19-23 2015, Berlin, Germany. J Rehabil Med Supp 54, June 2015 p24.

44. Fletcher S, Sinclair C, **Rhee J**, Goh D, & Auret K. *Rural health professionals' experiences in implementing advance care planning: a focus group study*. Australian Journal of Primary Health. 2015. doi: 10.1071/PY15004. Epub 2015 Sep.

45. **Gresham M**. *Going to Stay at Home: An OT working with carers*. Occupational Therapy Practice in Dementia Forum. Sydney Australia. 1 May 2015

46. **Gresham M.D**, Clemson L. *Technology and toilets: Improving the experience of personal care for older people in nursing homes. Changes, Challenges, Choices*. Occupational Therapy Australia 26th National Conference. Melbourne Australia, 1 July 2015

47. **Gresham M.D**, Clemson L. *The electronic bidet in residential aged care: A feasibility study*. Health Facilities Design and Development. Melbourne, Australia. 18 August, 2015

48. **Gresham M.D**. *What does DBMAS tell us about supporting people with complex needs? The Future of Dementia Care*. Annual Conference of Japan Dementia Group Home Association. Tokushima Japan, 12 October 2015

49. **Gresham M.D**, Geeves M. *Dementia Care in Australia*. Sagamiara Regional Dementia Care Conference, Sagamiara Japan, 13 October 2015

50. **Gresham M.D**, *Pitfalls and Problems – the tale of a PhD project in an aged care facility*. Ageing Work and Health Research Unit. The University of Sydney. Sydney, Australia 19 November 2015

51. **Gresham M.D**, Shute J. *Bidets in Aged Care: old habits, new ways*. Place, Spirit, Heart. 48th Australian Association of Gerontology National Conference. Alice Springs Australia, 6 November 2015

52. **Gresham M.D**, Shute J. *The electronic toilet top bidet in residential aged care: a potential improvement in clinical care*. 14th National Conference of Emerging Researchers in Ageing. Melbourne Australia, 8 December 2015

53. Hosie A, Lobb E, **Agar M**, Davidson PM, Phillips J. *Building delirium recognition and assessment practice in palliative care inpatient setting: a mixed method knowledge translation study*. Oral presentation. 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015.

54. Johnson S, Butow P, **Clayton J**, Silvester W, Detering K, Stockler M, Beale P, Clarke S, Cebon J, Hall J, Kiely B, Parente P, Michael N, Tattersall M. *Conducting an advance care planning randomised trial for incurable cancer patients: an Australian experience*. 5th International Advance Care Planning and End-of-life Care conference, Munich September 2015.

55. Johnson S, Butow P, **Clayton J**, Silvester W, Detering K, Stockler M, Beale P, Clarke S, Cebon J, Hall J, Kiely B, Parente P, Michael N, Tattersall M. *Advance care planning for cancer patients: preliminary results of an Australian RCT*. 5th International Advance Care Planning and End-of-life Care conference, Munich September 2015.

56. **Kohler F**, Radhakrishnan S, Schiappacasse C, Gutenbrunner C, Li J, Fialka-Moser V, Jayaraman A: *An ICF Based Mobility Assessment Tool : Step 1 Reliability*. 23rd ASM, AFRM, 14-16 October 2015, Wellington, New Zealand.

57. **Kohler F**. *Evidence and Prosthetics and Orthotics in non-industrialised countries*. ISPO Canada Symposium October 2-3, 2015, From Evidence to Action, Toronto Canada.

58. Lobb EA, Mowll J, Lane L, Lacey J, Chochinov HM, Kelly B, **Agar M**, Links M, Kearsley JH, Brock C, and Liauw W. *An explorative study of an intervention for couples to facilitate*

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*communication around end of life issues.* Oral presentation. 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015.

59. **Lovell M**, Phillips J, **Agar M**, Boyle F, Davidson PM, Luckett T, Currow D, Lam L, McCaffrey N, Shaw T. *Changing behaviour and systems to improve cancer pain care.* NHMRC Symposium on Research Translation. Poster presentation. Sydney. 27th October 2015.

60. **Lovell MR**, Luckett T, Phillips J, **Agar M**, Ryan L, Lam L, McCaffrey N, Boyle, F, Stubbs J, Shaw T, Currow D, Hosie A, Davidson PM. *Implementing clinical practice guidelines for cancer pain in adults to ensure equitable, cost-effective, evidence-based, person-centred care.* Clinical Oncological Society of Australia Annual Scientific Meeting, Hobart, November 17-19 2015.

61. **Lovell MR**, Phillips J, **Agar M**, Boyle F, Davidson PM, Luckett T, Currow D, Lam L, McCaffrey N, Shaw T. *Changing behaviour and systems to improve cancer pain care.* 4th Annual NHMRC Symposium on Research Translation jointly with CIPHER, Sydney, 27-28th October 2015.

62. Luckett T, Davidson P, Marie N, **Birch M-R**, Stubbs J, Phillips J, **Agar M**, Boyle F, **Lovell MR**. *Development of patient-held resources to overcome barriers to cancer pain assessment and management.* Behavioural Research in Cancer Control Conference, Sydney, 12-15th May 2015.

63. Luckett T, Davidson P, Marie N, Birch M-R, Stubbs J, Phillips J, Agar M, Boyle F, **Lovell MR**. *Development of patient-held resources to overcome barriers to cancer pain assessment and management.* Behavioural Research in Cancer Control Conference, Sydney, 12-15th May 2015.

64. **MacLeod RD**. *Why not? Making sense of the case against assisted suicide.* The Maxim Institute & the Care Alliance. Auckland and Christchurch, NZ. September, 2015

65. **MacLeod RD**. *Spirituality in end of life care.* Psycho-Oncology New Zealand (PONZ) Tauranga, NZ. September, 2015

66. **MacLeod RD**. *Caring to the end.* BaptistCare Dementia Forum "Living well, dying well". Sydney, September, 2015

67. **MacLeod RD**. *Models of care and strategies to provide early palliative care delivery.* International Palliative Care Network Conference - an online conference held under the auspices of the European Association for Palliative Care. July, 2015

68. **MacLeod RD**. *Caring for people with MND near end of life* Special Interest Group (SIG) Workshop, Motor Neurone Disease Association of NSW. Sydney, June 2015

69. **MacLeod RD**, **Yule S**, Johnson C. *A bridge to the community* (P1-253) 14th European Association for Palliative Care Congress, Copenhagen, Denmark. May 2015. Poster

70. **MacLeod RD**. *Suffering: meaning making and relieving* 11th Asia Pacific Hospice Conference. Taipei, Taiwan, May 2015

71. **MacLeod RD** Chair, *Culture and spirituality*, 11th Asia Pacific Hospice Conference 2015, Taipei, Taiwan, May 2015

72. **MacLeod RD**. *Physician assisted suicide and palliative care.* 11th Annual Paediatric Palliative Care symposium. Westmead, Sydney, March 2015

73. **MacLeod RD**. *Palliative and end of life care.* Royal North Shore Hospital Department of Social Work. Sydney, January 2015

74. **MacLeod RD**. Radio presentation. *Palliative care, comfort and meaning at life's end.* In search of a good death. <http://insearchofagooddeath.com.au/> PBA FM Adelaide, South Australia

75. McCaffrey N, Flint T, Kaambwa B, Fazekas B, Currow D, Hardy J, **Agar M**, and Eckermann S. *Cost-effectiveness of subcutaneous ketamine in the management of chronic cancer pain.* Oral Presentation. 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015

76. McCaffrey N, Hardy J, Fazekas B, **Agar M**, Devilee L, Rowett D, and Currow D. *Translating the Palliative Care Clinical Studies Collaborative (PaCCSC) ketamine randomized controlled trial findings into clinical practice.* Speed talk. 13th Australian Palliative Care Conference, Melbourne, September 1- 4, 2015

77. McCaffrey N, Flint T, Kaambwa B, Fazekas B, Currow D, Hardy J, **Agar M**, Eckermann S. *Economic evaluation of the randomised double-blind placebo-controlled study of subcutaneous ketamine in the management of chronic cancer pain.* European Association for Palliative Care, Copenhagen, oral presentation, May 2015

78. Middleton J, **Siddall P**, Nicholson Perry K, Katte L & Johnson J, *Spinal cord injury & chronic pain - development of an online toolkit*, 4th ISCoS and ASIA Joint Scientific Meeting, Montreal Canada 14 May 2015

79. Mitchell G, Senior H, Young S, Teo CK, **Clayton J**, **Rhee J**. *Comparing the ability of Australian general practitioners to predict death of their older patients using intuition or a predictive tool: a randomised controlled trial.* 13th Palliative Care Australia conference, Melbourne, September 2015.

80. Mitchell G, Senior H, **Rhee J**, Young S, Teo C, **Clayton J**. *Comparing the Ability of Australian General Practitioners to Predict Death of their Older Patients Using Intuition or a Predictive Tool: A Randomised Controlled Trial* 14th World Congress of the European Association for Palliative Care, Copenhagen, Denmark, May 2015

81. Mortimer N J, **Rhee J**, Guy R, Hayen A, & Lau A. Y. *A Web-Based Personally Controlled Health Management System Increases Sexually Transmitted Infection Screening Rates in Young People: A Randomized Controlled Trial.* Journal of the American Medical Informatics Association: JAMIA. 2015; 22(4):805-14

82. Morton R, Luckett T, Spencer L, Silvester W, Sellars M,

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Detering K, Tong A, Butow P, Pollock C, **Clayton JM**. *Current Practice of Advance Care Planning in Australia and New Zealand.* American Society of Nephrology annual meeting, San Diego USA, November 2015.

83. Patel A, **MacLeod R**. Keogh J, Masters J. *"Perceived barriers and facilitators for physical activity in prostate cancer survivors on androgen deprivation therapy"*. International Society of Behavioural Nutrition and Physical Activity. Edinburgh, Scotland. June 2015

84. **Poulos CJ**. (Invited speaker). *Improving the rehabilitation patient journey.* Hong Kong Hospital Authority Convention. Hong Kong. 18th – 19th May 2015.

85. **Poulos CJ**. (Invited speaker). *A comprehensive approach to ambulatory rehabilitation.* Hong Kong Hospital Authority Convention. Hong Kong. 18th – 19th May 2015.

86. **Poulos CJ**, Poulos RG, Travaglia J, Kolker M. *The early identification of functional decline in community dwelling older people receiving home care packages – the Focus on Function project.* British Society of Gerontology. Newcastle (UK). 1st – 3rd July 2015.

87. **Poulos CJ**, **Kelly J**, **Gresham M**, LeGrange R, Neylon S. *The seating needs of older people with dementia in Australian residential aged care homes.* British Society of Gerontology. Newcastle (UK). 1st – 3rd July 2015.

88. **Poulos CJ**, Poulos RG, **Marwood S**, **Beilharz K**, **Rhee J**, **Robertson M**, Khut G. *Arts on Prescription for community dwelling older people.* 7th Annual International Arts and Health Conference. Sydney. 17th – 19th November 2015.

89. Read S, Stancliffe RJ, Wiese M, Jelts G, **Clayton J**, Barton R. *The Dying to Talk project: Exploring understandings about dying and death.* 50th Australasian Society for Intellectual Disability Conference, Melbourne, Australia, November 2015.

90. Spencer L, Luckett T, Morton R, Silvester W, Pollock C, Sellars M, Detering K, Tong A, Butow P, **Clayton J**. *A survey of clinician's practices and attitudes to advance care planning for patients with chronic kidney disease.* Australian and New Zealand Society of Nephrology, Canberra, September 2015.

91. Radhakrishnan S, **Kohler F**, Schiappacasse C, Fialka-Moser V, Li J, Gutenbrunner C, Jayaraman A. *Mobility post amputation from the patient's perspective: An International comparison using the International Classification of Functioning, Disability and Health (ICF).* ISPO World Congress, 22-25 June 2015, Lyon, France, Book of abstracts p651

92. Radhakrishnan S, **Kohler F**, Zhang X. *IBMAT: Pilot Validation Study of an ICF Based Mobility Assessment Tool.* Rehab Tech Exhibition and Conference, 26-28 March 2015, Singapore

93. **Rhee J**, Mitchell G, Senior H, Teo C, **Clayton J**. *Qualitative Study of Australian GPs and Palliative Care Practitioners on the Role of General Practice in End-of-Life Planning and Care,*

14th World Congress of the European Association for Palliative Care, Copenhagen, Denmark, May 2015.

94. **Rhee J**, **Clayton JM**. *The 'surprise' question may improve the accuracy of GPs in identifying death in patients with advanced stage IV solid-cell cancer.* Evid Based Med 2015; 20 (2):71; doi: 10.1136/ebmed-2014-110114

95. **Robertson M**. *"Care of the Dying"*, MSW, Death, Dying & Mourning, 24th March, 2015. Faculty of Education and Social Work, University of Sydney.

96. **Robertson M**. *"Healthy Aging: befriending death and dying."* Lifespan Research Network, Office of Research & Research Training, Sydney Medical School, University of Sydney 16th July, 2015.

97. **Robertson M**. *"Loss & Grief across different cultures"*. Bachelor of Nursing, Sydney Nursing School, University of Sydney, 24 September, 2015.

98. **Robertson M**. *'3rd Victorian Psych-Oncology Research Conference'*, Walter and Eliza Hall Institute of Medical Research. 16th October, 2015. Conference attendance.

99. **Robertson M**, **MacLeod R**, Duggleby, W. *'A Qualitative research project: An exploratory study of the spiritual, psychosocial and physical factors in palliative care that support hope during a home death according to family members'*. 2nd October 2015, HammondCare Research Colloquium, Pallister House, Sydney.


100. Rogers ES, Sasidharan R, Sequeira GM, Wood MR, Bird SP, Arroll B, Stewart J, Keogh JW, **MacLeod RD**. *A randomised feasibility study of Eicosapentaenoic acid and Cox-2 inhibitor versus EPA, Cox-2 inhibitor, Progressive Resistance Training followed by essential amino acids high in leucine in NSCLC cachectic patients: Results from the ACCeRT study.* 8th International Conference on Cachexia, Sarcopenia and Muscle Wasting, Paris, France. December 2015

101. Radhakrishnan S, **Kohler F**, Schiappacasse C, Fialka-Moser V, Li J, Gutenbrunner C, Jayaraman A. *Mobility post amputation from the patient's perspective: An International comparison using the International Classification of Functioning, Disability and Health (ICF).* ISPO World Congress, 22-25 June 2015, Lyon, France, Book of abstracts p651

102. Shute J, **Gresham M.D**. *Operational considerations when trialling assistive technology in the residential aged care setting. Bringing Research to Life.* 14th National Conference of Emerging Researchers in Ageing. Melbourne Australia, 8 December 2015

103. **Siddall PJ**, *Primary care pain management: key messages for primary care*, NSW ACI Pain Network Annual Workshop, Sydney Australia, 28 February 2015

104. **Siddall PJ**, *The challenges of treating chronic pain: from medications to the multidisciplinary approach*, Chronic Pain Workshop, Broken Hill Australia, 12 March 2015

 Academic Conference+Industry Seminars

105. **Siddall PJ**, *Greenwich Hospital Spinal Cord Injury Pain Program*, Australian Pain Society Annual Scientific Meeting, Brisbane Australia, 16 March 2015

106. **Siddall PJ**, *Let's talk about values*, National Pain Week Conference, 24 July 2015

107. **Siddall PJ**, *The pharmacological management of neuropathic pain*, Emerging Trends in Neuropathic Pain Symposium, Sydney Australia, 1 October 2015

108. **Siddall PJ**, *Pain and neuroplasticity: what does it mean for physiotherapy?* Australian Physiotherapy Association Annual Conference, Gold Coast, Australia, 4 October 2015

109. **Siddall PJ**, *The lesser known consequences of spinal cord injury*, Australian Physiotherapy Association Annual Conference, Gold Coast, Australia, 4 October 2015

110. Wiese MY, Stancliffe RJ, Jeltos G, **Clayton J**, Read S, Barton R. *Supporting people with intellectual disability to make plans and decision for the end of life: Lessons and challenges*. National Supported Decision Making Conference convened by Capacity Australia, Sydney, Australia, November 2015.

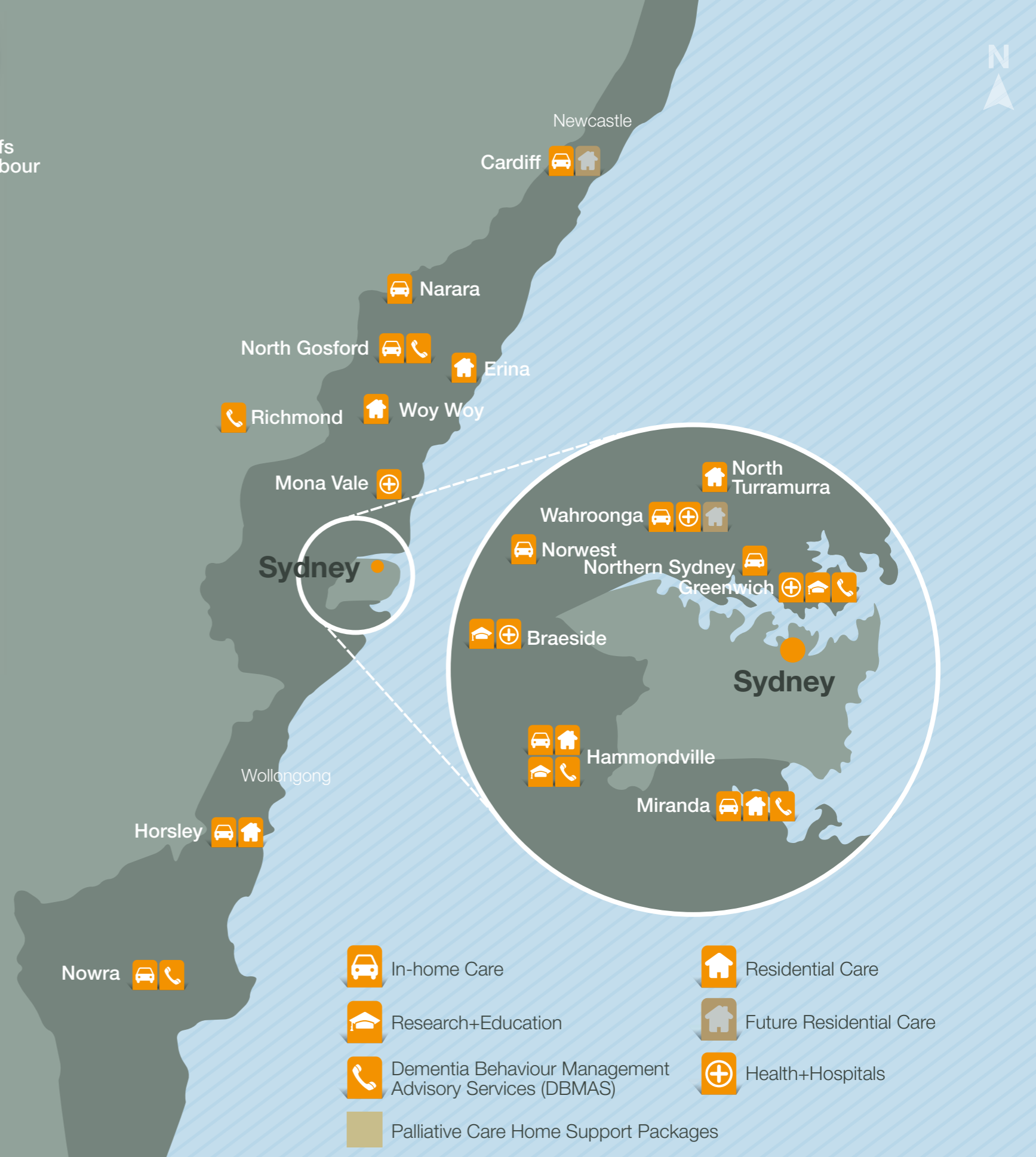
111. Wiese MY, Stancliffe RJ, Jeltos G, **Clayton J**, Read S. *Palliative care and people with intellectual disability. Disability Forum: Palliative care and planning for your care*, co-convened by Palliative Care Australia and ADACAS Advocacy, Canberra, Australia, July 2015.

112. Wilson D. M, Houttekier D, Cohen J, **MacLeod R**, Nayak S. S. *Population-based bereavement research findings for needed developments*. Margaret Scott Wright Research Day, Edmonton, Alberta, Canada. November, 2015. Poster

113. Wilson D. M, Houttekier D, Cohen J, **MacLeod R**. *Bereavement incidence, prevalence, and other population-based evidence needed for policy and practice developments*. 14th World Canadian Association on Gerontology Annual Conference, Calgary, Canada. October 2015. Poster

114. Yule SA, **MacLeod RD**, Johnson C. *A good enough death?*, (P1-233), 14th European Association for Palliative Care Congress, Copenhagen, Denmark. May 2015. Poster





-  In-home Care
-  Residential Care
-  Research+Education
-  Future Residential Care
-  Dementia Behaviour Management Advisory Services (DBMAS)
-  Health+Hospitals
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# Grants+Statistics

## Successful Grant Applications

**Agar M.** Perpetual Foundation. *Phase II randomised non-comparative placebo-controlled double blind trial of Acetazolamide plus Dexamethasone versus dexamethasone alone for management of cerebral oedema in recurrent and/or progressive High Grade Glioma.* Awarded \$100,000 for 2015.

Currow D, **Agar M**, Allcroft P, Muircroft W, Price T, Gott M, Gooden H, Carey S. Flinders Medical Foundation Grant. *Pancreatic Enzyme Replacement Therapy (PERT) in carcinoma of the pancreas - A multi-centre, double blinded, placebo controlled randomised controlled trial.* Flinders centre for innovation in cancer (FCIC). Awarded \$15 000 for 2015.

Luckett T, Phillips J, Newton P, Disler R, Davidson P, Currow D, Johnson M, Carrieri-Kohlman V, Chye R, Sheehan S, **Agar M**, Whelan B, Lam L. *Measuring breathlessness in people with life limiting illness to inform practice and research.* Awarded \$25,000 for 2015.

**Agar M**, Currow D, Lintzeris N, Solowij N, Quinn S, McCaffrey N, Phillips J, Martin P, **Lovell M**, McGregor I, Martin J and Allsop D. NSW Government. *Evaluation of pharmaceutical cannabinoids and standardized botanical leaf cannabis for anorexia in advanced cancer: A pharmacokinetic and feasibility pilot phase II study; and a phase III double-blind double-dummy multi-site parallel-arm randomized controlled trial.* Awarded \$3,281,666 for 2015-2019.

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 from July 2015 for 5 years.

Alexander Smith, Jason Karlawish, Sei Lee, Patricia Moran, **Josephine Clayton** (Consultant), Rebecca Sudore (Consultant). 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). *Enhancing Prognosis Communication with Disabled Elders.* Awarded \$140,000 from July 2015 for 2 years.

**Lovell MR(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.* (2014-2018) 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.

**Lovell MR (CI)**, Ms Bronwyn Raymond, Ms Jane Phillips & Mr Tim Luckett UTS, Ms Fran Boyle USyd. *Ritchie Foundation*

*Grant.* Stop Cancer Pain, (ongoing funding).

Mowll J, Sanderson C, Lobb L, **MacLeod R, Robertson M**, Duflou J, Cahill J, Fitzpatrick C. *Title: 'Mapping Grief' Australian Government Collaborative Research Network CRN funding. 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, and to be correlated with their grief and trauma outcomes over the first 25 months post loss.* Awarded \$720,000 for 2015.

Duggleby 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. 2015-7.

**Poulos CJ, Rhee J**, Poulos R, **Marwood S, Beilharz K, Robertson M**, Opher S, Clift S. 'Arts on Prescription'. Department of Social Services Aged Care Service Improvement and Healthy Ageing Grant \$876,238. *Investigating the use of participatory arts in promoting healthy and active ageing.*

**Poulos CJ**, Poulos RG, **Cunningham C**, Beattie E. *Arts on Prescription @ Home.* Dementia Collaborative Research Centre (DCRC) – Carers and Consumers (NHMRC). \$22,000. Extends the *Arts on Prescription* model to a home-based program for people with dementia and their carers.

**Poulos CJ, McLeod RD.** Quantitative evaluation of a state-wide *Community Palliative Care Service.* HammondCare internal grant. \$19, 800. Quantitative evaluation of HammondCare's new community palliative care home support service.

**Poulos CJ, Harkin D, Gresham M**, Beattie E. *Helping carers focus on their own wellness needs – translational project.* Dementia Collaborative Research Centre (DCRC) – Carers and Consumers (NHMRC). \$8,800. Developing a consumer resource to assist carers of people with dementia.

Poulos RG, **McLeod RD, Poulos CJ, Cole AMD, Harkin D.** Qualitative evaluation of a state-wide *Community Palliative Care Service.* HammondCare internal grant. \$110,000. In-depth qualitative evaluation of HammondCare's new community palliative care home support service.

**Robertson M, MacLeod R**, Duggleby W. *'Investigating Hope during a Home Death'.* Awarded \$50,000, NSW Health grant.

Wrigley PJ, **Siddall PJ.** Australian and New Zealand College of Anaesthetists. *Optimising the neurophysiological assessment of residual thermociceptive sensation following spinal cord injury.* Awarded \$29,000, from Jan 2015 for 12 months.

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