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I am delighted to introduce you to HammondCare's 2014 Research Report.

This report contains a summary of HammondCare's research activities from July 1st 2013 to December 31st 2014. In the following pages you will find details of hundreds of studies, publications and presentations from HammondCare's researchers in fields such as dementia care, palliative care, pain management, restorative and rehabilitation care and aged care psychiatry.

However, within these details you will also be able to spot the strands of a larger story – a story about caring for people in need.

For us, research begins with practical problems affecting real people. For example, in the late 1990s dementia-specific care was in its infancy. Back then we were trialling some new ways of looking after people with dementia and we continually bumped up against the question - How do you make the best environment for someone with dementia?

The in-situ research that developed as a result has led to us developing, trialling and building completely new and innovative models of design for better dementia care. And as a result HammondCare is now a global leader in dementia design. More recently we've been asking – *Why is food usually terrible in nursing homes?* This has led us to the cutting edge of transforming food culture in aged care.

One of the most exciting current research projects is the \$25 million National Health and Medical Research Council Partnership Centre focused on dealing with cognitive and related functional decline in older people.

Like all our research projects, this begins with a practical problem. Thirty five years from now, in 2050, the scale of cognitive decline and its functional sequelae will dwarf almost all other social issues facing Australia. Instead of today's 400,000 people over the age of 85 there will be 1.8 million. While physical ailments among the elderly tend to receive the lion's share of attention at present, it is the burden created by cognitive decline that is the hidden time-bomb.

The focus of this Partnership Centre is to make sure the world's best research informs the way people living with dementia are cared for in the community, in residential aged care, and in acute and sub-acute health services. It signals something entirely new in the research of some of our most pressing health and social concerns.

It is bittersweet for me to pen this introduction, since I have just stepped down after serving on the HammondCare Board for the past 16 years. The most significant development I have seen in that time is the sheer growth of HammondCare. And I don't simply mean numerical growth but also growth in expertise, in knowledge, in creativity, and in the ability to meet need effectively.

It is in HammondCare's DNA to seek out better ways to care for people. The research activities collected in the 2014 Research Report testify to HammondCare's continued growth in applying the fruits of rigorous research to help improve the quality of life for people in need.





Professor Susan Kurrle
Curran Professor in Health Care of Older People
Faculty of Medicine, University of Sydney
Director, NHMRC Cognitive Decline Partnership Centre
Senior Staff Specialist Geriatrician

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Welcome to HammondCare's 2014 Research Report.

This document presents the full scope of HammondCare's efforts in research, teaching and learning - three enterprises critical to our future. The report is for the period July 1st 2013 to December 31st 2014. The reason this report covers an 18 month period is because previous reports were prepared on a financial year basis, but from now on, reports will be prepared on a calendar year basis, to align with the usual timetable of academic activities.

Research

During the academic (calendar) year 2014, HammondCare invested more than \$3.3 million in research and academic education.

Research is essential to translate new ideas into improved care, making today's best care for those in need, even better in the future. Projects are grouped within the priority categories, together with a brief description of each project, its present status, who is involved, and any partner organisations.

As well as reading about our research activities, you will have the opportunity to meet several of our researchers, and gain an insight into their passions. In particular, you have already met Professor Susan Kurrle of the University of Sydney, until recently the Deputy Chair of the HammondCare Board, and one of the most senior researchers in dementia care in Australia. We are very grateful to have had the benefit of Professor Kurrle's time and counsel, as Deputy Chair of the HammondCare Board and Chair of its Research Committee.

Another piece describes how research is developed, governed and conducted. Best practice in research demands that the best interests and well-being of individuals taking part in research are completely protected, at all stages of all projects.

Teaching and learning

Teaching and learning are complementary activities essential for the acquiring and maintenance of professional excellence in providing care for those in need.

HammondCare staff are extensively involved in training students in their primary professional qualifications in Medicine, Nursing and a whole range of Allied Health disciplines. We hosted a total of 450 students in clinical placements, many attending for multiple placement segments in the academic year. We have Memoranda of Understanding with 13 different Universities and 4 TAFE/Registered Training Organisations, governing the training of their students in HammondCare facilities.

Selection and retention of high-quality inspirational teachers will influence students to consider seriously the possibilities of working in aged and subacute hospital care, as they set career directions at critical stages in their learning. A majority of our senior staff have conjoint academic teaching University appointments, and spend many hours each year, trying to infect students with their passion for the work we do!

After nearly 30 years' teaching at UNSW in aged care and rehabilitation, it is a delight to see former students choosing to come into our HammondCare work force, having become infected with the passion, and attracted to work in what the rest of the clinical establishment often perceives as 'Cinderella' areas of practice.

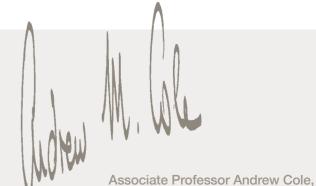
In the period under review in this report, new inter-disciplinary teaching in restorative care has been implemented at Hammondville, together with a new distant-outreach video-conferencing case method-based teaching approach for training our staff working in residential aged care.

In December 2014, our Registered Training Organisation, the Hammond College, was successfully re-accredited by ASQA for the teaching of Certificate III and IV vocational education programmes, for our Special Care Workers in residential and community aged care.

Finally, several of our staff have successfully completed higher degrees in 2014, and other staff are involved in the supervision of higher degree candidates, and the formal assessment of academic progression.

It has been a great time for research, teaching and learning in HammondCare, and I hope you enjoy reading this report.





Chief Medical Officer, HammondCare Conjoint Associate Professor, UNSW Chief Executive, Hammond RTO

Doing the best possible research.

The best possible research does not 'just happen'. It needs support, encouragement and investment, operating inside a legal framework.

Good research is a critical step in examining new possibilities to improve the way we care for people in need, while validating the quality of what we do now. That is, rigorous research is essential to improve today's best care to provide something even better in the future.

In HammondCare, we have excellent clinicians working in our core services, in care of the frail elderly, those with dementia and other mental health problems of old age, those with incurable disease in need of palliative care, those with chronic pain, and disabled people in need of rehabilitation.

A reflective clinician always thinks about how they are providing care, and will discuss with colleagues new ideas for researching how to improve care. As shown in this report, these ideas include the best way to use certain drugs in a particular setting, or how to deliver particular therapies in a more effective way, or working out how best to meet the spiritual needs of people in our care. Our research ideas and projects are deliberately 'translational' – they must inform and have potential to transform the way we provide the best care to those in need.

Clinicians then think about whether a research question is best answered quantitatively or qualitatively, or through a combination of both. Quantitative research focuses on measurements and the use of statistics, while qualitative research seeks to gain an understanding of the motivations and reasons why people think or act in a particular way, primarily through the use of interviews or focus groups. In every case, it will also involve thinking about how to provide information to individuals and their families about the research in a way that empowers them to provide full, informed consent prior to participation.

Given that research involves time and other resources, it needs to be funded. External funding may be sought from government grants or benevolent sources, or the researchers may have sufficient time within their existing commitments to allow for small projects to be supported internally. At HammondCare, we invest significantly in both researchers' time, and in sound and strong governance of our research. Our framework of principles, processes and standards of good research conforms to the legal requirements of ethical review and practice, of Commonwealth and State governments. These describe everybody's roles, responsibilities and accountabilities, so that all research proposed to be conducted in any HammondCare facility, or by HammondCare staff, will be monitored and reviewed to ensure the conduct of high quality research, the safety of the individuals involved and full administrative compliance. Good governance also considers whether the research project has sufficient scientific merit to be able to answer the questions posed.

To achieve this, HammondCare's research governance staff interact closely with our researchers throughout the initial development of a research idea, which culminates in a firm written proposal being sent to an Executive group for review and decision to proceed further. At a minimum, this group comprises the Chief Medical Officer, the Executive administrator of the area of HammondCare where the research proposed will take place, a senior academic and a member of HammondCare's business team.

After all these steps have been completed, a proposed project is ready to be submitted for an arms-length external review by a Human Research Ethics Committee (HREC), or Panel, either in a University or Local Health District setting. The membership of an HREC is prescribed under law, and as well as all the usual academic/ health experts, also includes community representatives and a Minister of Religion.

It is the role of the HREC to consider every research proposal in systematic fashion, to rule out conflicts of interest, and ensure that each one they consider meets the ethical standards contained in the World Medical Association declarations from Geneva (1948) and Helsinki (1964), and as amended subsequently. These were developed following appalling 'research' done without respect for, or consent by individual subjects involved, in the 1930s and 1940s. As a United Nations member, Australia is a signatory to these declarations.

When applying these standards, an HREC considers especially carefully any proposal that involves vulnerable patients/residents, which is the case for nearly all the people we provide care for.

An HREC may approve or reject a proposal, or may ask for further information or modification to a proposal, to inform their further consideration of it.

Gaining HREC approval for a research project, together with funding support, is the watershed moment at which a proposal moves from possibility to reality. About two-thirds of good ideas do not succeed in making this transition, many because of the difficulties in obtaining external funding in today's very tight and competitive financial environment.

After HREC approval, our research governance staff then support our clinical research staff, tracking each project through its implementation, to its completion and reporting of the results.

We undertake quality research because our projects are focused into a range of topics chosen for relevance to the people we care for and the care we provide. Further, time and resources are not wasted in producing research findings that are not relevant to improving our services, in fulfilling HammondCare's mission.

As part of HammondCare's corporate social responsibility, our staff members publicise research findings as widely as possible, both in local and international meetings and publications. In this way, evidence about new and better ways of providing care is made available to benefit anyone in need of care, anywhere. We teach widely about how we provide care to people in need. We provide good quality evidence that is able to influence public policy.

To summarise, our research is aimed at bringing about steady real improvements in the way that we provide care for people in need, transforming today's best-available care into something even better in the future.

This is the best possible research for us to do.

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Good research is a critical step in examining new possibilities to improve the way we care for people in need, while validating the quality of what we do now.

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Palliative Care
Dementia + Mental Health
Ageing, Restorative Care
+ Reablement
Rehabilitation
Pain + Spinal Cord Injury
Spiritual Dimension
Advanced Care Planning

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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms **Natalie Ohrynowsky** Site: Braeside Hospital Researchers: Dr Melanie Lovell & **Ms Alison Hession** Site: Greenwich Hospital

Duration: Nov 12 to Mar 15 Funding Source: Department of Health & Ageing (DoHA) **Project Partners: Palliative Care Clinical Studies Collaborative Study Status: In Progress**

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

Multi-Site Clinical Trial

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

Researchers: Associate 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 pilot study to explore the safety of pyridostigmine in constipated palliative care patients

Multi-Site Clinical Trial

Constipation is a difficult problem for palliative care patients.

This study will allow assessment of colonic transit and use of a more targeted therapy for this patho-physiology.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Mar 14 to Dec 15**

Funding Source: Calvary Mater Newcastle & Paccsc Project Partners: Calvary Mater Newcastle & PaCCSC Study Status: On hold

A randomised, doubleblind, 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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Jan 10 to Oct 15**

Funding Source: DoHA & PaCCSC Project Partners: PaCCSC Study Status: In Progress

A randomised doubleblind 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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrvnowsky Site: Braeside Hospital **Duration: Nov 10 to Dec 15**

Funding Source: DOHA/ PaCCSC/ **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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms **Natalie Ohrynowsky** Site: Braeside Hospital **Duration: Apr 14 to Dec 15**

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



The challenges in Palliative Care are very real for all of us and the more we question, perhaps the more we will understand.

The measurement of function limited by breathlessness in advanced cancer

Multi-Site Study

This study will help clinicians assess function in patients with breathlessness in a more relevant way and inform ways of maintaining or improving function and independence.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital Duration: May 10 to May 15

Funding Source: Internally Supported Project Partners: None 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: Associate 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 Il 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.

There is currently no medication registered for delirium treatment. This study puts HammondCare on the cutting edge of delirium research internationally. 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: Associate 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

A qualitative study of caregiver experience witnessing delirium in palliative care patients

Multi-Site Study

This research project aims to understand the experience of caregivers who have witnessed delirium symptoms in a loved one who has an advanced illness.

We want to understand what symptoms were seen, how they affected the caregiver, how the caregiver was involved in management choices, and participant insights about the best way to care for someone with delirium.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital Duration: Feb 14 to Dec 14

Funding Source: UNSW student supervised by Associate Professor Meera Agar Project Partners: UNSW

Project Partners: UNSW Study Status: Completed

Translational Outcome(s):

This study has provided insights into the caregivers' experiences in witnessing delirium. This will be utilised to develop a resource for caregivers to ensure they feel supported and equipped to care for a loved one with delirium.

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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Jacaranda Unit, Hammondville Duration: May 12 to Jun 15

Funding Source: DoHA Project Partners: None Study Status: In Progress Integrated care framework for advanced dementia: a national web-based resource for best practice palliative dementia care

Single-Site Study

This project has developed a webbased resource providing point of care assessment and care planning, with corresponding communication guides, to improve care of those with advanced dementia in Residential Aged Care Homes (RACH).

It has also developed a literature filter with Caresearch to ensure professionals caring for someone with dementia have access to the best quality evidence. The result of this project is a product which can be used within HammondCare, but can also be developed as a resource for the RACH sector more broadly.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Southwood, Hammondville Duration: May 12 to Jun 14

Funding Source: Competitively funded by Alzheimer's Australia Consumer Dementia Research Network Project Partners: None Study Status: Completed

Translational Outcome(s):

The pilot results of this project demonstrated the framework and web-resource was helpful, particularly for care staff. We are now working with Intersect to further refine the web-based resource and seeking funding to integrate it into existing IT platforms.

Rod MacLeod -

Translating research into better care

Tell us about one of the research projects you have been working on?

A lot of people, when they develop advancing cancer, begin to lose a lot of weight. It's called cancer cachexia. They get thin, tired, lose weight, and it's a stigma. And for most people, it's a sign that things are really not good. Because classically, cancer cachexia is not reversible. So you just get thin and lose weight, and you die essentially wasting away.

There are all sorts of important aspects to this. There's the "if I don't eat, I'll die" notion. There's the social aspect of eating, the preparing of food, sharing food - and no matter how much you eat with this cachexia, you still lose weight. So it's a real challenge and various people around the world are trying all sorts of methods to reverse it.

So my collaborator Elaine and I spent a lot of time thinking and reading and researching, and we came up with this idea that because it's a multi-factorial problem, you have to have a multi-factorial solution. Eventually we spoke with exercise physiologists and oncologists, and the solution that we came up with is a limited exercise program - not quite pumping iron, but resistance training. And we provide then the essential amino acids, because with any exercise and body building, along with the pumping iron, you need to give yourself the nutrients.

There are also some specific anti-inflammatory drugs that you can use, because cachexia can be shown to be an inflammatory process as well. So we're attacking the disease at different angles. And then we're testing various markers in the blood, and were testing using MRI scanning to see how much muscle is being built up, or lost.

And were also asking them about how they feel, how they rate the quality of their life.

And essentially they all feel great. They all love doing exercise, because when we started this program there wasn't the wealth of information that there is now, that exercise is far more beneficial than just about any chemotherapy drug. So we have the exercise program combined with the nutrients and the anti-inflammatory drug, and the translation will be that we can plan to develop exercise programs for people with all sorts of cancers, that needn't stop when they get to the palliative care component.

In fact, introducing exercise into palliative care is something where you think "well, does it really fit? Should we have a gym in a hospice?" And the answer is, yes, you should!

Early results show that there is not only the sense of wellbeing that goes with this, but pain improves, quality of life improves, and it actually helps to slow the reduction in muscle volume. So it looks very much as if that approach is seen to have benefit

for cancer cachexia - what the research has taught us is that progressive resistance training combined with these other elements is important for people who have cancer. And if we can continue to show these improvements, then I think people will feel the benefit of it.

So I'm feeling pretty positive that our enquiry of "well why can't we do something to stop this?" will produce a result that is going to benefit thousands and thousands of people.

Why did you become involved in research?

Firstly, I have an inquiring mind, and it's always been a thread in my life and my work.

When I started working in Palliative Care, there was no specific medical training available; Palliative Medicine had only just been recognised as a specialty in the UK and it would be years before that recognition extended to Australia and New Zealand. So I visited these community based hospice programmes based in the south of England and spent my time asking questions - "Why do you do it that way? Why don't you do it this way?" So that sort of enquiry was the seed from which my research program grew.

I've been fascinated by how doctors learn to care; could people tell if their doctor cared? And so I got enveloped in qualitative research and different methodologies. Much of my research has been what you might call softer research, focused on the notions of care and what matters most to people who are near the end of life. I later became involved in a broad range of collaborative projects with students by supervising their doctoral research.

This led to a diverse and fascinating range of research projects. One aspect was that I discovered that the medical students I was teaching acknowledged that there was a spiritual component to the relationships they developed with patients they were working with in Palliative Care.

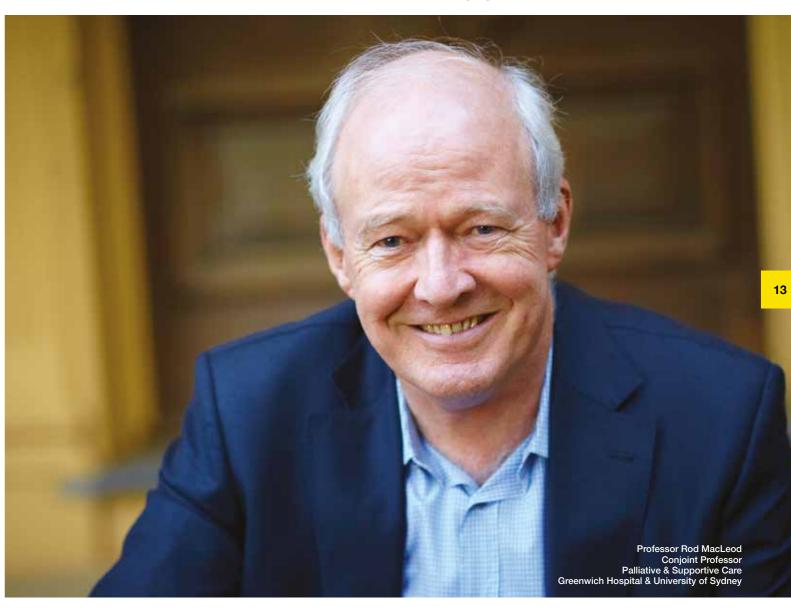
That surprised me. Because I'd been brought up to work within a bio-psycho-social model, where spirituality gets left out. How wrong could that be?

I eventually became involved in a broader research portfolio, investigating amongst other things, hope, suffering and spirituality in palliative care. Overall, it's about improving quality of life, both for the patient and the family - and for the professional carers too. The challenges in Palliative Care are very real for all of us and the more we question, perhaps the more we will understand.



Should we have a gym in a hospice? And the answer is, yes, you should!

Rod MacLeod



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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital Duration: Jan 13 to Jul 15

Funding Source: Internally Supported Project Partners: None Study Status: In Progress What is the feasibility of using the Palliative Care Outcomes Collaborative (PCOC) data sets to guide end-of-life care practices in Residential Aged Care?

Multi-Site Study

HammondCare will benefit from being involved in an innovative project and encourage reflection on ways to improve practice.

HammondCare staff will develop a more in-depth knowledge of the research process and preliminary skills. They may then be motivated to consider further research. Their involvement will add to their professional development as a specialist in a currently underdeveloped area.

Researchers: Professor Roderick MacLeod & Dr Peta McVey Site: Greenwich Hospital Duration: Jul 13 to Jun 15

Funding Source: Internally Supported Project Partners: None Study Status: In Progress Psychiatry registrars' views and educational needs regarding the care of patients with life limiting illnesses

Multi-Site Study

This project will inform better psychiatric care for our palliative care patients as well as better end of life care for patients with chronic psychiatric illnesses.

It involves mentoring and supervision of one of our palliative care registrars, Dr Ben Forster.

Researchers: Associate Professor Josephine Clayton & Dr Ben Foster Site: Greenwich Hospital Duration: Sept 13 to Dec 14

Funding Source: Friends of Greenwich

Project Partners: Hunter New England and Northern Sydney Psychiatry Networks

Study Status: Completing

Translational Outcome(s):

Paper submitted for publication, findings being incorporated into training sessions for psychiatry registrars.

Translating evidence into practice: implementing clinical pathways to relieve psychological distress and improve wellbeing for cancer patients

Multi-Site Study

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

Researcher: Associate Professor Josephine Clayton Site: Greenwich Hospital Duration: Jul 12 to Dec 15

Funding Source: Funded by Sydney Catalyst & funds administered by USyd

Project Partners: 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.

Non-HammondCare
Researcher 1: 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 A double-blind, placebo-controlled cross-over study of the effect of corticosteriods on sleep quality - a pilot study in patients with advanced cancer

Multi-Site Clinical Trial

Disturbed sleep is one of the side effects of corticosteroids in palliative care. This study is exploring if changing the time of dosing improves sleep quality.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital Duration: Nov 12 to Sep 18

Researchers: Dr Melanie Lovell & Ms Alison Hession
Site: Greenwich Hospital
Duration: Oct 12 to Sep 18

Funding Source: Improving
Palliative Care through Clinical
Trials (ImPaCCT) Project Partners:
University of Technology
Study Status: In Progress

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Quality end-of-life care and practices in Residential Aged Care

Quality improvement in Residential Aged Care Homes.

Researchers: Professor Roderick MacLeod & Dr Peta McVey Site: Greenwich Hospital Duration: Nov 13 to Oct 15

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

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.

Improving quality of

randomised control

life at end of life: a

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 Jun 15**

Funding Source: Funded by NHMRC administered by USvd **Project Partners: External PhD** supervision (Sydney University) & NHMRC grant with various collaborators **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: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Sep 10 to Sep 15**

Funding Source: National Health & Medical Research Council (NHMRC) & PaCCSC **Project Partners: Queensland University of Technology Study Status: In Progress**

Management of nausea in cancer patients study 2

Multi-Site Clinical Trial

This study is exploring the use of medications in intractable nausea which usually requires hospitalisation.

These medications are currently only available via a special access scheme and are expensive. If this study is positive it will allow a submission to the Therapeutic Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC) to facilitate a subsidy which will make these medications more widely available for people with advanced illness.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Sep 10 to Sep 15**

Funding Source: NHMRC & PaCCSC **Project Partners: Queensland University of Technology** Study Status: In Progress (with recruitment completed)

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: Dr Melanie Lovell & Ms Alison Hession Site: Greenwich Hospital **Duration: Jul 12 to May 17**

Funding Source: DoHA Project Partners: Paccsc Study Status: In Progress (with recruitment completed)

Efficacy of elastic compression stockings in treatment of chronic oedema in palliative care patients

Lymphoedema is a significant burden to palliative care patients as well as older frail individuals generally.

Greenwich Hospital aims to be a lymphoedema centre of excellence and this trial documented the efficacy of our current programme.

Researcher: Dr Megan Best Site: Greenwich Hospital **Duration: Jul 11 to Dec 14**

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

Translational Outcome(s):

This research has demonstrated that chronic leg swelling is a common problem in the palliative care community. Early intervention looks promising as a way of reducing progression of the condition and associated complications, thereby improving patient wellbeing.

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

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Jun 11 to Dec 15**

Researchers: Dr Melanie Lovell & Ms Alison Hession Site: Greenwich Hospital **Duration: May 11 to Dec 15**

Funding Source PaCCSC Project Partners: PaCCSC 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 15

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

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

Researchers: Dr Melanie Lovell (PhD supervision) & Ms Skye Dong Site: Greenwich Hospital Duration: Oct 13 to Oct 14

Funding Source: Internally Supported

Project Partners: University Sydney Study Status: Completed

Translational Outcome(s):

This study helped us understand how multiple coexistent symptoms impact the patients we care for leading to improved treatment. Which Way from
Here? Navigation
Competencies for the
Care of Older Rural
Adults at the End of
Life

Information from this project will inform service delivery of palliative care in rural NSW.

Researcher: Professor Roderick MacLeod Site: Off-Site research Duration: Jan 13 to Mar 14

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

Translational Outcome(s):

Report and presentation to North Sydney Local Health District, further study ongoing in other hospitals in the district. Audit toll developed to be used on wards in Royal North Shore Hospital.

Metasynthesis study to explore the experiences of First nations/ Aboriginal peoples at the end of life

This project will build on knowledge of providing palliative care to Aboriginal and Torres Strait Islanders.

Researcher: Professor Roderick MacLeod

Site: Off-Site research Duration: Jan 13 to Mar 14

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

Translational Outcome(s):

Publication pending, findings to be applied to Australian context in HammondCare consortium home care program.

Ethnic differences in resource utilisation and decision making in end of life care in New Zealand hospitals

This study provided the basis for the quality of end of life in Northern Sydney Local Health District project and will provide useful comparative data.

Researcher: Professor Roderick MacLeod

Site: Off-Site research Duration: Mar 12 to Mar 14

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

Translational Outcome(s):

Report and presentation to North Sydney Local Health District, further study ongoing in other hospital in the district. Audit toll developed to be used on wards in Royal North Shore Hospital. 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 Sep 15

Funding Source: Funded by NSW

-lealth

Project Partners: None Study Status: In Progress



I visited these community based hospice programmes based in the south of England and spent my time asking questions - "Why do you do it that way? Why don't you do it this way?" So that sort of enquiry was the seed from which my research program grew.

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. Non-HammondCare Researcher 2:

Understanding Care:

The Volunteering

experience in the

Care

space of Palliative

Ms Holi Birman (UNSW) Sites: Greenwich, Braeside & **Neringah Hospitals** Duration: Jun 14 to Jun 15

Funding Source: Administered by

Project Partners: Not Applicable 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 HammondCare service.

Researcher: Professor Roderick MacLeod (PhD Supervision) Site: Off-Site research **Duration: Aug 11 to Jun 15**

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

Researcher: Professor Roderick MacLeod (PhD Supervision) Site: Off-Site research **Duration: Sept 11 to Dec 15**

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 Jul 15**

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

Anamorelin HCl in the treatment of non-small cell lung cancer cachexia (NSCLC-C): An extension study

Multi-Site Clinical Trial

This study was an extension of the aforementioned study.

This study provided access to ongoing medication supply for our patients who responded in the first study without cost to patients or HammondCare.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Aug 11 to Aug 13**

Funding Source: Helsinn Therapeutics Project Partners: Liverpool Hospital Duration: Completed

Translational Outcome(s):

These studies have shown that the new drug, Anamorelin, which mimics the hunger hormone "Ghrelin", improves appetite and body mass in patients with advanced lung cancer who are suffering anorexia - cachexia syndrome (characterised by loss of weight and muscle, fatigue, weakness and poor appetite). Results presented at the 2014 ASCO meeting (http://meetinglibrary.asco. org/content/133165-144).

Anamorelin HCl in the treatment of non-small cell lung cancer - cachexia: A randomised. double-blind, placebo controlled, multicentre. Phase III study to evaluate the safety and efficacy of anamorelin HCI in patients with

Multi-Site Clinical Trial

NSCLC-C

This study explored the use of ghrelin analogue to maintain or improve weight in patients with advanced lung cancer.

Weight loss is highly distressing to patients and alters body image and also worsens the ability to function independently. Very few effective treatments exist. This study provided access to a medication for our patients we would otherwise not be able to use.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky Site: Braeside Hospital **Duration: Aug 11 to Aug 13**

Funding Source: Helsinn Therapeutics Project Partners: Liverpool Hospital Study Status: Completed

Translational Outcome(s):

These studies have shown that the new drug. Anamorelin, which mimics the hunger hormone "Ghrelin", improves appetite and body mass in patients with advanced lung cancer who are suffering anorexia - cachexia syndrome (characterised by loss of weight and muscle, fatigue, weakness and poor appetite). Results presented at the 2014 ASCO meeting (http://meetinglibrary. asco.org/content/133165-144).

Meera Agar -

Translating research into better care

Tell us about one of the research projects you have been working on?

One of the really distressing things that people experience during end of life care is what's known as delirium. The patient experiences a lot of very distressing behavioural disturbances agitation, restlessness, hallucinations, delusions. They may think the nurse who is coming to give them medications is going to poison them. Their sleep cycle may be reversed, so they are asleep during the day and awake during the night. So it's very distressing for patients. And that's something we are keen to

One of the main treatments we currently use is anti-psychotics. Millions of people are exposed to anti-psychotics when they have delirium. But currently we use them without an evidence basis one way or the other. It's an international problem.

We have been running a trial exploring the impact of the effect of anti-psychotics on the management of delirium in end of life illness. It's probably one of the largest trials of delirium treatments ever undertaken in any clinical setting. We recruited 239 participants, and the results are now finally with the bio statistician for analysis, which will take some time - it's a very complex data base.

But once we know what the results have shown, it will provide an evidence basis that will fundamentally change one way or the other how we treat delirium, and that will inform the delivery of palliative care. From there, it will be really important to engage with the organisations that develop clinical practice guidelines for the management of delirium, so that this new data can help us to review guidelines and be guided by evidence in terms what we recommend in pharmacological treatment.

Five years on we are close - its been a long hard road. Whichever way the results pan out, it's going to have a major impact on the quality of life for patients facing their final times in palliative care. This project is actually something that hasn't been done before.

How did you get involved in research?

In everyday practice there are many scenarios for which the current evidence or current clinical experience doesn't really give us great options to manage a particular clinical scenario. So we see those gaps on a regular basis, and ultimately that drives us to try and unpack those problems and find concrete answers as to how to do things better. In 2004 I began an integrated work life of 60% case load and 40% research.

Overall - my focus is on people with advanced illness.

In another project - the end of life experience for people with advanced dementia in residential care can be very difficult. We have been working on a project focused on that area. Essentially, we have been holding meetings combining families, staff and GP's within residential aged care homes, to examine future delivery of care and what that might mean for loved ones and families, and look at outcomes in terms of quality of life care for residents.

We involved the whole range of staff in the care home we trained senior registered nurses in the facilities to be coordinators and run the meetings. And we included the care staff, GPs, families, and other staff. We discovered that the care staff were initially apprehensive about meeting with families. feeling that they were not equipped to contribute. But once they had attended a few of the meetings, they really felt that the families valued their presence there, as being the people that know the residents best.

And remarkably, the attendance of GPs got close to 100% by the end of the project. This was amazing. It went from being totally problematic to even get them to attend, to having them engaged and wanting to attend after 18 months of the project. That was very exciting.

What sort of feedback did you receive?

So in terms of the feedback, it was overwhelmingly positive, to the point that care staff involved eventually became comfortable, and were proactively working with families. So the whole concept for staff, of learning that you can have a positive experience engaging with families through that difficult time, was a key outcome I think.

Our ultimate goal is to increase the quality of end of life care, and we are still measuring that outcome. But all the other processes that were developed, and the insights, the learning and and attitude changes that resulted are just as important.

It's all very well to hold your meetings, but if no one follows up in terms of the actions, then you're not going to change outcomes for residents.

The first thing we are going to do is to develop a toolkit. As a result of the research, we have a good understanding of the kind of core competencies needed for the meeting coordinator role, and we have a good idea of the training we need to put in



This project is actually something that hasn't been done before





place to help all members of the care home staff feel comfortable about engaging with the families. We also now have a good understanding of the topic areas that should be brought up. So with all that information, we will develop a toolkit and conversation guide that will help with those difficult conversations.

And we know the kind of audit and follow up needed to ensure you are actually changing outcomes in your facilities. But I think

it's these broader outcomes, the attitude change with staff, the family feeling engaged informed and included, and care that's driven by proactive and positive planning, rather than retrospective fixing up of problems, that are important.

We are hoping for a real impact in terms of symptom control, and also in terms of the satisfaction of the family with the quality of the end of life care provided for people living with advanced dementia. It is however a double-edged sword

causing many significant adverse effects.

This study developed a measure which

allows patients and caregivers to report

such side effects to clinicians. This is

important because having the clinician

rate them, without understanding fully

the patient experience, is well known to

underestimate impacts of symptoms on

Researchers: Associate Professor

Meera Agar, Ms Julie Wilcock &

Researchers: Dr Melanie Lovell &

Funding Source: Internally Supported Project Partners: University of Sydney

Ms Natalie Ohrynowsky

Site: Braeside Hospital

Site: Greenwich Hospital

Duration: Aug 11 to Sept 14

(Cooperative Trials Group for

Study Status: Completed Translational Outcome(s): Paper has been submitted to Supportive Care in Cancer for review. The Dexamethasone symptom questionnaire 'Chronic' was found to be a useful clinical tool for patients and caregivers to self report toxicities experienced due to dexamethasone: often side effects the clinician may have

not otherwise picked up.

Ms Alison Hession

Neuro-oncology)

Duration: Mar 11 to Dec 14

quality of life.

This project reinforced academic links with the University of NSW, through the Hammond Chair of Positive Ageing, in providing education on Australia's health and aged care systems.

The project assisted HammondCare staff skills and potentially opens up new international opportunities. This project is in two stages – an aged care course (previously completed) and a palliative

Researchers: Associate Professor Andrew Cole & Professor Rod MacLeod

Sites: Various

Funding Source: Shanghai City Government Health Bureau Project Partners: None

Teaching links strengthened with Shanghai City Health care professionals. providers of palliative and aged health

Shanghai Delegation **Teaching Program**

through the development of their teaching care course.

Duration: Feb 2014

Status: Completed

Translational Outcome(s): care to a population in excess of 8 million people.

The lived experience of Self-reported evaluation of the Occupational Therapy adverse effects of in palliative care at Greenwich Hospital Dexamethasone -Seed

The study may benefit patients indirectly because the results Multi-Site Study will help us better understand Dexamethasone is used frequently to Occupational Therapists' practice manage symptoms in palliative care. in palliative care and so we hope to better serve people receiving In particular it is used to manage raised palliative care. intracranial pressure in brain tumours.

> HammondCare Occupational Therapists will be able to draw on the results to validate or improve practice.

Researcher: Professor Roderick MacLeod (Honours Supervision) **Site: Greenwich Hospital Duration: Mar 14 to May 14**

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

Translational Outcome(s): Degree awarded. Paper submitted for publication. Results to be disseminated to Occupational Therapy teams.

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, Study Status: In Progress

Palliative care nursing research project

This project enhanced nursing skillsets in communication and reflective practice resulting in better patient/ family outcomes and experiences when admitted to HammondCare **Health and Hospitals inpatient** services.

Researcher: Ms Margaret Brown Site: Neringah Hospital **Duration: Aug 12 to Mar 14**

Funding Source: HammondCare Foundation Project Partners: University of Technology Study Status: Completed

Translational Outcome(s):

Nursing staff reported increased selfawareness and confidence in dealing with patients and families in emotionally charged situations, and that they felt better equipped to minimise undue distress and engage with and support grieving families. Also identified strategies to overcome barriers to effective communication with patients and family members as well as and within the multidisciplinary team.

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 & Associate **Professor Josephine Clayton Sites: Various Duration: Sept 14 to Dec 15**

Health) **Project Partners: Respecting Patient Choices Program (Austin Health) Status: In Progress**

Funding Source: DoHA (Austin

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Project Partners: None

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(s):

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.

Improving service delivery for early onset memory and related disorders:

The INSPIRED Study

This project developed a model of care for people with younger onset dementia (YOD) across NSW.

HammondCare is part of the steering committee to provide experience and

Researchers: Ms Meredith Gresham & Associate Professor Christopher

Site: Horsley and Young Onset Dementia Services in the Community Duration: Aug 12 to Sept 13

Funding Source: NHMRC & Internally Supported **Project Partners: UNSW**

Study Status: Completed

Translational Outcome(s): The project aimed to compile an accurate picture of the number of people that have Younger Onset Dementia and what type of dementia they have. This information could assist policy makers and service providers identify key priority areas and work with this population more effectively.

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 **Duration: Apr 12 to Dec 15**

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.

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 May 15**

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**

Literature review of the environmental correlates of function and wellbeing of people living with dementia

This study will update our knowledge and evidence base for good dementia design.

Researcher: Dr Ronald Smith & Ms **Meredith Gresham** Site: Not applicable **Duration: Apr 13 to Nov 13**

Funding Source: Dementia Centre Project Partners: None Study Status: Completed

Translational Outcome(s):

This comprehensive review of literature has assisted in the development of the Dementia Centre's new Dementia Design Rating Tool and ensure the Dementia

Centre is up-to-date with comprehensive evidence-based design.

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 Aug 15**

Project Partners: None Study Status: In Progress

Determination of contributions

Researcher: Associate Professor Janine Stevenson

Funding Source: Internally Supported Study Status: In Progress

Lead Investigator: Professor lan

Study Status: In Progress

Cognitive Decline Partnership Centre (CDPC)

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)** is a dynamic partnership designed to deliver excellence in research and knowledge exchange to improve health and care for older people living with cognitive and related functional decline.

The CDPC brings together clinicians, researchers, aged care practitioners, policy makers and consumers who have a wide range of expertise in working with older people with cognitive and related functional decline.

HammondCare provides a range of individuals 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.

Lead Investigator: **Professor Susan Kurrle**

Funding source for all **CDPC Projects:**

National Health and Medical Research Council. HammondCare. Alzheimer's Australia. Brightwater Group and Helping Hand.

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

Stage 1: 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.

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 Sept 14**

Study Status: Completed

Translational Outcome(s):

The outcomes of this project will assist those providing and designing services at HammondCare, as well as providing determinants of good residential aged care across the sector.

This is the first stage of a larger comprehensive NHMRC Partnership Centre project investigating the real costs of long term care for people living with cognitive decline. The research aimed at finding what residents and families most valued in residential care. The over arching findings were that residents most valued their personhood; that their identity be valued, recognised and

supported and that their relationships likewise be valued, recognised and supported. Families differed subtly in that they valued personhood of the resident being recognised and supported, but also valued a supportive or enabling environment. Outcomes have been presented to the new Aged Care Quality Standards Commission and have been included in Dementia Centre Design Smart seminars reinforcing that design has a critical role to play in reinforcing identity and nurturing relationship.

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.

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 15 **Study Status: In Progress**

Evaluating the Dementia Key Worker Role

An evaluation of the dementia keyworker 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 kev 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: In Progress**

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: Associate Professor Meera Agar Designated System Based 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**

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

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

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

Lead Investigator: Professor Simon Biggs, Melbourne University **Designated System Based** Investigators: Ms Angela Raguz, Ms Meredith Gresham, Ms Rebecca Forbes & Ms Catriona Lorang Sites: Dementia specific residential care homes: Erina, Hammondville, Horsley, Miranda, North Turramurra and Woy Woy **Duration: Not yet commenced** Study Status: Literature review &

planning stage

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

Improving quality of

residential dementia

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

homes.

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 **Duration: Stage 1: Jun 14 to Aug 14** and Stage 2: Sept 14 to Feb 15

and Stage 2: In Progress

Establishing the prevalence of Vitamin D and calcium supplementation in Australian residential aged care facilities

Study Status: Stage 1: Completed

Adequate Vitamin D lowers risks of falls and fall related injury.

Cameron, The University of Sydney **Designated System Based Investigators: Ms Meredith Gresham** & Ms Rebecca Forbes Sites: Various HammondCare care homes **Duration March 14 to Dec 15**

Beyond respite: designing effective wellness programs for caregivers

This very successful project looked at the wellness needs of carers of HammondCare clients with dementia. The project reinforced HammondCare's role in dementia care.

Researchers: Associate Professor Christopher Poulos & Mr Damian Harkin

Sites: HammondAtHome: Hammondville; Sylvania Waters; Hornsby Ku-ring-gai; Bathurst; Gosford; Horsley **Duration: May 12 to Sept 13**

Funding Source: Dementia Collaborative Research Centre (DCRC) 3 Carers and Consumers **Project Partners: Queensland** University Technology (QUT), Griffith University, Alzheimer's Australia, **Curtin University of Technology, LaTrobe University Study Status: Completed**

Translational Outcome(s):

The output from the project has already included two presentations at a national conference (Sept 2013) and one international (Oct 2013) and we anticipate two academic publications.

Improving carer wellness through better partnering with general practitioners

Follow-on project to the Beyond Respite (R002) project looking at strategies to better engage GPs in promoting carer wellness.

Researchers: Associate Professor Christopher Poulos & Mr Damian

Sites: Not Applicable Duration: Sept 14 to Jun 14

Funding Source: DCRC 3 Carers and Consumers

Project Partners: Professor Elizabeth Beattie, Queensland University of Technology (QUT)/ Dementia **Collaborative Research Centre** (DCRC); Professor Dimity Pond, **University of Newcastle Study Status: Completed**

Translational Outcome(s):

This project will help strengthen HammondCare's credentials in this area and inform practice in the new Academic Primary Care Unit at Hammondville.

Evaluating the effectiveness of a Nordic Walking program to enhance physical function and to promote exercise adherence amongst older adult males

A pilot project to build capacity within HammondCare in the positive ageing space through the engagement of older men residing in Independent Living Units.

Researchers: Associate Professor Christopher Poulos & Ms Natalie Robson

Sites: HammondGrove Independent **Living Units Duration: Sept 13 to Dec 13**

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

Translational Outcome(s):

The aim was to support various aspects of positive ageing by providing opportunities for social engagement, development of new skills and enhancement of physical function through participation in regular physical activity

Monitoring and assessing noise levels in a residential aged care home (RACH)

This project provides an evidence base (measurements) of the noise levels in one RACH, leading to recommendations for noise abatement in this setting.

Researchers: Associate Professor **Christopher Poulos & Dr Alison Short** Site: Bond House Hammondville Duration: Aug 13 to Oct 14

Funding Source: Internally Supported Project Partners: UNSW BEng Student Study Status: Completed

Translational Outcome(s):

The information assisted with promoting and maintaining an "at home" environment for our residents, as part of the HammondCare philosophy.

Effect of auditory environment on choices about community activities undertaken by older adults

Engagement in community activities is essential to older adults to promote physical, emotional, social and spiritual wellbeing.

Researchers: Associate Professor Christopher Poulos & Dr Alison Short Sites: HammondGrove Independent **Living Units Duration: Feb 14 to July 14**

Funding Source: Internally Supported **Project Partners: UNSW Medical** Student

Study Status: Completed

Translational Outcome(s):

Exploring the effect of the auditory environment (noise and music) on choices of community activities undertaken by older adults will inform further understanding and planning of community initiatives to reduce barriers and enable healthy lifestyle choices across a range of community activities within the independent living setting.

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: Associate 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: In Progress**

I love being in the clinic, where I can apply what I know to help people.

DeCAPS

This study demonstrated the benefits of the provision of preventive oral health care in HammondCare Residential Aged Care Homes.

Researcher: Associate Professor Andrew Cole & Dr Jan Galton Sites: Hammondville Residential Care Home

Duration: Feb 13 to Sept 13

Funding Source: Health Education & Training Institute Project Partners: Interdisciplinary Clinical Training Network NSW Study Status: Completed

Translational Outcome(s):

Teaching links strengthened with Shanghai City Health care professionals, providers of palliative and aged health care to a population in excess of 8 million people.

InterMed

This study developed a new model of inter-disciplinary teaching of medical students, preparing them for future work in teams in healthcare settings after graduation.

Researcher: Associate Professor Andrew Cole & Dr Jan Galton Sites: Hammondville Residential Care Home Duration: Feb 13 to Sept 13

Funding Source: Health Education & Training Institute Project Partners: Interdisciplinary Clinical Training Network NSW Study Status: Completed

Translational Outcome(s):

New oral health care practitioner commenced at Hammondville RACF as a result of benefits to residents demonstrated from this project, leading to provision of a full dental care service for Hammondville residents from 2015.

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.

Researcher: Associate Professor
Andrew Cole, Associate Professor
Christopher Poulos & Ms Anne Loupis
Sites: Bond House, The
Meadows, The Pines, Southwood
(Hammondville); Leighton
House, Princess Julianna Lodge
and Waldegrave House (North
Turramurra); 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: In Progress

Focus on Function

The focus of this study was to educate community care workers and managers in the identification and management of early functional decline in HammondCare clients in the community.

Researchers: Associate Professor Christopher Poulos and Ms Miriam Kolker

Sites: HammondAtHome South West Sydney and South East Sydney Community Aged Care Packages (CACP)

Duration: Jul 12 to Jan 14

Funding Source: DCRC 3 Carers and Consumers

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

Study Status: Completed

Translational Outcome(s):

The aim is to up-skill care workers and managers in the use of mobile technology.

Reforming and Enabling Aged Care Teams (REACT)

The aim of the study was to gain an understanding of the team dynamics within residential aged care and find opportunities to improve teamwork and coordination of resident care.

Researchers: Associate Professor Christopher Poulos & Dr Alison Short Sites: Residential care homes at Hammondville, Leighton Lodge and Erina.

Duration: Sept 12 to Jan 14

Funding Source: Workforce Australia Project Partners: School of Public Health and Community Medicine, UNSW

Study Status: Completed

Translational Outcome(s):

Funding allowed the implementation of a comprehensive education package for residential aged care staff in three sites.

Building Workforce Capacity for Complex Care Coordination in the Community (CHIPPER)

This project tested a new model of care for community aged sector. Early project learnings have already informed the new HammondAtHome model which will only strengthen over time.

Researchers: Ms Sally Yule, Ms Julie Flood, Ms Sally Day & Associate Professor Christopher Poulos Sites: Various

Funding Source: Health Workforce

Duration: July 12 to Jan 14

Australia

Project Partners: School of Public Health and Community Medicine, UNSW as local evaluators and South West Sydney Medicare Local. Study Status: Completed

Translational Outcome(s):

There are strategies in place to achieve sustainability across all areas of HammondAtHome. Longer term it is anticipated there will be a positive impact on productivity and staff recruitment and retention. The position of HammondCare as a market leader will also be enhanced.

Analysis of a converted ICF (International Classification of Functioning) based ADL (Activities of Daily Living) outcome measure and its comparison to FIM (Functional Independence Measure)

Using WHO classification (ICF) and looking at its potential to adapt it and compare it to current measures of disability which are known to be inadequate and at times inaccurate in assessing the true burden of disability of people in our lives. There are no costs associated with ICF.

In contrast, the Functional Independence Measure (FIM) requires payment for use.

Researcher: Associate Professor Friedbert Kohler Site: Braeside Hospital Duration: Mar 12 to Dec 14

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

Translational Outcome(s):

It looks feasible that the ICF can be used to assess and measure function. This opens the possibility of using the classification, or parts of it, for assessment and monitoring changes in patient's function (also refer to publications listing).

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

The Six-Minute Walking Test (6MWT) plays a key role in assessing ambulation capacity and evaluating effectiveness of surgery in people undergoing a TKA. This study will outline the clinically relevant change in 6MWT distance following a TKA, by incorporating the patient's perspective regarding change in their status with functional outcome measures.

Researcher: Mr Mark Buhagiar Site: Braeside Hospital Duration: Jun 12 to Dec 15

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 Jun 15

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 subacute 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 15

Funding Source: Internally Supported Project Partners: None Study Status: In Progress A randomised controlled trial to evaluate a model of comprehensive stroke care

Multi-Site Study

A local multi-centre trial of stroke rehabilitation in different settings to evaluate whether the model of care provided by Braeside Hospital is efficient and meeting patients' functional needs.

Researcher: Associate Professor Friedbert Kohler Site: Braeside Hospital Duration: Feb 13 to Jun 14

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

Translational Outcome(s):

The model of stroke rehabilitation care as practiced at Braeside hospital is efficient in meeting the patients functional improvements (also refer to publications listing).

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 15

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

Looking ahead, I see our clinical work and our research going hand in hand, and feeding off each other, and growing together.



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 15

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

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.

Non-HammondCare
Researchers 3: 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: In Progress 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.

Non-HammondCare Researcher 4: 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



In everyday practice there are many scenarios for which the current evidence or current clinical experience doesn't really give us great options to manage a particular clinical scenario. So we see those gaps on a regular basis, and ultimately that drives us to try and unpack those problems and find concrete answers as to how to do things better.

Meera Agar

Pilot evaluation of a new clinical pathway for assessment and management of pain

This is a national guideline developed by a team led by HammondCare staff. It has been presented at several international and national meetings and is the standard of care for pain in cancer patients across settings.

It is hosted on the Cancer Council Australia website. Piloting the guideline has improved our pain management practice and will enable the guideline to be trialled nationally.

Researchers: Dr Melanie Lovell & Ms Mary-Rose Birch Site: Greenwich Hospital **Duration: Jun 12 to Nov 14**

Funding Source: Pfizer International Grant **Project Partners: None Study Status: Completed**

Translational Outcome(s):

This project has refined implementation strategies for the cancer pain guideline which has provided pilot data for a funded randomised trial (also refer to grant section).

Ritchie Foundation project

This is funding towards the overall Cancer Pain guideline project.

Researcher: Dr Melanie Lovell **Site: Greenwich Hospital Duration: Ongoing**

Funding Source: Ritchie Foundation Project Partners: None Study Status: In Progress

Thalamic neuroplasticity and pain following spinal cord iniury

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 Oct 14

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

Translational Outcome(s):

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).



So the research is really resulting in innovative specialist care for people with pain right across the board, throughout NSW.

Spinal cord injury and chronic painresources and service development

This grant is very clinically focused and aims to develop a state-wide model of care for pain management for people with spinal cord injuries.

As part of this grant, Greenwich Hospital has been proposed as a state-wide hub for the delivery of pain management services to this group of people. This will attract expertise in this area to Greenwich, and contribute to sustainable service provision.e.

Researcher: Professor Philip Siddall Site: Off-Site research **Duration: May 13 to Dec 14**

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

Translational Outcome(s):

As part of this grant, Greenwich Hospital has been proposed as a state-wide hub for the delivery of pain management services to this group of people. We have also published a book written for people with pain following a spinal cord injury and developed on-line resources now available through the NSW Agency for Clinical Innovation web site (also refer to publications and books 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 15**

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

Phil Siddall -

Translating research into better care

Tell us about one of the research projects you have been working on?

A big research project that's coming to completion is in the area of spinal cord injury. I've worked as a medical specialist and researcher in the area of spinal cord injury for over 20 years. As a result of that work, I was part of a team that was able to gain a research grant to develop resources and a new model of care to address spinal cord injury pain - this means pain that people with quadriplegia, paraplegia experience after their injury.

So it is great to be involved in a project that translates the research I have been involved in over 20 years into best possible care.

And the result is that we have now developed a model for a program of care that is based at Greenwich Hospital but about 80% is delivered by tele-health - which is fantastic for someone suffering pain from a spinal cord injury who may be in say Broken Hill or Wee Waa. We can link up via video to do a pre-assessment to see the issues involved before we meet them in person. Then they come down just for a day, for further assessment and to begin treatment. Then after that, they can go back home, and we have a six month follow up program, again via video link.

So that works tremendously well. And we have been able to do that because we have the specialist multidisciplinary team expertise in the one place.

Following on, as part of the model of care, we have developed resources that are now available to the community via the NSW Agency for Clinical Innovation website. The website provides practical resources that GPs can now go to, derived from the research in collaboration with NSW ACI. Through HammondCare Media, we have also published "The Spinal Cord Pain Injury Book", which provides education and tools for managing pain following spinal cord injury and further translates our research into practical resources that will support care for people with pain.

What sort of response has the project received?

Since launching that program and publishing those resources, the NSW Government has asked for a business plan for people who have a spinal cord injury but are not covered by insurance. They want a business plan that will allow them to fund care for people in that situation and therefore currently unable to access the program we have developed.

That's basically funding for a pain specialist, a clinical psychologist, a physiotherapist, a registered nurse and a researcher, to provide

care in that area on a one day a week basis.

So the research is really resulting in innovative specialist care for people with pain right across the board, throughout NSW. With the potential of public funding by NSW Health, who recognised the expertise and service the model provides, and who want to see it available for people in need across the state.

It's also about recognising the value of tele-health, where if you have spinal cord injury pain out in Wee Waa, you get specialist expertise and ongoing help simply by connecting via your computer, tablet or phone.

Telehealth will work well in other areas of HammondCare, where we have specialist expertise in aged care, dementia care, palliative care, cancer care, rehabilitation and other areas. Developing specialty pain services in these areas is something new, something we are equipped to do, and it's where I see us going in the years ahead. So I want us to be seen as a pain service with specialised links into those other areas such as dementia, cancer, palliative care, rehabilitation and others by using the high level of expertise that we already have in these areas within HammondCare to provide high quality, specialist expertise to people in need across the state.

How did you get involved in medical research?

When I was at Medical School, the idea of research just left me cold! At that time, as a doctor, I thought seeing patients was where it's at.

But then, still quite early in my career, at someone's prompting, I decided to embark on a PhD. And about a year into that, I fell in love with research. In some ways, research is about being a detective, and about solving jigsaw puzzles. It's about finding a problem and asking "what's going on here? How do I solve this problem and what are the pieces of information I need?" Sometimes you may only find one piece of the puzzle. Yet, as anyone who does jigsaws knows, when you find that one piece, it's like - aha, that's the one that fits!

Pain is such a difficult condition. When we are working in the Pain Clinic, so often it's frustrating - you wonder, well, what's going on here? No-one really has the answers. You're always hoping you'll make a big breakthrough that will solve everything - as you go on you realise that's a bit idealistic. But even being able to find one small piece can be incredibly satisfying.

But for me, being in the clinic, you're with someone experiencing pain, wondering 'what's going on here...' then you're able to look at that in research and start to try to work things out - one informs



I love that search to find out what's going on to get to the bottom of some of the problems we are facing.

Phil Siddall



the other so my practice informs my research and my research informs my practice - so I'm incredibly fortunate to be able to work in both those areas at the one time. I love being in the clinic, where I can apply what I know to help people - but I love that search to find out what's going on to get to the bottom of some of the problems we are facing.

Its around three years now since we set up the Pain Clinic

at HammondCare and I'm fortunate to work with a wonderful team. I've also got great colleagues here in palliative care, rehabilitation, dementia care, where we can work together and mix across the disciplines, and share the different perspectives and skills we have in treating pain. Looking ahead, I see our clinical work and our research going hand in hand, and feeding off each other, and growing together.

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Outpatient pain selfmanagement 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 May 15

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 develop 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 & Mr Phil Austin Site: Greenwich Hospital Duration: Feb 14 to Feb 15

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

The SCI Pain
Course: Examining
a low-intensity selfmanagement 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 15

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 May 15

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)

This project will develop a pain management pathway along with systems and processes through classroom training, hands on mentoring and a web based portal.

Researchers: Associate Professor Colm Cunningham, Dr William McClean, Prof Philip Siddall, Dr Chris Papadopoulos & Ms Juliet Kelly Site: Residential and HammondAtHome – specific sites TBA Duration: Phase 1 Apr 14 to Jun 15

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

Spiritual needs of patients and the role of doctors in identifying them

Palliative care by definition includes attending to the spiritual needs of the patient. Current evidence shows this is not done well.

Researchers: Dr Megan Best Sites: Braeside & Greenwich Hospitals Duration: Sep 12 to Sep 14

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

Translational Outcome(s):

The HammondCare mission statement specifically mentions our commitment to nurturing the spiritual well-being of patients. This study identified ways we can do this (also refer to publications listing).

Exploring Australian palliative care nurses' current practices in assessing, documenting and supporting spiritual and existential concerns of palliative care patients

This project helped inform spiritual care by nurses for our palliative care patients as well as self-care for our palliative care nurses.

Researchers: Ms Robyn Keall & Associate Professor Josephine Clayton (PhD supervisor) Site: Greenwich Hospital Duration: Feb 12 to Jun 14

Funding Source: Internally Supported

Project Partners: PhD supervision of Robyn Keall, University of Sydney Study Status: Completed

Translational Outcome(s):

Two papers were published regarding the results of this study (see publication list). The findings have informed teaching sessions for nursing staff. A card with question prompts and strategies identified through this project is being developed and will be disseminated to nursing staff to assist with communicating about these issues.

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 & Dr Melanie Lovell (Spiritual wellbeing in chronic and cancer pain)

Site: Greenwich Hospital Duration: May 13 to Jun 15

Funding Source: Australian & NZ
College of Anaesthetists
Project Partners: University of Sydney
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 Feb 15

Funding Source: Friends of Greenwich Project Partners: None Study Status: In Progress



Our ultimate goal is to increase the quality of end of life care, and we are still measuring that outcome. But all the other processes that were developed, and the insights, the learning and and attitude changes that resulted are just as important....We are hoping for a real impact in terms of symptom control, and also in terms of the satisfaction of the family with the quality of the end of life care provided for people living with advanced dementia.



Matra Robertson Translating research into better care

Tell us about one of the research projects you have been working on?

Think of the population of a town like Goulburn; three times that number are dying in Palliative Care, each year in NSW.

Yet their needs are great. Each of them would usually have a family member, a partner, and often children, so there is actually a very large number of people involved. But they are amongst the most under researched and resourced groups in our community.

Most of these people, if given the choice, would prefer to die at home. But while a loved one dying at home was perhaps a more common experience a hundred years ago, today it's really quite a rare occurrence. For many people today, when they lose a family member, it's a new experience - often it will be the first time they will care for a person who is dying. So if we are to support the majority of people and their families in their preference to experience a death at home, we have a real challenge.

It is our experience that a person who has a life limiting illness may say, "I would like to die at home", and their family members may say "I would like to support you in that, but I'm not sure how it will be and I'm a bit nervous about that..."

So how do we help the person and their family to know what to expect? And how to help the family to support their loved one?

My background is in allied health and social work, and I've worked with the disadvantaged, including the homeless and people with mental health issues, and also people approaching end of life in palliative care.

In 2011 I completed my PhD, which arose directly out of my clinical work. I found in that work that people close to death at times expressed feelings of hopelessness. This led me to want to understand that experience.

So we came to look at hope during a home death. This is building on the Palliative Care Home Support packages that HammondCare delivers.

How did you get involved in research?

In my clinical work, though I believe the care we provided was of real benefit to our patients, I started to question, "was this the best care - was there a better way?". And in reality, we were really making some guesses about the sorts of care that is provided.

I began looking for an evidence basis to that care, which led me to research. I began looking for a consensus in the literature that was available. What do world experts think, in regard to hope and hopelessness in end of life care? So I interviewed world experts as part of my PhD.

This led me to realise that it is our patients who are the experts, and so I began to interview patients close to death, to try to identify what were the factors that gave them hope and hoplessness at end of life. And what surprised me was, that to a degree, what they reported was quite different to what professionals thought.

I concluded that with the limited resources we have in health care, that research is vital to inform what we provide - and also in a mission like ours at HammondCare, to reach people who are vulnerable and disadvantaged, research to identify the very best way to commit our resources is vital. To ask - what should we be doing? What is the best practice? What is the best time and place to provide care, and how should we provide it?

What are the next steps?

So to this end, we are about to recruit for a research project that will invite family members who have received our support, to tell us about the experience. To tell us what in our care promoted the hope that the death would be as they would be hoping for. What is their experience of the spiritual, psychosocial and physical factors in palliative care that support hope during a home death? And also what may have been less than helpful for them.

We need to draw out and explore that experience, to support them. We need to create an environment where we can understand that experience. This is an extremely challenging area, but it will be very important if we can tailor our care informed by their experiences to meet that need.

So we will be inviting participants to take part - they will be interviewed in their own home, in a collaborative project with myself, my co-investigators, Professor Rod MacLeod here in Sydney, and Professor Wendy Duggleby from the University of Alberta in Canada.

We will take the time to develop a questionaire which will guide us through the research. All the participants will be asked the same questions, and when we have completed that process, we will analyse the data.

From there, after the analysis is completed, and we draw out the themes from what families tell us, and begin to draw evidence based conclusions. Then we feed the conclusions back into practice, for example into the home care packages. Where needed, we will be changing the way we do things, our training, and our delivery.



Matra Robertson



We will also be publishing and presenting at national and international conferences to share and dialogue internationally. Because we believe that making the information available to the wider community, on a global basis, is so important.

Because death as birth, is an experience we will all share, and that with proper research and understanding, we can be at that fragile sacred space, in an informed way, to deliver the best care, evidence based, that will best meet the needs of those involved in the end of life experience.

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Facilitating discussion on treatment preference and advance care planning in cancer patients using the vignette technique

This study will inform the development of better advance care planning processes for patients with cancer and in turn will improve the care for our palliative care patients.

This research involves collaborating with researchers from Peter MacCallum Cancer Centre in Victoria.

Researcher: Associate Professor Josephine Clayton Site: Greenwich Hospital **Duration: Aug 11 to Dec 14**

Funding Source: Peter MacCallum Cancer Institute administered by Peter McCallum Cl **Project Partners: Peter MacCallum Cancer Institute, Victoria Study Status: Completed**

Translational Outcome(s):

Two papers have been published (see publication list) and a third IN PRESS regarding the outcomes of this study, and the results have also been presented at various national and international conferences. The results informed the design of a nurse-facilitated advance care planning intervention. This intervention is currently being evaluated to assess its effectiveness.

Advance care planning: Attitudes, barriers and practice of respiratory physicians. A survey of advance trainees and respiratory physicians at four Sydney Hospitals

Multi-Site Study

This study will inform education for respiratory physicians about advance care planning.

This will in turn help respiratory physicians to have earlier discussions with patients and their families about end of life issues, and thereby reduce barriers to referral to our palliative care service for people with end stage respiratory illnesses.

Researcher: Associate Professor Josephine Clayton Site: Greenwich Hospital **Duration: Jun 11 to Feb 14**

Funding Source: Internally Supported **Project Partners: Cunningham Centre for Palliative Care, Woolcock Institute of Medical Research Study Status: Completed**

Translational Outcome(s):

The results have been published (see publication list). The findings will inform education for respiratory physician trainees and specialists regarding advance care planning.

A single-centre crosssectional analysis of advance care planning among elderly inpatients

Single-Site Study

This study will inform advance care planning for elderly people in acute care settings.

It will inform improvements to care that are important for HammondCare's inreach palliative care services to acute hospitals as well as for elderly people in the community. The project involved mentoring and supervision of one of our palliative care registrars, Dr Flora Cheang.

Researcher: Associate Professor Josephine Clayton & Dr Flora Cheang Site: Greenwich Hospital Duration: Dec 12 to Jun 14

Funding Source: Internally Supported Project Partners: Royal North Shore Hospital Departments of Palliative Care and Aged Care Study Status: Completed

Translational Outcome(s):

The results of this study were published with an accompanying editorial (see publication list) and the findings presented at a National and International conference. The advance care planning screening tool that was developed for this study is now being evaluated with elderly patients in the community, to facilitate earlier discussion of advance care planning.

Systematic review of advance care planning for patients with chronic kidney disease

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

This program of research will strengthen HammondCare's ties with non-cancer referrers to palliative care, which has been identified as an important target for the palliative care service.

Researcher: Associate Professor Josephine Clayton **Site: Greenwich Hospital** Duration: Jun 12 to Feb 14

Funding Source: Internally Supported Project Partners: Improving Palliative Care though Clinical Trials (ImPaCCT), Caresearch, Respecting Patient **Choices Program Study Status: Completed**

Translational Outcome(s):

The findings were published with an accompanying editorial (see publication list) in the American Journal of Kidney Disease and presented at a National conference. The findings have identified the gaps in the existing literature and enabled the development of a research protocol, now funded by Kidney Health Australia, that will help improve clinical practice in this area.

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.

Researcher: Associate Professor Josephine Clayton 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.

Researcher: Associate Professor Josephine Clayton 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 USvd **Study Status: In Progress**

Investigating barriers and facilitators to advance care planning for dialysis and predialysis 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

Researcher: Associate Professor Josephine Clayton (Supervision of PhD student) Site: Greenwich Hospital **Duration: Jan 14 to Dec 15**

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**

Teaching Academic
Professional Activities
Higher Research Degrees
Academic Degree Supervision
Academic Conference Industry
Seminars
Journal Articles
Books Chapters
Technical other reports
Industry magazine articles

Teaching+Academic Professional Activities

Professor Roderick MacLeod

As Senior Staff Specialist with HammondCare and Conjoint Professor in Palliative Care with the University of Sydney, Rod is committed to teaching and learning about palliative and end of life care. He teaches Sydney University medical students, GPs and hospital staff as well as HammondCare personnel. He continues to supervise research students including a number of PhD studies.

Along with other HammondCare staff he is proud to have developed the Palliative Care Bridge which provides easy access to professionals and the public to education on many aspects of end of life care - www.palliativecarebridge.com.

In 2014, Rod co-wrote HammondCare's submission to the Australian Senate enquiry into the Exposure Draft of the Medical Services (Dying with Dignity) Bill (2014), and was invited to appear before the Senate as one of HammondCare's two representatives.

In 2013/2014 Rod continued to be involved on the editorial board of several medical publications, as well as being involved with up to a dozen in other ways, including peer reviewing. He has been an external peer reviewer for the National Health and Medical Research Council's 2014 Project Grants round and a reviewer for Genesis Oncology Trust Research Project Grant Applications, New Zealand.

Rod is a member of the Cancer and Palliative Care Network Executive Committee (Northern Sydney LHD); member of the NSW Paediatric Palliative Care Advisory Group; Chair of the State-wide Education Strategy Development Committee and the Steering Committee for Community Palliative Care Home Support Program. He is international advisor to Hospice New Zealand (NZ) and continues to chair Hospice NZ's investigation into the effectiveness of their spirituality professional development programme. Rod also maintains research links within Australia, New Zealand and Canada.

Professor Philip Siddall

Phil holds a conjoint professorial position at the University of Sydney and is involved in teaching in the Sydney University 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 College trainees in anaesthesia, pain medicine and rehabilitation. During 2014, he presented lectures to community groups and doctors, nurses and allied health practitioners in general practice, anaesthesia, pain medicine, palliative care and rehabilitation.

In 2013/2014, Phil served as a member of a number of local, national and international committees including the executive 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. He was also a member of several international ad hoc committees responsible for developing clinical guidelines for the management of pain following spinal cord injury.

Associate Professor Andrew Cole

Andrew has been a conjoint teacher with UNSW Medicine since 1985, and his educational roles include: Presiding Member of UNSW medical student selection group; Convenor of and teacher in the Aged Care & Rehabilitation course (Medicine Year 3 & 4); Member of the Phase 2 Administration Committee, and the Faculty Curriculum Development Committee; Chair of various PhD and MPH candidate review committee meetings in the School of Public Health & Community Medicine at UNSW; UNSW representative on the Undergraduate Medical Sciences Admission Test, Test Management Committee; and the design and delivery of teaching programs on palliative/end of life care for visitors from Shanghai Municipal Health Bureau.

Andrew has helped develop and teach Royal Australasian College of Physicians trainee-supervision skills workshops for consultant physicians around Australia, and has taught aged care and rehabilitation topics in CME programs for medical staff in China, Greece and Thailand, and in community education programs in NSW and Victoria.

In 2014, Andrew co-wrote HammondCare's submission to the Australian Senate enquiry into the Exposure Draft of the Medical Services (Dying with Dignity) Bill (2014), and was invited to appear before the Senate as one of HammondCare's two representatives.

In 2013/2014, Andrew served as Chair of the Education Committee of the Australasian Faculty of Rehabilitation Medicine (RACP), until elected as AFRM President-Elect in June 2014, from which time he has chaired the AFRM Policy & Advocacy Committee.

He is Australia-New Zealand national representative for the International Society of Physical & Rehabilitation Medicine, the Oceania regional representative on the ISPRM leadership group, and a member of the ISPRM Education Committee. Andrew is a board member of the Evergreen Family Friendship Service, a faith-based NGO that delivers medical, community and agricultural services in Shanxi Province, NW China.

Associate Professor Christopher Poulos

As Foundation Hammond Chair of Positive Ageing and Care, UNSW, Chris has a number of teaching roles: undergraduate within the Medical Faculty, on rehabilitation, frailty and community aged care; postgraduate in the MPH/MHM programs; postgraduate (including PhD) and undergraduate student supervision; and the design and delivery of teaching programs on aged care and rehabilitation for overseas visitors.

In 2013/2014 Chris served as: President, Australasian Faculty of Rehabilitation Medicine; Director, Royal Australasian College of Physicians; and Chair of the College's Fellowship Committee. He was an Executive member of the ACI Rehabilitation Network (NSW Ministry of Health) and is Visiting Principal Fellow, Australian Health Services Research Institute, University of Wollongong. He undertook consultancies on rehabilitation and subacute services (for ACT Health, Austin Health and the WA Department of Health), and was on the project team that developed the new AN-SNAP Version 4 patient classification system for the Independent Hospital Pricing Authority.

Teaching+Academic Professional Activities

Associate Professor Meera Agar

As a clinical academic at both 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 2013/2014 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 a number of clinical trial collaborative committees: NSW Palliative Care Clinical Studies Collaborative for Improving Palliative Care through Clinical trials (IMPaCCT); Palliative care clinical trials collaborative (PaCCSC) trials management committee. 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 subcommittees: Palliative care clinical trials collaborative (PaCCSC) Risperidone trial management subcommittee; Palliative care clinical trials collaborative (PaCCSC) Management Advisory Board; and is a Board Member of the European Delirium Association.

Associate Professor Friedbert Kohler

As a clinical academic with UNSW, Friedbert has numerous teaching roles involved with undergraduate medical students, and the supervision of PhD and masters' degree student programs.

In 2013/2014 Friedbert served in many positions including: Honorary Secretary of the International Society of Prosthetics and Orthotics and a number of committees of ISPO; chair of the ISPRM WHO liaison subcommittee for the implementation of the ICF; and chair of the SW Sydney LHD Clinical Council. He is a member of the Editorial Board of a number of rehabilitation journals and is the chair of several international research collaborations to assist in the clinical implementation of the ICF for patients with lower limb amputations.

Associate Professor Josephine Clayton

Josephine coordinates palliative care teaching for medical students 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 professional contributions in 2013/2014 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 Ministry of Health working group to develop online resources for health professionals regarding "EOL decisions, the law and clinical practice"; evaluation advisory group for the National Decision Assist project to improve palliative care and ACP in aged care; and NHMRC Cognitive Decline Partnership Centre advisory committee to implement a national approach to dementia specific ACP.

In 2013/2014 Josephine also chaired the expert advisory group for Australian Research Council funded "enabling people with intellectual disability to understand dying" project and co-chaired the Australasian Chapter of Palliative Medicine Communication Skills training group. She is a member of the management committee for ImPaCCT (improving palliative care through clinical trials) and in 2013 was a member of Scientific Committee for International ACP & EOL Care conference, and Abstract Review Committee for 15th IASLC World Conference on Lung Cancer.

Dr Melanie Lovell

As a Sydney University conjoint academic, Melanie is active in teaching undergraduates through lectures and small group tutorials; basic physician trainees of the RACP; advanced trainees in palliative medicine and oncology through lectures, tutorials and weekly teaching round; nurses and allied health staff; supervising post-graduate students of the University of Sydney in PhD and masters programs; and giving lectures to GPs.

During 2013/2014 Melanie's professional contributions included committee membership of the ImPaCCT (NSW Palliative Care Trials group) Management Advisory Committee, Palliative Care Clinical Studies Collaborative Trials Management Committee and Publications Subcommittee, Caresearch Knowledge Network Management Committee, and the Side Effects in Dexamethasone Trial 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.

Associate Professor Janine Stevenson

As a clinical academic at Sydney University Janine has both teaching and supervisory roles, lecturing, tutoring and examining postgraduate medical students, both in general medicine and psychiatry; teaching and supervising Master of Medicine candidates in psychotherapy; and supervising doctoral research students. Janine also teaches and examines psychiatry trainees for the College of Psychiatry.

In 2013/2014 Janine served on the Examinations Committee of the RANZCP, both in writing and preparing written and oral exams. She is the NSW representative on the binational committee of the Faculty of Psychiatry of Old Age (FPOA) and was on the organising committee for the annual FPOA conference, Sydney November 2014. She is a board member and website manager of the International Society for the Study of Personality Disorders (ISSPD) and is currently a member of the scientific committee for the ISSPD biannual conference, Montreal, Canada, 2015. Janine is involved in the assessment and training of overseas-trained psychiatrists and is a member of the NSW Assessment Panel for overseas-trained psychiatrist to the RANZCP.

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 2014 he was invited to take part in the review of rehabilitation course content for the recently established postgraduate physiotherapy degree at Macquarie University.

In 2013/2014 Mark maintained his role as an Adjunct Supervisor at Macquarie University. In addition, he was an invited speaker at the NSW Palliative Care state conference and continued his regular contribution to the Ingham Institute research seminars, as well as HammondCare and local district conferences, workshops and forums.

Dr Matra Robertson

Matra is passionate about end of life care and the social, spiritual and psychological factors that support hope, meaning and wellbeing in vulnerable people. As Allied Health Academic, Clinical Senior Lecturer Northern Sydney Medical, University of Sydney, Matra teaches Medical students and Bachelor of Nursing students, (Advanced Studies). She supports postgraduate students with supervision that promotes professional activities.

A life member of the Social Work and Hospice and Palliative Care Network of the USA, Matra supports her professional peers internationally in her area of special interest. She is a member of the Editorial Board of Palliative Medicine and Hospice Care-Open Journal and a Reviewer for Australian Social Work Journal. In the state-wide education programme Palliative Care Bridge, Matra presented "Communicating Hope near the End of Life". Matra is Chair of the Palliative Care Education Committee, HammondCare. As the Bereavement Team Leader in HammondCare North, she teaches professionals on bereavement support, hope and end of life.

Dr Megan Best

As a Clinical Senior Lecturer with the University of Sydney, Megan has a number of teaching roles within the Medical Faculty in the development of the curriculum for spirituality and in the Professional and Personal Development course. As an ethicist she teaches as a visiting lecturer at the University of NSW as well as in the medical and nursing Palliative Care education activities at HammondCare. She is involved with postgraduate student supervision and speaks regularly at conferences in Australia and overseas.

Megan is working towards a PhD in spiritual needs of patients at the end of life at the University of Sydney. As chair of the Ethics Committee for Christian Medical & Dental Fellowship of Australia, she is involved with writing educational material in medical ethics and is involved with lobbying on bioethical issues. In 2014, Megan co-wrote a submission to the Australian Senate enquiry into the Exposure Draft of the Medical Services (Dying with Dignity) Bill 2014 on behalf of the Social Issues Executive for the Anglican Diocese of Sydney and was invited to appear before the Senate as a representative of the Archbishop, Dr Glenn Davies.

Higher Research Degrees

Student Name: Mr Phil Austin

Degree: PhD candidate

University: University of Edinburgh

Supervisors: Dr Gordon Drummond and Dr Sarah

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: Grad Dip Qualitative Health Research

completed 2014

University: University of Sydney

Student Name: Dr Megan Best

Degree: PhD candidate

University: University of Sydney

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: Ms Mary-Rose Birch

Degree: Master of Cancer and Haematology Nursing

University: University of Sydney

Student Name: Mr Mark Buhagiar

Degree: PhD candidate

University: University 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-

Thesis Title: Effective approaches to leadership skill

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: Mr Damian Harkin

Degree: PhD candidate

University: University New South Wales

Supervisors: Professor McLaws (UNSW) and Ms C

Kilpatrick (WHO)

Thesis Title: Hand hygiene compliance in clinical

Student Name: Ms Robyn Keall

Degree: PhD completed 2014

University: University of Sydney

Supervisors: Associate Professor Josephine Clayton

and Professor Phyllis Butow

Thesis Title: Enhancing spiritual and existential well-being of palliative care patients from the patient and nurse perspective

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 Garrard Pearce

Degree: PhD candidate

University: University of Sydney

Supervisor: Professor Michael Nicholas, Royal North

Thesis Title: Early intervention screening and treatment in workers compensation to reduce costs and improve patient outcomes

Student Name: Dr Joel Rhee

Degree: PhD completed 2014

University: University New South Wales

Supervisors: Professor Nick Zwar and Associate Professor Lynn Kemp

Thesis Title: Advance Care Planning in the Australian primary care context

implications of this for the ethics of contraception? Integrative project for Sydney Missionary and Bible College.

University of Technology, Sydney

of Notre Dame, Sydney

Clayton J. Doctoral Thesis: Enhancing spiritual and existential well-being of palliative care patients. PhD submitted June 2014; University of Sydney

Clayton J. Doctoral Thesis: Improving quality of life at the end-of-life; University of Sydney

Clayton J. Doctoral Thesis: Delivering patient-centred advance care planning in chronic kidney disease (CKD): the perspectives of patients, caregivers and healthcare providers; University of Sydney

Kohler F. & Dickson H. Master of Medicine; Thesis: Development of ICF Core Set for individuals with a lower limb amputation; University of NSW

Kohler F. & Dickson H. Master of Medicine; Thesis: Development of ICF based mobility assessment tool; University of NSW

Lovell M. Masters of Pain Management; University of Sydney

MacLeod R. Bachelor of Applied Science (OT) Honours; Thesis: The Lived Experience of Occupational Therapy in Palliative Care at Greenwich Hospital; University of Sydney

MacLeod R. Doctor of Health Science; Thesis: Collaborative practice in the New Zealand palliative care environment; AUT University, Auckland

MacLeod R. Doctoral Thesis: The nature of grief in family and professional carers of people with dementia (Advisor); University of Auckland

MacLeod R. Doctoral Thesis: Does a multi-targeted approach of supportive care improve the cancer cachexia status in lung cancer patients? University of Auckland

MacLeod R. Doctoral Thesis: Transnationals' experience of end of life care in New Zealand (Advisor); University of Auckland

Academic Degree Supervision

Agar M. Doctoral Thesis: Improving the safety and quality of

prescribing for aged care residents with advanced dementia;

Agar M. and Lovell M. Doctoral Thesis: Delirium prevalence.

practice and systems in NSW palliative care setting; University

Agar M. Doctoral Thesis: Symptom clusters in palliative care:

patients' experiences and their patterns of care; University of

Best M. How should the Biblical teaching that humans are

created in God's image affect our understanding of the

concept of 'personhood' in bioethics, and what are the

Agar M. Master of Medicine; University of Sydney

MacLeod R. Doctoral Thesis: A rural perspective on quality end of life care; Australian National University

Poulos CJ. Doctoral Thesis: Early rehabilitation after acute injury or illness; University of NSW

Poulos CJ. Mater of Public Health, Thesis: *What is the impact* on efficiency, capacity and patient outcomes of "in reachto acute" rehabilitation models of care to the health care system? University of NSW

Poulos CJ. Independent Learning Project (ILP) MBBS student supervisor, Thesis: Effect of the Auditory Environment on Choices about Community Activities Undertaken by Older Adults, University of NSW

Siddall PJ. Doctoral Thesis: Central sensitisation in visceral and somatic pain; University of Sydney

Stevenson J. Doctoral Thesis: The effect of the CM model of psychotherapy on mother/infant interaction in mothers with borderline personality disorder; University of Sydney

Academic Conference+Industry Seminars

White, KM. **Agar M.** Currow, D. *Feasibility of measurement of function in advanced cancer: Comparison of the 6-minute walk test, 2-minute walk test, isometric arm exercises and reading numbers aloud.* World Conference on Lung Cancer, Sydney, Australia, October 27-30th 2013

Marston C, **Agar M**, and Brown T. *Patients' and carers'* perceptions of the occupational therapy role in facilitating discharge from an inpatient setting. 12th Australian Palliative Care conference, Canberra 2-6 Sept 2013

McCaffrey N, **Agar M**, Harlum J, Karnon J, Currow D, and Eckermann S. *Is community palliative care cost effective? Economic evaluation of the Australian Palliative Extended Care at Home (PEACH) pilot*. 12th Australian Palliative Care conference, Canberra 2-6 Sept 2013

Crawford G, **Agar M**, Quinn S, Phillips J, Litster C, Michael N, Doogue M, Rowett D, Currow D. *Pharmacovigilance in hospice/palliative care: net effect of haloperidol for delirium.* 12th Australian Palliative Care conference, Canberra 2-6 Sept 2013

Agar M and **Hosie A**. *Recognising, assessing and managing delirium in palliative care populations* (invited workshop), Palliative Care Nurses Australia Conference, April Sydney 2014

Currow D, Quinn S, **Agar M**, Fazekas B, Hardy J, McCaffrey N, Eckermann S, Abernethy A and Clark K. *Double-blind*, placebo-controlled, randomized trial of octreotide for malignant bowel obstruction. Oral Presentation. Australian and New Zealand Society of Palliative Medicine Conference, Gold Coast September 2014

Sanderson C, Quinn S, **Agar M**, Chye R, Clark K, Doogue M, Fazekas B, Lee J, **Lovell M**, Rowett D, Spruyt O, and Currow D. *Pharmacovigilance in hospice/palliative care: net effect of gabapentin for neuropathic pain.* Oral Presentation. Australian and New Zealand Society of Palliative Medicine Conference, Gold Coast September 2014

Best M. Do patients want doctors to talk about spirituality? Postgraduate Cancer Research Symposium, University of Sydney. 29 November 2013.

Best M. Spiritual support of cancer patients and the role of the doctor. IPOS 15th World Congress of Psycho-Oncology, Amsterdam, The Netherlands. 8 November 2013.

Best M. Suffering in cancer – conceptualization, assessment and interventions. IPOS 15th World Congress of Psycho-Oncology. Rotterdam, The Netherlands. 8 November 2013.

Best M. *If euthanasia is the answer, what is the problem?*RE: THINKING a public faith conference. Sydney. 18-20 March 2014

Best M. *The truth about contraceptives.* The Gospel Coalition Women's Conference, Orlando Florida, USA. 28 June 2014

Best M. Screening in normal pregnancy. The Gospel Coalition Women's Conference, Orlando Florida, USA. 28 June 2014

Best M, Butow P, Olver I. *Do cancer patients want spiritual care from their doctors?* ANZSPM Conference. Gold Coast, Queensland. 3 September 2014.

Best M, Aldridge L, Butow P, Olver I, Price M, Webster F. *Conceptualisation of suffering in cancer – a systematic review.* ANZSPM Conference. Gold Coast, Queensland. 3 September 2014.

Birch MR, Luckett T, Davidson P, Green A, Marie N, Stubbs J, Phillips J, **Agar M** and Boyle F. *Pain management can be achieved with commitment and support*. Palliative Care NSW State conference, Sydney October 2014

Buhagiar M. Investigating elements of post-operative rehabilitation for total knee replacement: effectiveness, considerations and controversies. Three Minute Thesis Competition (Winner), Ingham Institute 8th Annual research and Teaching Showcase 2013, Thomas and Rachel Moore Centre, Liverpool Hospital, 29th November 2013

Buhagiar M. Meandering along the path of PhD undertaking, trial management, job juggling and family: a fantasised, uncontrolled trail?, 3rd SWSLHD Allied Health Research Forum, Thomas and Rachel Moore Centre, Liverpool: 13th September 2013

Clayton JM. Invited keynote presentation on *Recommendations for discussing advance care planning with patients and families*, Annual Scientific Meeting, Hong Kong Society of Palliative Medicine, Hong Kong, 28th November 2014.

Clayton JM, Detering K. Invited keynote presentations and workshop facilitation for 2 day workshop on advance care planning for the Hong Kong Hospital Authority, Hong Kong, 26th to 27th November 2014

Clayton JM. Facilitator and oral presentation for Palliative Care Communication Skills Training workshop for Shanghai Municipal Bureau Delegation convened by HammondCare, February 27th February 2014

Clayton JM. Expert panel member and presenter on palliative care, Multidisciplinary Lung Cancer Care Workshop, Basic Sciences in Oncology Course, Sydney, 25th July 2014

Clayton JM. Facilitator and speaker at Advance care planning communication skills training for oncology nurses workshop, University of Sydney, 20th February 2014

Clayton JM. Communication skills in dealing with the threat of death, Physical & Mental Health Interface Conference, The 6th St. Vincent's Mental Health & University of Melbourne Conference in conjunction with Swinburne University, Friday 22nd November 2013, Melbourne

Clayton JM. A case of attempted suicide of a palliative care patient and the medico-legal and ethical issues in the subsequent management, Physical & Mental Health Interface Conference, The 6th St. Vincent's Mental Health & University of Melbourne Conference in conjunction with Swinburne University, Friday 22nd November 2013, Melbourne

Clayton JM. End of life discussions – evidence-based communication, 15th World Conference on Lung Cancer, Sydney, 29th October 2013

Brandes K, Butow P, **Clayton J**, Davidson P, Young J, Epstein R, Walczak A. *Metastatic cancer patients' and care-givers' use of an intervention on interpersonal communication regarding end-of-life issues*. International Communication Association, Seattle, USA, May 2014

Shaw J, Price M, Thien T, Grimison P, **Clayton J**, Rankin N, Shaw T, Butow P. *Development of clinical pathways for anxiety and depression for patients with cancer in Australia:* A Delphi Consensus Study. 16th World Congress of Psycho – Oncology, Lisbon 20-24th October 2014

Michael N, O'Callaghan C, Gough K, Krishnasamy M, **Clayton J**. *A phase 2 study of a patient and family centred advance care planning intervention for cancer patients*. Australian and New Zealand Society of Palliative Medicine Conference, September 2014

Cheang F, Finnegan T, Stewart C, Hession A, **Clayton J**. *A* single-centre audit of advance care planning among elderly inpatients. Inaugural Annual International Conference on Ethics, Capacity and Abuse Prevention, Hong Kong, September 2014.

Sellars M, Luckett T, Tieman J, Pollock CA, Silvester W, Butow PN, Detering KM, Brennan F, **Clayton JM**. *Advance Care Planning for adults with chronic kidney disease: A systematic integrative review*. Australian and New Zealand Society of Nephrology 50th Annual Scientific meeting, Melbourne, August 2014

Cole A. *Intensive Rehabilitation in Stroke,* International Society of Physical Medicine & Rehabilitation, Eighth Assembly, Cancun, Mexico; 03 June 2014

Cunningham C. What is quality dementia care? Jockey Club Centre for positive ageing Symposium on Dementia Care in Old Age Home, Hong Kong, 22nd November 2013

Cunningham C. Why design matters, the Australian experience in HammondCare; Night time design environments, what we don't know; University of Salford Oral Presentations; 20 January 2014

Cunningham C. Keynote presentation: *Perseverance in pain management: the road less travelled;* 2014 Risky Business 2 – International Dementia Conference Sydney, Australia – 26-28 June 2014

Dong S, Butow P, Tong A, **Lovell M**, **Agar M**. Poster presentation: *Longing for an end to the emotional rollercoaster: patients' experiences of multiple symptoms in advanced cancer.* International Psycho-oncology Society Conference Oct 2014

Dong S, Butow P, Tong A, **Agar M**, **Lovell M**. Poster presentation: *Finding the balance between art and science: healthcare providers' perspectives on multiple symptoms in advanced cancer.* International Psycho-oncology Society Conference Oct 2014

Downes J, Buhagiar M and **Shaik A**. *Providing quality clinical placements to allied health students in palliative care:* NSW Palliative Care state conference; Oct 2014

Duggan N. From concept to operation: Delivering an aged care service designed for people with dementia; University of Salford; 20 January 2014

Duggan N. From concept to operation: Delivering an aged care service designed for people with dementia; University of Ulster; 27 January 2014

Forster B, Proskurin H, Kelly B, Lovell M, Ilchef R, Clayton J. Psychiatry registrars' views and educational needs regarding the care of patients with life limiting illnesses. Clinical Oncological Society of Australia Conference, December 2014

Gresham M. Dementia Interventions to Maximise Function, Flinders University Department of Rehabilitation, Repatriation General Hospital, Daw Park Adelaide, June 2014

Gresham M. Technology, Toilets and Taboos. The use of the electronic wash and dry bidet in aged care; Risky Business 2 Sydney; 26th June 2014

Gresham M, Closing the loop- partnering in translation, dissemination and implementation, NHMRC Cognitive Decline Partnership Centre Annual Meeting, Melbourne, Victoria; 10th November 2014

Gresham M. Improving the toileting experience for older people in nursing homes: A feasibility study of the electronic bidet in residential aged care; ImagIneU: creating the Future Conference. Faculty of Health Sciences, University of Sydney. Awarded second place for best oral presentation, ImagIneU: creating the Future Conference. Faculty of Health Sciences, University of Sydney 3-5th November, 2014

Gresham M. The electronic bidet in aged care, Presentation for visiting delegation from Singapore Ministry of Health to HammondCare. Miranda, NSW; 17 September 2014

Gresham M. Poster presentation: When the researchers leave... A personal reflection on translating evidence in to everyday practice; and 'lightening bolt' presentation. Dementia Collaborative Research Centre Forum, Wesley Centre Sydney, September 2014

Harkin D, Poulos CJ, Beattie E, Gresham M. A tale of two carers - resilient and challenged: understanding what factors can influence carer wellness. 8th National Dementia Research Forum, Dementia Collaborative Research Centres, Brisbane, September 21st – 22nd 2013

Harkin D, Poulos CJ, Beattie E, Gresham M. Between a rock and a hard place - being a carer for a person with dementia who lives alone. International Dementia Conference 2014, Sydney, 26th – 27th June 2014.

Hosie A, Phillips J, **Agar M**, Lobb E, and Davidson P. *Exploring recognition and assessment of delirium symptoms by palliative care nurses: A qualitative study.* 12th Australian Palliative Care conference, Canberra 2-6 Sept 2013

Academic Conference+Industry Seminars

Hosie A, Bush S, Lawlor P, Weckmann M, Phillips J, **Agar M**. *Interdisciplinary management of delirium in palliative care: collaboratively building the evidence base* (invited workshop). 4th Annual Meeting of the American Delirium Society, Baltimore, June 1 – 3 2014

Hosie A, Davidson PM, Agar M, Lobb E, & Phillips J.

Nurse perceptions of barriers and enablers to recognition and assessment of palliative care inpatients' symptoms of delirium: a qualitative study, Delirium Clinical and Research Day (DECLARED), Melbourne Australia, May 2014

Hosie A, Davidson PM, Agar M, Lobb E, & Phillips J. Barriers and enablers to palliative care nurse recognition and assessment of inpatients' delirium symptoms: a qualitative study, PCNA Conference, Sydney Australia, April 6-7th 2014

Mendonca R; Velitchko T; **Kohler F**, Xu J. Assessing Sensitivity to Change of the ICF Brief Core Set for geriatric patients in acute rehabilitation; 21st ASM AFRM, Sydney, 17-20th September 2013

Xu J, **Kohler F**, Dickson H. *Patient perspective: Functioning Disability and participation restriction following lower limb amputation;* 21st ASM AFRM, Sydney, 17-20th September 2013

Gupta N, Rahakrishnan S, **Kohler F.** Sensitivity and reliability of stroke ICF core set in the acute setting; 21st ASM AFRM, Sydney, 17-20th September 2013

Kohler F. Summary of progress in the development of *ICF* assessment tools. Hannover Medical University, 13th November 2013

Kohler F. Presentation 1: Introduction to the ICF and the ICF mobility assessment tool project; Presentation 2: Outline of the ICF mobility assessment tool project; Presentation 3: The literature review and findings; Presentation 4: The expert survey and results; Presentation 5: The patient survey and results; Presentation 6: The ICF as an assessment tool; Presentation 7: The collated ICF categories for the development of the ICF assessment tool; Presentation 8: Version 1 of ICF mobility assessment tool (IBMAT); IBMAT (ICF Based Mobility Assessment Tool) consensus conference; Shanghai, P.R.China; 9th February to 11th February 2014

Kohler F. Looking outside: Road Safety: A global perspective; 13th NSW Brain Injury Rehabilitation Program Forum Participation: Making it Happen 5th – 7th March 2014

Kohler F. Challenges of implementing the ICF in routine clinical practice, Experiences from Australia Functioning in health information systems, Spring Lecture Series, Faculty of Humanities and Social Sciences, Department Health Sciences and Health Policy, University of Lucerne, 14th May 2014

Kohler F. 1: Introduction to the ICF and the ICF mobility assessment tool project Presentation 2: Provision with assistive technology, The functioning approach; OT World 2014 World Congress Leipzig Germany, 13-16 May 2014

Kohler F. Posters: Mobility in Patients with Lower extremity amputations: Using the ICF to Quantify Expert views; Rehabilitation for people with visual impairment: A case report describing the particular challenges in the rehabilitation of cortical blindness. (co-author first author Anderson C from Braeside) 22nd Annual Scientific Meeting of the Australasian Faculty of Rehabilitation Medicine: Off the grid Adelaide, 9-13 September 2014

Phillips J, **Lovell MR**, Stubbs J. *Improving Cancer Pain Outcomes Cancer Nurses Society of Australia* 16th Winter congress Brisbane, July 2013

Lovell MR, Agar M, Luckett, T, Phillips J, Boyle FM, **Clayton JM**, Green A, Davidson PM. *Implementation Forum for Cancer Pain Assessment and Management guideline*. 12th Australian
Palliative Care Conference, Canberra, September 2013

Lovell MR. *Cancer Pain Management*. Hospice New Zealand Palliative Care lecture series. November 2013

Lovell MR. Phillips J. Cancer Pain Management for Advanced trainees. Sydney Institute of Palliative Medicine, October 2013

Lovell MR. Cancer Pain Management. Royal Australasian College of Physicians, Chapter of Palliative Medicine Advanced Trainee Day. Canberra, Sept 2013

Lovell MR, Agar M, Luckett T, Chapman M, Chye R, Clark K, **Clayton J**, Davidson P, Hardy J, Lee J, Liauw W, Lobb E, Noble B, Pene C, Phillips J, Sanderson C, Xuan W. Invitation to participate in *ImPaCCT - the New South Wales clinical studies collaborative in palliative care*. Palliative Care NSW Conference, Sydney, October 2014

Lovell MR, Luckett T, Phillips JL, **Agar M**, Boyle F, Stubbs J, **Birch M-R**, Green A, Marie N, Davidson PM. *A systems approach to improving cancer pain management.* Cancer treatment and care innovations conference. Sydney, October 2014

Lovell MR, Birch MR, Luckett T, Davidson PM, Stubbs J, Phillips J, **Agar M**, Boyle F, Spruyt O. *Pilot of pain indicator audit tool as part of a complex intervention to improve cancer pain outcomes*. Melbourne, World Cancer Congress, 2014.

Lovell MR. Cancer pain – closing the evidence practice gap. Invited presentation. Clinical Oncological Society of Australia Melbourne 2014

Lovell MR, Birch MR, Luckett T, Davidson PM, Green A, Marie N, Stubbs J, Phillips J, **Agar M**, Boyle F. *Pain management can be achieved with commitment and support*. Palliative Care NSW Conference. October 2014.

Lovell MR, Luckett T, Phillips, JL, **Agar M**, Boyle F, Stubbs J, **Birch MR**, Green A, Marie N, Davidson PM. Poster: *A systems approach to improving cancer pain management*. Cancer Treatment and Care Innovations Conference Sydney Sept 2014

MacLeod. R, *Models of Care and Strategies to Provide Early Palliative Care Delivery*, New Zealand International Palliative Care Network Conference http://www.pcn-e.com/community, August 2013

Lambie D, Walker S, Egan R, **MacLeod R**. *Colouring outside the lines*, 2013 Teaching About Spirituality in New Zealand Medical Schools. Prague, Czech Republic. August 2013

Keogh J, Krägeloh C, Shepherd D, Ryan C, Masters J, Osborne S, **MacLeod R**. Poster presentation, *A cross-sectional comparison of quality of life between physically active and under-active men with prostate cancer*. 14th Australasian Prostate Cancer Conference and Prostate Cancer World Congress. Melbourne, August 2013

MacLeod R. *The nature of suffering*. Grand round – Royal North Shore Hospital. Sydney, June 2014

MacLeod R. Please connect with me – I'm still here. Exploring spirituality and dementia. St George Hospital, Kogarah NSW May 30 2014

MacLeod R. End of life care in the community. Sydney North Shore and Beaches Medicare Local, Kogarah, NSW May 27 2014

MacLeod R. *Exploring spirituality and dementia*, St George Hospital Annual Seminar, Sydney. May 2014

MacLeod R. Assisted dying – dilemmas for the health professional, ANZSPM Palliative Medicine Specialist Trainee Day, Sydney May 2014

MacLeod R. Maintaining a balance (surviving and thriving), 7th annual advanced trainee oncology and haematology meeting (ATOM) Sydney, February 2014

MacLeod R. Difficult conversations with patients and families, 7th annual advanced trainee oncology and haematology meeting (ATOM) Sydney, February 2014

MacLeod R. How do you do it? Caring to the end, Risky Business 2: This time it's personal, Sydney, June 2014

MacLeod R. End of life care issues, SE Sydney Medicare Local, Kogarah, NSW March 26 2014

MacLeod R. *Difficult conversations*, 7th Annual Advanced Trainee Oncology and Haematology Meeting (ATOM) Darling Harbour, Sydney. February 2014

MacLeod R. *Palliative care and people with dementia.*Parliamentary Friends End of Life Group, Federal Parliament, Canberra. February 2014

MacLeod R. Ethical issues in end of life care and Spirituality in end of life care. Workshop for delegation from Shanghai Municipal Health Bureau, February 2014

MacLeod R, How to support palliative care in the home. How to support those who expressly wish to die at home. Corowa, NSW February 18 2014

MacLeod R. *Not just a pain in the neck.* 67th Annual General and Scientific Meeting of the NZ Society of Otolaryngology – Head & Neck surgery. Rotorua, New Zealand. October 2014

MacLeod R, Wilson, D. M, Woytowich, B., & Houtekkier, D. Bereavement grief: a mixed-methods exploratory study focused on perceived death quality. Canadian Association on Gerontology 43rd Annual Scientific and Educational Meeting, Niagara Falls, ON October 2014

MacLeod R. The Palliative Care Home Support Program: Creating partnerships, improving connections and supporting the choice to die at home. 21st Hospice NZ Palliative Care Conference. Wellington, October 2014

MacLeod R. Caring to the end. How do you do it? 21st Hospice NZ Palliative Care Conference. Wellington, October 2014

MacLeod R, Morgan A, Egan R, Crombie R, Schumacher M. Spiritual care is a core component of palliative care so how do we ensure this vital domain of care is incorporated into clinical practice? 21st Hospice NZ Palliative Care Conference, Wellington, October 2014

MacLeod R. HammondCare's Palliative Care Home Support program; Last Days. ABC documentary film presentation. 21st Hospice NZ Palliative Care Conference. Wellington, October 2014

MacLeod R, Wilson DM, Woytowich B, Houttekier D. Bereavement Grief - A Mixed-methods Exploratory Study Focused on Perceived Death Quality, Canadian Association on Gerontology: Landscapes of aging. Niagara Falls, Ontario, October 2014

MacLeod R. What should palliative care mean? UNSW Management of aged care services course. Sydney, October 2014

MacLeod R. *The Palliative Care Bridge*. Agency for Clinical Innovation – Service Development Officers meeting. Sydney, November 2014

MacLeod R. Hope near the end of life. Royal North Shore Hospital - Basic Physician Trainees. Sydney, October 2014

MacLeod R. *Palliative care development: a snapshot.* WNSWLHD End of life and palliative care planning clinical services. Dubbo, NSW, September 2014

MacLeod R. *End of life symptoms and management*. North Shore Private Hospital, Oncology Study Day Sydney, August 2014

Academic Conference+Industry Seminars

MacLeod R, Lambie D, Walker S, Egan R. *Teaching About Spirituality in New Zealand Medical Schools*. 10th Palliative Care Congress Harrogate, England, March 2014

MacLeod R, Rogers ES, Sasidharan R, Sequeira GM, Wood MR, Bird SP, Arroll B, Stewart J, Keogh JWL. Poster presentation; *Precision Medicine in Cancer Care.* "ACCERT: Auckland's cancer cachexia evaluating resistance training study" European Society for Medical Oncology, Madrid Spain, September 2014

McCabe R, Murray R, Corbett M, Lovell M, Siddall P. Poster presentation: Addressing spiritual and existential factors in the context of chronic pain: outcomes of the Greenwich pain program. International Association for the Study of Pain Meeting, Argentina. October 2014

McVey P, MacLeod RD, White K. Quality end-of-life care in residential aged care settings: a review of current practices. 5th Biennial Palliative Care Nurses Australia Conference, Sydney, April 2014

McIntosh D. Food glorious food. Concurrent Session speaker at HammondCare's International Dementia Conference, Sydney, 26-27 June 2014

McIntosh D. Creating enabling environments: Stories of success. Presentation at Universal Design Conference, Sydney, 21 August 2014.

McIntosh D. Good design: We know what we want but how do we get it?; Presentation at New Zealand Aged Care Association Conference, Wellington, 16 October 2014

McIntosh D. *Using the building blocks of today: refurbishing interiors that enable*. Presentation at New Zealand Aged Care Association Conference, Wellington, 16 October 2014.

McIntosh D. *Night time care*. Presentation at New Zealand Aged Care Association Conference, Wellington, 17 October 2014

McIntosh D. Streeton and beyond: stories of need and care in younger people with dementia. Aged Care Quality Agency better Practice Conference, Hobart, 20 November 2014

Poulos CJ, Harkin D, Beattie E, Gresham M. Practical Impacts of caring: the lived experience of dementia carers - Lessons still to learn. 8th National Dementia Research Forum, Dementia Collaborative Research Centres, Brisbane, September 21st – 22nd 2013,

Poulos CJ, Harkin D, Beattie E, **Gresham M**. *Understanding the Wellness Needs of Family Caregivers of People with Dementia*. International Conference on Aging and Society. Chicago. 8th – 9th November 2013

Poulos CJ, Harkin D, Beattie E, **Gresham M**. *Discords in families - supporting carers with family education*. International Dementia Conference 2014, Sydney, 26th – 27th June 2014

Poulos CJ. How good is good enough for the elderly? Positive ageing in the nursing home sector. Equity in disease prevention: vaccines for the elderly NHMRC Centre of Research Excellence in Population Health Research. Melbourne, 20th June 2014

Poulos CJ. *Inspiring Positive Ageing*. Plenary Panel. National Retirement Living Summit, Sydney, 19th-20th November 2014

Radhakrishnan S, Kohler F. Review of mobility concepts concerning persons with lower limb amputation using ICF framework; 21st ASM AFRM, Sydney, 17-20th September 2013

Rhee J, Mitchell G, Senior H, Teo CK, Clayton J. Prediction of death in general practice: a cluster randomised controlled study. The RACGP conference for General Practice, Adelaide, October 2014

Robertson, M. *Dying Time: people in palliative care describe experiences of time*, 10th International Conference on Grief and Bereavement in Contemporary Society, University of Hong Kong, 10-13 June 2014

Siddall PJ. Pain Management in the Person with Dementia, Specialist Mental Health Services for Older People Benchmarking Forum, Sydney, July 2013

Siddall PJ. *The Pain of It All*, 14th HammondCare Annual Palliative Care Seminar, October 2013, Sydney

Siddall PJ. *Early outcomes from a Tier 2 pain service*, NSW Agency for Clinical Innovation Pain Management Network Workshop, Sydney, November 2013

Siddall PJ. A Holistic Approach to Pain Management: Covering all Bases - Fifty Shades of Pain, Keynote lecture, Pain and Palliative Care Conference, Brisbane, November 2014

Siddall PJ, Asghari A, **Corbett M, Lovell, M, McCabe R**, Danially H, Akbarzade G, Farajzadegan Z. Poster: *A comparison of levels of spiritual distress in Iranian and Australian people with chronic pain*. International Association for the Study of Pain Meeting, Argentina October 2014

Stevenson J. Halliburn J. *An outcome study of* psychodynamic psychotherapy in patients with treatment-resistant depression. International Psychiatry Conference, Gold Coast, Queensland, Oct 2013

Stevenson J. *CBT, dementia and depression*, Changsha, China, April 2014

Stevenson J. *Depression, dementia, psychotherapy;* Shenyang, China, April 2014

Yule S, MacLeod RD. The Palliative Care Home Support Program: Creating partnerships, improving connections and supporting the choice to die at home. Palliative Care NSW State Conference. Sydney, October 2014



It is our experience that a person who has a life limiting illness may say, "I would like to die at home", and their family members may say "I would like to support you in that, but I'm not sure how it will be and I'm a bit nervous about that..." So how do we help the person and their family to know what to expect? And how to help the family to support their loved one?



Journal Articles

Lawlor P, Bush S, Ansari M, Kanji S, Momoli F, Hartwick M, Pereira J, Marchington K, Barnes C, Bratjman S, Wright D, Gagnon P, Gagnon B, Nekolaichuk C, **Agar M**. Bruera E. 2014 *Pursuing knowledge synthesis, consensus and collaboration regarding delirium research: An overview of the SUNDIPS (Studies to understand delirium in palliative settings) program.* Palliative Medicine. 2014; 28 (6), p 647 abstract P97. 8th World Congress of the European Association for Palliative Care. Lleida, Spain June 4- 6 2014

Smith T, **Agar M**, Jenkins C, Ingham J and Davidson P. 2014 *Non-Invasive Ventilation: Better Than You Think-Insights From 'Behind The Mask'*. Respirology Vol19; Issue S2: p99. Thoracic Society of Australia & New Zealand and the Australian & New Zealand Society of Respiratory Science 2014 Annual Scientific Meetings, Adelaide Convention Centre, Adelaide, SA, 4-9 April 2014

Smith T, Dunford M, Clarke E, **Agar M**, Davidson P, Piza M, Jenkins C, Ingham J. 2014 *Symptom Burden and Delirium Prevalence in Patients Undergoing Acute Non-Invasive Ventilation. Respirology Vol19;* Issue S2: p98. Thoracic Society of Australia & New Zealand and the Australian & New Zealand Society of Respiratory Science Annual Scientific Meeting, Adelaide Convention Centre, Adelaide, SA, 4-9 April 2014

Currow D, Quinn S, **Agar M**, Fazekas B, Hardy J, McCaffrey N, Eckermann S, Abernethy A and Clark K. 2014 *Double-blind, placebo-controlled, randomized trial of octreotide for malignant bowel obstruction*. Journal of Pain and Symptom Management. Accepted for publication 23rd September 2014.

Sanderson C, Quinn S, **Agar M**, Chye R, Clark K, Doogue M, Fazekas B, Lee J, **Lovell M**, Rowett D, Spruyt O, and Currow D. 2015 *Pharmacovigilance in hospice/palliative care: net effect of gabapentin for neuropathic pain*. BMJ Supportive & Palliative Care. Accepted 10th September 2014

To T, **Agar M**, Yates P, Currow D. 2014 *Prescribing for nausea in palliative care: a cross-sectional national survey of Australian palliative medicine doctors*. Journal of Palliative Medicine. 2014. Epub ahead of print. 10.1089/jpm.2013.0610

Virdun C, Brown N, Phillips J, Luckett T, Green A, Davidson PM, **Agar M**. 2014 *Elements of optimal paediatric palliative care for children and young people: An integrative review using a systematic approach*. Collegian, 2014. Epub ahead of print Received: April 3, 2014; Received in revised form: July 2, 2014; Accepted: July 4, 2014; Published Online: August 08, 2014 http://dx.doi.org/10.1016/j.colegn.2014.07.001

Yamaguchi T, Kuriya M, Morita T, **Agar M**, Choi YS, Goh C, Lingegowda KB, Lim R, Liu R, **MacLeod R**, Ocampo R, Cheng S, Phungrassami T, Nguyen Y, and Tsuneto S. 2013 *Palliative care development in the Asia-Pacific region: an international survey from the Asia Pacific Hospice Palliative Care Network* (APHN).https://www.researchgate.net/publication/263896099—Palliative_care_development_in_the_AsiaPacific_region_an_international_survey_from_the_Asia_Pacific_Hospice_Palliative_Care_Network_%28APHN%29?ev=prf_pub> BMJ Support Palliat Care. 2014 Jul 10. pii: bmjspcare-2013-000588. doi: 10.1136/bmjspcare-2013-000588.

Bush S, Leonard M, **Agar M**, Spiller J, **Hosie A**, Wright D, Meagher D, Currow D, Bruera E and Lawlor P. 2014 *End of Life delirium: issues regarding recognition, optimal management and the role of sedation in the dying phase. <i>Journal of Pain and Symptom Management*. Accepted 21st May 2014.

Vardy J and **Agar M**. 2014 Should corticosteroids be used for the treatment of pain, fatigue and loss of appetite in cancer patients receiving opioids? Journal of Clinical Oncology Podcast. Accepted 21st May 2014

Leonard MM, Nekolaichuk C, Meagher DJ, Barnes C, Gaudreau JD, Watanabe S, **Agar M**, Bush SH, Lawlor PG. 2014 *Practical Assessment of Delirium in Palliative Care*. J Pain Symptom Manage. 48(2):176-90

Clark K, Lam L, Currow D, **Agar M**. 2014 *A prospective study to investigate contributory factors that lead to constipation*. Journal of Pain and Symptom Management. epub ahead of print. March 28 2014. DOI: http://dx.doi.org/10.1016/j. jpainsymman.2014.01.005

Luckett T, Phillips J, **Agar M**, Virdun C, Green A, Davidson PM. 2014 *Elements of effective palliative care models: a rapid review*. BMC Health Services Research.2014, 14:136 DOI: 10.1186/1472-6963-14-136

Best M, Butow P, Olver I. 2014 *The doctor's role in helping dying patients with cancer achieve peace: A qualitative study*. Palliative Medicine. 2014 Oct; 28(9):1139-45. doi: 10.1177/0269216314536455. Epub 2014 Jun 9.

Best M, Butow P and Olver I. 2014 *Spiritual support of cancer patients and the role of the doctor*. Supportive Care in Cancer. 2014; 22: 1333-9

Best M, Aldridge L, Butow P, Olver I, Price M, Webster F. 2014 Assessment of spiritual suffering in the cancer context: A systematic literature review. Palliative Support Care. 2014:1-27

Buhagiar M, Naylor J, Harris I, Xuan W. 2014 *Does inpatient* or clinic-based rehabilitation provide superior outcomes after total knee arthroplasty when compared to a home-based program? PROSPERO 2014: CRD42014014517 (systematic review registered online. Available from http://www.crd.york. ac.uk/PROSPERO/display_record.asp?ID=CRD42014014517; October 2014

Michael N, O'Callaghan C, Baird A, Hiscock N, **Clayton JM**. 2014 *Cancer caregivers advocate a patient- and family-centred approach to advance care planning*. Journal of Pain & Symptom Management (Impact Factor 2.60) June 2014; 47 (6): 1064-77

Walczak A, Butow PN, **Clayton JM**, Tattersall MHN, Davidson PM, Young J, Epstein RM. 2014 *Discussing prognosis* and end-of-life care in the final year of life: A randomised controlled trial of a nurse-led communication support program for patients and caregivers. BMJ Open. 2014 Jun 29; 4(6):e005745. doi: 10.1136/bmjopen-2014-005745. PMID: 24969786

Smith TA, Kim M, Piza M, Davison PM, Clayton JM, Jenkins CR, Ingham JM. 2014 Specialist respiratory physicians' attitudes to and practice of advance care planning in COPD. A pilot study. Respiratory Medicine (Impact Factor 2.585) June 2014: 108(6): 935-939

Luckett T, Sellars M, Tieman J, Pollock C, Silvester W, Butow PN, Detering K, Brennan F, **Clayton JM**. 2014 *Advance Care Planning for adults with chronic kidney disease: A systematic integrative review*. American Journal of Kidney Disease (Impact Factor 5.294), May 2014 63(5):761-770 (associated editorial and highlighted in this month in AJKD)

Clayton JM, Silvester W, Pollock CA. 2014 In Reply to 'Decisions about dialysis and other life-sustaining treatments should not be made separately' (letter to editor). American Journal Kidney Disease (Impact Factor 5.294) Nov 2014; 64 (5): 817.

Brandes K, Butow PN, Tattersall MHN, **Clayton JM**, Davidson PM, Young J, Epstein RM, Walczak A. 2014 *Advanced cancer patients' and caregivers' use of a question prompt list*. Patient Education and Counselling (Impact Factor 2.37), Oct 2014; 97(1): 30-7.

Walczak A, Henselmans I, Tattersall MHN, **Clayton JM**, Davidson PM, Young J, Bellemore FA, Epstein RM, Butow PN. 2014 *A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program Psycho-Oncology*, 2014 Jul 30. doi: 10.1002/pon.3635. [Epub ahead of print] PMID: 25079976

Wiese M, Stancliffe R, Read S, Jeltes G, **Clayton JM**. 2014 Learning about dying, death and end-of-life planning: current issues and future actions. IN PRESS Journal of Intellectual & Developmental Disability (Impact Factor 1.02), accepted November 2014

Simpson PL, Scicluna HA, Jones PD, **Cole AM**, O'Sullivan AJ, Harris PG, Velan G, McNeil HP. 2014 *Predictive validity of a new integrated selection process for medical school admission*. BMC Medical Education, 14:86 (23 Apr 2014) http://www.biomedcentral.com/1472-6920/14/86

Strand MA, **Cole AM**. 2014 *Framing the Role of Christians in Global Health;* Christian Journal of Global Health 1 (2); 7-15.

Cunningham C. *Confronting the reality of pain;* Australian Ageing Agenda Title; January – February 2014:

Cunningham C. A Constant Companion; Australian Ageing Agenda Title: January – February 2014

Dong S, Butow P, Costa D, **Lovell M**. 2014 *Symptom clusters in patients with advanced cancer. A systematic review of observational studies*. Journal of Pain Symptom Management. 2014. 48 (3). 411-450.

Gresham M, Tsang, R. Heffernan, M. Brodaty, H. 2014 *Study* protocol of the Going to Stay at Home program: evaluation of a residential carer training program to reduce dementia carer distress and burden. *SpringerPlus*, vol. 3, pp. 330, http://dx.doi.org/10.1186/2193-1801-3-330

Gresham M. 2014 Occupational Therapy and late-life depression- a chasm between practice and evidence? International Psychogeriatric Association Bulletin. Volume 31 (2) 5-7

Cheang F, Finnegan T, **Hession A, Clayton JM**. A Single-Centre Cross-Sectional Analysis of Advance Care Planning among Elderly Inpatients. Internal Medicine Journal; Oct 2014, 44 (10): 967-74

Lawlor P, Davis D, Ansari M, **Hosie A**, Kanji S, Momoli F, Bush S, Watanabe S, Currow D, Gagnon B, **Agar M**, Bruera E, Meagher D, De Rooij S, Adamis D, Caraceni A, Marchington K, Stewart D. 2014 *An Analytic framework for delirium research in palliative care settings: integrated epidemiological, clinician-researcher, and knowledge user perspectives.* Palliative Medicine. 2014; 28 (6), p765 Abstract P345. 8th World Congress of the European Association for Palliative Care. Lleida, Spain June 4- 6 2014, epub ahead of print; Pain Symptom Manage. 2014 Aug; 48(2):159-75. doi: 10.1016/j. jpainsymman.2013.12.245. Epub 2014 Apr 12.

Hosie A, Lobb E, Agar M, Davidson PM, Phillips J. 2014 Identifying the Barriers and Enablers to Palliative Care Nurses' Recognition and Assessment of Delirium Symptoms: A Qualitative Study. Journal of Pain and Symptom Management. epub ahead of print http://www.ncbi.nlm.nih.gov/pubmed/24726761

Hosie A, Agar M, Lobb E, Davidson PM, Phillips J. 2014 Palliative care nurses' recognition and assessment of patients with delirium symptoms: A qualitative study using critical incident technique. Int J Nurs Stud. 2014. epub ahead of print Int J Nurs Stud. 2014 Oct; 51(10):1353-65. doi: 10.1016/j. ijnurstu.2014.02.005. Epub 2014 Feb 28.

Keall R, Clayton JM, Butow PN. 2014 *Australian palliative care nurses' reflections on existential/spiritual interventions*. Journal of Hospice and Palliative Nursing, April 2014; 16 (2): 105 - 112

Keall R, Clayton JM, Butow PN. 2014 *Therapeutic Life Review in Palliative Care: A Systematic Review of Quantitative Evaluations. IN PRESS* Journal of Pain and Symptom
Management, accepted August 2014.

Keall R, Clayton JM, Butow PN. 2014 *How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies*. Journal of Clinical Nursing (*Impact Factor 1.316*) Nov 2014; 23 (21-22): 3197-3205.

Keall R, Clayton JM, Butow PN. 2014 Therapeutic Life Review in Palliative Care: A Systematic Review of Quantitative Evaluations; 'In Press' in Journal of Pain and Symptom Management

Egen C, Gutenbrunner C, **Kohler F**. 2014 *Entwicklung* eines international gueltigen und ICF-basierten Assessmentinstruments zur Mobilitaetserfassung beinamputierter Menschen (Development of a mobility Assessment Tool for lower limb amputees based on the International Classification of Functioning, Disability and Health). Physikalische Medizin Rehabilitationsmedizin und Kurortmedizin 2014, 24 (3):155-157

Journal Articles

Dillon MP, **Kohler F**, Peeva V. 2014 *Incidence of lower limb amputation in Australian hospitals from 2000 to 2010* Prosthet Orthot Int 2014:38:122-132.

Leong RWL, Huang T, Ko Y, Jeon A, Chang J, **Kohler F**, 2014 Kariyawasam V. *Prospective validation study of the International Classification of Functioning, Disability and Health score on Crohn's Disease and Ulcerative Colitis*. Epub ahead of print: doi: 10.1016/j.crohns.2014.02.028

Faux SG, **Kohler F**, Mozer R, Klein LA, Courtenay S, D'Amours SK, Chapman J, Estell J. 2013 *The ROARI project – Road Accident Acute Rehabilitation Initiative: A randomised clinical trial of two targeted early interventions for road related trauma*. Clinical Rehabilitation, online before print. doi: 10.1177/0269215514552083. IF 2.180

Lovell M, Agar M, Luckett T, Davidson PM, Green A, **Clayton J.** 2013 *Australian survey of current practice and guideline use in adult cancer pain assessment and management: perspectives of palliative care physicians.* J Palliat Med. 2013 Nov;16(11):1403-9. doi: 10.1089/jpm.2013.0245. Epub 2013 Oct 29. PMID:24168350

Lovell MR, Phillips J. 2014 *Pain Assessment*. Pain Management Today, 2014 Aug; 1(2) p35-38.

Lovell MR. 2014 *Patient education, coaching and self-management for cancer pain*. Journal of Clinical Oncology, Epub ahead of print 5 May, 2014 http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2013.52.4850

Lovell MR, Phillips J. 2014 *Pain Assessment*. Pain Management Today, 2014 Aug; 1(2) p35-38.

Lovell MR, Phillips J, Luckett T, **Agar M**. *Improving Cancer Pain Management*. Submitted Internal Medical Journal; Accepted Dec 19, 2014.

Egan R, Walker R, **MacLeod R**, Tiatia, R, Wood S, Mountier J. 2014 *Spiritual care and kidney disease in NZ: a qualitative study with New Zealand renal specialists* BMJ Supportive and Palliative Care 4 Supp 1 A28 doi:10.1136/bmjspcare-2014-000654.76

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Grants, Patents-Statistics

Successful Grant Applications

Apte M, Shah R, McNeil P, De Souza P, Agar M, Kienzle N, Spring K, O'Neill S, Killingsworth M, Wang B. Major research equipment and infrastructure initiative 2014 UNSW. Circulating Tumour Cell Platform Technical Officer (2014);

Brown M, Luttrell P, Clayton J. Delivery of workshops on advance care planning and palliative care to aged care staff, working in both residential and community settings. across NSW and the ACT. Funding awarded from July 2014 to Blended Learning Approach to Supervisor Training, BLAST December 2015; \$387,600

K, Spencer L. Kidney Health Australia Grant: Investigating barriers and facilitators to advance care planning for dialysis and pre-dialysis patients Investigators; \$43,200

Cole A, Poulos C. Commonwealth Department of Health, TRACS grant extension, June 2014; \$85,000

Gresham M: The Clinical utility of the electronic bidet for Australian nursing home residents and staff; Australian Unity Heritage Fellowship Grant: \$46,167

Kohler F, Buhagiar M. Is inpatient rehabilitation necessary after knee replacement; HCF: \$140,463

Kohler F, Buhagiar M. Clinician and patient preference for rehabilitation following a total knee replacement; HCF; \$43,440

Lovell M (CI), Phillips J, Agar M, Boyle F, Davidson P, Luckett T, Currow D, Ryan L, McCaffrey N, Shaw T. 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 National Breast Cancer Foundation Grant. (2014-2018); NBCF total grant is \$939,139: Year 1: \$218,501 Year 2: \$242,694 Year 3: \$238,051 Year 4: \$239,893 (2014-2018)

Rhee J. UNSW Learning and Teaching Innovation Grant,

Clayton J, Pollock C, Luckett T, Morton R, Silvester W, Detering Rhee J, Zwar N, Clayton J, Meller A. HCF Research Foundation/RACGP Research Grant: A pilot study of a systematic patient-centred and practice nurse coordinated model of Advance Care Planning in Australian general practice; Awarded \$60,000

> Siddall PJ. Australian and New Zealand College of Anaesthetists Academic Enhancement Grant, Neurobiological, psychological and existential contributors to pain: an integrated approach; \$89,000

Inventors: P. Siddall. A. Woodhouse. P. Stanwell. C. Mountford, R. Somoriai, System and method for detecting pain and its components using magnetic resonance spectroscopy, US Patent 08755862, Granted June 17, 2014

Statistics



The Spiritual

Planning.



Education, Grants Patents

Successful Grant



80 Publications



Because death as birth, is an experience we will all share, and that with proper research and understanding, we can be at that fragile sacred space, in an informed way, to deliver the best care, evidence based, that will best meet the needs of those involved in the end of life experience.



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