

REHABILITATION, AGEING AND INDEPENDENT LIVING (RAIL) RESEARCH CENTRE

Member eBulletin #11

A message from the Director

Well, a month is a very long time at present – in the last e-bulletin a month ago Victoria was entering the very strict lockdown and curfew restrictions, with the upward trends of more than 700 new cases of Covid-19 each day. It is extremely pleasing to see the substantial improvements in case numbers (although tragically the delayed effects on death rates following on from this peak of case numbers are still very high). Despite these improvements, and the expectation of easing of restrictions to some degree in the next couple of weeks, the prolonged nature of the restrictions in Victoria continue to have significant impact on many people, and in particular many of the vulnerable people who our research aims to impact positively on.

We have all seen and heard of the major problems in the residential care sector, which are rightly in the news headlines, and under close scrutiny for what can be done now and into the future to improve this situation. There needs to be prolonged focus on this, even well beyond the direct impact of Covid-19 on the sector. Many of the problems being recognised now are reflections of long-term problems in the system, and these need to be a strong focus to be addressed going forwards.

However, there are also less obvious implications of the sustained lockdown in Victoria on the health and wellbeing of many other vulnerable groups which also warrant current and ongoing focus. For example, many frail older people living at home, or people with disabilities, who previous to March-April this year, might

have been going out (possibly with carers / family) a couple of times a week, doing a little bit of outdoors walking etc, have not had the opportunity for this for nearly six months now (as even when restrictions were easing for the majority of Victorians, many of these people were concerned about their increased risk of catching the virus, so did not resume usual activities away from home). Coupled together with the miserable Melbourne winter we have endured (I still luxuriate in the beautiful winters we had in Perth for 8 years before my return to Melbourne mid last year) which means people are not even spending time sitting outdoors in the backyard, which in itself can have some positive health benefits that they are missing out on. All of this means increased risk of things like frailty (less physical activity), osteoporosis / osteopenia (less physical activity and vitamin D exposure), social isolation (less personal visits at home and away from home – not fully addressed through increased IT based communications), depression, and even poorer temporal orientation (external anchors to days and times through regular activities / events have been lost), as well as other problems. It is important that as things open up again, that avenues for addressing these issues, and resuming where possible normal activities and engagements are facilitated as fast as possible, while continuing to have a focus on safety from risk of Covid infection.

As has been the case in recent months, I close with a screen shot of the RAIL team's most recent "virtual drinks" session, which had a "mask" theme – which attracted an interesting mix. I hope you, and your teams are also working well to ensure your own health and well-being in these challenging times.

Stay safe and well.

Professor Keith Hill



Member profile

Dr Barbara Barbosa Neves

Dr Barbara Barbosa Neves is a Senior Lecturer in Sociology at Monash University.

Barbara is a sociologist of technology, examining the links between digital and social inequalities. In particular, she studies the role of emerging technologies in later life. She bridges Sociology and Human-Computer Interaction, specializing in mixed methods and participatory approaches.



Prior to moving to Australia, she was an Associate Director at the 'Technologies for Aging Gracefully Lab' (TAGlab), [Department of Computer Science, University of Toronto](#), Canada. At TAGlab, Barbara led interdisciplinary teams designing and evaluating digital technologies with/for older people living in long-term care facilities.

Her recent research explores the role of VR and robotic companions in later life, as well as co-designed sociotechnical interventions to help tackle loneliness and social isolation among older people.

She is currently conducting a study on loneliness among older Australians living alone and the role of social technology.

Barbara's research has been awarded in North America, Japan, Europe, and Australia. In 2019, she was named by the [ABC and the University of Sydney](#) among the Top 5 Humanities and Social Science Scholars in Australia.

Her latest op-ed for the ABC, published this week, is on frail older people and their societal contributions: [“Older Australians are never disposable — not even during a pandemic”](#).

Grant success



Project with Scope Australia Ltd – Falls risk in people with intellectual disability

Keith Hill, Aislinn Lalor and Libby Callaway are undertaking a small project with a team from Scope Australia Ltd to evaluate the research literature and grey literature to identify existing falls risk assessment tools for people with intellectual disability. The team from Scope Australia Ltd include Dr Stella Koritsas (Manager Strategic Research), and three clinicians (Andrea Curran-Bennett, Rachele Zannier, and Richard Wong). People with intellectual disability have high risk of falling, however have had limited research of approaches to identify and minimise falls risk factors, or interventions to reduce their high falls risk. The project outcomes will help inform Scope Australia in working towards reducing risk of falls for their clients.

Higher degree by Research students

Lisa Knightbridge

Title: Healthy ageing through increased community participation. Developing an assessment and theoretical framework to guide occupational therapy practice.



Healthy ageing is the process of developing and maintaining the functional ability that enables well-being into older age.

An important determinant is for older people to remain physically active and socially connected, and to engage in occupations that contribute positively to their own well-being. Participation in activities in the community, such as shopping, walking in nature, neighbourhood mobility, going to clubs, arts and culture, volunteering, social activities, education and civic life are integral to life satisfaction, health and wellbeing. Research has demonstrated that an older person engaging in any form of out-of-home occupations is more engaged, independent, socially connected and physically active; has a slowed rate of functional decline; and experiences less risk for depression than one who does predominately in-home activities.

Occupational therapists are well situated to lead the field in enabling community and social participation for community dwelling older people. This research aims to develop an assessment, supported with an underpinning theoretical framework that can be used in occupational therapy practice when addressing community participation restrictions for older, community dwelling people.

Supervisors for this research are Associate Professor Helen Bourke-Taylor (Department of Occupational Therapy) and Professor Keith Hill (RAIL).

Events

Member forums

The next RAIL member forum:

The RAIL research team is pleased to announce our next member forum '**Valuing, supporting and working with carers to sustain their role**' is scheduled for 3.00pm - 4.00pm Thursday 3rd September via Zoom.

Speakers include:

- Professor Briony Dow (Director, National Ageing Research Institute) on - Unmet needs of family carers: findings from the Survey of Disability and Carers (SDAC).
- Associate Professor Susan Slatyer (Discipline of Nursing, Murdoch University) on - The Further Enabling Care at Home program: Supporting family carers of older people after hospital discharge. and
- Associate Professor Helen Bourke-Taylor (Occupational Therapy Dept, Monash University) - How can family carers improve their own health and wellbeing?: One evidence based example.

In addition, Dr Margaret Boulos (Senior Policy and research Advisor) from Carers Victoria will provide commentary at the end of the session from Carers Victoria's perspective.

RSVP: [Online](#)

VALUING, SUPPORTING AND WORKING WITH CARERS TO SUSTAIN THEIR ROLE

Professor Briony Dow, Director, National Ageing Research Institute

Unmet needs of family carers: findings from the Survey of Disability and Carers (SDAC)

Briony Dow is Director of the National Ageing Research Institute (NARI) and Honorary Professor at the School of Population and Global Health, University of Melbourne and Honorary Professor, School of Nursing and Midwifery, Deakin University. At NARI Briony oversees a range of both aged care and social and clinical gerontology research programs, including her own research into elder abuse and carer mental health.

Family (unpaid) carers provide the bulk of care for older people in Australia and are relied on as a largely unacknowledged but essential component for the government's "ageing in place" policy. Our review and analysis of the Survey of Disability and Carers (SDAC) (2015) reveals that Australian carers of older people have numerous unmet needs and this impacts on their mental health. Prof Dow will present the findings from the 2015 SDAC as well as preliminary findings from the 2018/19 SDAC, which suggest that government supports for carers are still falling short of meeting their needs.



Associate Professor Susan Slatyer, Discipline of Nursing, Murdoch University

The Further Enabling Care at Home program: Supporting family carers of older people after hospital discharge

Susan is Associate Professor of Nursing at Murdoch University, and holds nursing research consultancies at both Sir Charles Gairdner and Fiona Stanley hospitals. Her research interests focus on older person's healthcare across the care continuum and support of family caregivers. She was 2016 WA Nurse of the Year and winner of the Excellence in Research award in the 2016 WA Nursing and Midwifery Awards. This presentation will describe the development and evaluation of the Further Enabling Care at Home program, a post-discharge intervention that supports carers of older people to sustain home-based caregiving after the older person's hospital discharge.



Associate Professor Helen Bourke-Taylor, Dept of Occupational Therapy Dept, Monash University

How can family carers improve their own health and wellbeing?: One evidence based example

Helen Bourke-Taylor is an occupational therapist and associate professor in the Department of Occupational Therapy at Monash University. Helen's work with Carers has included review of the eligibility criteria for the Carer Payment and Carer Allowance for DSS, assistance with creation of online modules for carers on the Carer Gateway and analysis of the situation of young carers who apply for the Education Carer Bursary. Helen is author and facilitator of the Healthy Mothers Healthy Families program for mothers of children with disabilities.

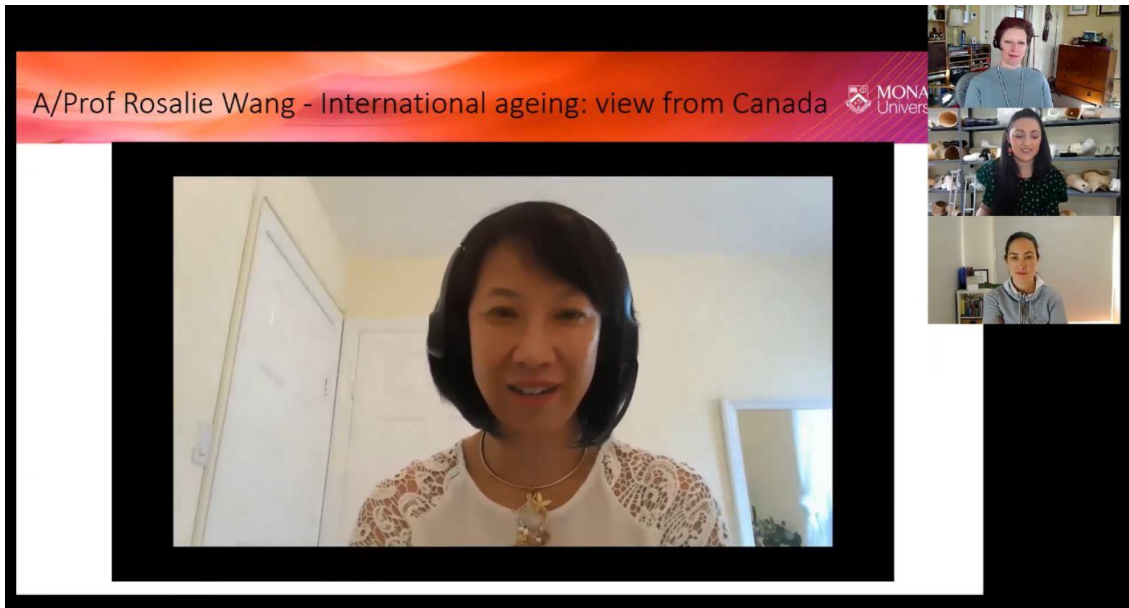


Long term family caring can have an impact on the carers' daily routines. Participation in activities that would otherwise support health and wellbeing may be chronically compromised. This presentation provides an overview of a program for mothers of children with high care needs. Nearly 300 mothers attended the program in 2018-2020. The intention of the program, training and credentialing of 7 carer facilitators, fidelity in the provision of 23 workshops and results of the pre-post-test will be described.



Commentary: Dr Margaret Boulos (Senior Policy and Research Advisor) Carers Victoria, will provide brief commentary from Carers Victoria's perspectives

International Perspectives RAIL Member Forum July - the dialogue continues.....



It was lovely to see so many RAIL members at the July 31 Forum on international perspectives. While we were fortunate to have Louise Puli our WHO speaker able to join us live, it was midnight in Canada so A/Prof Rosalie Wang provided her presentation via recording. Rosalie was discussing research networks, working with end-users, and her national project on enhancing equitable access to assistive technologies (<https://agewell-nih-appta.ca/2019/09/16/aging-disability-and-technology-access-with-dr-rosalie-wang/>).

We are pleased to report that Rosalie has had the opportunity to listen to our recorded session, and has responded to some of the discussion as follows:

Q: Citizen Panels – tell us more about this method and sample size

A: Regarding the citizen panels, we engaged 37 participants (3 panels - western, central and eastern Canada). Regarding representativeness, there is a stratification process that aims for fair representation among the diversity of citizens who may be affected by the problem (e.g. geography, age, gender, urban/suburban/rural/, with or without lived experiences, socioeconomics). We did not engage people from Indigenous communities specifically, as there are different (best) practices. See the McMaster Health Forum website for more information <https://www.mcmasterforum.org/>)

Q: In terms of translating your research, how do you go about informing a national strategy?

A: To inform our national strategy, we did do a national survey with about 1000 participants. Again, we do have the limitations of capturing those AT users/prospective users who are harder to reach. This survey is still to be written up as a paper, though our final stakeholder dialogue brief and summary will detail some of the findings. Once this is finalized, I will distribute

Q: In research, how do we ensure true 'co-design' occurs?

A: Regarding true co-design of policies and practices with AT users/caregivers, this is certainly something I am interested in pursuing and we were not able to do this yet. You may be interested also in looking at the APPTA Hub <http://agewell-nih-appta.ca/> but it might be interesting to discuss with them as well. They are doing some really neat things with policy labs with government policy advisors, so bringing together the people in government who create the policies, working to share across jurisdictions, and coming up with solutions together for problems collectively identified. Candice Pollack, the Executive Director, and her team are just an amazing lively bunch. (If I pursue this co-design avenue, I will let you know, but it's only going to be productive if we have some government stakeholders who are champions, though the charity sector seems to be really interested!)

And a final word from Rosalie: Thank you again for the invite! Looking forward to more collaborations.

Monash RAIL to host GAATO @ RESNA global assistive technology forum



What is GAATO?

The Global Alliance of Assistive Technology Organisations ([GAATO](#)) is a world body based in Geneva, Switzerland, representing global assistive technology (AT). GAATO works strategically and globally towards a world where all people can access the assistive technology they need. RAIL staff Libby Callaway and Natasha Layton support the work of GAATO through Australia's AT peak body, [ARATA](#). RAIL are proud to be working with ARATA's North American sister organisation, the Rehabilitation Engineering Society of North America (RESNA), to facilitate an online platform for the free global education event:

GAATO@RESNA Virtual Opening Forum on AT Outcomes & Impacts

Australian Eastern Standard time of 10.30 – 11.45 pm on Wednesday, 23rd Sept, 2020

The GAATO @ RESNA Opening Forum provides an opportunity for colleagues, especially from low and middle income countries, to join some of the world's leading outcomes researchers discussing the future of international outcomes research, and take part in the launching of the 2020 **GAATO AT Outcomes & Impact Initiative**

Hosted by Professor Luc de Witte, GAATO President and members of the GAATO Board, Professor Marcia Scherer & Professor Roger O. Smith will deliver the plenary address, *Different Strokes for Different Folks: Different Outcomes are Valued by Different Stakeholders* during this event.

The GAATO @ RESNA Opening Forum precedes the **GAATO AT Outcomes and Impacts Summit** held on 24 September and embedded within the RESNA Scientific Program.

How can I participate?

Register for the free GAATO@ RESNA Virtual Opening Forum [here](#) or visit the [GAATO](#) website for more details

RAIL paper of the month

“I didn’t wait for them to say go”

‘Adaptation, self-motivation and support services are key to physical activity participation three to five years after major trauma: a qualitative study’ was published by [Dr Christina Ekegren](#) (RAIL Senior Research Fellow) and colleagues this month in the Journal of Physiotherapy. This longitudinal qualitative study followed 66 participants up to five years following major trauma to investigate the perceived impacts of their injuries on physical activity participation. Despite wanting to be physically active, many participants experienced significant, long-term physical activity restriction after their injury. Restrictions were often related to a fear of re-injury or of exacerbating pain and fatigue levels. These restrictions were a source of distress and frustration for many participants, given the perceived impacts on their social life, family roles and enjoyment of life. Participants were also concerned about weight gain, health decline and reduced physical fitness. Participants valued the support of insurers and specialised services in facilitating access to modified activities, such as clinical Pilates and hydrotherapy. Many participants also recognised the importance of adaptation, goal-setting, self-motivation and determination to be physically active despite limitations.

Health Economics

The RAIL research team is presenting a 6 part mini-series on economic evaluations alongside Rehabilitation, Ageing and Independent Living (RAIL) research programs. This series will explore:

1. Economic evaluations: What are the different types?
2. Determining the perspective of an economic evaluation
3. Defining the units of health care and disability service utilisation, as well as defining the effect of the intervention
4. **The impact of the time horizon and adjusting for risk and methodological assumptions in an economic evaluation**
5. How to present results from an economic evaluation

6. How to use the results of an economic evaluation to inform health and disability service delivery and policy

Today we are reporting on Part 4: The impact of the time horizon and adjusting for risk and methodological assumptions in an economic evaluation

The time horizon refers to the period of time which the costs and consequences are being evaluated (Husereau, Drummond et al. 2013). It is important to describe why the chosen time horizon is important in the context of your study. While most economic evaluations will align the time horizon for the costs and consequences, this is not always the case. For example, an intervention in the acute hospital setting may only consider costs during the hospital admission, however the consequences may include 5 year survival rates.

The time horizon brings up two subsequent issues. The first is adjusting historic cost data into one consistent base year, and the second is discounting future costs and consequences.

1) Historic cost data includes costs which have been collected over more than one year (often a financial year). It is common practice to use the Consumer Price Index (<https://www.abs.gov.au/ausstats/abs@.nsf/mf/6401.0>) to inflate historical data into the base year. For example, "All costs were reported as 2012/2013 Australian dollars (AUD\$)... Administrative cost data collected for the primary health service, Medicare and PBS covered three financial years. Inflation rates of 3.7% and 7.2% respectively, were applied to the 2010/2011 and 2011/2012 data consistent with the health care inflation rate of the national Consumer Price Index [12]" (Brusco, Watts et al. 2015). However, when data is being combined across multiple international studies, sometimes a representative inflation rate is applied, for example in a systematic review of international economic evaluations "An inflation rate of 3% per annum was assumed to determine net present value (NPV) on the first of January 2012" (Brusco, Taylor et al. 2014).

2) Discounting future costs and consequences is recommended to adjust for time preference, as individuals place a different value on a benefit realised at an earlier time, compared with a benefit realised at a later time. For example, if an intervention received today saves your life now, you are more likely to place a

high value the intervention, compared to an intervention received today which saves your life in 10 years' time. Discount rates vary from country to country, according to the intervention, setting and study perspective. It is important to detail your choice of discount rate and the rationale for the choice.

Adjusting for risk can explore uncertainty across multiple variables, as well as methodological assumptions, within an economic evaluation. This includes the choice of study perspective, discount rates as well as sampling variability. This can occur within the primary analysis where several economic models are presented, or as a stand-alone sensitivity analysis. For example, a modelled economic evaluation which is based on published literature, may find that the different publications report a mean survival rate that varies between 2 and 4 years following a particular intervention. The primary cost-effectiveness analysis may use the conservative 2 year survival rate in the analysis, whereas the sensitivity analysis may use the more favourable 4 year survival rate. It is essential that you detail variation in the literature and justify choice of your subsequent methodological assumptions.

References

- Brusco, N. K., N. F. Taylor, J. J. Watts and N. Shields (2014). "Economic evaluation of adult rehabilitation: a systematic review and meta-analysis of randomized controlled trials in a variety of settings." *Archives of physical medicine and rehabilitation* 95(1): 94-116. e114.
- Brusco, N. K., J. J. Watts, N. Shields and N. F. Taylor (2015). "Is cost effectiveness sustained after weekend inpatient rehabilitation? 12 month follow up from a randomized controlled trial." *BMC health services research* 15(1): 165.
- Husereau, D., M. Drummond, S. Petrou, C. Carswell, D. Moher, D. Greenberg, F. Augustovski, A. H. Briggs, J. Mauskopf and E. Loder (2013). "Consolidated health economic evaluation reporting standards (CHEERS)—explanation and elaboration: a report of the ISPOR health economic evaluation publication guidelines good reporting practices task force." *Value in Health* 16(2): 231-250.



**Evidence and
Implementation
Summit 2021
30-31 March**

Bringing together evidence, implementation, policy, and politics: Towards a better future for all

30-31 March 2021 - Sydney

The Evidence and Implementation Summit 2021 is an evolution of the Australasian Implementation Conference and the Global Evidence and Implementation Summit that was held in 2018. EIS 2021 will mark 10 years since the creation of the event series; it continues to be one of the leading evidence and implementation events on the global calendar.

If you are a policy maker, practitioner, organisational leader, researcher, implementation scientist or a funder, EIS 2021 is for you. Our focus is on the intersection of research, policy and practice. Share advances in the fields of evaluation, evidence synthesis and translation and implementation science and debate their impact on policies and programs to change the lives of people and communities for the better.

The Centre for Evidence and Implementation (CEI) has successfully partnered with some of the field's leading organisations to share and deliver collaborative vision, practical strategies, experience, knowledge and networking opportunities. This year we will host the two-day event alongside Monash University.

VENUE Online or in person at the Sofitel Sydney Wentworth, Australia

REGISTER eisummit.org/registrations

ABSTRACTS CLOSING SOON: 6 October 2020

For more information: eisummit.org

Early and mid-career research support activities

Although the staffing level for RAIL at this point is small, we are keen to provide support for any early or mid career researcher that we can. We are happy to provide an external review perspective of grants you are preparing as one avenue of support. If you would like to discuss possibly accessing this service, please email Cassie in the first instance (spahc.rail@monash.edu).

Member contributions

We would love to showcase current research from our members. We invite you to submit a short story (and relevant images) about any research you are working on that aligns with RAIL. Submissions are due by the 30th of each month to spahc.rail@monash.edu