1. UPDATE

Once again, we have been very busy and there are many new things that have been happening since the last newsletter. Here are a few highlights:

- **Growth of PCRC**: The structure of our centre which was announced last year has developed significantly over the last few months (see “Current Shape of PCRC” — Section 3) leading to some exciting new project ideas.
- **Grants and funding**: We have two new projects underway as a result of successful grant applications to AUT’s Contestable Grant Round this year—the “If-Then” study piloting a new approach to goal setting (Paula Kersten et al.) and a study investigating fatigue management following TBI (Alice Theadom et al., joint project with NISAN). In addition, Julie Reeve (Living well with chronic conditions cluster) has received a grant from the Genesis Oncology Trust enabling her to visit the University of Northern Colorado, USA next month to learn about the oncology exercise programmes with a view to implementing and researching its benefits in New Zealand.
- **Outreach**: We had a notable presence at the Innovation in Rehabilitation conference in March, with several team members presenting findings of our research projects (see page 4 for more details on this). Jessica Besley, who did a Summer Studentship with us last year, won the prize for best presentation from an emerging researcher (sponsored by AUT HRRI), and Nicola Kayes won the prize for best presentation in the area of stroke and applied neurosciences (sponsored by AUT NISAN).
- **Visitors**: PCRC hosted (resourced by ABI Mgt Ltd) the following international visitors in a two day think tank to produce a special issue of the journal Disability and Rehabilitation: Professor Skip Rizzo, Professor Judy Deutsch, Professor Lynne Turner Stokes, Assistant Professor Barbara Gibson.
- **New partnership**: AUT University has entered into an exciting partnership with ABI Rehabilitation New Zealand to establish a new centre focusing on rehabilitation research and practice (See section 4).

2. FOCUS— WELCOME TO ASSOCIATE PROFESSOR PAULA KERSTEN

Associate Professor Paula Kersten joined the team as Associate Director in January this year. Paula was previously at the University of Southampton in the UK so she is settling in to New Zealand with her family as well as her new role in the Person Centred Research Team. We are very lucky to have Paula, as she comes to us with considerable experience in university leadership roles, and expertise in outcome measure development.

Paula trained as a physiotherapist in the Netherlands and graduated in 1988. Her clinical career has been based predominantly in the UK, though she also worked in Germany for one year. She completed her MSc Rehabilitation and her PhD at the University of Southampton in the UK and has worked as an academic since 1994. At Southampton she developed and managed various postgraduate educational programmes for allied health professionals, nurses and midwives.

Since completing her PhD Paula has developed a research programme with a focus on:

1) **The development and evaluation of meaningful outcomes in rehabilitation.** This work has included detailed investigations of commonly used measurement tools such as the visual analogue scale, as well exploration of cultural validity and clinical utility of measures. Paula has advanced skills in Rasch analysis and traditional psychometrics and uses both in her work. Look out for an invited paper she has just submitted with Nicola Kayes to the New Zealand Journal of Physiotherapy, entitled ‘Outcome measurement and the use of Rasch analysis, a statistics-free introduction’.

2) **The evaluation of new ways of working in rehabilitation.** For example, recent work has included a multi-centre randomised controlled trial to assess the effectiveness of a group-based cognitive behavioural approach to managing fatigue in people with Multiple Sclerosis (soon to be published). She is also finishing a RCT examining whether a cardiac rehabilitation programme is effective for people with TIA in reducing their cardiovascular risk factors. At AUT she has just started a new project, which explores the use of ‘implementation intentions’ in bridging the gap between rehabilitation goal intentions with responses that are effective in attaining goals or desired outcomes (for further information see our section ‘Current Research’).

At AUT Paula is leading the PCRC Outcomes Research Cluster. This cluster has a major focus on “Outcomes that matter – Addressing meaning and measurement”. Its aims include furthering the science of outcome measurement through methodological research, building research capacity, supporting clinicians and service leaders in the use and interpretation of their outcomes data. She also works closely with Waitemata District Health Board to support building research capacity.
3. CURRENT SHAPE OF PCRC

In the last few months the Person Centred Research team has been settling into its new status as a Centre. Its purpose is to produce and promote high quality research enhancing knowledge in disability, rehabilitation and diversity. Each of the research clusters within the centre have their own specific aims, but all work towards this purpose. We will highlight the work of each cluster over the coming months, but if you are interested in finding out more please don’t hesitate to contact the relevant cluster leader/co-leader.

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4. NEW PARTNERSHIP

One exciting development for our team is a recent partnership with ABI Rehabilitation New Zealand to establish a new centre which will focus on rehabilitation research and practice. The Person Centred Research Centre has worked with ABI Rehabilitation on various research projects in recent years. This formal partnership will open up opportunities for more explicit collaboration and sharing of ideas. One of the first projects taking advantage of this new partnership is a project which will explore the experiences of taking part in research for participants who have had a TBI.

The key contacts for the new centre are:

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5. CURRENT RESEARCH PROJECTS

Reducing fatigue after a brain injury: a pilot study
Applicants: Alice Theadom, Suzanne Barker-Collo, Kathryn McPherson, Nicola Kayes, Suze Mudge, Valery Feigin
Funding: AUT Contestable Grant
Research Assistant: Rohit Bhattacharjee

Fatigue is a common problem following a brain injury. This study aims to explore two different types of interventions designed to improve persistent fatigue for people who have experienced a mild or moderate brain injury. One intervention will focus on an educational approach and the other will focus on increasing physical activity. The outcomes of these groups will be compared to a group receiving usual care. The study is being run in collaboration with ABI Rehabilitation and Integrated Partners in Health Services in the Auckland region. Thirty people will be recruited into the study to test the acceptability of the group based interventions and to identify any modifications needed.

Bridging the intention-action gap in rehabilitation; a pilot study of an implementation intention intervention
Applicants: Paula Kersten (Principal Investigator), Nicola Kayes, Alice Theadom, Kathryn McPherson
Funding: AUT Contestable Grant
Research Assistant: Alana McCambridge

As part of the rehabilitation process people usually develop goals. However, many people struggle to work towards their rehabilitation goals, despite the very best intentions. This pilot study aims to test the two different approaches to help people overcome this goal 'intention-action' gap in rehabilitation. Twenty people with multiple sclerosis and stroke will develop mobility related goals with a physiotherapist using one of these approaches. If the strategy shows promise in improving rehabilitation outcomes the findings will inform a future definitive trial.

Experiences of recovery and adaption after disabling traumatic brain injury
Applicants: Kathryn McPherson (Principal Investigator); Alice Theadom, William Levack, Joana Fadyl, Matire Harwood, Nicola Kayes, Nicola Starkey, Grant Christy, Valery Feigin
Funding: Health Research Council
Project Manager: Laura Wilkinson-Meyers

This is a longitudinal qualitative study exploring the experiences of recovery and adaption after a traumatic brain injury for both the individual injured and their family/whanau. 50 people who have experienced a TBI and are experiencing persistent difficulties and their whanau/family will be interviewed for the study. The findings will be used to gain a better understanding of the impact of TBI. The interviews are currently underway.

The Breathe Easy Study
Applicants: Kathryn McPherson (Principal Investigator), Marion Gray, David Nicholas, Ahmed Al-Jumaily, Olaf Diegel, Anthony Leicht, Justin Travers
Funding: Health Research Council
Research Assistant: Alana McCambridge

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality. Bronchodilators alleviate some symptoms of airway obstruction, but reduced exercise tolerance and difficulty with activities of daily living are common. Devices to support respiratory effort are available but are expensive and not easily portable. We have developed two small, affordable devices using Continuous Positive Airways Pressure (CPAP) and applied Positive End-Expiratory Pressure (PEEP). This is a small feasibility trial designed to determine if the prototype portable CPAP and/or PEEP devices we have designed can provide airway support and be used in a larger clinical trial. The first phase of the study assessing acceptability with healthy volunteers is completed and the next stage involving patients will begin shortly.

Experience of brain injury research participation.
Applicants: Kathryn McPherson, Alice Theadom, Allison Foster, Nicola Kayes
Funding: AUT Summer Studentship
Summer Student: Tania Hollands

The main aim of this project is to explore the experiences of adults with TBI taking part in research in NZ. Specifically the study will identify perceived benefits and burdens. 30 people with TBI will be recruited through ABI Rehabilitation to take part in an interview about their experiences. The recruitment phase is currently underway.

Goals and self regulation skills in brain injury rehabilitation: a RCT
Funding: Health Research Council
Project Manager: Nicola Kayes, Data Manager: Greta Riley

This clinical trial explores two novel interventions around goal planning for people with TBI. The research is being carried out in three locations—Auckland, Wellington, and Hamilton. Recruitment is now coming to an end but follow-up assessments will take place for another year.

The Living Well as a Disabled Person Project
Applicants: Kathryn McPherson, Nicola Kayes, Suzie Mudge, Grant Schofield, Elaine Rush, Deborah Payne, Richard Hoskin, Sarah Travaglia, Julianne McEndowney, Brigit Mirfin-Veitch
Funding: Health Research Council (RFP)
Project Managers: Nicola Kayes & Suzie Mudge

Despite numerous public health initiatives aimed at preventing obesity and related chronic diseases, many may be inappropriate or inaccessible for disabled people. In partnership with disabled people this project aims to identify key strategies for reducing the incidence and risk of obesity and associated chronic diseases for disabled people. The second round of focus groups are currently underway and online forums open for comment / discussion - www.LivingWellstudy.aut.ac.nz

New Zealand validation of the international QOLIBRI (Quality of Life after Traumatic Brain Injury) measure for assessing the quality of life after brain injury
Applicants: Kathryn McPherson, Graeme Hawthorne, Robb Kydd, Christine Cummins
Funding: Philip Wrightson Centre of Excellence
Research Assistant: Christine Cummins

Working in conjunction with Melbourne University, this study aims to contribute Australasian data towards testing a traumatic brain injury specific quality of life instrument; the QOLIBRI (Quality of Life after Traumatic Brain Injury). This project is now in the follow-up phase.

5. CARERS STUDY—UPDATE

In 2009 the team carried out a study funded by the National Health Committee investigating the interface between formal and informal carers in New Zealand. The final report was presented to the National Health Committee in November that year, and was used to inform the report the National Health Committee presented to the Minister of Health1. Since then the Ministry of Health has announced a ‘New Model for Supporting Disabled People’2, two key aspects of which include creation of a new ‘Local Area Coordinator’ role and a more open funding structure which are currently being trialled.

As part of the commitment to translating research findings into practice, the team is hoping to submit a paper to the upcoming “Disability Studies: Everybody in” conference (http://www.otago.ac.nz/disabilitystudiesconference) in Dunedin in November which will examine how the new model addresses the concerns raised by the informal carers we talked to.

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1 National Advisory Committee on Health & Disability, 2010. How should we care for the carers, now and into the future? Wellington: Ministry of Health
6. RECENT PUBLICATIONS SINCE OUR LAST NEWSLETTER

PEER REVIEWED PUBLICATIONS


The New Zealand Rehabilitation Association Biennial Conference, March 2011, Auckland (oral presentations):

Armstrong J, McPherson KM, Nayar S. A qualitative investigation into the process of external memory aid and training by occupational therapists.

Besley J, Kayes NM, McPherson KM. Assessing the measurement properties of two commonly used measures of therapeutic relationship in physiotherapy.

Bright F, Boland P, Rutherford S. Prioritising the therapeutic relationship in rehabilitation by ‘being with’ and ‘enabling’.

Fadyl J, Nicholls D, McPherson KM. The last 100 years in vocational rehabilitation: a tale of innovation and progress or change and rediscover.


Kayas N, McPherson KM, Moloczij N, Cummins C. Exploration of the interface between formal and informal care giving in New Zealand.


8. PCRC OPEN MEETINGS

Over the last few months we have had some interesting and well attended PCRC open meetings. Presentations were given by Paula Kersten, Laura Wilkinson-Myers, Rod McLeod, Keith Tudor and summer students Nadine Mesnage, Tania Hollands and Kylee Sterling.

Look out for our next three open PCRC meetings on:

- 29th June: John Parsons, TARGET trial: Goal setting as a feature of homecare services for older people: does it make a difference?
- 27th July: Prof Ngaire Kerse, title to TBC
- 31st August: TBC (Contact Chris Slade, christine.slade@aut.ac.nz)

We are delighted that Alana McCambridge has joined the team as Research Assistant working on the “Breathe Easy” study with Kath and the “If-Then” study with Paula. Welcome!

Congratulations to Laura Wilkinson-Meyers on gaining one of the sought after AUT Postdoctoral Research Fellowships. The award will support her in publishing from her doctoral thesis and in developing new research in the field of disability and health services research under the guidance of Kath McPherson.


The American Congress of Rehabilitation Medicine, October 2010 Montreal, Canada.

Levack W, McPherson KM, Kayes N, Fadyl J, Gewurtz R, Dejong G. The Role of Qualitative Metasynthesis in Evidence-Based Rehabilitation


Fadyl JK, McPherson KM, Kayes N. Quality of life of those who experience disability - NZ contribution to the international WHOQOL-DIS project. Quality of Life Conference, Auckland, 2010


9. CONTACTS

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