Early Career Spotlight: Dr Moyra Mortby

The Dementia Collaborative Research Centres (DCRCs) have a strong tradition of building early career researchers, and helping young scientists discover and apply new knowledge in Australian dementia care. This includes recruiting international talent.

In 2011 Dr Moyra Mortby (pictured) came to Australia from the University of Zurich to join the DCRC team at the Centre for Research on Ageing, Health and Wellbeing at the Australian National University (ANU) in Canberra. Her early work involved brain imaging and risk factors for brain ageing outcomes. Working on projects in early diagnosis and prevention, Moyra explored the use of normative structural imaging databases to assess brain ageing across the adult lifespan.

Since starting in Australia with the DCRCs, Moyra has driven the development of a research program on dementia and behavioural and psychological symptoms of dementia (BPSD). She leads a number of research projects investigating BPSD in dementia and pre-clinical stages of dementia, both in community-based and residential care settings.

Gaining recognition

Gaining recognition as an independent researcher, Moyra has received a fellowship from the Alzheimer’s Australia Dementia Research Foundation in 2013 and the Alzheimer’s Australia Dementia Research Foundation Hazell Hawke Research Grant in Dementia Care. She is also the recipient of the 2015 New Investigator Award by the International Society to Advance Alzheimer’s Research and Treatment (ISTAART) and the Neuropsychiatric Syndromes in Neurodegenerative Diseases Professional Interest Area.

Moyra is also one of 76 early career researchers from around Australia to have been awarded an NHMRC-ARC Dementia Research Development Fellowship in 2015. This fellowship funds a four-year project (BPSD-CARE) which is aimed at reducing the prevalence of BPSD and medication used to manage BPSD in Australian residential aged care facilities. The program will equip residential aged care staff with specialised training and skills needed to provide care proactively for all residents with BPSD and improve quality of life for residents, carers and relatives.

The BPSD-CARE program

The BPSD-CARE program adapts a Swedish program which has been implemented since 2010, and was developed to help ensure and improve residential care for people with BPSD, reduce BPSD prevalence and improve quality of life for people with BPSD. The Swedish program has shown promising evidence of efficacy, and will now be adapted and evaluated by Moyra for use in Australia.

Outcomes from this project will help inform the aged and healthcare systems to deal more effectively and efficiently with the rising number of individuals with dementia and BPSD.

The case for a National Dementia Registry in Australia

The need for a clinical registry to collect data on dementia in Australia was raised publicly in 2013. Karolina Krysinska, Pernminder Sachdev and Henry Brodaty explain the benefits and outline their progress in developing the first stage of a National Dementia Registry in Australia.

The data we have about people with dementia and their carers in Australia are based on information collected in general population surveys, longitudinal studies, administrative datasets (such as hospital use), and the integration of different data sources (called ‘data linkage’). This information helps clinicians and other health and aged care professionals to better identify, treat and care for people with dementia, and support their carers and family members.

However, the sources of this information are often inconsistent in terms of the data that are collected and definitions used. This makes it difficult to accurately estimate the prevalence of dementia and the use of health and aged care services by people with different types of dementia and from diverse needs groups (AIHW 2014).

One proposed solution is to establish a clinical registry of dementia in Australia. Clinical registries are databases collecting information about people diagnosed with a particular disease, who use a particular health resource or undergo a particular procedure.

Registries are important tools for monitoring quality and appropriateness of care, measuring the impact of disease and treatments, including quality of life, and estimating cost-effectiveness of treatments in real-world medical practice. Registries also support recruitment for research studies.

The number of clinical registries operating in Australia has been increasing, and these registries inform clinical practice in many fields (Wilkins et al 2015). There are currently more than 30 such registries – including national registries on renal dialysis, joint replacement and kidney transplant.

Why Australia needs a dementia registry

Evidence from other countries shows that dementia registries can be valuable tools for aged care and health planners, policy makers and researchers in providing much-needed consistent information on diagnosis, treatment and management of dementia.

The need for a National Dementia Registry in Australia was emphasised at the Alzheimer’s Australia Multidisciplinary Roundtable Discussion in Hobart, Tasmania in May 2013.

Researchers, clinicians, policy makers and carers, in their call for action, concluded that such a registry is “a means of ensuring that recommended therapies and services are logged and followed up from the point of diagnosis and to enhance research” (Alzheimer’s Australia 2013 p.16).

A National Dementia Registry in Australia could provide quality data about the natural history and outcomes of dementia as well as being a valuable source of data on the quality of assessment, diagnosis and management of dementia.

The report from the 2013 roundtable suggested that newly diagnosed people could opt-in (on a voluntary basis) to a National Dementia Registry. This registry would link individuals with dementia and their carers to appropriate services available in their area and to potential participation in research, helping to ensure a clear pathway for diagnosis and follow-up.

The report also said the registry would enable approved healthcare professionals to review whether people with dementia...
had accessed a particular service. This information could be used to remind ‘non-users’ of the services about availability and potential benefits. Information on currently available treatments, clinical trials as well as discontinued drugs could also be included. The registry could be linked to electronically-controlled personal health records (Alzheimer’s Australia 2013).

Planning for an Australian registry
In late 2015 our team from the Dementia Collaborative Research Centre: Assessment and Better Care (DCRC: ABC), at UNSW Australia, began a scoping project to design and develop the first stage of a National Dementia Registry in Australia.

The registry would provide performance feedback for dementia services and clinicians and supplement research data with information about routine diagnosis, treatment and care of people with dementia in health and aged care services. It would also help to identify people with dementia and their carers who are interested in participating in research studies, including clinical trials of pharmacological interventions.

The scoping study involved reviewing the literature, liaising with other registries in Australia and internationally and establishing and maintaining relationships with future registry stakeholders.

The results of that project are presented here, along with some of the steps that will be taken to progress the proposed registry. It is our belief that a case can be made to the National Health and Medical Research Council (NHMRC) National Institute for Dementia Research (NNIDR) and philanthropic organisations for funding to set up a dementia registry in Australia.

Dementia registries worldwide
Dementia-specific registries are operating in many countries in Europe, the Americas and Asia. Some of the registries collect data at the national level (eg France, Sweden, US) while others collect data on dementia in a particular region or part of the country (eg Denmark, Italy, Spain). In some countries (eg India, Japan, Pakistan) there are local hospital-based registries. There are also international initiatives, such as the European Prevention of Alzheimer’s Dementia (EPAD) registry.

These dementia registries all have differences in design, operation, recruitment, number of registered people and funding sources, reflecting their varying aims and functions (Leach & Levy 1993). However, in general, dementia registries:

- Collect information on the epidemiology of dementia and its different types.
- Provide insight into the aetiology and natural history of dementia.
- Help evaluate and refine the diagnostic criteria and tests.
- Collect information on use of health and aged care services and carer support.
- Inform planning and future development of services.
- Help to identify people willing to be involved in research studies and clinical trials.
- Support dementia education of health and aged care personnel.

Three dementia registries are described below which show the range of applications of databases collecting information about people with dementia and their carers.

SveDem (Sweden)
The Swedish Dementia Registry (SveDem) (www.svedem.se) includes people newly diagnosed with dementia in specialist care, primary care units or aged care homes (see box above). The registry was established in 2007 and is one of over 100 in Sweden which monitor quality of care (Religa et al 2015).

SveDem aims to improve the quality of diagnosis, treatment and care of people with dementia. It is an online registry, collecting information about diagnosis, medical treatment and community support. These indicators can be followed over time.

In March 2016, almost 60,000 people with dementia were registered in SveDem and more than 40,000 were followed-up. The database covers almost the entire country; all memory clinics in Sweden provide data to the registry. Registry data inform further development of the national guidelines for dementia, enable monitoring of quality of care and help to generate new research hypotheses.

European Prevention of Alzheimer’s Dementia Registry
The European Prevention of Alzheimer’s Dementia (EPAD) project (http://epad.org) is a major initiative, which involves more than 30 universities, consumer organisations and commercial partners throughout Europe and the UK.

The EPAD project began in 2015 to create a novel environment for testing interventions to prevent Alzheimer’s dementia. It draws on existing national and regional registers of people at risk of developing Alzheimer’s dementia in order to create an EPAD register of 24,000 at-risk individuals. These people will be screened and 6000 participants at greatest risk of Alzheimer’s dementia will be selected and invited to join an EPAD longitudinal cohort study. Finally, 1500 participants from the EPAD cohort will take part in innovative clinical trials of drugs designed to prevent Alzheimer’s dementia. The project is ongoing.

Join Dementia Research (UK)
Join Dementia Research (JDR) (www.joindementiaresearch.nihr.ac.uk) is a service which allows people with dementia, their carers, and anyone over the age of 18 with and without dementia, to register their interest in participating in dementia research and to be matched to suitable studies.

The JDR research volunteer register was launched in 2015 in the UK by the National Institute for Health Research in partnership with Alzheimer Scotland, Alzheimer’s Research UK and Alzheimer’s Society.

The key objective of the JDR initiative is to increase the number of people with dementia and their carers and other interested people involved in dementia research. The service is available nationwide. In September 2016 there were more than 22,500 volunteers on the JDR, of whom almost 5500 were enrolled in 76 dementia studies.

Sweden’s dementia registry: practical outcomes
SveDem was established primarily as a registry to monitor and improve the diagnosis, treatment and care of people with dementia in Sweden. It also offers many opportunities for research. Recent studies based on the registry data show that:

- Physicians’ assessment of driving fitness in dementia needs improvement; in almost 20% of people with dementia, Swedish physicians did not address the issue of driving.
- Dementia diagnosis differs in men and women and depends on age and severity of cognitive impairment; the diagnostic procedure for dementia is more extensive for younger than for older people, as the diagnostic possibilities are greater in younger people with dementia.
- The registry offers valuable information on the costs of diagnostic procedures for dementia in daily clinical practice; diagnostic costs are higher in younger people with dementia.
Where to now?
Substantial funding is required to establish and maintain a National Dementia Registry in Australia. There is a business case that the return on investment would be positive. The registry could be hosted at a university or another institution with relevant expertise.

The DCRC: ABC will publish a report by the end of this year on dementia registries internationally, in conjunction with Alzheimer’s Disease International and The Global CEO Initiative on Alzheimer’s Disease (a group linked to the World Council of Dementia). A summary academic paper is also planned for publication later this year.

While the DCRCs have achieved much in 10 years, a great deal more can be achieved in the next decade with the support of a National Dementia Registry.

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References

Dr Karolina Krysinska is a Research Fellow in the School of Psychiatry/Dementia Collaborative Research Centre: Assessment and Better Care (DCRC: ABC), UNSW Australia; Professor Perminder Sachdev is a DCRC: ABC Chief Investigator; Co-Director of the Centre for Healthy Brain Ageing (CHeBA) UNSW and Clinical Director of the Neuropsychiatric Institute (NP), Prince of Wales Hospital, Sydney; Professor Henry Brodaty is DCRC: ABC Director, Co-Director of CHeBA, Scientia Professor of Ageing and Mental Health, UNSW Australia and Consultant Psychiatrist/Adjunct Aged Care Psychiatry and head of the Memory Disorders Clinic, Prince of Wales Hospital. To follow up on this article contact Karolina at: k.krysinska@unsw.edu.au.

Inspiring action: Australian team at forefront of young onset dementia research

Australia’s INSPIRED Study is leading young onset dementia research internationally, with the aim of improving services and support for this previously under-researched group. Adrienne Withall explains

The foundations of the INSPIRED Study began in 2007 after I was fortunate enough to not only be offered a three-year postdoctoral fellowship at the Dementia Collaborative Research Centre: Assessment and Better Care (DCRC: ABC) at UNSW Australia, but also afforded the opportunity to choose my research focus.

I had observed that more people younger than 65 seemed to be presenting with cognitive complaints to our Academic Department of Old Age Psychiatry at Prince of Wales Hospital, Sydney. Professor Brian Draper agreed to partner with me to investigate this further. When we started to research young onset* dementia (an onset of symptoms under the age of 65; at that time also known as presenile dementia or early onset dementia), it soon became evident that there was very little known about this group. Further, people under the age of 65 were not really factored into calculations about the need for dementia services as there was an assumption that that this population was so small as to be inconsequential. Often they fell into the gap between disability and aged care services.

The INSPIRED Study (Improving Service Provision for Early Onset Dementia) was thus born out of the desire to establish how many people had young onset dementia in Australia so that a robust, evidence-based argument could be made to establish adequate services for this group.

Prevalence in Australia
Dementia in young people is more common than most people think. Our prevalence study, funded by an Alzheimer’s Australia Research grant, indicated that approximately one in every 750 people aged 45-64 are diagnosed with young onset dementia. Additionally some people are very young at the onset of their dementia symptoms; in particular, five people in our study were aged less than 40 years at the time of the study. Overall, it is currently estimated that there are 25,000 Australians with young onset dementia, accounting for 8% of all dementia cases; certainly not an insignificant group.

More clinically diverse
Young onset dementia is much more clinically diverse than dementia in older people, so you are more likely to see a greater range of dementias and also rarer causes of dementia.

Some dementias tend to have an earlier age of onset, such as frontotemporal dementia, and are seen more often in this group. There are also more people with the autosomal dominant, or genetically inherited, dementias although the rate is still only around 15–20% of young onset cases. This means that the majority of dementias in younger people are not inherited but are instead primarily due to environmental, lifestyle and/or other (as yet unknown) risk factors.

Within diagnostic groups, such as Alzheimer’s disease, there does not seem to be great differences between young and older people with the condition. In fact, when Alois Alzheimer first described the neurodegenerative illness that would later be named for him, he believed it to be a ‘presenile’ condition; his first patient had an onset of symptoms in her forties and the second in his fifties.

Importantly there are a number of young onset dementias with potentially preventable causes, such as dementia secondary to alcohol abuse and/or head injury.

Unexpected hurdles
We did not expect the significant level of stigma regarding the term ‘dementia’. This initially created a barrier to some groups participating in our study and caused us to rethink our terminology. We eventually used the term ‘young onset memory and related disorders’ and people seemed happy to endorse this.

We also learnt that people assisting with

*Footnote: The International Psychogeriatric Association Young Onset Dementia Shared Interest Forum uses the term “young onset dementia” in preference to “younger onset dementia” and is striving to make this the international convention.