The need for a clinical registry to collect data on dementia in Australia was raised publicly in 2013. Karolina Krysinska, Perminder 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 p16).

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...