

Review Article

# Dementia registries around the globe and their applications: A systematic review

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## Abstract

Patient registries are valuable tools helping to address significant challenges in research, care, and policy. Registries, well embedded in many fields of medicine and public health, are relatively new in dementia. This systematic review presents the current situation in regards to dementia registries worldwide. We identified 31 dementia registries operating on an international, national, or local level between 1986 and 2016. More than half of the registries aimed to conduct or facilitate research, including preclinical research registries and registries recruiting research volunteers. Other dementia registries collected epidemiological or quality of care data. We present evidence of practical and economic outcomes of registries for research, clinical practice and policy, and recommendations for future development. Global harmonization of recruitment methods and minimum data would facilitate international comparisons. Registries provide a positive return on investment; their establishment and maintenance require ongoing support by government, policy makers, research funding bodies, clinicians, and individuals with dementia and their caregivers.

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## Keywords:

Alzheimer's disease; Database; Dementia; Epidemiology; Quality of care; Preclinical; Registry; Systematic review

## 1. Introduction

The prevalence of dementia is estimated to double every 20 years from 46.8 million in 2015 to nearly 131.5 million by 2050 [1,2]. The natural history of different dementias, the quality of diagnosis and care, the use of community services and long-term care, the costs of care, and the effects on caregivers at a population level are largely unknown or rely on extrapolations from smaller samples. Such data would be beneficial in shaping policy and planning particularly in low-

and middle-income countries (LMICs) where such information is even more wanting. Harnessing innovative approaches for effective prevention, treatment and care, and changes in policy could improve quality of care and quality of life for people with dementia and their families and help to minimize the financial costs of Alzheimer's disease (AD) and other dementias [3,4]. Clinical registries are one approach to help recruitment for research and monitoring quality of care.

The many definitions and classifications of registries in medicine are typically embedded within broader frameworks and models of public health surveillance and reporting on the quality of health care [5]. In general, in epidemiology, the term "register" refers to a "file of data concerning all cases of a particular disease or other health-relevant condition in

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a defined population” and a “registry” is a “system of ongoing registration” ([6] p211; see Appendix 1 for Definitions and Classifications of Registries). The first patient registries were established in Scandinavian countries at the end of the 19th century. The increasing public health concern with chronic diseases during the 1950s led to a proliferation of registries [5]. The Scandinavian countries, such as Denmark, Finland, and Sweden, remain world leaders in regards to extensive register networks and linkage of individual-level data from different sources (“an entire country [as] a cohort”) ([7] p2398). For instance, in Sweden, in 2012, there were more than 100 health care registries [8]. National repositories of patient registries have been set up in Denmark [9], the UK [10], and the USA [11] to improve sharing of information about existing health data collection systems and, where possible, facilitate data sharing. Another type of registry, a research participant registry, aims to recruit people who are at increased risk of a condition, for example, women with gestational diabetes or persons with family history of a disease [12]. Patient registries inform health policy and contribute to health care value. A 2011 health economics study in Sweden revealed that an annual investment of US\$70 million in registries could reduce the annual growth in health care spending by 0.6%, with the estimated cumulative return of more than US\$7 billion for more than 10 years—a \$10 return on every dollar invested [13].

Despite popularity of registries in many fields of medicine since the 1950s, and their tangible outcomes, registries collecting dementia-related data are relatively new. The first dementia registries, which focused on diagnostic and clinicopathologic data on AD, were established in USA, including the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) in 1986. The principal goal of CERAD was to standardize procedures for the evaluation and diagnosis at the Alzheimer’s Disease Centers (ADCs) [14]. A decade later, in 1999, the National Institute on Aging

funded the National Alzheimer’s Coordinating Center (NACC) [15] to develop and maintain a large database of clinical and neuropathologic information collected by the ADCs. Other pioneering dementia registries, such as the IMAGE Project Population-Based Registry of AD in Quebec [16] and the Camberwell Dementia Case Register in the UK [17], focused on the study of genetic transmission patterns in AD and the prevalence and natural history of AD.

Dementia registries [18–24] aim to advance dementia research by optimizing clinical trials for interventions in the prodementia phase of AD (i.e., preclinical registries), collecting epidemiological data, monitoring the quality of dementia care, and recruiting volunteers for dementia studies (Table 1). Interest in dementia registries has been accompanied by expansion of international research consortia on AD, development of comprehensive national databases on healthy aging, international harmonization in sharing longitudinal data sets, and harnessing big data in dementia research [3,25]. There is considerable potential in linking data across health, care, research, and administrative systems using electronic health records and dementia registries. Linkage of big data, that is, “deep” biological and clinical data and “broad” population-based health and health care data, can advance the understanding of progression of dementia and assessing effectiveness of treatments and interventions [4].

Systematic reviews have mapped registries in many areas of health care, such as renal replacement therapy [26] and trauma [27], but not yet for dementia-related data and their applications. Our study aims to address this gap and to present the current situation in the field including the benefits and outcomes of registries, as well as to inform their further development as tools for dementia research, care, prevention, and policy. This systematic review identifies and classifies dementia registries, including AD registries, operating around the world and reviews their characteristics and functions. We describe the outcomes of dementia

Table 1  
Aims and categories of dementia registries

Category of registry	Aims
Dementia research registry	<ul style="list-style-type: none"> <li>• To support research into causes and risk factors for dementia.</li> <li>• To provide data on the natural history of dementia, determinants of progression, and their implications for clinical management.</li> <li>• To develop and measure effectiveness of interventions to reduce the risk and incidence of dementia, its treatment and management.</li> <li>• To evaluate and refine the diagnostic criteria for dementia, to standardize and validate screening instruments and diagnostic tests.</li> </ul>
Subcategory: preclinical dementia research registry	<ul style="list-style-type: none"> <li>• To optimize conduct of clinical trials in preclinical stages of AD/dementia, to accelerate cohort development and trial recruitment.</li> </ul>
Epidemiological dementia registry	<ul style="list-style-type: none"> <li>• To collect epidemiological data on the prevalence, incidence, and risk of dementia.</li> </ul>
Quality of dementia care registry	<ul style="list-style-type: none"> <li>• To monitor the quality of dementia care.</li> <li>• To provide information on utilization and cost of health and aged care services and carer support, and to inform planning and development of dementia services.</li> </ul>
Dementia research volunteer registry	<ul style="list-style-type: none"> <li>• To identify people with dementia, their carers, and healthy volunteers who are willing to be involved in research studies and clinical trials.</li> </ul>

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