A scoping study for a national dementia registry in Australia

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An overview

- Impact of dementia
- Review of dementia registries
- Outcomes of dementia registries
- Practicalities (and challenges) of a dementia registry
- Discussion
Impact of dementia

- Dementia is an umbrella term describing a syndrome associated with >100 different diseases.
- The most common types of dementia are Alzheimer disease (50-75%), vascular dementia (20-30%), frontotemporal dementia (5-10%), and dementia with Lewy bodies (5%).
- Dementia is related to the impairment of brain functions, including language, memory, perception, personality and cognitive skills.
- Type and severity of symptoms and pattern of development varies with the type of dementia.

Dementia is usually of gradual onset, progressive in nature and irreversible.

The course of dementia is often characterised as occurring in three stages:
- mild or early-stage dementia
- moderate or middle-stage dementia
- severe or late-stage dementia

Dementia is more common after the age of 65 years; although there is also younger onset dementia.

Dementia is not a normal part of ageing.
Table 1.1: An overview of the stages of dementia

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild or early</td>
<td>Deficits are evident in a number of areas (such as memory and personal care) but the person can still function with minimal assistance. Symptoms include: moderate memory loss especially for recent events, some disorientation in time, moderate difficulties with problem solving, reduced interest in hobbies, and the need for prompting regarding personal care tasks.</td>
</tr>
<tr>
<td>Moderate or middle</td>
<td>Deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community. Symptoms include: severe memory loss, considerable difficulty orienting to time and place, obvious difficulties in finding words, severe impairment of judgement and problem solving, need for assistance with personal care tasks, and emergence of behavioural difficulties (for example, wandering, aggression, sleep disturbance and disoriented behaviour).</td>
</tr>
<tr>
<td>Severe or late</td>
<td>Characterised by almost total dependence on the care and supervision by others. Symptoms include: very severe memory loss, very limited language skills, unable to make judgements or solve problems, regularly not recognising familiar people, frequent incontinence, requires substantial assistance with personal care, and increased behavioural difficulties. By this stage the majority of people with dementia are in residential care.</td>
</tr>
</tbody>
</table>

Sources: Draper 2011, Morris 1993.

Source: AIHW, 2012

Dementia in Australia

342,800

Australians were estimated to have dementia in 2015. Based on projections of population ageing and growth, the number of people with dementia will reach almost 400,000 by 2020, and around 900,000 by 2050.

1 in 10

Australians aged 65 and over (10%) had dementia in 2015.

3 in 10

Australians aged 85 and over (31%) had dementia in 2015.

Over 50%

of permanent residents in Australian Government-funded aged care facilities in 2013-14 had a diagnosis of dementia.

Impact of dementia

Carers of people with dementia (AIHW, 2012)

- About 9 in 10 people with dementia living in the community receive care from informal carers (~200,000 Australians)
  - mostly spouse/partner or son/daughter
  - mostly women
- 40+ hours of care per week
- Caring for a person with dementia can be physically, mentally, emotionally and economically demanding
- Unmet needs for support, incl. respite care

Impact of dementia

The National Health Priority Areas (NHPAs) are diseases and conditions that Australian governments have chosen for focused attention as they contribute significantly to the burden of illness and injury:

- Cancer control (first set of conditions, 1996)
- Cardiovascular health (first set of conditions, 1996)
- Injury prevention and control (first set of conditions, 1996)
- Mental health (first set of conditions, 1996)
- Diabetes mellitus (added 1997)
- Asthma (added 1999)
- Arthritis and musculoskeletal conditions (added 2002)
- Obesity (added 2008)
- Dementia (added 2012)
Impact of dementia

There is no sure way to prevent dementia.

However...

http://yourbrainmatters.org.au
Review of dementia registries

Literature review:
- Commenced November 2015
- Search terms: Alzheimer OR dementia / register OR registry OR database
- Databases, including Scopus, MEDLINE/PubMed, Web of Science, and ProQuest Central
- Additional references: hand-checking references and online search (grey literature)
- Contact via email with registry manager (where possible)

Outcome: 31 AD/dementia registries operating on an international, national or local level between 1986 and 2016

Excluded:
- local hospital/University-based registries in Canada, India, Italy, Pakistan, Japan and Taiwan, and the USA given their limited geographic coverage
- planned but yet not operating national dementia registries in Cuba and the Netherlands
Relatively new

The first dementia registries, in particular AD registries, were established in the US and in Canada in the 1980s

The first dementia case register in Europe (the Camberwell Dementia Case Register) was established in the UK in 1992

The continuing proliferation of dementia registries has been a phenomenon of the last decade
<table>
<thead>
<tr>
<th>Registry</th>
<th>Country</th>
<th>Year</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Impairment Centralized Case Registry in Argentina (ReDiCaAr)</td>
<td>Argentina</td>
<td>2010</td>
<td>national</td>
</tr>
<tr>
<td>PRODEM-Austria</td>
<td>Austria</td>
<td>2008</td>
<td>national</td>
</tr>
<tr>
<td>IMAGE Project Population-Based Registry of Alzheimer's disease</td>
<td>Canada</td>
<td>1986</td>
<td>local (Quebec)</td>
</tr>
<tr>
<td>Alzheimer's Prevention Initiative (API) Colombian Registry</td>
<td>Colombia</td>
<td>2010</td>
<td>local (Antioquia)</td>
</tr>
<tr>
<td>Danish Dementia Registry</td>
<td>Denmark</td>
<td>2005</td>
<td>local (Copenhagen)</td>
</tr>
<tr>
<td>European Prevention of Alzheimer's Dementia (EPAD)</td>
<td>Europe</td>
<td>2015</td>
<td>international</td>
</tr>
<tr>
<td>French National Alzheimer Database</td>
<td>France</td>
<td>2009</td>
<td>national</td>
</tr>
<tr>
<td>Bavarian Dementia Survey (BayBem)</td>
<td>Germany</td>
<td>2012</td>
<td>local (Bavaria)</td>
</tr>
<tr>
<td>Experimental Registry for AD and Other Dementias</td>
<td>Italy</td>
<td>1999-2005</td>
<td>local (Tuscany)</td>
</tr>
<tr>
<td>Health and Memory Study (HMS) of Nord-Trandelag</td>
<td>Norway</td>
<td>1995-2011</td>
<td>local (Nord-Trandelag)</td>
</tr>
<tr>
<td>Norwegian Dementia Registry (NorKog)</td>
<td>Norway</td>
<td>2013</td>
<td>national</td>
</tr>
<tr>
<td>Clinical Research Center for Dementia of South Korea (CREDOS) Study</td>
<td>South Korea</td>
<td>2005</td>
<td>national</td>
</tr>
<tr>
<td>Registry of Dementia of Girona (ReDeGi)</td>
<td>Spain</td>
<td>2007</td>
<td>local (Girona)</td>
</tr>
<tr>
<td>Swedish Dementia Registry (StvDem)</td>
<td>Sweden</td>
<td>2007</td>
<td>national</td>
</tr>
<tr>
<td>Swedish FBSD Registry</td>
<td>Sweden</td>
<td>2010</td>
<td>national</td>
</tr>
<tr>
<td>Camberwell Dementia Case Register</td>
<td>UK</td>
<td>1993-1995</td>
<td>local (Camberwell)</td>
</tr>
<tr>
<td>CHARDOT Register</td>
<td>UK</td>
<td>2011-2014</td>
<td>local (London)</td>
</tr>
<tr>
<td>Scottish Dementia Research Interest Register</td>
<td>UK</td>
<td>2008</td>
<td>local (Scotland)</td>
</tr>
<tr>
<td>Dementia Register (DemReg) (DeNDRON EVIDE)</td>
<td>UK</td>
<td>2009</td>
<td>local (North Thames)</td>
</tr>
<tr>
<td>Join Dementia Research</td>
<td>UK</td>
<td>2015</td>
<td>national</td>
</tr>
<tr>
<td>Consortium to Establish a Registry for AD (CERAD)</td>
<td>USA</td>
<td>1986-1994</td>
<td>national</td>
</tr>
<tr>
<td>National Alzheimer's Coordinating Center (NACC) Database</td>
<td>USA</td>
<td>1997</td>
<td>national</td>
</tr>
<tr>
<td>Alzheimer's Prevention Registry</td>
<td>USA</td>
<td>2012</td>
<td>national</td>
</tr>
<tr>
<td>Arizona Alzheimer Registry</td>
<td>USA</td>
<td>2006</td>
<td>state-wide (Arizona)</td>
</tr>
<tr>
<td>AD and Related Dementia State Registry</td>
<td>USA</td>
<td>2014</td>
<td>state-wide (Georgia)</td>
</tr>
<tr>
<td>Global Alzheimer Platform Trial Ready Cohort for Preclinical/Prodromal Alzheimer’s Disease</td>
<td>USA</td>
<td>2013</td>
<td>national</td>
</tr>
<tr>
<td>New York State Department of Health AD and Other Dementias Registry</td>
<td>USA</td>
<td>1988</td>
<td>state-wide (NY)</td>
</tr>
<tr>
<td>South Carolina AD Registry</td>
<td>USA</td>
<td>1988</td>
<td>state-wide (SC)</td>
</tr>
<tr>
<td>West Virginia AD Registry</td>
<td>USA</td>
<td>2011</td>
<td>state-wide (WV)</td>
</tr>
<tr>
<td>Wisconsin Registry for Alzheimer Prevention (WRAP)</td>
<td>USA</td>
<td>2001</td>
<td>state-wide (Wisconsin)</td>
</tr>
<tr>
<td>Dominantly Inherited Alzheimer Network (DIAN) Expanded Registry</td>
<td></td>
<td></td>
<td>international</td>
</tr>
</tbody>
</table>

Review of dementia registries

- There are significant differences in the design, operation, recruitment, number of registered patients, and funding sources of dementia registries.
- These differences reflect the varying aims and functions of dementia registries:
  - Research on dementia
  - Epidemiology of dementia
  - Dementia services and care
  - Recruitment for dementia research
Research on dementia

- Supporting research into causes and risk factors for dementia.
- Providing data on the natural history of dementia, determinants of progression, and their implications for clinical management.
- Evaluating and refining diagnostic criteria for dementia, standardising and validating screening instruments and diagnostic tests.
- Developing and measuring effectiveness of interventions to reduce the risk and incidence of dementia, its treatment and management.

European Prevention of Alzheimer’s Dementia (EPAD) project

- Since 2015
- Collaboration of 30 universities, patient organisations and commercial partners in Europe and the UK
- Creating a novel environment for testing AD prevention interventions
- Drawing on existing national and regional registers of people at risk of developing AD to create an EPAD register of 24,000 at-risk individuals → 6,000 participants at-risk to join a longitudinal cohort study → 1,500 participants taking part in clinical trials

Ritchie et al., 2015; http://ep-ad.org/
Review of dementia registries

National Alzheimer’s Coordinating Center (NACC) database (USA)

- Since 1999
- Data collected from 29 Alzheimer’s Disease Centers
- Three datasets: Uniform Data Set (UDS), Minimum Data Set (MDS) and Neuropathology Data Set (NP)

Beekly et al., 2007; https://www.alz.washington.edu/index.html

Epidemiology of dementia

- Collecting epidemiological data on the prevalence, incidence, and risk of dementia.
Review of dementia registries

Alzheimer’s Disease and Related Dementia (ADRD) State Registry in Georgia (USA)

• Since 2014
• To collect data to inform programs and services, to identify epidemiological trends, to bring awareness to issues affecting healthy aging, to inform planning and future registry needs
• Data-linkage based
• ~112,430 Medicare beneficiaries with diagnosed ADRD (2013)

http://dph.georgia.gov/alzheimers-registry/

Dementia services and care

• Monitoring the quality of dementia care.
• Providing information on utilisation and cost of health and aged care services and carer support, and informing planning and development of dementia services.
Review of dementia registries

Swedish Dementia Registry (SveDem)

- Since May 2007
- One of 100+ quality registries in Sweden
- Registration of patients newly diagnosed with dementia; annual follow-up
- Almost 60,000 registered patients; over 40,000 patients followed-up (March 2016)
- 100% of memory clinics participating
- Seven indicators of quality of care, incl. dementia diagnosis, treatment, care, and follow-up

Religa et al., 2015; http://www.ucr.uu.se/svedem/

Swedish BPSD Registry

- Since November 2010
- One of 100+ quality registries in Sweden
- Management of behavioural and psychological symptoms in dementia (BPSD)
- Over 34,000 persons with dementia included
- Training of 19,000 staff members in health and aged care
- 300 certified educators providing support and training at the local level

http://www.bpsd.se/
Recruitment for dementia research

- Identifying people with dementia, their carers, and healthy volunteers who are willing to be involved in research studies and clinical trials.

Join Dementia Research (UK)

- Since January 2015
- A nation-wide service allowing people with dementia, their carers and anyone aged 18+ to register their interest in dementia research and to be matched to suitable studies
- Over 20,000 registered volunteers; almost 5,500 volunteers enrolled in studies; 74 ongoing dementia studies (July 2016)

- [https://youtu.be/tt5FdfsQy_4](https://youtu.be/tt5FdfsQy_4)
- [https://www.joindementiaresearch.nihr.ac.uk/](https://www.joindementiaresearch.nihr.ac.uk/)
Outcomes of dementia registries

- Research outcomes and publications
- Recruitment of research volunteers
- Standardisation of evaluation and diagnosis procedures
- Monitoring the quality of dementia care
- Informing policy and service planning
- Cost-effectiveness of dementia diagnosis and care
- Active engagement of healthcare staff
- Monitoring epidemiology of dementia
- International collaboration in dementia research and care

Practicalities of a dementia registry

- “The technical challenges of establishing and maintaining registries are substantial. They should be established in a strong research environment with extensive access to the appropriate skills (…).”

- “The key activities involved in the establishment of a registry can be summarised as establishing collaboration with clinicians and other interest groups (…), development of a governance framework, data collection and data-management, biostatistical analysis, clinical interpretation and quality improvement.”

*Registry Science Handbook (2013); p. 5*
Practicalities of a dementia registry

- “Registry development involves collaboration with a series of partners. Amongst these are: clinical craft groups (...), clinical colleges, State and Commonwealth Departments of Health, private insurers, medical indemnity insurers, and patient advocacy and consumer groups.”

Registry Science Handbook (2013); p. 5

Practicalities of a dementia registry

**Challenge 1**

- **Aim(s) of a dementia registry:**
  - Research
  - Epidemiology
  - Quality of care
  - Research recruitment

“No single [dementia] registry will be able to solve all problems” (Kuller, 1990; p. 200)
**Challenge 2**

- Recruitment:
  - Patients with dementia/cognitive impairment, carers, clinicians/health/aged care personnel (and healthy volunteers)
  - Ethical issues, incl. consent procedures
  - Volunteering and incentives
  - Collaboration

**Challenge 3**

- Registry dataset:
  - Minimum dataset
    - National Dementia Data Analysis and Development Reference Group (AIHW, 2007)
  - Optional *versus* mandatory data fields
  - Data entry
  - IT infrastructure
  - Data linkage
Practicalities of a dementia registry

Table 4.2: Framework for proposed dementia data elements

<table>
<thead>
<tr>
<th>1 Identification of cognitive impairment and dementia</th>
<th>2 Cognitive impairment and dementia diagnosis information</th>
<th>3 Current behaviour related to dementia and its impact on care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1: Identification of cognitive impairment (essential)</td>
<td>2.1: Type of dementia (highly desirable)</td>
<td>3.1: Nature of current challenging behaviour (desirable)</td>
</tr>
<tr>
<td>1.2: Identification of a diagnosis of dementia (essential)</td>
<td>2.2: Date of first formal diagnosis (highly desirable)</td>
<td>3.2: Frequency of occurrence of current challenging behaviour (desirable)</td>
</tr>
<tr>
<td>2.3: Professional occupation of the person who first identified cognitive impairment or diagnosed dementia (highly desirable)</td>
<td>2.4: Severity of dementia (highly desirable)</td>
<td>3.3: Duration of episodes of current challenging behaviour (desirable)</td>
</tr>
<tr>
<td>2.5: Treatment with medication for cognitive impairment due to dementia (desirable)</td>
<td>2.6: Treatment with medication for behavioural and psychological symptoms of dementia (desirable)</td>
<td>3.4: Disruption due to current challenging behaviour (desirable)</td>
</tr>
<tr>
<td>4 Coexisting health conditions</td>
<td>5 Impact of care</td>
<td>5.1: Impact of care measure (desirable)</td>
</tr>
<tr>
<td>4.1: Coexisting health conditions (desirable)</td>
<td>5.2: Impact of care measure (desirable)</td>
<td></td>
</tr>
</tbody>
</table>

Source: AIHW, 2014

Challenge 4

- **Standardisation:**
  - International collaborations
  - Integration of existing datasets
  - Harmonisation of research initiatives
  - Defining data-sharing guidelines, esp. informed consent
Practicalities of a dementia registry

Challenge 5

- Funding and policy implications:
  - Sustainability
  - Cost-effectiveness
  - Quality of care
“The register itself is the tool that is used to capture measurement, analysis, and intervention data but the real power lies in the training and enabling of the care workers so that better care can be given to people suffering from dementia.”

Richard Bibby, Swedish BPSD Register
(personal communication, June 2016)
Dementia Collaborative Research Centres
• http://www.dementiaresearch.org.au/

Centre for Healthy Brain Ageing (CHeBA)
• https://cheba.unsw.edu.au/

Alzheimer’s Australia
• https://fightdementia.org.au/

Thank you for your attention!

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