A scoping study and a pilot dementia registry to improve dementia clinical care in Australia

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Registry Special Interest Group (SIG)
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OVERVIEW

1. Impact of dementia
2. Systematic review of dementia registries
3. Outcomes of dementia registries
4. Pilot clinical quality dementia registry in Australia
5. Time for discussion
Dementia

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

  - Dementia is not a normal part of ageing
DEMENTIA IN AUSTRALIA

Nearly 1 in 10
Australians aged 65 and over had dementia in 2016

43%
of people with dementia are aged 85 and over

354,000
Australians were estimated to have dementia in 2016

52%
of people in permanent residential aged care had dementia

Figure 1.3.3: Leading causes of death, by sex, Australia 2013

1. Coronary heart disease: 11,016 (male), 8,750 (female)
2. Dementia and Alzheimer disease: 3,656 (male), 7,277 (female)
3. Cerebrovascular disease: 4,181 (male), 6,368 (female)
4. Lung cancer: 4,995 (male), 3,222 (female)
5. Chronic obstructive pulmonary disease: 3,572 (male), 2,890 (female)

Note: Leading causes of death are based on underlying causes of death and classified using an AIMM-modified version of ICD-10-AM. Source: AIHW national mortality database.

SYSTEMATIC REVIEW

METHOD

• Database/grey literature search (Aug 2016)
• Self-identified “dementia registries”
• Collecting information on patients with a diagnosis of dementia/AD, individuals at risk, carers, and control subjects
• In operation any time up to August 2016
• Collecting data on international, national or local/regional/state-wide level
Thirty-one national, local/regional and international dementia or Alzheimer’s Disease registries established in 14 countries over 1986-2015.

Four categories:

• Dementia research registries
  • Preclinical dementia research registries
• Epidemiological dementia registries
• Registries for recruitment for research studies
• Registries monitoring quality of dementia care
TYPES OF DEMENTIA REGISTRIES
RESULTS

SYSTEMATIC REVIEW

national/local hospital/Uni-based planned international collaboration
Welcome to Join Dementia Research, a place to register your interest in participating in dementia research.

Dementia affects 850,000 people in the UK.

The only way to beat the condition is through research.

Help us beat dementia

People with dementia or memory problems, their carers and anyone who is interested can sign up. You can also sign up for someone else, providing that you have their consent. Registering is the first step in becoming involved in supporting vital research studies across the nation.

Join Dementia Research - the numbers so far...

32,611 Volunteers
9,128 Volunteers Enrolled in Dementia Studies to date
187 NHS, University & Commercial Research organisations have used the system to date
932 Trained Researchers using the service
93 Research studies currently open to recruitment
Welcome to EPAD
Collaborative research to better understand the early stages of Alzheimer’s disease and prevent dementia before symptoms occur.

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The EPAD project is part of a global effort in the fight against Alzheimer’s disease and is a major European initiative to create a research environment for testing innovative interventions targeted at the prevention of Alzheimer’s dementia.

One of our biggest challenges, after several efforts that didn’t yield the result that we hope for, was that we probably wanted to intervene much earlier. We now have an opportunity to affect the disease early before significant damage is done and give those disease-modifying drugs a chance to show what they can do.
QUALITY OF DEMENTIA CARE REGISTRIES

• Newly diagnosed dementia patients
• 100% of memory clinics in Sweden
• Annual follow-up
• Since May 2007
• October 2016:
  • 63,160 patients
  • 46,448 follow-ups
OUTCOMES OF DEMENTIA REGISTRIES

SUMMARY

• Provide epidemiological data, support clinical best practice and facilitate research.
• Significantly contribute to outcomes in dementia research, clinical practice and policy.
• Inform policy and service planning, and promote cost-effectiveness of dementia diagnosis and care.
• Save money and provide a positive return on investment.
Dementia has been identified as a National Health Priority Area since 2012.

The Australian Commission on Safety and Quality in Healthcare (ACSQHC) identified dementia as a priority area for the establishment of a registry in December 2016.

The aim of the current project is to pilot and assess the feasibility of a Dementia Clinical Quality Registry (CQR).

This project will develop and test methodology for a dementia CQR by utilising data acquired from the ASPREE study cohort.
ASPREE (ASPirin in Reducing Events in the Elderly)

- ASPREE is the largest primary prevention aspirin study ever undertaken in healthy older people.
- It will determine whether daily low-dose aspirin prevents or delays the onset of age-related illness such as cardiovascular disease, dementia, depression and certain cancers and if the benefits outweigh the risks, such as bleeding.
- ASPREE is a randomised, double-blind placebo controlled study.
- It involves 16,703 Australian males and females, 70 years of age and older.
- Results of the principal ASPREE study should be known in 2018.

https://aspree.org/aus
**Phase 1: 2nd Analysis of ASPREE data and Delphi for CQI’s & MDS**

**Delphi**
- Literature review, incl. guidelines, evidence-base
- Ethics approval for the Delphi study
- 1. Inform CQI’s and MDSs
  2. Delphi panel process

**ASPREE**
- Existing dementia and MCI cases as of 12 June 2017. ASPREE participants provided consent for secondary data analysis.
- 1. Interrogation of data and information on ASPREE participants with adjudicated dementia (Endpoint Yes=490; No=385) or MCI in the ASPREE database.
  2. Determine utility of data linkage via current processes for ASPREE.
- Testing feasibility of proposed CQI’s and MDS elements using the ASPREE data

**Phase 2: ASPREE Cohort**
- Prevalent “legacy” dementia and MCI cases
- Incident “new” dementia and MCI cases
- Data collected in pilot registry will be determined by Phase 1 by ASPREE data interrogation and the Delphi process, and will broadly include:
  - Clinical quality indicators for diagnosis, follow-up, treatment, management (for some, additional data collection and consent by ASPREE will be needed).
  - PROMs and CROMS
- Annual data collection for the DPR will be conducted.
  Consent for participation will be re-negotiated at each data collection point with the person with dementia/MCI.
  If person with dementia/MCI does not have capacity to consent, carer consent will be obtained and assent will be sought from the person with dementia/MCI.

**Phase 3: Community cohort**
- Incident “new” cases - person with dementia/MCI identified via GP, hospitals, memory clinics, ACAT assessments, etc.
**Phase 1: 2º Analysis of ASPREE data and Delphi for CQIs & MDS**

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CLINICAL PRACTICE GUIDELINES FOR PEOPLE WITH DEMENTIA (NHMRC CDPC, 2016)

To provide health professionals and carers in primary care, aged care and hospital settings with access to recommendations reflecting current evidence on dementia care to better respond to the needs and preferences of the person living with dementia.

These guidelines contain 109 recommendations:
• 29 are evidence-based recommendations
• 7 are consensus-based recommendations
• 73 are practice points

CQI/MDS DEVELOPMENT
MODIFIED DELPHI STUDY

Across stages of dementia:
• Mild Cognitive Impairment (MCI)
• Mild
• Moderate
• Severe

Across the continuum of care:
• Pre-diagnosis
• Diagnosis
• Management and treatment
• Outcomes – living with dementia
CQI/MDS DEVELOPMENT
EXAMPLE FROM THE SWEDISH DEMENTIA REGISTRY (SveDem; Religa et al., 2015)

• Proportion of patients diagnosed during last year in reference to the estimated overall dementia incidence in Sweden (i.e., approx. 20,000 patients p.a.)
• Proportion of patients undergoing basic dementia work-up (aiming for 90%)
• Proportion of AD patients treated with cholinesterase-inhibitors or memantine (aiming for 80%)
• Proportion of patients with dementia treated with antipsychotics in nursing homes
• Proportion of patients with dementia receiving day-care
• Proportion of patients with dementia living in nursing homes
• Proportion of patients with dementia followed-up at least once a year
RESOURCES

RESOURCES

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/

ASPREE Study
• https://aspree.org/aus/
THANK YOU!

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