A National Dementia Registry for Ireland: A Feasibility Analysis

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We would like to thank sincerely

- Our participants in this study
  - Irish Dementia Working Group
  - Experts

- Our Expert Advisory Panel
  - Dr Tony Foley (University College Cork)
  - Prof. Anthony Staines (Dublin City University)
  - Prof. Carol Brayne (University of Cambridge)

- The Alzheimer Society of Ireland
  - Dr Emer Begley

Objectives:

1. Review **patient registry models** in Ireland and examine their function and operation.

2. Review **dementia registries** that exist in other jurisdictions and examine their function and operation.

3. Undertake a **'landscape analysis'** identifying the impact of relevant legal, ethical, clinical, IT systems and financial issues crucial to the development of a national dementia registry.

4. Provide **evidence-based policy recommendations** that can progress the issue of improved recording structures for dementia in Ireland.

Method:

- Rapid literature review (published and grey literature)
- Semi-structured expert interviews with national and international experts (n=21)
- Focus groups (n=2) with the Irish Dementia Working Group (n=9)
  - Potential benefits and risks of a national dementia registry from the perspective of those with a diagnosis of dementia

The study ran from January to July 2016 - Report was launched on 1st December 2016

- **Reliable, accurate, valid, comprehensive and timely data** has a significant record of contributing to the effective and efficient planning, operation and evaluation of health and related social services

- But, data collection can be expensive in terms of **time and cost**, requires **ethical justification** and **flexibility** to adapt to a changing legislative environment (cost-benefit analysis recommended).

- The Swedish Dementia Registry is the most comprehensive model (it has a national mandate) but smaller models do exist (e.g. Girona).

- Ireland lacks any strategic policy related to patient registries.
  - Irish registries are heterogeneous with regard to size, function, disease, funding, cost and governance
  - Yet, existing patient registries in Ireland demonstrates that a lot can be achieved within the current limitations of the Irish health system

Six general and three cross-cutting themes were identified

A registry should **provide information** that **improves** dementia-related **policy and decision making** in Ireland, **improves the care** provided to people living with dementia and **supports research**.

"Knowing who, where, when and why so that we can actually do planning for the future by looking at data"

[Health Informatics Expert]

"So there's a group of people out there that actually aren't even being recognised as having dementia. So when we talk of 48,000, that's a rubbish number really"

[Person with Dementia]

The registry must be very clear about:
- **whose data** will be collected (formal dementia diagnosis)
- the **type of data** that will be held (anonymised, de-/pseudo)
- the **consent** model (mandatory, opt-in, opt-out)
- that the data is **accurate, complete and fit-for-purpose**

"The entry point should be a diagnosis of dementia."

[Policy Expert]

"I think anonymising the information in one phase. If there is any move outside of that phase, for any reason, then I think the individual needs to be in charge."

[Person with Dementia]

Experts agreed that data collection is a **complex** process as the registry will need to gather data from **primary care** and from **secondary care**.

"We don't have a joined up system here, we don't have electronic records systems… There are going to be lots of practical issues in terms of assessing records [and] *in terms of data protection."*

[Clinical Expert]

"So, a universal patient identifier makes life easier. It doesn't completely avoid some of the difficulties... But it does make cross-referencing a bit less tedious." [Registry Expert]

"I think there has to be some incentive to be able to get data out of different organisations." [Health Informatics Expert]

Clear procedures and safeguards are needed:

- to ensure that registry data remain **private**
- to decide who can **access** registry data and for what purpose

"You've got to think about things like access controls to that information… should there be a hierarchy of access based on the sensitivity of the information concerned?"

[Legal Expert]

"I think people would have to be very assured of confidentiality and the use of a register beforehand."

[Person with Dementia]

- The registry should be **independent** and **formal management structures** need to be set up.

- The **quality** of the registry should be evaluated over time and these results should be publically available.

- The registry must ensure that enough **funds** are available to sustain the registry over time.

"Ours is a professional board which I would very, very strongly urge… You need a technical board. You need a board you can actually go to for advice."

[Registry Expert]

The feasibility of any patient registry is influenced by the environment in which it operates. Experts highlighted relevant legislation for Irish registries including:

- European Data Protection Reform 2016

- Assisted Decision Making (Capacity) Act 2015

- Potential Health Information and Patient Safety Bill

"*But data protection should not be seen as a barrier to obtaining this information. It's a worthwhile goal and it will ensure that the way you treat the information is proper and correct.*"

[Legal Expert]

1. **Benefits and risks**
   - The majority of experts agreed that dementia registries are beneficial.
   - Although there are associated risks, these can be mitigated.

2. **Barriers and facilitators**
   - Barriers: Lack of strategic policy and suitable funding mechanisms, and complexity of data collection.
   - Facilitators: Recent legislation changes, the availability of registry expertise in Ireland and the acknowledged lack of dementia data.

3. **Dementia-specific challenges**
   - The complexity of a dementia diagnosis, the degenerative nature of dementia, and the stigma associated with dementia.
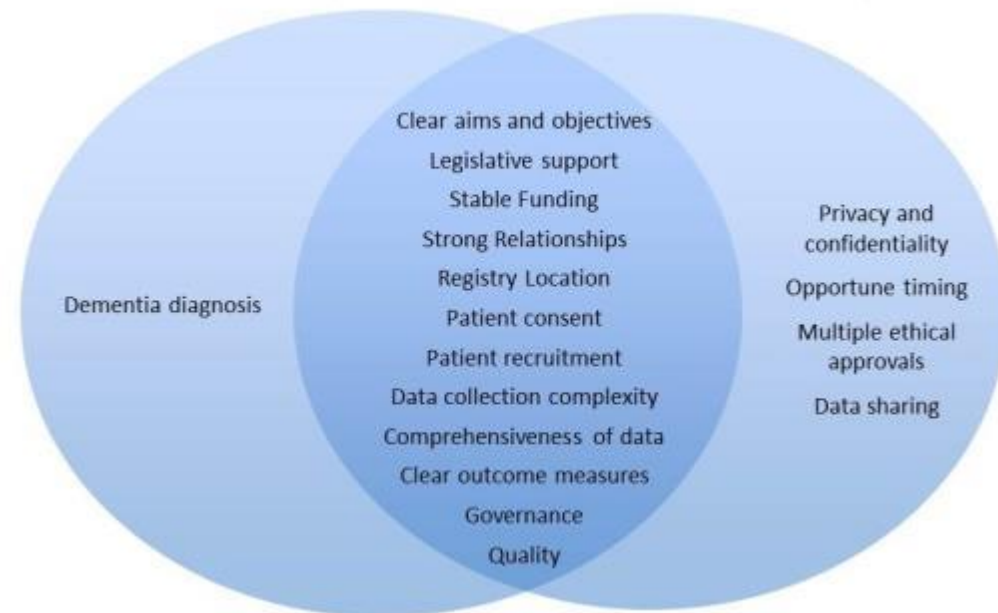
Characteristics of successful patient registries

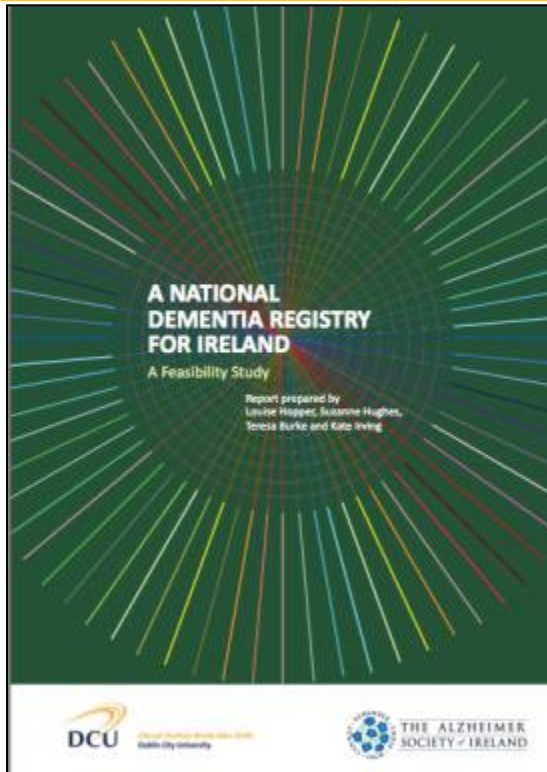|		
Clear, focused and agreed aims and objectives	Appropriate and adaptable data collection methods	Establishment of a multi-disciplinary registry team
Tangible benefits	Reimbursement for data providers	Dedicated registry administrator with guaranteed funding
Stable funding	Data and reports useful to frontline staff	Formal consent, privacy, confidentiality and data protection procedures
Registry defined with respect to its primary purpose	Web access to registry reports (and data entry in many cases)	Formal data analysis, publication and sharing principles
Clear participant inclusion and exclusion criteria	Clear and transparent governance with clear roles and responsibilities for all stakeholders	Formal quality control and registry evaluation procedures
Clearly defined data sources	Patients treated as partners	Flexibility – ability to adapt to changing environment
Agreed minimum dataset	Clear ownership of the registry	Registry functions include raising awareness of value of registries
Minimal data collection – concise, avoid duplication	Clear and visible leadership	Educational support for all those interacting with the registry

- There is general agreement that patient registries have a role to play in national public health strategies

- Existing Irish patient registries demonstrate that a lot can be achieved within the current limitations of the Irish health system

- An Irish National Dementia Registry could feasibly address the need for more accurate and comprehensive dementia data

- Next step is to establish a collaborative multi-disciplinary registry team to develop a business case proposal

International Dementia Registries / Irish Patient Registries

Dementia diagnosis

Clear aims and objectives
Legislative support
Stable Funding
Strong Relationships
Registry Location
Patient consent
Patient recruitment
Data collection complexity
Comprehensiveness of data
Clear outcome measures
Governance
Quality

Privacy and confidentiality
Opportune timing
Multiple ethical approvals
Data sharing

Available on the Alzheimer Society of Ireland and DCU web sites

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