

The Feasibility of a National Dementia Register for Ireland

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Background

Patient registries provide data that enable the course of a disease to be observed, to identify inequities in service provision and use, to assess the efficacy of clinical outcomes, and to explore the impact of the condition on patients' lives. Each is essential to informed clinical and policy decision-making and health economic assessment¹.

The Medical Research Charities Group (MRCG) and the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) argue that patient registries should be "central to the planning, delivery and review of health care in Ireland"¹. Although Ireland does not as yet have a national patient registry strategy, many registries already exist and more are in the process of development.

In response to the very poor recording and coding of dementia across all care settings², and the scarcity of data needed to inform clinical and policy decisions with regard to dementia, the Alzheimer Society of Ireland commissioned this evidence-based review of the feasibility of creating a National Dementia Register for Ireland.

Aims & Objectives

- Review patient registry models in Ireland and dementia registries that exist in other jurisdictions and examine their function and operation.
- Identify the impact of relevant legal, ethical, clinical, technology, and financial issues crucial to the development of a national register.
- Provide evidence-based policy recommendations to progress the issue of improved recording structures for dementia in Ireland.

Methodology

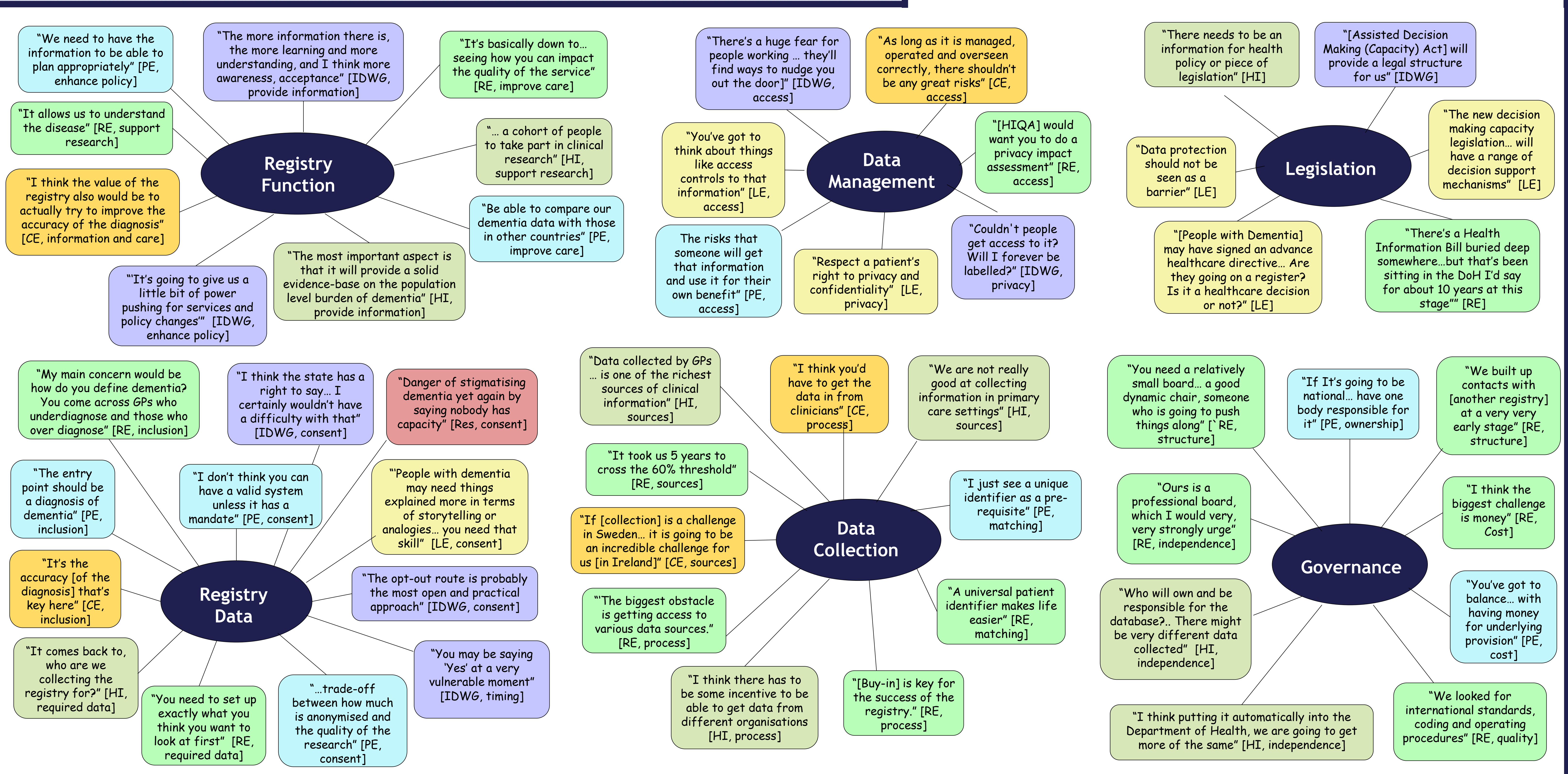
1. Rapid review of policy documents, published research and grey literature pertaining to patient and to dementia registries.
2. Semi-structured interviews ($n=21$) with national and international experts: clinical, policy, health informatics, legal, technical, international dementia registries and the National Cancer, Cystic Fibrosis, and Idiopathic Pulmonary Fibrosis Registries of Ireland.
3. Focus groups ($n=2$) with representatives of the Irish Dementia Working Group (IDWG; $n=9$; Male=5, Mean age = 63.56 years). Interviews and focus groups were audio-recorded, transcribed, anonymised and analysed using inductive content analysis.
4. Personal communication with other experts ($n=13$) who were unavailable for formal interview.

Findings

Analysis of the expert interviews and focus groups revealed six themes and these are illustrated with anonymised direct quotes. Three high-level cross-cutting themes were also identified:

1. Benefits and Risks
2. Barriers and Facilitators
3. Dementia-specific Challenges.

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|----------------------|-------------------------------------|
| Policy Expert (PE) | Irish Dementia Working Group (IDWG) |
| Clinical Expert (CE) | Research Expert (Res) |
| Registry Expert (RE) | Legal Expert (LE) |



Lessons from Existing Registries

A number of key lessons can be learned from existing registries; most are common across registries, but the subjectivity of a dementia diagnosis is particularly problematic and while the timing is opportune, aspects of the Irish health environment are also challenging.

Table 1. Active International population and clinical dementia registries

| Registry | Country | Category | Year | Size | Inclusion | Assessment | Data Sources | Data Collected | Ownership | Consent | Funding |
|----------|---------|------------|------|--|----------------------------------|------------|---|---|--|---------------------------|---|
| SveDem | Sweden | Population | 2007 | 58,823 | Dementia diagnosis | ICD-10 | Specialist Clinics, Primary Care, Nursing Homes | Unique Identifier, Diagnosis, Dementia sub-type, MMSE, Diagnostic data, Pharmacological and non-pharmacological treatment and support, BMI, Demographic data, annual follow-up data | Karolinska University Hospital | Opt-out | State and Swedish Brain Power Network |
| DCDR | Denmark | Population | 2005 | 30% of Danish population of PwD as of 2011 | Dementia and query including MCI | ICD-10 | Geriatric, psychiatric and neurology clinics | Data relating to eight quality indicators including diagnosis, sub-type, medication [see section 3.1.1.2] | Danish Clinical Register | Mandatory | State |
| ReDeGi | Spain | Clinical | 2007 | 70% Girona population to date | Dementia diagnosis | DSM-IV-TR | Geriatric and neurology departments | Data source, diagnosis, diagnostic data, MMSE, CDR, IQWiP | Department of Health (Cataluna) | Opt-in | State |
| SCADR | USA | Population | 1988 | 230,000 | Dementia diagnosis | ICD-9 | Federal, diabetes, Revenue and Fiscal Affairs Offices | Case-identifying data, diagnosis, source, socio-demographic data, Caregiver contact details, other medical diagnoses | Department of Health and South Carolina University (joint) | Mandatory HIPAA exemption | Partial state funding (not guaranteed) |
| WVADR | USA | Population | 2011 | 28,000 | Dementia diagnosis | ICD-10 | Medicare Clinicians | As for SCADR | West Virginia University | Mandatory HIPAA exemption | Previous state funding; currently uncertain |
| GAADR | USA | Population | 2014 | 112,430 (2013) | Dementia diagnosis | ICD-9 | Medicare | As for SCADR plus diagnostic test results | Georgia Department of Health | Mandatory HIPAA exemption | State |

International Dementia Registries vs Irish Patient Registries

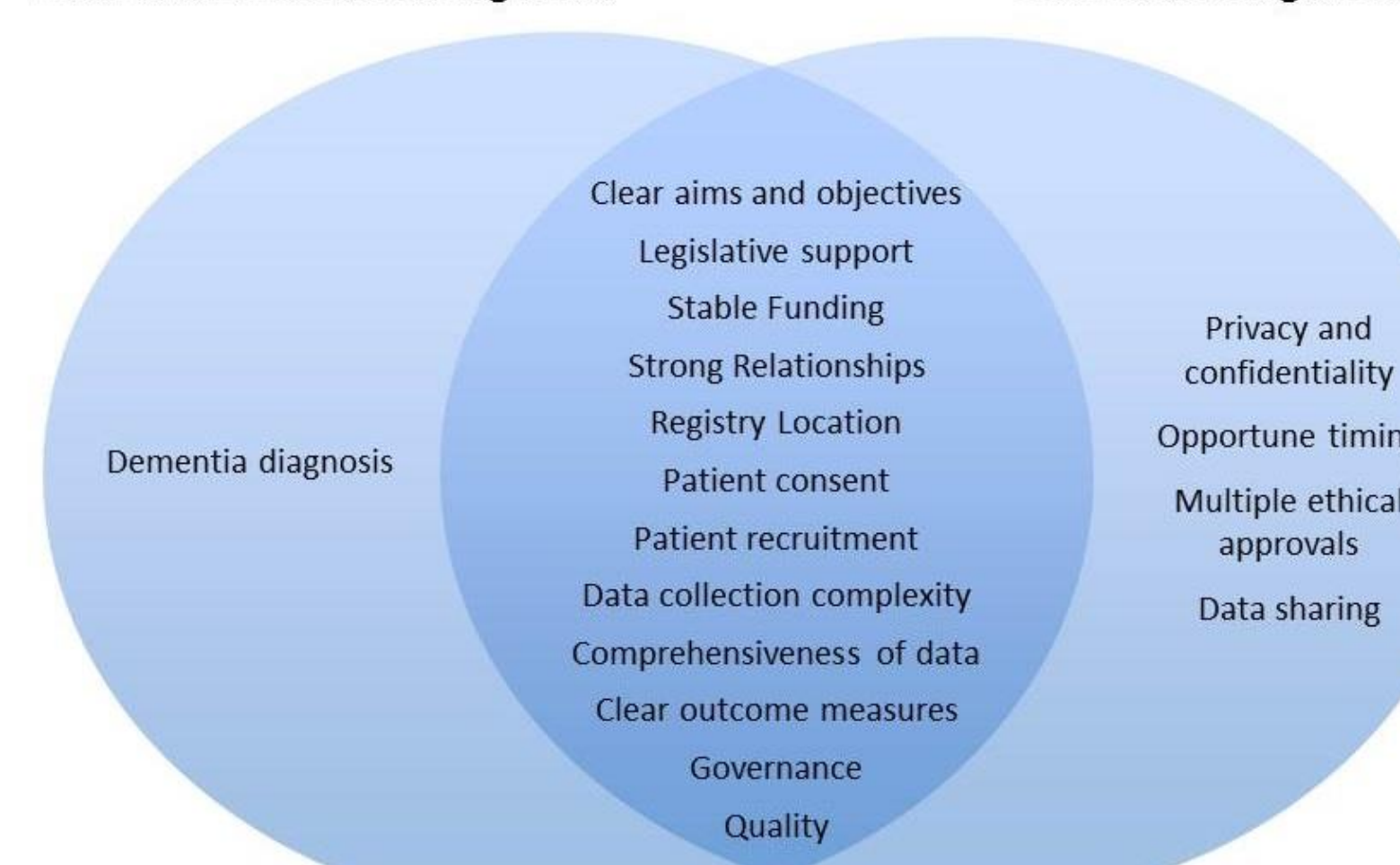


Figure 1. Lessons learned from discussions with existing registries

Conclusions

There is general agreement that patient registries have a role to play in national public health strategies. Successful registries capture data from the patient's point of entry into the health system and across all subsequent interactions, and they illustrate the clear need for collaboration and data sharing. 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.

References

1. Medical Research Charities Group (MRCG), & Irish Platform for Patients' Organisations Science and Industry (IPPOSI). (2011). *Towards a National Strategy for Patient Registries in Ireland: Considerations for Government*.
2. Cahill, S., O'Shea, E., & Pierce, M. (2012). Creating excellence in dementia care: a research review for Ireland's national dementia strategy.