

# Development of a Model for the National Dementia Registry



## ACCESSIBLE SUMMARY DOCUMENT

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### Background

There is very poor recording of dementia data across all care settings in Ireland. Many other countries recognise the importance of having a dementia registry and they use data from the registry to support the development, the operation and the quality of their dementia health and social care services. This summary presents the main results and conclusions from a study to determine a suitable model for a national dementia registry for Ireland. This study was funded by Dormant Accounts through the Department of Health (DoH), commissioned by the National Dementia Office (NDO) in the HSE and conducted by the School of Psychology in Dublin City University.

The study aimed to:

- Identify all stakeholders that need to be involved and establish expert teams
- Agree the primary aims and objectives for an Irish national dementia registry including reaching agreement on the outcome measures that should be included
- Determine the scope and target population of the registry
- Decide what data will be collected, identify the appropriate data sources and determine how this data will be managed and stored
- Develop the consent process that will be required to gain access to this data
- Decide how the registry data will be analysed and how results will be disseminated
- Determine the most appropriate and practical design for the registry
- Test the model for efficacy and effectiveness;
- Estimate the costs involved and develop a business case for a national model
- Determine who will own the National Dementia Registry of Ireland
- Develop governance and quality procedures for the National Dementia Registry of Ireland.

The study ran for 30 months from May 2018 to October 2020 and it involved the following activities:

- The creation of an expert Steering Group and a Special Interest Group of people with lived experience of dementia who supported the DCU team and guided the direction of the study
- A review of published literature and international policies and guidelines relating to developing a dementia registry
- Collaboration between stakeholders and registry experts to develop the recommended outcomes that the registry will monitor and the minimum set of data that will need to be captured to allow that monitoring to take place
- The development of a suitable model for the National Dementia Registry. This included recommending a suitable technical infrastructure to support the running of the registry and the secure storage of registry data
- A test of the efficiency of the model with sample data
- Preparation of a full report including presenting the recommended registry model and recommendations for next steps



## What we Learned

The review of the literature and the experience of existing dementia registries clearly showed that the Irish dementia registry should focus on quality and clinical improvement.

The aims of the registry will be to:

- Improve patient care and outcomes for the person with dementia
- Provide quality assurance and /quality indicators
- Assist with dementia planning/policy
- Assist in the long term with research.
- Although best practice guidelines recommend that patient registries should be independent of the health service, legislation and health regulations make that difficult in Ireland. As a result, the registry will sit inside the health system, more specifically with the HSE.

### Outcome Measures

It is important that the National Dementia Registry tracks and reports on meaningful dementia indicators. The outcomes that matter most to people with dementia, their families, health and social care professionals, service providers and policy makers were examined and prioritised. Fourteen outcomes were identified and the top five priority indicators are:

- Proportion of patients undergoing basic dementia work up
- Overall quality of life of person with dementia
- Proportion of patients with dementia who receive a specific dementia diagnosis
- Overall Quality of Life and wellbeing of Carer
- Proportion of patients treated with antipsychotic drugs

At a minimum, the national dementia registry will need to collect the data that is needed to measure these outcomes.

### Possible Data Sources

Dementia data is collected and captured in primary care, in hospitals, and in public and private parts of the health service. In the absence of an electronic health record, there is no one obvious source of data that can be used for a Dementia Registry. It may be possible in the future to link the registry with GP, hospital or pharmacy systems. In the short-term, the most logical starting point for the registry will be in memory clinics. These capture a rich source of data, although not everything that the registry will need. Some updates will be needed to ensure that all the required data is gathered and sent to the registry.

### Developing and Testing the Model

It became clear that a model was needed that balanced the urgent need to create a dementia registry with the ability to integrate with electronic data sources as they become available. This study recommends a model that comprises of a registry database, a web-based user interface and modules that will support data collection, data management, data analysis and reporting, and system administration. This model can grow over time making it possible to start implementing the registry in memory clinics and expanding to include other settings and other sources of data.

We began testing a prototype model in February 2021. Unfortunately COVID-19 closed the clinics shortly afterwards, but the test found that the majority minimum dataset is available in memory clinics and relatively easily to collect. The biggest gap in the data related to treatment and care (e.g. quality of life data).

### Funding

The estimated cost of implementing phase 1 (memory clinics) is €356,000 (inc VAT)

Table 27 National Dementia Registry Minimum Dataset

Patient Characteristics	Service Provider Characteristics	Diagnostic Characteristics	Treatment and Care Characteristics
Registry ID	Clinic ID	Dementia diagnosis	Dementia medication
Patient IHI number	Referral from	Has the person been told about their diagnosis	Anti-depressant medication
Patient GMS /MCN number	Date of receipt of referral	Translation to other disease classifications	Anti-Psychotic medication
First Name	Date of Initial Assessment for dementia	Diagnosis made by	Benzodiazepines
Family Name	Date of Dementia Diagnosis	Brief cognitive test	Total number of medications the person is taking
Date of Birth		Comprehensive neuro-psychological evaluation completed	Has a personalised care plan been created
Sex at Birth		Neuroimaging testing completed (e.g. CT/MRI/MRI dementia protocol)	Who created the care/ support plan
Address		Bio-markers completed	Current Supports
Eircode		Functional Evaluation	Psychosocial interventions Post-diagnostic Support
Marital Status		Disease progression measure	Advanced care planning
Living Status		Disease stage (translation from disease progression measure)	Has this person a dedicated single point of contact within the health service?
Socially active			Has this person a case manager?
Physically active			QoL-AD Quality of Life measure carried out with the person who has dementia
Hearing impairment			WHOQOL Quality of Life measure carried out with Carer
Vision impairment			Date of Death
Driving			
Education			
Employment status			
Employment position			
ID			
Aetiology of ID			
Weight in kg			
Height in M2			
Body Mass Index			
Alcohol Status			
Smoking Status			

## High-Level Recommendations

This study makes five high-level recommendations to support the successful development of a national dementia registry in Ireland. Each of these recommendations are broken down into the key actions that are required in order to implement each recommendation. The evidence to support all of these recommendations has been presented in the full report.

### Funding and Long-term Commitment

- HSE ownership; Establish governance structures
- Stable funding stream; Dedicated Dementia Registry team

### Infrastructure and Systems are developed

- Phase 1: Develop model and infrastructure to support implementation with memory clinics
- Complete procurement; engage software vendor with registry experience
- Work with stakeholders and developers to complete registry build and test

### Adopt a phased implementation - Implement Phase 1

- Initial implementation with memory clinics; integration with electronic data (HSE datasets) in later phase (e.g. Phase 2 or 3)
- Continue to align with Chronic Disease Management System; Minimum dataset can evolve over time as needed

### Continued and prioritized work on projects that assist the National Dementia Registry

- Standardisation of required data in memory clinics (includes quality of life and disease progression measures)
- In-depth review of the feasibility of bringing primary care into the registry in a future phase (e.g. Phase 2 or 3)
- Continued work on national guidelines, diagnostic and post-diagnostic care pathways; KPIs (PROMs) for dementia care
- National rollout of Individual Health Identifiers; and the InterRAI™ single assessment tool including care plans

### Progress Strategic initiatives that would assist the National Dementia Registry

- Strategic direction with regard to patient registries urgently needed in Ireland; Standardised approach to registry development
- Consideration and clarity regarding legislation and health regulations