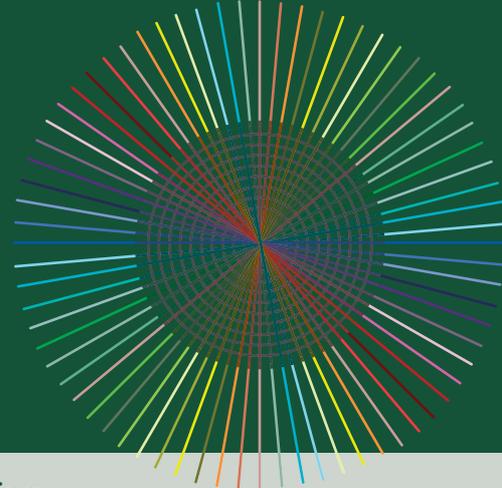


# A NATIONAL DEMENTIA REGISTRY FOR IRELAND:

## A Feasibility Analysis

### ACCESSIBLE SUMMARY DOCUMENT



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## Background

There is very poor recording and coding of dementia across all care settings. This is unlike other countries that have national structures, such as registries which play a vital role in the development of many aspects of healthcare services. This summary presents the main results and conclusions from a research study to determine the feasibility of creating a national dementia registry for Ireland. This study was commissioned and funded by the Alzheimer Society of Ireland.

The study aimed to:

- Examine existing patient registries in Ireland to determine their purpose, function, and how they operate.
- Review dementia registries that exist in other countries to determine their function. How they operate and how their data is used.
- Examine the legal, ethical, clinical, technical and financial issues that arise when developing a national dementia registry.
- Provide policy recommendations based on this evidence with the aim to improve how we currently gather data related to dementia in Ireland.

The study ran from January to July 2016 and it involved the following activities:

- A review of published literature and international guidelines related to creating patient registries in general and to developing dementia registries more specifically.
- Interviews with 21 experts including healthcare professionals involved in dementia care, policy makers in Ireland and the UK, representatives of existing Irish patient registries and existing international dementia registries, patient advocacy groups, and funding groups.
- Two focus groups with a total of nine members of the Irish Dementia Working Group.
- Analysis of the information gathered from the expert interviews and focus groups to identify the main areas (themes) that emerged.
- Preparation of the feasibility report including key conclusions and recommendations for potential next steps.

## What we learned

The review of the literature clearly showed that patient registry data are essential for informing public health policy, improving patient care, supporting health research and facilitating health technology assessment. Best practice guidelines have emerged in recent years that provide direction regarding the purpose of registries, data selection, collection and management, registry management and registry quality.

Several international dementia registries are currently operating, but they tend to follow different models. The Swedish Dementia Registry is the most comprehensive dementia registry. It gathers data from all individuals who have been formally diagnosed with dementia (unless they decide to opt-out of the process). This is collected from GPs, hospitals

and memory clinics. A variety of smaller dementia registries also exist and the Registry of Dementia in Girona, Spain is a good example of a simpler model that could be used as a starting point. It also allows for the scope of the registry to expand over time.

Although we do not as yet have a dementia registry in Ireland, a number of other patient registries exist. For example, the National Cancer Registry of Ireland and the Cystic Fibrosis Registry of Ireland.

Unfortunately, there is a lack of strategic direction in Ireland with regard to patient registries so the models that are used by Irish patient registries vary considerably. However, their ability to successfully operate shows that a lot can be achieved within the current limitations of the Irish health system.

## Expert interviews and focus groups

The analysis of the expert interviews and focus groups revealed six general themes represented by the circles in the diagram below.

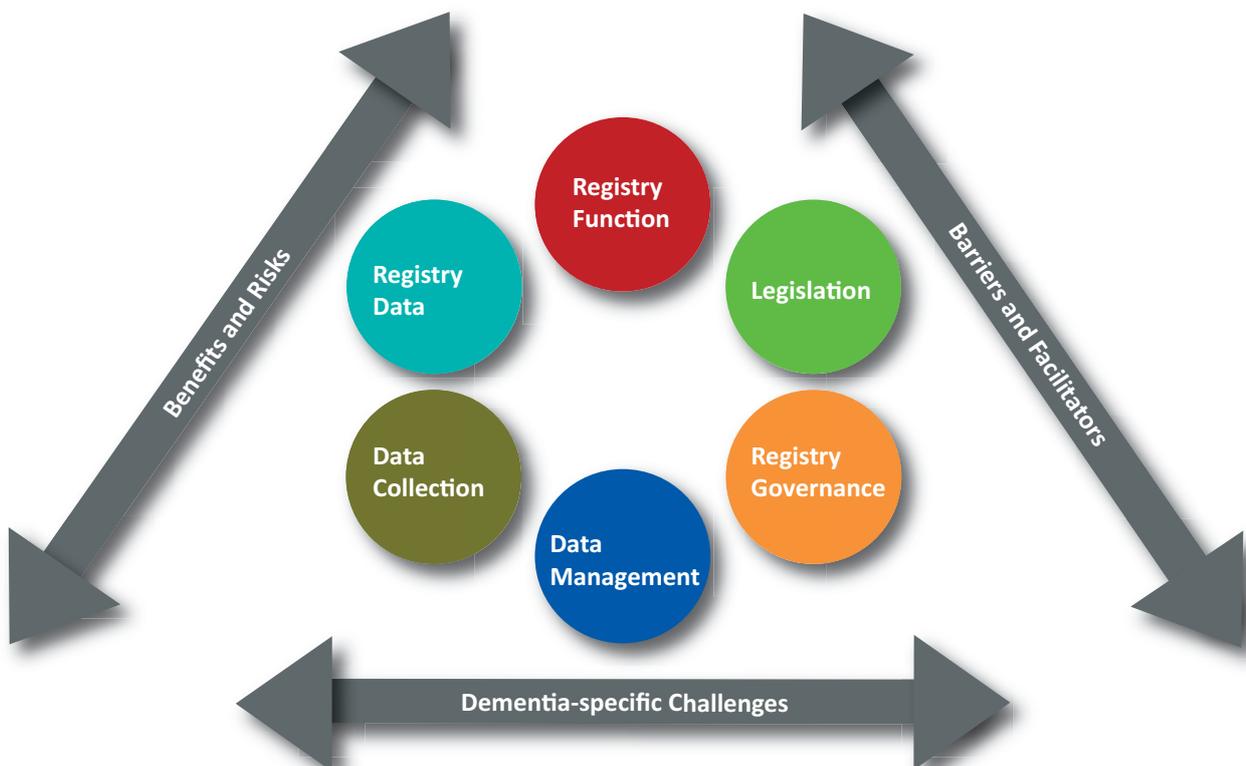


FIGURE 1 General and cross-cutting themes identified in the analysis of expert opinion

## 1. Registry function:

Experts and focus group participants agreed that 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 data 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]

## 2. Registry data:

The registry must be very clear about whose data will be collected and it was recommended that a formal diagnosis of dementia would be the starting point. Opt-in and Opt-out consent models are possible. In general, people were comfortable with the idea of providing the registry with anonymous ‘statistical’ data, but they felt that additional consent would be required for any identifiable data that would be collected. Finally, the registry must ensure that all data are accurate and complete.

“I think anonymising the information is one phase. If there’s any move outside of that phase, for any reason, then I think the individual needs to be in charge.” [Person with dementia]

## 3. Data collection:

Experts agreed that data collection is a complex process as the registry will need to gather data from primary care (e.g. GPs) and from secondary care (e.g. memory clinics and hospitals).

“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 accessing records [and] in terms of data protection.” [Clinical expert]

## 4. Data management:

Clear procedures and safeguards are needed to ensure that registry data remain private. Clear rules are also needed to decide who can access registry data and for what purpose. People giving their data to the registry need to be sure that it will be stored securely and that no identifiable information will be given out without their prior consent.

“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]

## 5. Registry governance:

Experts agreed that the registry should be independent and that 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. It is also important to ensure that enough funds are available to keep the registry operating over time.

“Ours is a professional board which I would very, very strongly urge... You need a technical board. You need a board that you can actually go to for advice.” [Registry expert]

## 6. Legislation:

Experts felt that the registry needs to pay particular attention to recent changes to data protection and capacity legislation.

“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]

In addition to the above, three high-level cross-cutting themes were also identified:

### (i) Benefits and risks:

The majority of experts and focus group participants felt that there were a lot of benefits to be gained from developing a national dementia registry as long as the risks (e.g. data protection, consent) are managed properly.

### (ii) Barriers and facilitators:

A lack of strategic direction for registries, no obvious funding source, and the complexity of data collection were the main barriers that were identified. However, there is a growing awareness of the lack of quality dementia data in Ireland. This coupled with available registry expertise in Ireland means that this is a good time to consider the creation of a dementia registry.

### (iii) Dementia-specific challenges:

Making a diagnosis of dementia is difficult and diagnosis rates remain low. In addition, there is still some stigma associated with the diagnosis in Ireland that might further reduce numbers of people willing to provide their data to the registry.

# Key conclusions and recommendations

This study highlights the characteristics that a registry needs to have to be successful and the pitfalls to avoid. We can learn a lot of lessons from international dementia registries and from existing patient registries in Ireland. It is also clear that a number of steps now need to be taken to ensure that a comprehensive proposal is developed quickly. These are:

- Establish an expert team to further the discussion regarding the feasibility of the National Dementia Registry of Ireland.
- Identify all stakeholders that need to be involved in these discussions.
- Determine if creating a national dementia registry is the right thing to do (a) at all and (b) now.
- Establish the funding that is needed to support proposal development.
- Agree the primary aims and objectives of an Irish national dementia registry.
- Agree the outcome measures that should be included in the registry.
- Determine the scope and the target population of the registry.
- Decide what data will be collected.
- Identify the best data sources.
- Develop the consent process that will be required to gain access to these data.
- Decide how data will be collected and stored.
- Decide how registry data will be analysed and how results will be disseminated.
- Determine the most appropriate and practical design for the registry.
- Identify potential long-term sources of funding for a national dementia registry.
- Estimate the costs involved in initially developing the registry and the ongoing operational costs.
- Determine who will own the National Dementia Registry of Ireland.
- Develop governance procedures for the National Dementia Registry of Ireland.
- Develop quality procedures for the National Dementia Registry of Ireland.
- Finally, it will be important for the registry team to advocate for a suitable policy and legislative environment, and suitable funding to support the development and operation of a dementia registry in Ireland.

For further information contact:

-  Alzheimer National Helpline: **1800 341 341**
-  [www.alzheimer.ie](http://www.alzheimer.ie)
-  Find us on Facebook at **The Alzheimer Society of Ireland**
-  [twitter.com/alzheimersocirl](https://twitter.com/alzheimersocirl)



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