Poster presentations

70 DEVELOPING A MODEL FOR A NATIONAL DEMENTIA REGISTRY IN IRELAND

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Background: With dementia prevalence set to increase as our population ages, there is an urgent need to gather valid epidemiological data that provides accurate and reliable national estimates of current and future dementia prevalence, facilitates the development of robust and effective dementia health and social policy, and enables the flexible provision of services nationally and at a local level.

Methods: Building on the recommendations of a study analysing the feasibility of a National Dementia Registry for Ireland (Hopper, Hughes, Burke & Irving, 2016), the Health Service Executive’s National Dementia Office have commissioned the development of a model for a dementia registry or national database that will support the roll-out of the National Dementia Strategy and has the potential to improve dementia care management, and inform and improve clinical outcomes for individuals living with the condition.

Results: Development of an appropriate model for the collection and management of dementia data nationally, includes input from policy makers, registry experts, clinicians and from people living with dementia in order to determine the primary aims and objectives of the registry, the scope and target population of the registry, the data to be collected, outcome measures and how best to use the data to meet the primary objectives of the registry. Legal, ethical and data protection expertise will assist in the development of appropriate consent and data management processes. Technical expertise will help identify a suitable technology platform and health economic expertise will assist in costing the resulting model. All stakeholders will inform the governance and quality procedures for the registry.

Conclusion: The resulting model will be aligned with national eHealth policy and provide a framework for the collection, analysis and dissemination of national dementia data in a reliable, accurate, valid, complete and timely way, thus delivering a sustainable platform to support dementia care and timely intervention in Ireland.