



The Need for a Multiple Sclerosis Patient Registry in Ireland

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An MS registry in Ireland – where are we now?

- There is currently no patient registry for multiple sclerosis in Ireland, despite Ireland having one of the highest incidences of MS in the world (9,000 approx)
- Multiple sclerosis registries exist in a number of countries internationally and there are now some collaborative efforts underway to conduct cross-border data collection
- E.g. European Multiple Sclerosis Platform's European Register for Multiple Sclerosis project ([EUReMS](#)) ran from 2011 to 2014 and collected data from MS registries in 12 European countries

An MS registry in Ireland – where are we now?

- In 2017 MS Ireland published a Briefing Document on the need for a registry: <https://bit.ly/2yVxg5l>
- This document was sent to key MS clinicians who all expressed support for a registry project
- No previous efforts have been made to establish a registry
- The National Clinical Programme for Neurology Model of care, launched in September 2016, also references the need to establish an MS registry (HSE, 2016, p.177)
- Electronic Patient Records for people with MS exist in some individual hospitals and pharmaceutical companies hold databases on particular MS medications. MS Ireland holds a non-medical database on people with MS who interact with the organisation and use their services

Thank You!

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