

Publication Summary



Scottish MS Register

National Report 2014

Information relating to 01.01.2010 – 31.12.2013

Publication date – 9th September 2014

About this Release

This is the 4th National Report from the Scottish Multiple Sclerosis Register (SMSR). The report provides information on all people who were reported by a General Neurologist as having a confirmed diagnosis of MS from 1st of January 2010 to 31st of December 2013. This information provides epidemiological data and allows us develop an increased focus on health improvement.

Summary & Key points

- On the 31st March 2014, 1698 people had been reported to the MS Register; 421 with a date of diagnosis in 2010, 389 in 2011, 437 in 2012, and 451 in 2013.
- Over the four year time period 20 people (1%) declined contact with an MS nurse specialist.
- In 2013, more than twice as many women (325, 72%) as men (126, 28%) were diagnosed with MS.
- 57% of people newly diagnosed with MS in 2013 had contact with an MS nurse specialist within two weeks of diagnosis. This is an 11% improvement on 2012.
- 7% of people were supported by an MS Nurse specialist prior to being given a confirmed diagnosis of MS in 2013.
- In 2013, nationally the time response within two weeks was very effective (86%) once the MS Nurse specialist received patients referral.
- Delays in referral to MS nurse and delays in MS nurse receiving referral continue to be problematic.

- The majority (83%) of people diagnosed in 2013 were referred to an MS nurse specialist within 2 weeks of receiving a confirmed diagnosis; however 11% of people waited over 6 weeks before being referred. This is a 4% improvement on 2012.
- The majority (84%) of referrals to an MS nurse specialist in 2013 were received within 2 weeks; however 13% of referrals took between 2 and 4 weeks before being received by an MS nurse. This is a 3% improvement on 2012.
- Quality feedback reports, targeting individual steps in the referral process, are sent quarterly to MS clinical Leads and MS Nurse Specialists in order to identify delays and target solutions at a local level.

Background

The Scottish MS Register (SMSR) is a national Register within the Scottish Healthcare Audits programme at the Information Services Division (ISD) of NHS National Services Scotland (NSS). The aim of the SMSR is to improve healthcare for people living with MS in Scotland. Establishing the incidence of MS and interpreting the implications of its demography allows us to facilitate service evaluation and drive improvement. The data on which this report is produced is provided by General Neurologists and MS clinical teams via a [standard proforma](#) which incorporates the patient journey from referral to diagnosis, including referral to an MS Nurse specialist.

The responsibility for the oversight of the Register including maintenance of reporting standards, adherence to aims, objectives and reporting of results rests with the Register Steering Group, with multidisciplinary representation from all of the Health Boards in Scotland. The Steering Group meets regularly throughout the year to review the progress and direction of the Register in achieving its aims and objectives. Presentations of the data at both national and international meetings have been made. It is hoped that further work will be undertaken comparing the Scottish MS Register information with previous epidemiological studies and current improvement work in the management of people with MS.

Contact

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Further information can be found in the [full report](#)  [1690Kb], on the [Audit/Registry website](#) or on the [ISD website](#).

About ISD

Scotland has some of the best health service data in the world combining high quality, consistency, national coverage and the ability to link data to allow patient based analysis and follow up. Information Services Division (ISD) is a business operating unit of NHS National Services Scotland - and has been in existence for over 40 years. We are an essential support service to NHSScotland and the Scottish Government Health Department and others, responsive to the needs of NHSScotland as the delivery of health and social care evolves. www.isdscotland.org/