



Publication Summary

Scottish MS Register National Report 2013

Information relating to 01.01.2010 – 31.12.2012

Publication date – 10th September 2013

About this Release

This is the 3rd National Report from the Scottish Multiple Sclerosis (MS) Register.

The aim of Scottish MS Register is to establish the incidence of MS in Scotland, to interpret the implications of its demography and so enable service evaluation and improvement. The system for reporting people with a new diagnosis of MS to the Scottish MS Register is improving year on year; the first national report in 2011 recorded 344 people with a new diagnosis of MS, in this report the number for 2010 is now 418.

Data on all known patients registered by a Consultant Neurologist with a new definite diagnosis of MS from 1st January 2010 to 31st December 2012 in Scotland were collected using a [standard proforma](#), which incorporated the patient journey from referral to diagnosis, including referral to an MS Nurse specialist. Analysis of the data was undertaken, including outline data checks to ensure data quality and validity.

Key Points

- On 31st March 2013, 1237 people were registered, 418 with a date of diagnosis in 2010, 388 in 2011 and 431 in 2012. Twice as many women (290, 67%) as men (141, 33%) were diagnosed with MS in 2012.
- In 2012, 8% of people were supported by an MS Nurse specialist prior to be given their diagnosis. 47% of people newly diagnosed with MS had contact with a MS Nurse specialist within two weeks of diagnosis. This is an 8% decrease from 2011.
- Delays in referral to MS nurse and/or delays in MS nurse receiving referral may be accountable for the 8% decline in people newly diagnosed with MS being contacted by an MS nurse specialist within 2 weeks of diagnosis. MS team should examine delays in the referral process locally to target solutions or resources.
- Targeting individual steps may actually realise greater improvement in the referral process. The key result is that in 2012 nationally the time response within 2 weeks was very effective (85%) once the MS Nurse specialist was aware that there was a person newly diagnosed with MS who wished to be contacted. From 31st July 2012 this information is reported to the

MS Clinical Lead and MS Nurse Specialist every 3 months.

- Linkage of information from the Scottish MS Register and information collected by [Health Boards in Scotland](#) regarding hospital admissions has resulted in a reduction in the amount of information collected by clinical staff leading to a simpler registration form.

Background

The Scottish MS Register is a national register within the Scottish Healthcare Audits programme at the Information Services Division (ISD) of NHS National Services Scotland (NSS). The Scottish MS Register has been established to collect information about people with a new diagnosis of MS since 1st January 2010; General Neurologists and MS clinical teams provide the data on which this report is produced. This information provides epidemiological data and will also develop an increased focus on health improvement.

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

All enquiries should be directed to the Scottish MS Register team

E-mail the team at: NSS.ISDscottishmsregister@nhs.net or telephone: 0141 282 2212.

Further information can be found in the [full report](#), 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/