

Publication Summary



Scottish MS Register

National Report 2012

Information relating to 01.01.2010 – 31.12.2011

Publication date – 11th September 2012

About this Release

This is the 2nd National Report from the Scottish Multiple Sclerosis (MS) Register. This report contains data on all known patients registered by a Consultant Neurologist with a new definite diagnosis of MS from 1st January 2010 to 31st December 2011 in Scotland. The data was collected using a standard proforma, which incorporated the patient journey from referral to diagnosis, including referral to an MS Nurse specialist.

Key Points

- On 31st March 2012, 791 people were registered, 416 with a date of diagnosis in 2010, and 375 in 2011. Twice as many women (252, 67%) as men (122, 33%) were diagnosed with MS in 2011. The ratio of 2 women to 1 man is the same as people registered in 2010.
- In 2011, 11% of people were supported by a MS nurse specialist prior to be given their diagnosis. 52% of people newly diagnosed with MS had contact with a MS nurse specialist within two weeks of diagnosis. This is a 3% improvement on 2010.
- Targeting individual steps may actually realise greater improvement in the referral process. The key result is that in 2011 nationally the time response within 2 weeks was very effective (81%) 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

Dr Belinda Weller

Chair of Steering Group, Scottish Multiple Sclerosis Register Project

belinda.weller@luht.scot.nhs.uk

0131 537 2403

Anita Pritchard

Clinical Co-ordinator, Scottish Multiple Sclerosis Register Project
Scottish Healthcare Audits, ISD, NHS National Services Scotland

anita.pritchard@nhs.net

0141 282 2212

David Readhead

Information Analyst, Scottish Healthcare Audits, ISD, NHS National Services Scotland

davidreadhead@nhs.net

0141 282 2314

Stuart Baird

Service Manager, Scottish Healthcare Audits, ISD, NHS National Services Scotland

s.baird@nhs.net

0131 275 6333

Further Information

Further information can be found on the [Scottish MS Register 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/