



## Publication Summary

### Scottish MS Register

#### National Report 2015

Information relating to January 2010 – December 2014

Publication date – 8<sup>th</sup> September 2015

### About this Release

This is the fifth 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 multiple sclerosis (MS) from January 2010 to December 2014.

This information provides epidemiological data and allows us to develop an increased focus on health improvement.

### Summary & Key points

- In 2014, 431 new patients were reported to the MS Register as having received a confirmed diagnosis of MS. This brings the total number of people reported over the five year period to 2164.
- The annual number of MS registrations has ranged from 392 to 474 over the five year period.
- According to the Register data, NHS Orkney had the highest incidence of MS across the 5 year time period (2010 - 2014) with an average annual incidence of 19 people per 100,000.
- The average annual incidence over the five year time period shows that more than twice as many women (300) as men (132) were diagnosed with MS. The higher level of reported incidence amongst women is across all age groups (chart 7).
- The level of new patients being reported to the MS Register is greatest amongst the 25-49 year age group.
- Over the five year time period 26 people (1%) declined contact with a MS Nurse Specialist.

- 63% of people newly diagnosed with MS in 2014 had contact with a MS Nurse Specialist within two weeks of diagnosis. This is a 7% improvement on 2013 (56%) though performance does vary across Health Boards.
- Delays in MS Nurse Specialists receiving referrals from Neurologists continue to be problematic lengthening the time taken for the patient to see a MS Nurse Specialist from the date of their confirmed diagnosis.
- In 2014, once the referral was received by the MS Nurse Specialist, contact within two weeks was achieved for 85% of the patients which is an improvement of 2% on 2013 (83%).

## 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 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 are provided by General Neurologists and MS clinical teams via a [standard proforma](#) which incorporates the patient journey from referral to diagnosis, including referral to a 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 within Health Boards to improve service delivery and care for patients with MS across Scotland.

## Contact

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Further information can be found in the full report on the Registry website (<http://www.msr.scot.nhs.uk/>) 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/](http://www.isdscotland.org/)