



Scottish Multiple Sclerosis Register National Report on 2010



Introduction

Multiple sclerosis is the result of damage to myelin—a protective sheath surrounding nerve fibres of the central nervous system. The central nervous system comprises the brain and spinal cord. Together with the nerves connecting to the rest of the body, they form the body's communication network.

In the earlier stages of MS, the central nervous system can often repair areas of damaged myelin or reroute messages via different pathways of neurons thereby avoiding the damaged areas. This explains why episodes of symptoms (relapses) can be followed by weeks, months or even years when symptoms improve or disappear (remission). However, if the area of damage becomes too large, communication with that specific part of the central nervous system may become permanently blocked.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

It is often said that MS is the “Scottish disease” so it is important to know how many people in Scotland are diagnosed with the condition each year and also both where and how they are diagnosed. This information will be useful to help in planning the sort of services that people with MS need.

In 2009, funding was provided by the Scottish Government to set up the **Scottish Multiple Sclerosis Registry**. We started collecting information in 2010 with the help of the MS nurse specialists and neurologists around Scotland and we are now reporting on the results of our first year of activity.

The MS Society has been involved in the Scottish MS Register since its inception. The **MS Society** has worked with **ISD** and the Steering Group to develop a register that has people with MS as its focus and this collaboration has proved effective. The steering group directs the activities of the Scottish MS Register and it comprises Consultant

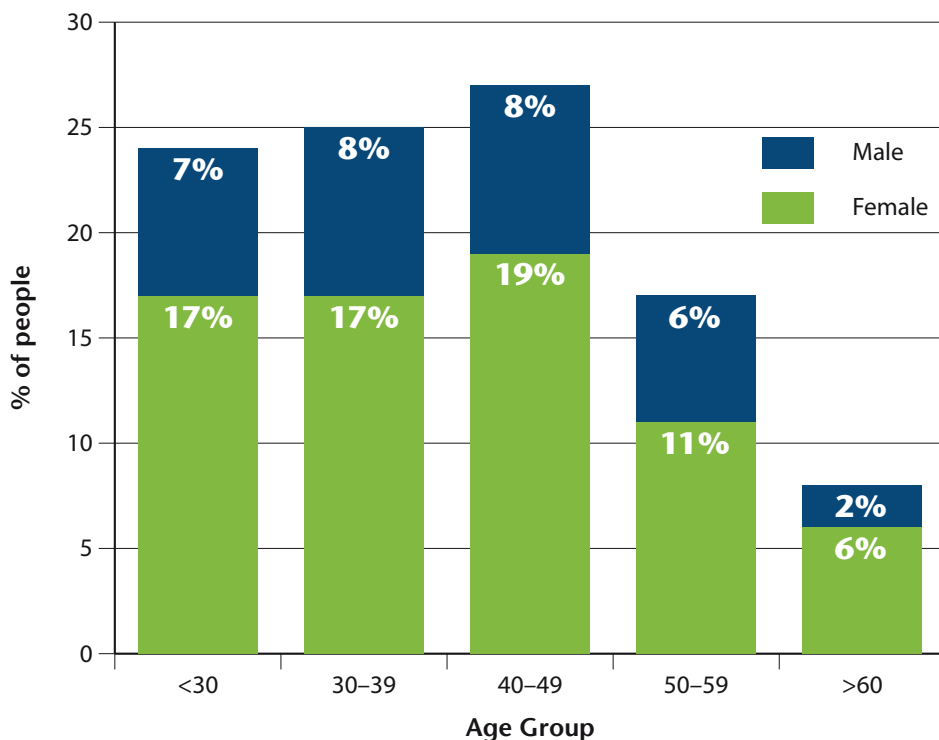
Neurologists from each health board, a patient representative, and representatives from the Scottish MS nurse group, Information Services Division, a Physiotherapist, a Consultant Epidemiologist as well as the Director of the MS Society Scotland. There is also a parallel patient representative group made up of people with MS and their carers. Both of these groups work collaboratively to guide the direction of the Scottish MS Register.

The Scottish MS Register is working with the **MS Society's UK Register project**. This project has built a working prototype register system that will be collecting information from three information sources: firstly, **from people with MS via a secure internet portal**, secondly, from clinical systems in 5 NHS MS teams from around the UK (Edinburgh being the Scottish participant), and thirdly, for the 5 NHS MS teams participating in the project, their data will be combined with routinely collected NHS patient information. Both registers will help us to develop a system that will collect information that will increase understanding and knowledge about MS at an individual and societal level, allowing regional and national authorities to make informed and tailored decisions about MS service provision.

In spite of inevitable problems in getting data from across Scotland, the data from the first year of the Scottish MS Register provide a picture of the potential of the register in its ability to provide a benchmark against which clinicians can raise standards and drive improvements in MS management across NHS Scotland.

Belinda Weller
Chair of Scottish MS Register

Figure 1 What was the age and gender distribution of people who were diagnosed with MS in Scotland in 2010, at time of diagnosis?

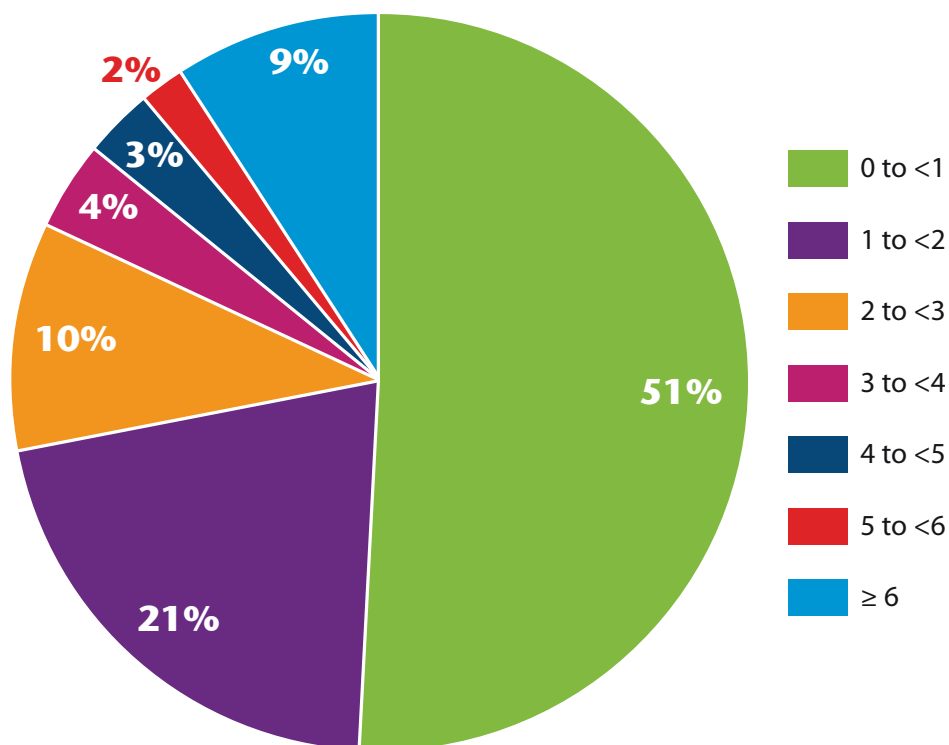


Twice as many women as men were diagnosed with MS in 2010.

The average age of all people diagnosed was 41 years.

Of the 344 people who were diagnosed in 2010, 30% (103) were male and 70% (241) were female.

Figure 2 From people reporting the first symptoms of MS, how many years did it take to be diagnosed with MS?



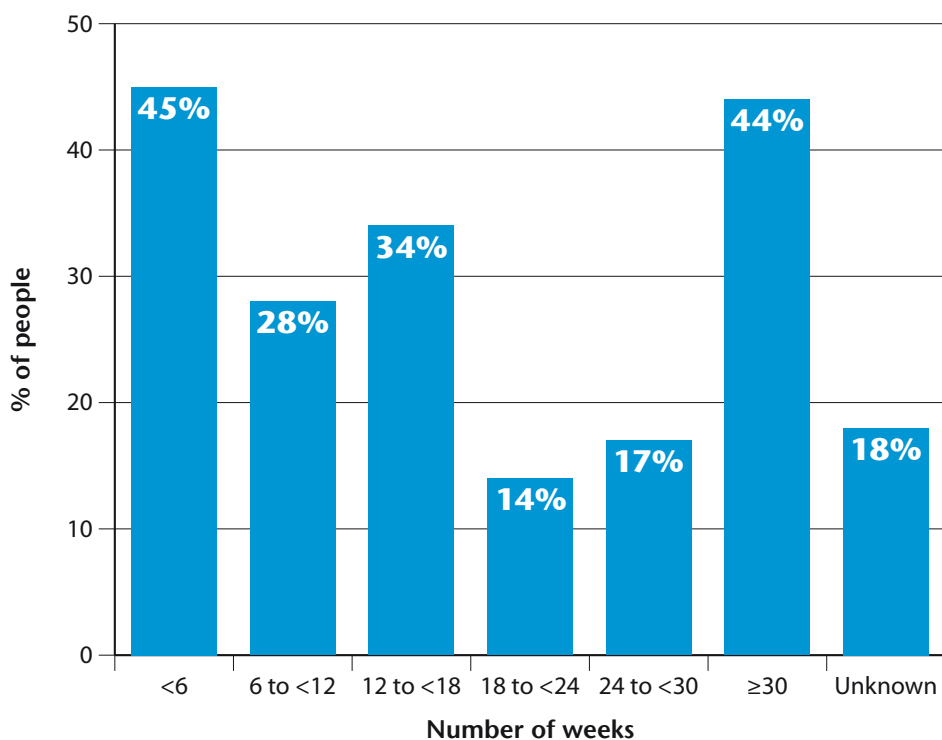
Just over half of people diagnosed with MS in 2010 were formally diagnosed within a year from the first sign of symptoms.

For a third of people, the date of first symptoms was unknown.

MS can be complex in its nature and has a variety of symptoms; this means that in some cases it can take more than six years to have a diagnosis confirmed.

Patient Journey

Figure 3 How many weeks after referral to the hospital did it take to receive a confirmed diagnosis?



As MS is complex in its nature and has a variety of symptoms it is not easy to diagnose. There is no single diagnostic test and other conditions with similar symptoms may need to be ruled out before a final diagnosis can be made. This explains why one third takes more than 18 weeks to diagnosis from referral to the hospital.



“The MS Reference Group canvasses and reflects the needs and concerns of MS Society members with this very Scottish condition—ensuring that these views are represented to consultants on the Steering Group.”

The neurologist will take an extensive medical history asking in particular about symptoms which may represent episodes of demyelination. They will then perform a physical examination. Although the neurologist may suspect MS at this stage, a diagnosis may not be possible until there are further investigations.

The most common test and procedures are:

Magnetic resonance imaging (MRI)

The MRI scanner uses strong magnetic fields to create a detailed image of the brain and spinal cord. MRI scans show changes in the central nervous system in over 95 percent of people with MS.

Lumbar puncture

This is carried out under a local anaesthetic and involves a needle being inserted into the lower back. A small sample of the fluid that flows around the brain and spinal cord is taken and tested. Most people with MS have abnormal proteins in this fluid, showing that the immune system has been at work in the central nervous system. A lumbar puncture tends only to be carried out if a diagnosis of MS has not been confirmed by other tests.

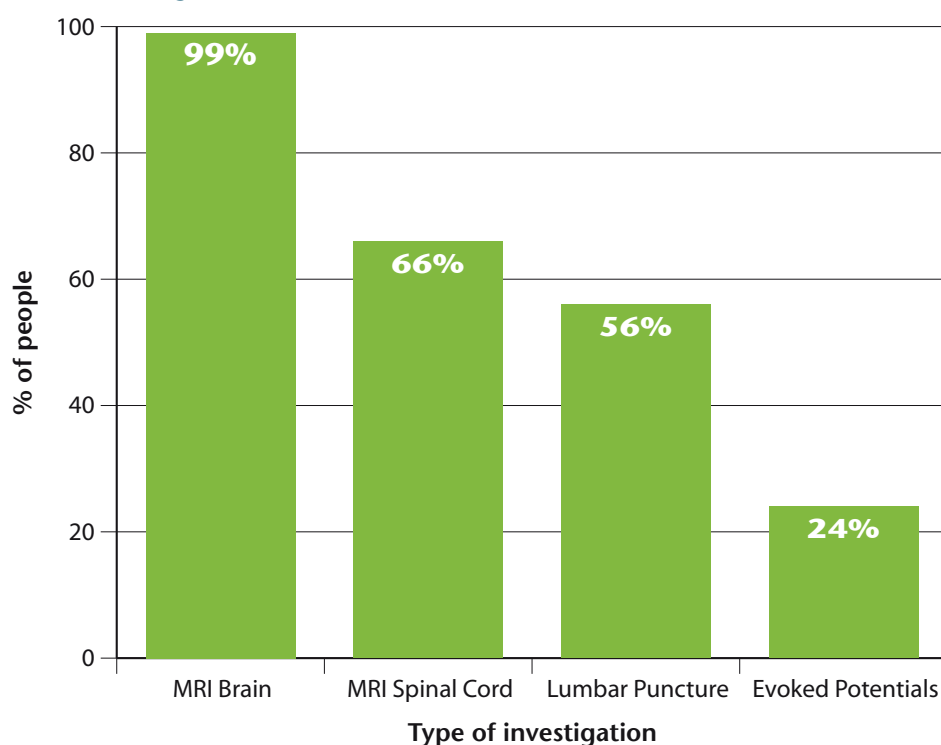
Evoked potentials

This involves testing the time it takes the brain to receive messages. Small electrodes are placed on the head to monitor how the brain waves respond to what is seen or heard. If there is damage to the myelin in the brain messages and responses will be slower or weaker.

Source What is MS
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Figure 4 How often was each type of investigation used to confirm MS diagnosis?



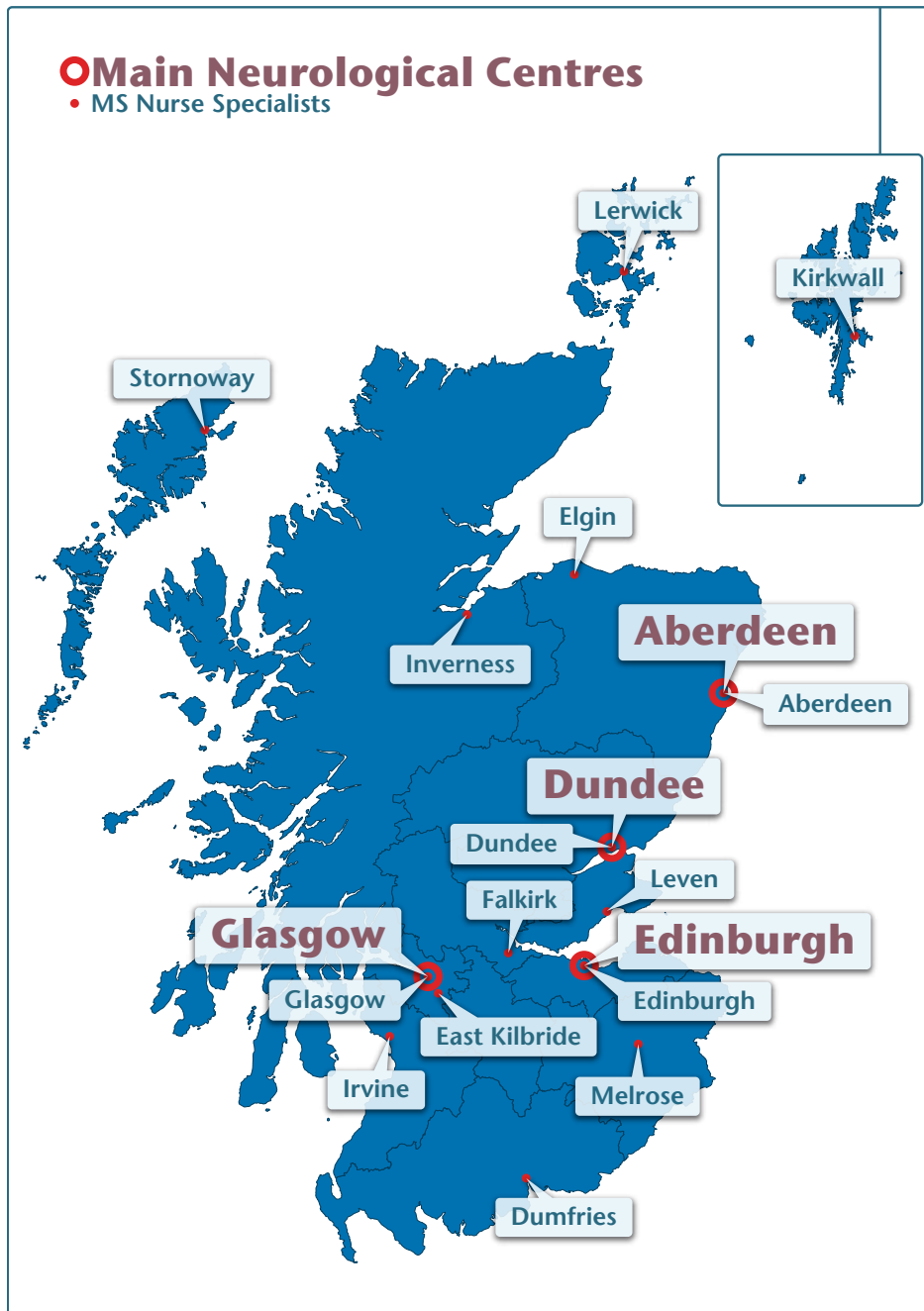
Nearly all people received a brain MRI.

Two out of three people received a spinal cord MRI.

Just over half of people received a lumbar puncture.

One out of four people received evoked potentials.

Patient Journey



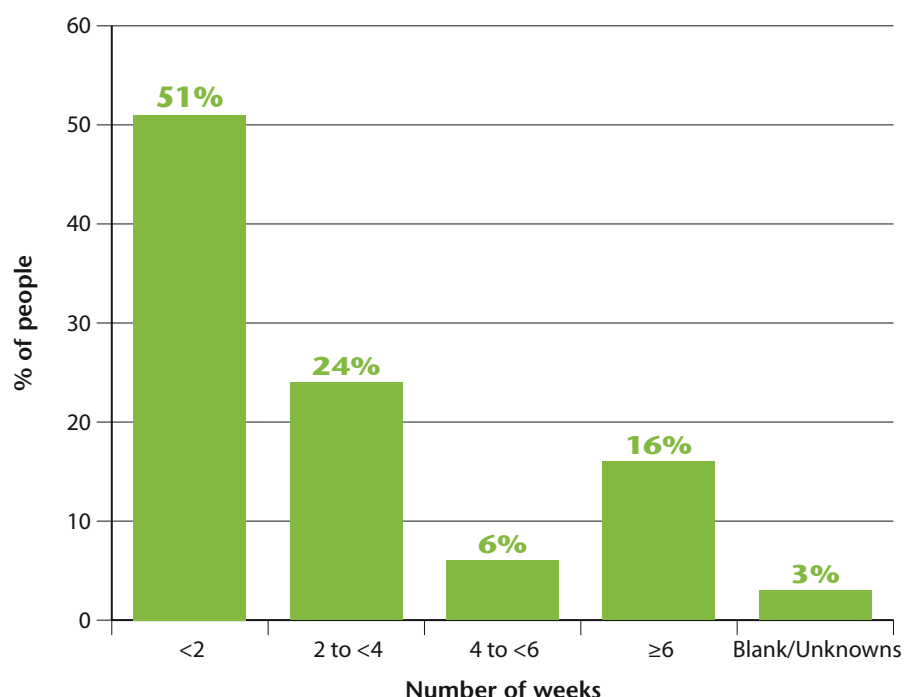
The MS Nurse Specialist is often a key role in MS Services that ensures ease of access into local, regional and national services.



“The MS incidence register creates an important infrastructure that will enhance our understanding of the distribution of MS in Scotland. Collecting reliable information on all new cases of MS in Scotland may demonstrate regional differences and potentially enable multidisciplinary teams to plan service design.”

Standard 15.2 states 'Contact with an MS clinical nurse specialist is offered at diagnosis to patients with MS. Contact is made within 10 working days of diagnosis.'

Figure 5 How many weeks after confirmed diagnosis did person have first contact with MS nurse?



Half of people newly diagnosed with MS had contact with MS nurse specialist within two weeks of diagnosis.

A small number of people were supported by MS nurse specialists prior to being given their diagnosis.

Most people (8 out of 10) were seen within six weeks.

The type of first contact with MS nurse specialist is:

- Phone 13%
- Letter 50%
- Clinic 27%
- Declined 2%
- Ward visit 4%
- Home Visit 1%
- Other not specified 1%

UK MS Society Project

As well as the Scottish MS register, the MS Society is also supporting a UK-wide MS register. Whereas the Scottish register focuses on newly diagnosed people with MS, the UK register aims to include, eventually, all people living with MS in the UK. Anyone with MS, regardless of where they live in the UK, can join the register by going to www.ukmsregister.org. You will then be asked a series of questions about your MS and how it impacts on your life. Crucially people will be asked to return to the site from time to time to update their information so that we can see how their MS changes over time.

In addition to the website which collects information directly from people with MS, we also aim to gather information from neurologists at 5 pilot

sites throughout the UK. The pilot site within Scotland is based in Edinburgh, and over time people who see a neurologist there will be asked if they are willing to have some basic medical data about them recorded on the register. If they agree then we can link information from people with MS with that provided by their neurologist, to help us to develop a complete picture. If the pilot project is successful we hope that this model can be rolled out at further sites throughout the UK.

To find out more about the project, and to join the register, please go to www.ukmsregister.org

Ed Holloway

Head of care and services research

Challenges we have faced in 2010 & 2011

- To maintain the participation of consultant neurologists and MS Specialist Nurses to improve registration of people with MS.
- To rectify gaps in the data within certain NHS Boards.
- To allocate central resources for administrative and analytical staff because of sporadic form completion.
- To secure on-going, long term funding

The Scottish MS Register is a forum for interaction between people with MS and their carers, clinicians and the voluntary sector. There is a great opportunity for Scotland to continue to develop this unique register of those newly diagnosed with MS. Further work is required to improve case identification and so to demonstrate the benefits of the register in order to secure on-going funding.

Useful Links

MS Society—What is MS?: www.mssociety.org.uk/support_and_services/free_publications/what_is_ms.html

MS Trust—What is MS?: www.mstrust.org.uk/information/aboutms/whatismis.jsp

The Scottish MS Register: www.msr.scot.nhs.uk

Multiple Sclerosis Society: www.mssociety.org.uk/about_ms/index.html

ISD Scotland: www.isdscotland.org

MS Society—What is the UK Register?: www.mssociety.org.uk/research/funded_research/major_investments/ms_register/index.html

MS Society—UK MS Register Portal: www.ukmsregister.org/Portal/Home

Healthcare Improvement Scotland: www.healthcareimprovementscotland.org

Steering Group	Role	
Belinda Weller (Chair)	Clinical Lead	Western General Hospital
Lynn Cherry	MS Nurse Specialist	Institute of Neurological Science
Ed Holloway	Head of care and services research	MS Society UK
Jane Lough	MS Physiotherapist	Institute of Neurological Science
Paul Mattison	Clinical Lead	Douglas Grant Rehabilitation Centre
Margaret Ann Macleod	Clinical Lead	Aberdeen Royal Infirmary
Nicola Macleod	MS Nurse Specialist	Western General Hospital
David McNiven	Director	MS Society Scotland
George Mowat-Brown	Patient Representative	
Christian Neumann	Clinical Lead	Forth Valley Royal Hospital
Colin O'Leary/ James Overell	Clinical Lead	Institute of Neurological Science
Johnathan O'Riordan	Clinical Lead	Ninewells Hospital
Anita Pritchard	Clinical Co-ordinator	National Services Scotland ISD
Lance Sloan	Clinical Lead	Cameron Hospital
Uwe Spelmeyer	Clinical Lead	Victoria Hospital
Ann Stewart	MS Nurse Specialist	Raigmore Hospital
Hester Ward	Medical Director	National Services Scotland ISD

NHS Health Board	Hospital	Lead Consultant
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Paul Mattison
Borders	Borders District General	David Simpson
Dumfries & Galloway	Dumfries General Royal Infirmary	Locum
Fife	Cameron Hospital	Lance Sloan
	Victoria Hospital	Uwe Spelmeyer
Forth	Forth Valley Royal Hospital	Christian Neumann
Grampian	Aberdeen Royal Infirmary	Margaret Ann Macleod
Greater Glasgow & Clyde	Institute of Neurological Science	Colin O'Leary/ James Overell
Highlands	Raigmore Hospital	Bethany Jones
Lothian	Western General Hospital	Belinda Weller (Chair)
Tayside	Ninewells Hospital	Johnathan O'Riordan
	Perth Royal Infirmary	Johnathan O'Riordan

NHS Health Board	Hospital	Register Co-ordinator
Ayrshire & Arran	Douglas Grant Rehabilitation Centre	Jacque Downs
Borders	Borders District General	Lorna Rogerson
Dumfries & Galloway	Dumfries General Royal Infirmary	Liz Clark
Fife	Cameron Hospital	Debbie McCallion
	Victoria Hospital	Uwe Spelmeyer
Forth	Forth Valley Royal Hospital	Hazel Gaylor
Grampian	Aberdeen Royal Infirmary	Rose Johnston
Greater Glasgow & Clyde	Institute of Neurological Science	Lynn Cherry
Highlands	Raigmore Hospital	Ann Stewart
Lothian	Western General Hospital	Nicola Macleod
Tayside	Ninewells Hospital	Pamela Walker
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Further Information

Further information can be found on the [Scottish MS Register website](#)