

Scottish MS Register Patient Reference Group

Terms of Reference

1. Background

Whenever someone in Scotland is diagnosed with Multiple Sclerosis (MS), the doctor or MS nurse records the relevant details. Hospitals and doctors pass this information on to the Scottish Multiple Sclerosis Register (SMSR).

Multiple Sclerosis, which results from damage to the protective sheath of myelin that surrounds the nerve fibres of our brain and spinal cord, is the most common disabling neurological condition amongst young adults in Scotland. MS presents itself in a multitude of ways with differing severity. For sixty years it has been accepted that there are more people with MS in Scotland per capita than anywhere else in the world—with the greatest occurrence being in the Northern Isles.¹

The Scottish Government has recognised and supported the need for robust national datasets to enable both individuals and organisations to assess and monitor the quality of care that is being provided against evidence-based standards and to ensure that this is compliant with the published guidelines. The SMSR was created in order to provide, for the first time in the UK, a valid assessment of the numbers of people with a confirmed new diagnosis of MS. The purpose of collecting reliable and valid information is that it will ultimately contribute to service improvements for those with MS in Scotland. As, over time, the SMSR will also show whether the numbers of people with MS in particular areas of Scotland are increasing or decreasing, the health service can ensure that the right services and staff are available in the right places.

To achieve this goal, the SMSR collects information on the person's journey, from first symptoms via a definitive diagnosis of MS to first contact with a MS Nurse Specialist. The data reported by the SMSR relates mainly to time from definitive diagnosis to first contact with a MS Nurse Specialist.

The SMSR aims to build on the progress made so far and:

- Support NHS Boards to improve neurological health services and achieve nationally agreed clinical standards;
- Build a reliable database on MS which is grounded in current clinical practice; and
- Work with key stakeholders to build a culture of improvement that will result in measurable improvements in neurological services for patients in Scotland.

The SMSR is now housed in the Public Health Intelligence (PHI) unit of NHS National Services Scotland (NSS) and is administered by a central team. The responsibility for the oversight of the SMSR lies with its own Steering Group consisting of key stakeholders who provide strategic direction and clinical input. The chair of this group is Dr Belinda Weller (belinda.weller@nhslothian.scot.nhs.uk). These responsibilities include: the maintenance of reporting standards, adherence to aims, objectives and reporting of results — the steering group encompasses multidisciplinary representation from all of the NHS Boards in Scotland and the voluntary sector.

¹ Sutherland, John M, 'Observations on the prevalence of multiple sclerosis in Northern Scotland', *Brain* Vol. 79 (1956), 635 -654.

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The SMSR has an established Patient Reference Group which was set up by the Scottish MS Society prior to the establishment of the SMSR to ensure that the views of patients and their carers were influential in the formation of the SMSR. The Patient Reference Group comprises a group of people with a confirmed diagnosis of MS drawn from various parts of Scotland. Some members attend with their carers whose views also contribute to the discussions. The Patient Reference Group ensures that the Register represents a wide range of views and concerns of people with MS and their carers and is a forum where its members can participate and guide the SMSR to focus on what matters to them. The chair of the Patient Reference Group is also a member of the SMSR Steering Group and acts, with the Clinical Co-ordinator, as an interface between the two groups.

2. Objectives of the group

- 2.1. To ensure that the views of people with MS and their carers are reflected in the issues explored and audited by the SMSR;
- 2.2. To act as advocates and to facilitate communication about the programme within the MS and neurological services and other networks; and
- 2.3 To review publications prepared by the central team to ensure information is grounded in plain English and the presentation (e.g. font and colour) is accessible to all.

3. Patient Reference Group Member's Responsibilities

The SMSR recognises that involvement in this project is in addition to existing commitments of its Patient Reference Group members and will support them as much as possible. It is important, however, to be aware of the commitment that will be expected of Patient Reference Group members. Although the SMSR is closely linked to, and frequently complements, other NHS, government, and charity initiatives, it is not intended to duplicate them.

Members are expected to:

- Participate in approximately two to three meetings per year of the Patient Reference Group which are normally held near Edinburgh. Additional meetings may be held to undertake specific pieces of work in relation to the SMSR;
- Influence the production of the SMSR national publications;
- Undertake necessary work outside of the meetings as required (e.g. reviewing and commenting on documents via email/ post etc); and
- Contribute to the development of a national programme of work aimed at improving the delivery of neurological services across Scotland.

Members of the Patient Reference Group will have their reasonable travel expenses reimbursed.

4. Reporting

The Clinical Co-ordinator will support and attend these meetings as appropriate and will report on progress with the SMSR to the MS Patient Reference Group as required — either directly or via the chair of the Group.

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5. Central Team Profile

The work of the SMSR Steering Group is facilitated by a small central team based within the Scottish Healthcare Audits team at Public Health Intelligence, National Services Scotland. The team comprises a Service Manager, Senior Nurse, National Clinical Co-ordinator, Information Analyst and Data Support Officer.

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