

# Terms of Reference

## Scottish Multiple Sclerosis Steering Group

### 1. Introduction

The Scottish Multiple Sclerosis Register (SMSR) has established a steering group of key stakeholders to oversee the work of the Register in collaboration with the central team from the Scottish National Audit Team (SNAP) within Public Health Scotland (PHS).

### 2. Objectives of the Group

- To direct the SMSR by the continued development of a clear vision and long term sustainable strategy;
- To contribute to the improvement of care for MS patients across Scotland by utilising the SMSR data to demonstrate good practice or to highlight areas requiring improvement;
- To utilise the data to highlight areas of high incidence of MS to inform service providers and contribute to equitable access of required resources/ services across Scotland;
- To maximise the use of the data by identifying research potential and establishing associated research projects;

- To provide a co-ordinated and integrated approach to clinical governance across SMSR, using agreed national neurological standards and linking with individual NHS Boards;
- To participate in the analytical processing of the dataset to ensure information collected continues to be relevant to current practice;
- To direct the clinical content of the SMSR Annual National Report and approve the release of any other routine data analyses by the group;
- To provide clinical advice and support to the central project team;
- To act as advocates and to facilitate communication about the programme within MS, neurological services and other networks; and
- To support the SMSR by maximising the opportunities for collaborative working with other local Scottish, national and international initiatives.

### **3. Membership**

The composition of the Steering Group will reflect the range of participating units in terms of size and location.

#### **Steering Group Chairperson**

- The Chair person will be a consultant health professional practicing within neurology in Scotland preferably with a special interest in MS;
- Nominations for the Chair of SMSR steering group will be sought from the neurology community of Scotland or by members of the existing steering group;
- The Chair will be elected by the participating members of the steering group; and
- The term of office will be three years. The Chair shall not serve more than two consecutive terms.

## SMSR Vice-Chair

- The Vice-Chair person will be a consultant health professional practicing within neurology in Scotland preferably with a special interest in MS;
- Nominations for the Vice-Chair will be self-nomination from members of the existing steering group;
- The Vice-Chair will be elected by the participating members of the steering group; and
- The term of office will be three years. The Vice-Chair shall not serve more than two consecutive terms.

## Consultants

- Medical staff will be drawn from neurology services in each Health Board, will have a special interest in MS and will be practicing in Scotland;
- Regional representation and individual enthusiasm are essential criteria; and
- The term of office for all nominees shall be three years with an option to renew every three years.

## Other Health Professionals

These may include: General Practitioners, Neurologists with special interest in MS, MS Nurse Specialists, Allied Health Professionals (e.g. Physiotherapists/Occupational Therapists with a special interest in MS), Epidemiologist, Consultant in Public Health Medicine etc.

Representation from groups of health professionals, e.g. Allied Health Professionals may be intermittent when the agenda requires specific input from these disciplines.

## Patient/Public Representative

- Patient/ public representation will be drawn from the MS community in Scotland;
- Public representation will also be sought from voluntary organisation colleagues, e.g. MS Society, MS Trust, MS Alliance etc.

## Public Health Scotland

- Service Manager, Scottish National Audit Programme (SNAP)
- National Clinical Coordinator
- Principle Information Analyst (on advisory basis)
- Information Analyst
- Caldicott Guardian (on advisory basis)

Additional parties/ advisors may be co-opted onto the steering group and sub-groups when necessary.

Further membership details can be found on our website at:

[www.msr.scot.nhs.uk/index.html](http://www.msr.scot.nhs.uk/index.html)

## 4. Members responsibilities

1. Participate in steering group meetings three times per year;
2. Undertake necessary work outside of the meetings as required, e.g. reviewing commenting on documents by email, reviewing information requests etc;

3. Liaise with colleagues from the area they represent to update them on progress and feedback views to the main group.

## 5. Meetings

Meetings are held at least 3 times per year.

Each member's attendance should be at least 2 out of 3 meetings per year. If a member does not attend 3 consecutive meetings, then membership will be reviewed by the steering group. If ongoing commitment is difficult an alternative representative may need to be sought.

Meetings will normally be held in the afternoon at a central location in either Edinburgh or Glasgow.

## 6. Reporting Arrangements

The Clinical Coordinator will report on SMSR progress to the steering group Chair and members and to senior managers within the SNAP audit team and PHS.

The Chair and Clinical Coordinator will report on progress to the Clinical Priorities Team at the Scottish Government.

The Clinical Coordinator will feedback SMSR activity to the National Neurological Advisory Group (NNAG) through its operational management group.

The Service Manager/ Clinical Coordinator and Chair will report back intermittently to the Scottish Government National Audit Programme Board (Health), the governing body of the Scottish Healthcare Audits.

## Privacy Notice

Public Health Scotland will retain information relating to Steering Group membership. This data includes name, role, employer, contact information and any self-declared declarations of interest members make. Contributions made by members in meetings may be reflected in any documented minutes which may be subject to disclosure under FOISA (Freedom of Information (Scotland) Act 2002). For further information please refer to the **Public Health Scotland Privacy Notice** or contact the SNAP team, email: [p hs.snap@p hs.scot](mailto:p hs.snap@p hs.scot).

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[p hs.otherformats@p hs.scot](mailto:p hs.otherformats@p hs.scot) or 0131 314 5300.

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