



# Patient Information Leaflet

## Scottish Multiple Sclerosis Register

**This leaflet explains what you need to know about the Scottish Multiple Sclerosis Register (SMSR) and why it is important for the future care of patients.**

## **Who are we?**

The Scottish Multiple Sclerosis Register is part of the Scottish National Audit Program within Public Health Scotland (PHS). PHS is a national special health board of NHS Scotland, jointly sponsored by the Scottish Government and COSLA, which launched on 1 April 2020. More information about PHS is available at:

<https://www.publichealthscotland.scot/our-privacy-notice/organisational-background/>

## **About the SMSR**

Each hospital / clinic collects information about the care of patients who have newly diagnosed Multiple Sclerosis (MS) and compares it with nationally agreed standards.

## **What is the aim of the register?**

To record all new cases of MS in Scotland and to use this information to change clinical practice to improve the care these patients receive.

## **What are the benefits?**

The SMSR uses this information to learn more about your condition, for example:

- how many people are being newly diagnosed with MS in Scotland each year
- what type of MS they have
- whether MS is becoming more common
- if hospitals / clinics have the right staff and resources in the right place to treat MS patients effectively

Including your information helps us to identify areas for improvement in the care of patients with MS in Scotland.

## How are the data collected?

Your hospital sends the information electronically to the Scottish National Audit Programme team.

## What personal information will the audit hold about you?

Only relevant information about you and your care is collected. We do collect the following personal information about you:

- name
- postcode
- date of Birth
- sex
- Community Health Index (CHI) Number
- your NHS Board

as well as the information about your care.

## How do we use your data?

The data we collect in the SMSR database is held electronically and securely within NHS Scotland.

The SMSR team managing the audit collate and check the information. Personal information is shared with clinical teams and hospital management who are directly involved in your care. Other non-identifiable information is shared with the Scottish Government and researchers. This information may be used for local or national projects or as part of research, but individual personal information will never be published. The Register Steering Group controls who has access to the data collected.

## Will anyone contact me from the audit?

You may also be invited to take part in other associated projects, related to SMSR in the future, but you will be informed about them and be able to decide whether you want to participate or not. If you decide not to take part this will not affect the standard of care you receive.

There are occasions when researchers need to access information about individual patients. There are strict processes they have to go through to do this and they cannot contact you without the approval of your doctor.

## Do I need to do anything?

You do not need to do anything – there are no forms to fill in and nothing to sign. Your hospital will record all of the information relevant to your care on their information systems/ records. Relevant information will be manually entered to SMSR database by appropriately trained auditors. Secure automatic processes will then transfer only the parts of these data that are relevant to the SMSR database.

## Is information about me safe?

Yes. We have to comply with the law to use your personal information.

The reports that the audit publish do not identify any individuals. PHS staff are bound by data protection legislation and confidentiality rules. All information is stored in ways that comply with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 on computers that can only be accessed with secure passwords.

Only NHS staff with specific security access can see any personal details.

## Your rights

Data Protection law gives you rights over how we use your personal details. These and other more detailed information can be found on the PHS website: <https://www.publichealthscotland.scot/our-privacy-notice/>

## Where can I get more information?

You can ask your doctor or nurse, another member of your healthcare team, or your hospital's data protection officers.

Or write to:

### **Scottish Multiple Sclerosis Register**

Scottish Multiple Sclerosis Register

NHS National Services Scotland

Gyle Square

1 South Gyle Crescent

Edinburgh

EH12 9EB

Email: [phs.scottishmsregister@phs.scot](mailto:phs.scottishmsregister@phs.scot)

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

## Useful links to other organisations

Public Health Scotland

[www.publichealthscotland.scot](http://www.publichealthscotland.scot)

Healthcare Improvement Scotland

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

MS Society Scotland

[www.mssociety.org.uk/near-me/branches/ms-society-scotland](http://www.mssociety.org.uk/near-me/branches/ms-society-scotland)

Neurological Alliance Scotland

[www.scottishneurological.org.uk](http://www.scottishneurological.org.uk)

MS Trust

[www.mstrust.org.uk](http://www.mstrust.org.uk)

## Accessibility and translations

If you need this information in another format or a community language please contact:

Email: [phs.otherformats@phs.scot](mailto:phs.otherformats@phs.scot)

Tel: 0131 275 7457

Text relay: 01800 275 7457

Website: <http://contactscotland-bsl.org/reg/>