

Information about you is held in confidence by SAIVMs.

## Who supports SAIVMs?

SAIVMs is part of NHS Scotland's National Audit Programme, and has been approved by a variety of organisations:

- The Chief Medical Officer of NHS Scotland ([www.scotland.gov.uk/Topics/Health/NHS-Scotland](http://www.scotland.gov.uk/Topics/Health/NHS-Scotland))
- NHS Quality Improvement Scotland ([www.nhshealthquality.org](http://www.nhshealthquality.org))
- Scottish Association of Neurological Sciences ([www.rcpe.ac.uk/education/clinical\\_standards/asnn/assn\\_index.html](http://www.rcpe.ac.uk/education/clinical_standards/asnn/assn_index.html))
- Stroke Association ([www.stroke.org.uk](http://www.stroke.org.uk))
- Chest Heart and Stroke Scotland ([www.chss.org.uk](http://www.chss.org.uk))
- AVM Support UK ([www.avmsupport.org.uk](http://www.avmsupport.org.uk))
- Angioma Alliance UK ([www.angiomaalliance.org.uk](http://www.angiomaalliance.org.uk))

## How can I obtain more information?

In this leaflet we have attempted to give a basic description of the audit. For more information, please visit our website [www.saivms.scot.nhs.uk](http://www.saivms.scot.nhs.uk). You may also seek advice about SAIVMs from your hospital consultant, or your GP. Please contact the SAIVMs team if you would like further information about your condition.

## What if I want my information removed from the audit?

If you wish to opt out of the audit, contact the SAIVMs Coordinator by telephone, email, or post using the National Coordinating Office contact details overleaf.



## Steering Committee

Aberdeen: Dr Carl Counsell  
Dundee: Dr Richard Roberts  
Edinburgh: Dr Rustam Al-Shahi Salman, Dr Vaughn Ritchie, Dr Robin Sellar, Prof Charles Warlow  
Glasgow: Dr Jo Bhattacharya, Mr Jerome St George

## National coordinating office:

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Web: [www.saivms.scot.nhs.uk](http://www.saivms.scot.nhs.uk)

Thank you for taking time to read this information leaflet. Please keep it in a safe place for future reference.



Scottish Audit of Intracranial Vascular Malformations (SAIVMs)

Patient information leaflet

## Patient information leaflet



An audit of the care of adults in Scotland who are affected by vascular malformations of the brain

This leaflet is about a nationwide Scottish clinical audit called SAIVMs, which may involve you if you have been diagnosed with one of the following vascular malformations of the brain: arteriovenous malformation, cavernous malformation, dural arteriovenous fistula, or carotid-cavernous fistula. It is important for you to understand why the audit exists and what it involves.

### What is SAIVMs?

The purpose of the Scottish Audit of Intracranial Vascular Malformations (SAIVMs) is to monitor the quality of care, treatment, and outcomes for adults with vascular malformations of the brain, in order to improve the care and services we provide.

SAIVMs does this by trying to find every adult resident in Scotland, who is newly diagnosed with one of the malformations above, and enrolling them in a confidential audit. SAIVMs aims to include every adult in order to get a truly representative picture of what happens to people with your condition in Scotland.

We are looking for people who were first diagnosed in the years 1999-2003, and 2006 onwards.

### How does SAIVMs work?

In the course of your care we collect information about you, your diagnosis, your investigations, your treatment, and how you get on. This information is obtained from your medical records, brain scans, general practitioner, Information Services Division, General Register Office for Scotland, and the NHS Central Register. The data are passed to the office coordinating the audit in Edinburgh, and are held confidentially under secure conditions.

The audit is purely observational – we do not influence your care in any way.

### What is SAIVMs used for?

SAIVMs is used to measure the quality of care we provide and to carry out work aimed at improving care and services. The audit also monitors how common the conditions are, and the problems they cause for those affected by them.

You may be invited to take part in associated research projects, but you will be informed about them and able to decide whether you want to participate in them or not. If you decide not to take part in these research projects, it will not affect the standard of care you receive.

### How does SAIVMs handle information?

The audit is run by a team in the Department of Clinical Neurosciences in Edinburgh, and is overseen by a Steering Committee representative of patients, general practitioners, and the relevant specialties at the four Scottish Neuroscience centres in Aberdeen, Dundee, Edinburgh, and Glasgow.

The information is being gathered and processed by the SAIVMs team on behalf of NHS National Services Scotland. Information about adults included in this audit is held securely in an electronic database. Any identifiable information about you is processed by the SAIVMs team in Edinburgh, which includes medical staff, as well as administrative and computing staff with NHS contracts and a duty of confidentiality. All names, addresses and other identifying information are removed before the data are analysed. We will not release any information to your general practitioner without your consent. We comply with the Data Protection Act 1998.

The information is used to provide reports for clinical staff on the care of their patients. No information is ever published which identifies individual patients.