

SAIVMs core audit standards

EIGHT STRAIGHTFORWARD STANDARDS

The Scottish Government's report Delivering for Health required mechanisms for the assessment of performance in neurosciences against standards, and action plans to address areas of improvement. The SAIVMs Steering Committee has approved standards for the care of adults with intracranial vascular malformations (IVMs) in Scotland. Current practice within NHS Scotland could be compared against these standards, under the direction of the SAIVMs steering committee.

Most of the SAIVMs audit standards are derived from existing guidelines for adults with neurological and neurosurgical disorders, published by **SIGN**, or by the three relevant professional organisations (**SBNS**, **ABN**, and **BSNR**). A complete, referenced document can be found at: <http://saivms.org/reports.asp>. The eight core audit standards are:

- 1. Every adult diagnosed with an IVM should be informed of their diagnosis.** If the adult has mental incapacity, their guardian, welfare attorney, legal representative, or next of kin should be informed.
- 2. Every adult diagnosed with an IVM should be assessed by a consultant neurologist or neurosurgeon.**
- 3. Every radiological diagnosis of an IVM should be confirmed by a consultant neuroradiologist, following their review of the adult's brain imaging.**
- 4. Patients undergoing neurosurgery** should receive SIGN recommended standards of care for post-operative management.
- 5. Patients with one or more epileptic seizures** should receive SIGN recommended standards of care.
- 6. Patients who have suffered a stroke** due to their IVM should receive SIGN recommended standards of care, which are themselves audited (<http://www.strokeaudit.scot.nhs.uk>). Subarachnoid haemorrhage management should adhere to the BSNR/SBNS consensus statement.
- 7. Patients who are admitted to hospital because they are acutely ill with a neurological problem** should be seen by a neurologist within 24-48 hours (ABN).
- 8. The provision of stereotactic radiosurgery** should include prospective audit (SBNS).

Evaluation of SAIVMs standard 1

ARE ADULTS INFORMED ABOUT THEIR DIAGNOSIS?

Our first audit standard expects an adult, or their representative, to be informed of the diagnosis of a vascular malformation. This is an important audit standard because patients have a right to be informed. Furthermore, members of the SAIVMs steering committee as well as research ethics committees have been concerned to learn about some patients who have not been informed of their diagnosis, because their vascular malformation had been regarded as a 'benign' abnormality or imparting the diagnosis was feared to cause distress.

DATA FROM THE 1999-2003 AUDIT...

In the first 5 years of the SAIVMs cohort, 369 adults were first diagnosed with one of the vascular malformations of interest. Of these people, it was unclear whether 10 (3%) were aware of their diagnosis, and 40 (11%) appeared to be unaware, from a review of their medical records. However, 22 of these

patients had died prior to the diagnosis being made, meaning that 18 patients who were alive appeared not to have been informed (5% of the whole cohort). The two leading explanations for the diagnosis not being passed on were that the patient had cognitive impairment or the vascular malformation had been an incidental discovery on brain imaging.

For some patients without mental capacity, who were alive at the time of the diagnosis, we couldn't discern from the medical records whether the welfare guardian, legal representative, or nearest relative had been informed of the diagnosis.

This discovery may be related to the 2008 SAIVMs audit report, which found that 5% of patients newly diagnosed with an arteriovenous malformation were not discussed with a specialist.

IMPLICATIONS

SAIVMs should encourage its collaborators to convey adequate information about diagnosis to affected patients or their representatives.

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