

Vestibular Schwannoma Registry

PATIENT INFORMATION LEAFLET

What is the Vestibular Schwannoma Registry (VSR)?

The VSR is a national database for recording treatment information and outcomes on patients with vestibular schwannoma. It was established in 2012 within the Outcome Registry Intervention and Operation Network (ORION), a national healthcare informatics network, as a partnership between the University of Cambridge and the British Skullbase Society. Its purpose is to improve the quality of care provided for patients with vestibular schwannoma through monitoring of national practice. You have been contacted as you have been diagnosed with a vestibular schwannoma.

What are the benefits of the VSR?

- It provides an accurate national picture of outcomes for patients with vestibular schwannoma undergoing different forms of treatment. It can therefore inform best practice and enhance patient choice.
- It monitors the quality of care provided by participating units by audit against national benchmarks to ensure treatment provided is as safe and effective as possible.
- It provides a valuable resource for research to improve future treatment of vestibular schwannoma.

How will the VSR benefit me?

- It enables continuous monitoring of treatment for your vestibular schwannoma even if this occurs across different centres.
- It allows access to your vestibular schwannoma record by skullbase units across the UK if you need to be treated in a different centre.

Who will have access to my information?

Your treating team will record basic demographic information such as your name, date of birth and NHS number to reliably identify your record over time. We collect data on your symptoms and quality-of-life, tumour size on scan, details on the type of treatment you have had (surgery or radiotherapy), and any treatment complications that may have occurred.

Data will be kept confidential at all times. Your personal data will only be accessible to your local team(s) to support your treatment. Authorised persons working for the VSR will only have access to your data in anonymised form for data analysis.

Where consent has been provided, the VSR may also use your NHS number (or equivalent identifier) to link your record to other NHS data for monitoring the quality and efficacy your treatment.

Is my information safe?

Keeping your information safe is of the highest importance. All those involved in the VSR comply with the requirements of the Data Protection Act 1998 and NHS Act 2006. Only your medical team and authorised persons working for the VSR will have access to your information. All personal information is securely stored in encrypted form, and there are strict procedures in place to ensure only those authorised will be able to view your records. Your personal information will not be shared or passed onto any third party unless required by law.

What if I have further question about the VSR?

Your treating team should be able to provide you with information about the VSR. If you would like to find out more information, or request access to view your information, please contact The Outcome Registry Intervention and Operation Network, Department of Clinical Neurosciences, University of Cambridge, Box 167, Addenbrooke's Biomedical Campus, Cambridge, CB2 0QQ.