



UK Shunt Registry

PATIENT INFORMATION LEAFLET

What is the UK Shunt Registry (UKSR)?

The UKSR is a national database for recording all shunt-related procedures and other procedures related to the cerebrospinal fluid (CSF) circulation. It was established in 1993 and is currently adopted by all UK neuroscience units. Its purpose is to improve the health of patients with hydrocephalus (build of fluid in the brain) and other CSF-related conditions through monitoring of national practice.

You have been contacted as you are about to undergo, or have recently undergone, a shunt operation or related procedure.

What are the benefits of the UKSR?

- It provides accurate independent information to patients, carers, healthcare regulators and implant suppliers about the use of different types of shunts and outcomes from surgical interventions. It can therefore be used to identify substandard shunt systems, informs best practice and enhances patient choice.
- It helps the medical team to monitor the outcome of different groups of patients with hydrocephalus, and drive improvements in best practice for treatment of hydrocephalus.
- It can prompt investigation and follow-up support where there has been an unexpected outcome or where practice is below the expected standard.
- It helps give up-to-date information on mortality in patients with hydrocephalus.

How will the UKSR benefit me?

- It enables continuous monitoring of your type of implant including any episodes of infection.
- It allows access to your shunt record by neurosurgical units across the UK if you need to be treated in a different centre.
- It allows prompt notification should there be a fault alert on your type of implant.

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 different operations. We will collect data on the type of surgery you had, the reason for your operation, and details of the operation itself, including any shunt equipment used or removed.

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 shunt registry will have access to your shunt data in anonymised form for data analysis.

The shunt registry may also use your NHS number to contact you promptly should we gather information suggesting you require a follow-up appointment urgently. Your NHS number may also be used to enable general analysis to monitor quality and efficacy of different implants across different age groups.

Is my information safe?

Keeping your information safe is of the highest importance. All those involved in the UKSR comply with the requirements of the Data Protection Act 1998 and NHS Act 2006. Only your medical team and authorised persons working for the UKSR 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 UKSR?

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