UK Shunt Registry

DATA MANAGEMENT AND REPORTING UPDATE

Registry objectives

Starting from 2014, the UK Shunt Registry began its transition to an electronic data collection and management platform, hosted within the Outcome Registry Intervention and Operation Network (ORION). As part of this transition, the strategic aims of the registry have been updated and expanded to include the following:

1. Define the current state-of-the-art in terms of long term management of different groups of patients with disorders of the CSF circulation and related disorders [‘hydrocephalus’] using shunting, endoscopic third ventriculostomy and other related procedures.

2. Provide an accurate picture of the use of different types of shunt.

3. Monitor in real time and through annual audit the outcomes of different groups of patients with ‘hydrocephalus’ achieved by types of operative intervention, type of implant, hospital and multidisciplinary team.

4. Inform patients, carers, clinicians, providers and commissioners of healthcare, regulators, and implant suppliers of the outcomes achieved in surgical interventions for ‘hydrocephalus’.

5. Provide participating centres with a local reference and audit resource, including live data access and independent data for the shunt infection CQUIN measure.

6. Enhance patient awareness of outcomes after surgical interventions for ‘hydrocephalus’ to better inform patient choice and patients’ quality of experience through engagement with patients and patient organisations.

7. Support suppliers in the routine post market surveillance of implants and provide information to clinicians, patients, hospital management and the regulatory authorities.

Dataset update

The revised dataset consolidates the recording of key operative indicators within an adaptive data capture electronic form to enable fast and accurate submission.

Procedure codes have been mapped to the standard ICD10-based coding adopted by the SBNS, and a complete live valve catalogue directory is now available on the system. Finally, acknowledging previous low submission rates, external ventricular drain insertion is no longer within the recorded registry procedures.

Baseline	Reason for shunting
	EVD insertion in last 30 days
	Procedure type
	Reason for revision
	Additional procedures
	CQUIN exclusion criteria
Operative	Time and duration
	Surgeon grade
	Responsible consultant
	Level of supervision
	Number of surgeons
	Operative note
	Study participation
Implants	Proximal catheter
	Valve
	Distal catheter
	Other implants
	All implants removed

Electronic transition

Thirty-two out of thirty-five neurosurgical units have now been successfully set up on the electronic registry.

The transition has been supported by 29 on-site training visits to date, updating clinicians and theatre staff on the updated data submission process. We anticipate that our target of all units will be submitting prospective data by the next financial year will be met in preparation for the new annual reporting cycle.

The trainee-led national external ventricular drain audit successfully catalysed the early phase of the electronic transition, enabling 669 procedures to be captured across 21 units over a 5 month period (Nov 2014 – April 2015) thereby demonstrating the feasibility of the electronic data capture process. Please do not hesitate to contact the UKSR if you require further training or support with the electronic data collection process.

Whilst parallel paper submissions have been accepted during the transition period, this was finally discontinued in June 2017, prompted by potential security concerns on outdated systems following the May 12th NHS cyber attacks. All data from the old shunt registry server have been extracted and are in the process of being mapped and imported within the new electronic platform over the next 12 months.

Data management, access and consent

Participating units remain data controllers for the information submitted to the UK Shunt Registry, with a provision that aggregate data may be used by the registry on an ongoing basis for reporting and surveillance. This procedure is in line with all other registries hosted within ORION.

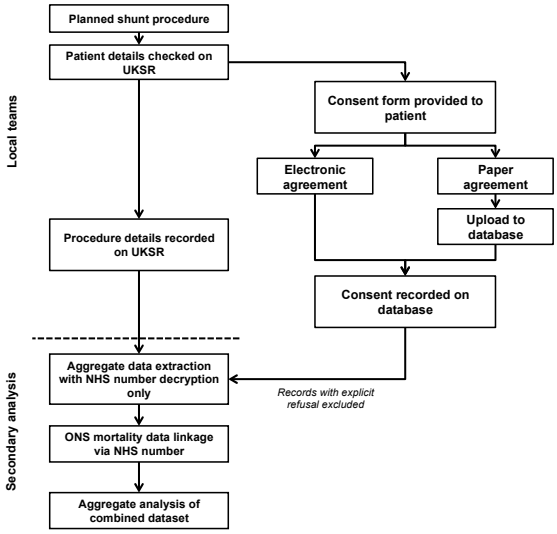
Local access: individual centres have ongoing access to their own submitted data with the ability to filter procedures based on operation type, underlying CSF diagnosis and responsible consultant. It is also possible to export local operative data in spreadsheet format and in individual printable form. When clinically required, access to a patient's entire recorded shunt history across units can be provided.

Access requests: the UKSR will be establishing a data monitoring committee, whose remit will include handling data access requests relating to aggregate data involving multiple units. The scope will include provision of aggregate data for CSF-related research, and linking with other neurosurgical initiatives including the NNAP and GIRFT. Details on the formal data request process are being finalised and will be circulated in the New Year.

Consent for linkage: in order to use identifiable information for linkage with mortality data from the Office of National Statistics (ONS) and procedure information from Hospital Episode Statistics (HES), the Registry submitted an application for a Section 251 exemption from the NHS Health Research Authority. Final S251 approval was granted in June 2017.

As a condition of this approval, it is now necessary for patients to be informed - whenever feasible - of their data being submitted to the UK Shunt Registry, and consent recorded within the registry.

A patient information leaflet for the UKSR in included, and further details of the consent process will be provided in due course.



Annual reporting, oversight and outlier policy

The UKSR is in the process of establishing a data monitoring committee under the auspices of the SBNS CSF subspecialty group. The committee will oversee the publication of an annual report in line with other established national audits. In line with the registry's objectives, the annual report will publish unit-level data on procedure volume and case-mix, and outcome stratified by types of intervention and implant. The first annual reporting cycle is planned to commence from 1st April 2018, to provide an opportunity for remaining units to fully engage with prospective electronic data collection.

Historically, case ascertainment was performed through local audit of theatre logs. Moving forwards, this process will be re-established and combined with cross-referencing using unit HES procedural data.

In line with HQIP requirements, a proposed outlier policy for the UKSR has been developed, and recent correspondence relating to this is attached. It is anticipated that the final outlier policy will be ratified by the data monitoring committee prior to next year's reporting cycle.