Neurosurgical Society of Australasia

Australasian Shunt Registry

Annual Report 2020

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Foreword

It is my pleasure to present the first Annual Report for the Australasian Shunt Registry. This Annual Report summarises the Shunt Registry activity since its inception.

The Shunt Registry is a population based, multisite, bi-national clinical quality registry established and run by the Neurosurgical Society of Australasia (NSA). The primary purpose of the Shunt Registry is to systematically collect information related to the use of cerebrospinal fluid (CSF) shunts to guide best clinical practice and processes to improve health outcomes for patients with CSF shunts.

The Shunt Registry was established by the NSA in 2013 with seed funding from the Australian Government resulting from lobbying by Associate Professor Brain Owler and the Hydrocephalus Support Association. The project received ethics approval from the Sydney Children's Hospital Network in October 2016 which acts as the lead Human Research Ethics Committee for all sites operating under the National Mutual Acceptance Scheme. In December 2016, the first patient was enrolled following site-specific governance approval at The Children's Hospital at Westmead.

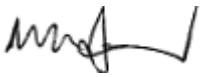
Since the inception, site engagement in the Shunt Registry has increased steadily and more than 95% of all eligible sites, from both the public and private sector throughout Australasia, are now approved to collect and contribute data.

I would like to gratefully acknowledge the patients who have agreed to participate in the Shunt Registry and the neurosurgeons, clinical and other support staff who make contributions to the Shunt Registry. Without their support the Shunt Registry would not be the success that it is. I would also like to thank the Shunt Registry Committee members who dedicate countless volunteer hours and the staff who have been instrumental to the continued growth and development of the Shunt Registry.

During 2020-2021 we were grateful to receive funding from the Australian Government and we would like to thank The Hon. Greg Hunt and the staff at the Department of Health for their support. This would not have been possible without Senator Catryna Bilyk, Labor Senator for Tasmania and The Hon Chris Bowen taking our cause forward.

Finally, I would also like to acknowledge Andrew Garde and all the members and supporters of the Hydrocephalus Support Association for their ongoing support of the Shunt Registry. It is as a direct result of their tireless efforts, advocacy and fundraising that the Shunt Registry has been able to continue its important work. We are heartened by their continued dedication and passion.

As the Shunt Registry continues to develop and mature, we are committed to delivering more comprehensive reports to guide best clinical practice and processes and to ultimately improve health outcomes for patients.



Mark Dexter
Chair, Shunt Registry Committee

Executive Summary

The Shunt Registry is a population based, multisite, bi-national clinical quality registry established and run by the NSA. The primary purpose of the Shunt Registry is to systematically collect information related to the use of cerebrospinal fluid (CSF) shunts to guide best clinical practice and processes to improve health outcomes for patients with CSF shunts.

Site engagement is voluntary. The first site approved was The Children's Hospital at Westmead with data collection commencing in December 2016. As of 31 December 2020, there were 58 sites fully approved across the public and private sector. An additional 11 site submissions were in progress and, upon approval, 98% of all eligible sites will be collecting data. Individual site activity ranges from one to over 100 admissions per annum.

During the reporting period (1 January 2017 – 31 December 2020), 2,858 records have been entered into the Shunt Registry for 2,022 unique patients. Patients over the age of 18 years contribute 62% of records. Full opt-out rates are currently at 7.9%, with a steady decrease from 13.8% in the first two years of the data submission.

The Shunt Registry has recorded 1,507 shunt insertions and 991 shunt revisions. Primary shunt insertion to revision has been recorded in 166 cases and there are 117 patients with more than one revision. The most common cause of shunt failure is blockage/underdrainage of one or more components of the shunt system.

Abbreviations

List of Abbreviations

CSF	Cerebrospinal fluid
ETV	Endoscopic third ventriculostomy
INPH	Idiopathic normal pressure hydrocephalus
NMA	National Mutual Acceptance
NSA	Neurosurgical Society of Australasia
PIS	Patient Information Statement

Table 1: List of Abbreviations

Common Terms and Definitions

Adult	A patient aged 18 years and over at the time of surgery.
Cerebrospinal Fluid	A clear, colorless fluid produced in the brain ventricles and found in the brain and spinal cord. CSF provides a mechanical barrier against shock, circulates nutrients and chemicals filtered by the blood and removes waste products from the brain.
Child	A patient aged over 12 months and less than 18 years at the time of surgery.
Congenital	A disease or condition present from birth.
Distal catheter	Outflow tube that takes fluid to another body compartment to be absorbed.
Endoscopic Third Ventriculostomy	A procedure where a small hole is made in the third ventricle of the brain allowing CSF to drain into the brain for normal absorption.
External Ventricular Drain	A temporary method where a catheter is placed into the brain space and gravity is used to drain CSF out of the brain ventricles to an external closed system.
Infant	A patient aged 12 months or under at the time of surgery.
Idiopathic Normal Pressure Hydrocephalus	A CSF disorder affecting elderly patients characterised by dementia, urinary incontinence and gait disturbance.
Primary procedure	The initial shunt procedure performed on the patient.
Revision procedure	A subsequent shunt procedure performed on a patient who has had a primary procedure where one or more of the device components are replaced, removed, or added.
Legacy Patient	Patient whose first record in the registry is for a revision procedure.
Opt Out	Patients who have requested that their data not be included in the Registry.
National Mutual Acceptance Scheme	A national system for mutual acceptance of scientific and ethical review.
Proximal catheter	The inflow tube that takes fluid from the cranial compartment.
Shunt externalisation	A procedure whereby the end of the shunt is connected to a external collecting system.

Table 2: Common Terms and Definitions

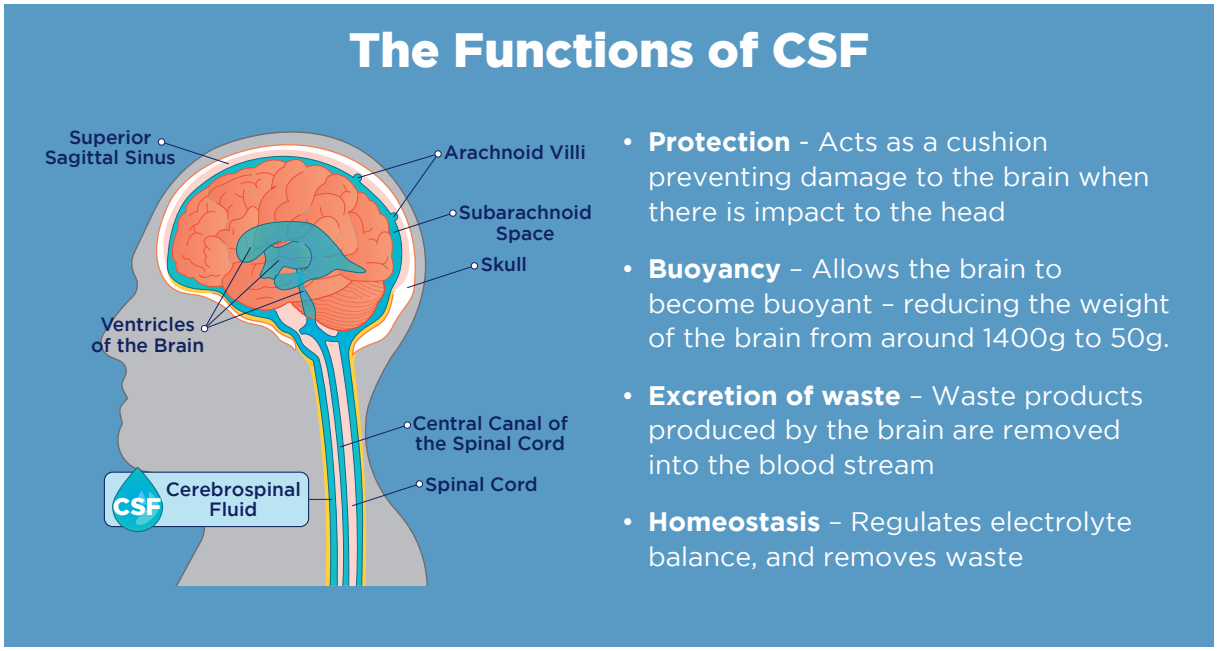


Figure 1 – Functions of CSF

Background

Hydrocephalus

Cerebrospinal fluid (CSF) is a clear colourless fluid produced in the brain that surrounds and protects the brain and spinal cord. CSF also circulates nutrients and chemicals filtered from the blood and removes waste products from the brain. [Figure 1]

Around 500mls of CSF is produced daily. It is continuously replaced as it is absorbed with around 120-150mls being present in the body at any one time.

Hydrocephalus is a neurological condition occurring when this balance is disrupted and CSF accumulates resulting in pressure on the brain. This may happen because one of the ventricles in the brain is blocked, too much CSF is produced, or the CSF cannot filter into the bloodstream.

Symptoms of hydrocephalus vary significantly and are often dependant on the age of the patient. In infants the condition may present with a rapid increase in, or a large, head size, vomiting, seizures, irritability and/or a downward or outward fixing of the eyes. Symptoms in older children, teens and adults include headaches, blurred vision, nausea and poor coordination whereas older adults may experience loss of bladder control, mental impairment and issues with gait.

Hydrocephalus is diagnosed through a clinical neurological exam.

Left untreated, hydrocephalus can cause severe disability and even death.

Around 1 in 800 children are born with hydrocephalus in Australia every year and many more children and adults acquire the condition.

Shunts

Hydrocephalus cannot be cured but it can be treated. The most common treatment is the insertion of a shunt.

A shunt consists of two main components – a proximal catheter (inflow tube) that takes fluid from the cranial compartment and a distal catheter (outflow tube) that carries the fluid to another body compartment where CSF is absorbed. The most common shunt pathway is from the brain to the abdominal cavity (Ventriculo- Peritoneal). [Figure 2].

Shunt systems also usually include a valve that regulates the flow of fluid through the shunt and may include a reservoir for fluid sampling and shunt testing and/or an antisiphon device to minimise drainage due to gravity.

Cerebrospinal fluid shunts are one of the most common to fail medical device with high complication and failure rates often requiring multiple revisions. [1] A retrospective single centre study of paediatric patients in the United States found that 84.5% of patients required one or more shunt revisions within a 15 year period whilst 17.5% required ten or more [2] Data from the United Kingdom Shunt Registry reports that the failure rate is 17.4% in the first 12 months with this figure being even higher in children [3]. No long terms studies of the Australasian population have been undertaken.

Shunt dysfunction and complications have a clinical and economic impact on both patients and the health system. The only Australian study of the economic costs associated with hydrocephalus was undertaken between 2007 and 2009 at The Children's Hospital at Westmead (NSW). Hydrocephalus procedures comprised more than a quarter of all neurosurgical procedures at the site and although the patients represented less than 0.3% of yearly hospital admissions, they used six times that in hospital bed days and total hospital expenditure.

Hydrocephalus
Ventriculoperitoneal (VP) Shunt

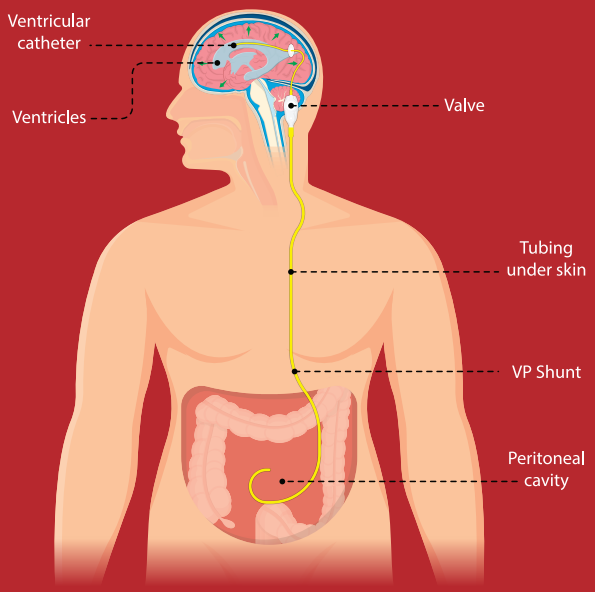


Figure 2: Shunt Placement and the Flow of CSF

25% of the total hydrocephalus -related hospital expenditure annually was used for the diagnosis and intervention of patients with newly diagnosed hydrocephalus and 7% by the ongoing surgical management of patients experiencing previous treatment complications.

The average cost for the index admission of newly diagnosed hydrocephalus was $13,989 compared with $83,649 for a subsequent admission for cases of shunt infection. Strategies that reduce shunt revision rates and especially shunt infection rates are therefore likely to be very cost effective [4].

The study underestimates the cost associated with the management of hydrocephalus. Cases secondary to trauma or malignancy and costs associated with presentations to the emergency department, outpatient visits or admissions where no surgical intervention was undertaken were excluded.

Adult onset hydrocephalus is less commonly studied and reported in literature. Development of hydrocephalus in adults is often secondary to other pathologies such as post cranial surgery, brain tumours, head injury, infection or intracranial haemorrhage [5]. Knowledge of the adult hydrocephalus population may assist in better management of the condition.

Registry Rationale

To date, there has been no longitudinal data collection of the shunted population throughout Australasia. The status of the population is unknown but estimated in to be in the order of several thousand admissions annually.

The number of shunts marketed in Australasia is numerous and increasing. The ability to choose between shunt systems is limited to the information provided by the manufacturers and by individual experience. Prior to the establishment of the Shunt Registry, there was no system in Australasia that collected information on shunt-related procedures enabling the reporting of independent information.

There is a gap in current knowledge regarding the factors that influence the clinical outcomes of patients with CSF shunts, device information and clinical performance bench marking. A large proportion of people who have shunts also suffer from additional chronic conditions. Shunt revisions and hospital readmissions related to shunt procedures are common. The public health burden of hydrocephalus is significant.

Shunts are foreign bodies which will eventually break down. The aim is to minimise revisions, and this can only be achieved with monitoring of patients and clinical information. Clinical registries are a clinically credible mean of monitoring health care processes. As long-term data repositories they have the ability to capture data on conditions or events.

The Shunt Registry is the first registry collecting information on Australasian participants.

Snapshot

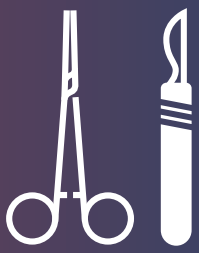
58 sites engaged

36 Public
22 Private

2022 unique patients have been entered into the Registry

62% aged 18 years and older
51.6% female, 48.4% male

Full opt out currently stands at 7.9% and partial opt out at 2.5%



There are 1507 insertions and 991 revisions in the Registry

404 are primary insertions

The most common clinical aetiolgy for shunt insertion in infants is haemorrhage, tumours in children and idiopathic normal pressure hydrocephalus in adults

The rate of revision for patients who have undergone primary insertion is 11.6%

The rate for patients undergoing more than one revision procedure is 28.5%

405 patients have been admitted more than once in the four year reporting period

19 patients have been admitted between 5 and 13 times

The most common reason for revision in infants is haemorrhage tumours in children and idiopathic normal pressure hydrocephalus in adults

Governance

The Australian Commission on Safety and Quality in Health Care is the author of the 2014 Framework for Australian clinical quality registries [6] (which includes operating principles and technical guidelines/standards) and the 2008 Operating Principles and Technical Standards for Clinical Quality Registries [7]. The Shunt Registry operates in accordance with these operating principles and technical guidelines/standards.

The NSA Board is responsible for the Shunt Registry and has delegated the management of the registry to the Shunt Registry Committee.

Committee

A Shunt Registry Committee was formed to develop policies for the operation and oversee management of the Shunt Registry. The Committee operates under the direction of policy guidelines determined by the NSA Board.

The Committee meets on a quarterly basis to discuss the Shunt Registry progress, data access and strategic direction.

The data custodian is the NSA. NSA, staff are responsible for the day to day management of the Shunt Registry.

The Committee is comprised of:
Mark Dexter, New South Wales (Chair)
Robert Campbell, Queensland
Andrew Garde, Victoria (Community Representative)
Erica Jacobson, New South Wales
Andrew Law, New Zealand
Sharon Lee, Western Australia
Stephen Santoreneos, South Australia
Martin Wood, Queensland
Alison Wray, Victoria
Stacie Gull, NSA Chief Executive Officer
Katrina Smith, NSA Shunt Registry Manager

Research Ethics and Site Governance

Australian sites operating under the National Mutual Aaceptance scheme have overarching ethics approval from the Sydney Childrens Hospital Network HREC.

New Zealand public hospitals have overarching ethics approval from the Southern Health and Disability Committee. Maori authorisation has been obtained for all New Zealand sites.

Private sites throughout Australasia have ethics/governance as required. All public sites have governance authorisation.

Registry Methodology

The Shunt Registry operates in accordance with the Australian Commission on Safety and Quality in Health Care 2008 Operating Principles and Technical Standards for Clinical Quality Registries [7].

Surgeon and Site Recruitment

Sites were invited to participate in the Shunt Registry via letter, phone, email or during the NSA Annual Scientific Meeting. The Shunt Registry aims for whole population data capture so all sites were invited to participate regardless of the number of surgeries undertaken annually (ranging from 1 to over 100).

Participation in the Shunt Registry is voluntary. Sites and surgeons receive no reimbursement for the contribution of data. NSA membership is not required for a surgeon to contribute data.

Approval is site specific not surgeon specific. Neurosurgeons operating at any approved site are eligible to contribute data.

Sites have progressively engaged in the Shunt Registry. At the end of 2020, 58 sites were fully approved. An additional 11 ethics/ governance submissions were in progress. Due to the cost of the ethics submission and the low surgical numbers, one site has elected not to participate in the Registry.

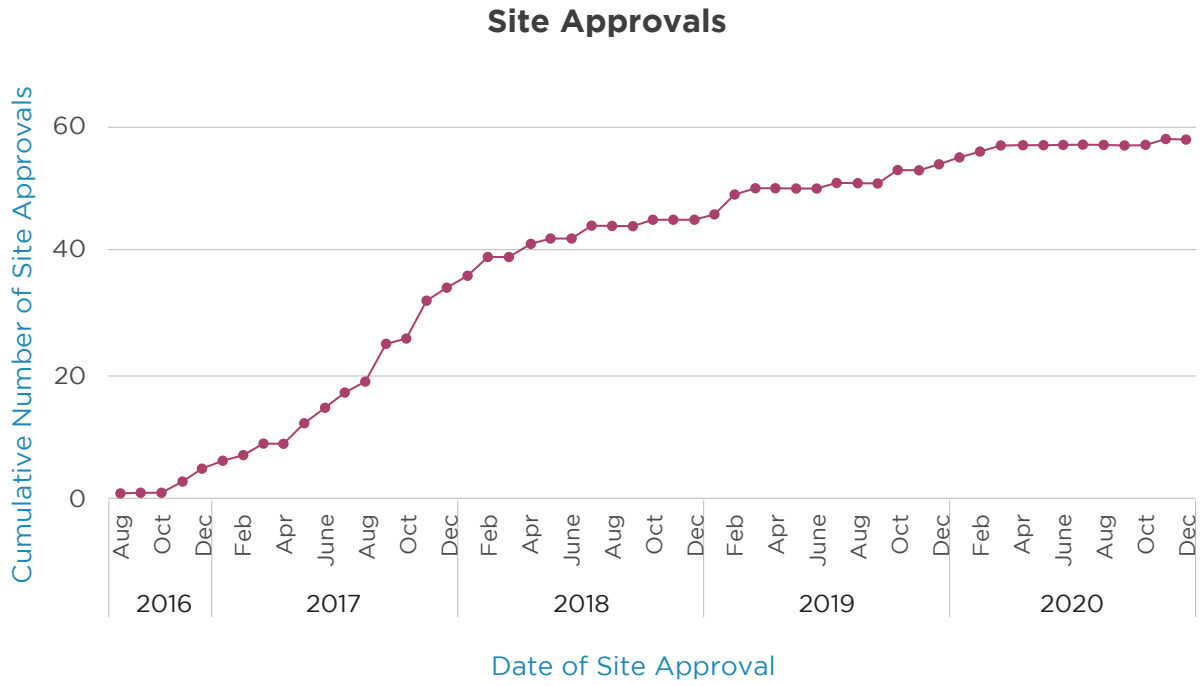


Figure 3: Timeline of Site Approval

State/Territory	Public	Private	Number of contributing surgeons (consultants)
NSW	13	6	46
VIC	6	2	32
QLD	5	8	32
WA	3	1	9
SA	3	3	12
ACT	1	1	6
TAS	1		5
New Zealand	4	1	14
TOTAL	**36**	**22**	**156**

Table 3: Site Engagement and Surgeon Contribution

Patient Population

Eligible participants are easily identified as all shunt surgery is performed by neurosurgeons within a hospital neurosurgical department. Any person undergoing CSF shunt related surgery in an ethically approved hospital is eligible for inclusion in the Shunt Registry. There are no additional inclusion or exclusion criteria. Hospitals agree to include all applicable cases to avoid selection bias.

Participation in the Shunt Registry is voluntary, and the care provided to the participant will not be affected in any way whether or not they choose to participate.

Participants receive no reimbursement for the inclusion of their data.

Patient Risk

The Shunt Registry is a data collection study, so there is no risk to any patient contributing data. The database conforms to all security standards and no patient is ever identified in any reports or publications stemming from the Shunt Registry.

Data Elements

The data collection form is one page, double sided, "tick and stick" form based on that developed by the established UK Shunt Registry [8]. Where applicable, data elements and definitions are based on the National Health Data Dictionary (METeOR) metadata standards [9]. All data elements are defined in the Shunt Registry data dictionary.

The data collected is grouped under five categories: clinical diagnosis, operation details, shunt details, reason for revision (if applicable) and product information. Responding to surgeon feedback and to formalise the collection of data that was regularly being provided as free text, there have been three amendments to the original data collection form. An Aboriginal/Torres Strait Islander ethnicity checkbox has been added to the data collection form. The new version of the form will be rolled out to sites throughout 2021.

Data Collection

Data can be collected in its entirety at the time of surgery and is a subset of what is routinely collected and recorded in the patient's medical record. The NSA provides the sites with data collection forms and completed forms can be returned to the Shunt Registry via secure e-fax, file transfer, email or reply paid postage. There is no site data entry.

Sites are not required to consent patients however sites in Western Australia must gain consent from the patient for the data to be sent to the Shunt Registry.

	Total Admissions			Unique Patients		
	Infant	Child	Adult	Infant	Child	Adult
NSW	72	198	542	52	134	473
VIC	55	113	387	38	81	312
QLD	119	313	432	63	187	348
SA	10	23	69	10	19	66
ACT/ TAS/WA[1]	2	18	136	2	16	120
NZ	62	100	207	46	76	168
TOTAL	**320**	**765**	**1773**	**211**	**513**	**1487**

[1]*Sites with low category numbers have been combined*

Table 4: Patient Participation

Process

Data Collection

- A member of the neurosurgery team completes the Shunt Registry data collection form at the time of or soon after surgery.
- Sites are not required to consent patients. Sites in Western Australia are required to obtain consent for identifiable data to be sent across State borders.
- Data is sent to the Shunt Registry via secure efax, email, post or secure file transfer software.

Patient Contact

- Participant information and opt out sheets are sent to patients directly from the NSA. Information is sent to the parent/guardian if the patient is aged under 18 years and from an Australian site.
- New Zealand participants aged between 7-15 years and 16-18 years receive an additional age appropriate information sheet.
- Patient Information is only sent to the patient at their first admission or upon transition from paediatric to adult care.

Opt Out

Participants are given the option of full or partial opt out.

Patients who opt out at their first admission remain opted out for subsequent admissions

Data Entry

Data entry is undertaken by NSA staff

There is no site data entry

Reporting

Site, ethics and governance, and annual reporting are undertaken within predefined timeframes.

Figure 4: Registry Methodology

Patient Contact and Opt Out

The Shunt Registry operates under a centralised opt-out model.

Within seven days of a completed data sheet being received at the Shunt Registry, a participant information and opt-out form is sent to the patient directly from the NSA.

Patients are offered the option of full or partial opt-out. Patients are sent participant and opt out information on their first admission only. The opt out form is completed by checking the box of field/s to be removed from the Shunt Registry. The patient name, date of birth and postcode is entered on the form and the form is signed. Signed forms received with identifying information but not opt-out fields checked are treated as full opt out.

Patients can contact the Shunt Registry at any time to request the removal of data even if it has been entered previously however patients who do not want their data included in the Shunt Registry remain opted out for all further admissions. All patients will be sent a PIS upon transition from a paediatric to adult site, irrespective of whether their data is currently in the Shunt Registry or if they have previously been opted out by a parent/guardian.

A separate password protected database is used to monitor opt out requests. Patients requesting partial opt-out through removal of their demographic data are assigned an identifier and their initials and date of birth recorded, allowing identification of the patient if readmitted. Patients requesting full opt-out have their surname, first initial and date of birth recorded to ensure they are not contacted on subsequent admissions. The month and year of surgery is recorded for site case ascertainment. Full opt out currently stands at around 7.9 % and partial opt out at 2.5%.

Registry Database

The NSA collaborated with the Monash University Department of Epidemiology and Preventive Medicine to develop the Shunt Registry database and supporting information technology structure.

The Shunt Registry is web-based and data is stored on Monash University's servers. The web-based system conforms to industry best practice. All data activity is in accordance with the University's Information Technology Services Security Framework Policy.

No data is entered into the Shunt Registry for a period of four weeks, allowing adequate time for a patient to opt-out. Data is entered into the Registry by NSA staff.

Data Completeness and Accuracy

Registry strength and the ability to report shunt survival outcomes is dependant on the accuracy and completeness of data submitted. For the data to be accurate in terms of shunt survival, the reporting rate must be high.

Every three months, an internal database audit is undertaken where 10% of randomly selected records are checked for data entry accuracy. To date, there have been no audits undertaken to check the accuracy of data collected at the site level.

Sites who fail to contribute data are contacted by the Shunt Registry staff on a regular basis.

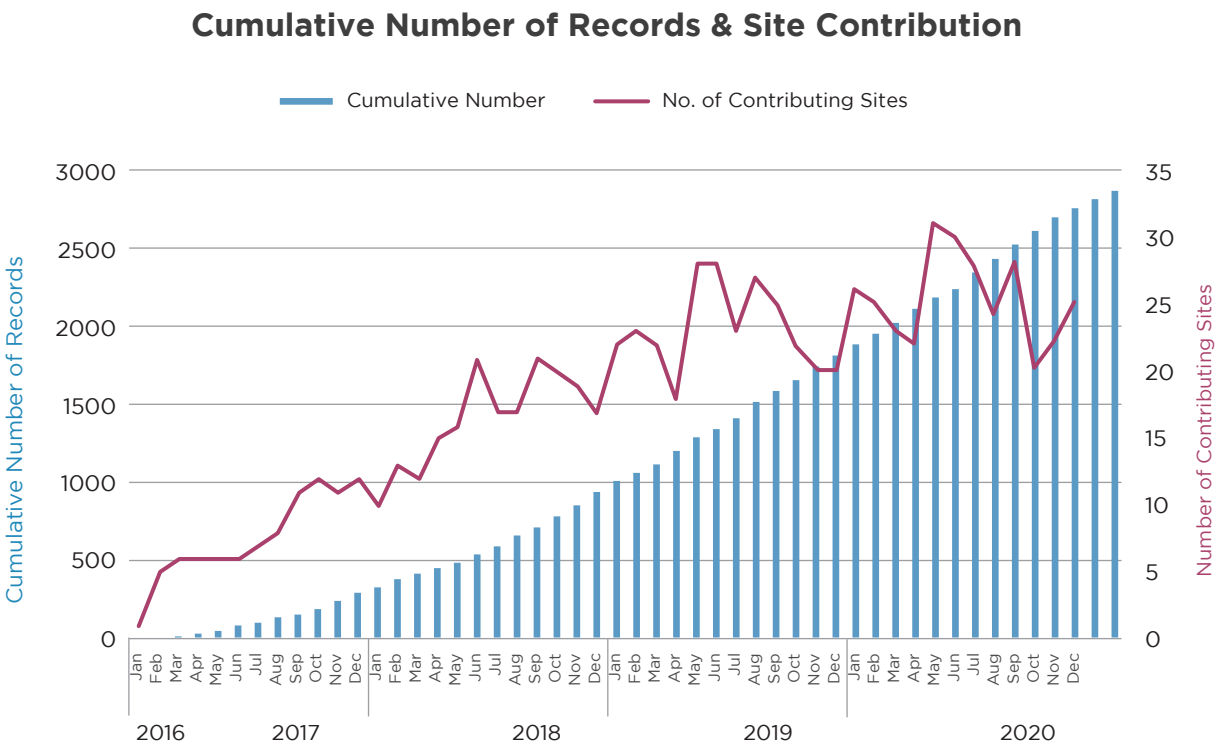


Figure 5: Data Submission and Site Contribution

Case Ascertainment

A number of sites have independently undertaken internal case ascertainment audits with results of between 97 and 100% data submission. Data identified as missing was subsequently submitted. Ongoing, sites who have collected over 50 records will be requested to report case ascertainment using theatre logs or via a report from the site health administration.

There are three scenarios where the date of surgery is recorded for case ascertainment but no data is entered in the Shunt Registry.

(1) On compassionate grounds no contact is made with the family, parent/guardian of patients who are notified as deceased when the data sheet is received at the Shunt Registry.

(2) If the patient record is received six months after the date of surgery.

(3) If the patient cannot be contacted (incomplete/incorrect address).

Ethics approval states that the data sheets from (2) and (3) can be retained for six months. If the patient is readmitted, can be contacted and does not opt out, all records can be entered. If the patient is not readmitted, the record is shredded.

429 records have been received that are not able to be entered into the Shunt Registry.

Full opt out Number of Patients (Number of Admissions)	Data received more than six months after the surgery date (Patients)	Notified as deceased	Patient cannot be contacted	Other
175 (213)	80	15	94	27

Table 5: Records not able to be entered

Reporting

A Shunt Registry reporting cycle has been established to report on site activity and whole data outcomes. As the Shunt Registry grows, site reports will include performance benchmarks.

A Shunt Registry reporting module is currently being developed and in the future, sites will be able to access the database to run site specific standardised reports (Table 6).

Who	Type	When	
Principal Investigators	Detailed Site report	Annually	Commences a year after the date of first data submission Sites with a minimum of 3 contributing surgeons or less than 10 records receive a modified report to ensure deidientification of data
Individual Surgeons	Individual Activity Report	Upon request	
Public	Annual Report	Annually	First published in 2021
HSA Newsletter, Social Media, NSA Website	Infographic snapshot reports	Quarterly	

Table 6: Registry Reporting

Registry Output

Patient Characteristics

As at 31 December 2020, there were 2,858 admissions for 2,202 unique patients.

Patient age is reported in three separate categories; Infant <=12 months, Child >12 months and <18 years and Adult >=18 years.

28 patients (35 admissions) requested that their date of birth be removed however they were still able to be placed in an age group dependant on their admitting hospital.

There were 51.6% females and 48.4% males. The most common age group undergoing shunt surgery are adults.

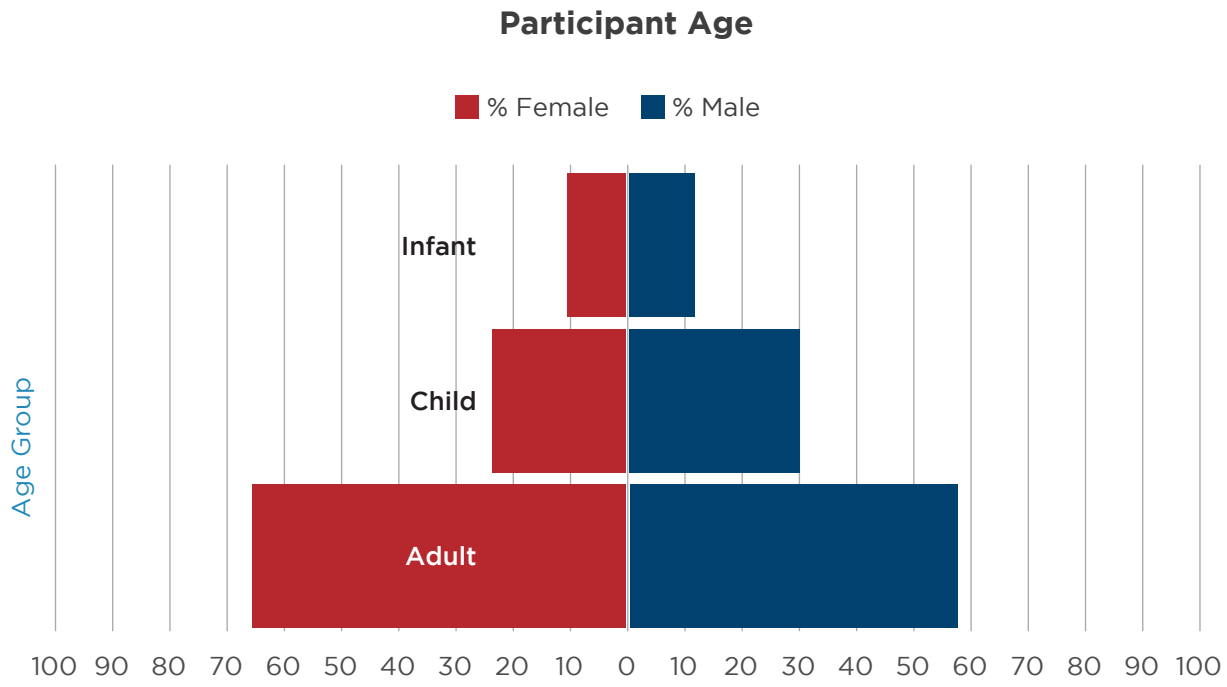


Figure 6: Participant Age at Time of Surgery

Reason for Shunting – Clinical Diagnosis

Numerous causes exist for hydrocephalus and as such there are a number of indications for implantation of a shunt. Different aetiologies influence the choice of shunt implanted and may have prognostic implications for shunt survival and revision rates. Hydrocephalus is diagnosed through neurological examination, brain imaging and other tests such as computed tomography (CT), magnetic resonance imaging (MRI), ultrasound and intracranial pressure testing.

Hydrocephalus may be present at birth (congenital) or may be acquired as a result of infection, brain or spinal cord tumours, injury or stroke causing bleeding in the brain or neurodegenerative conditions such as idiopathic normal pressure hydrocephalus.

The most common clinical aetiology for infants is haemorrhage (40%) and tumours in children (33.5%) with more than half of conditions for both the age group falling within the "acquired category". Idiopathic normal pressure hydrocephalus represents 26% of all adult admissions.

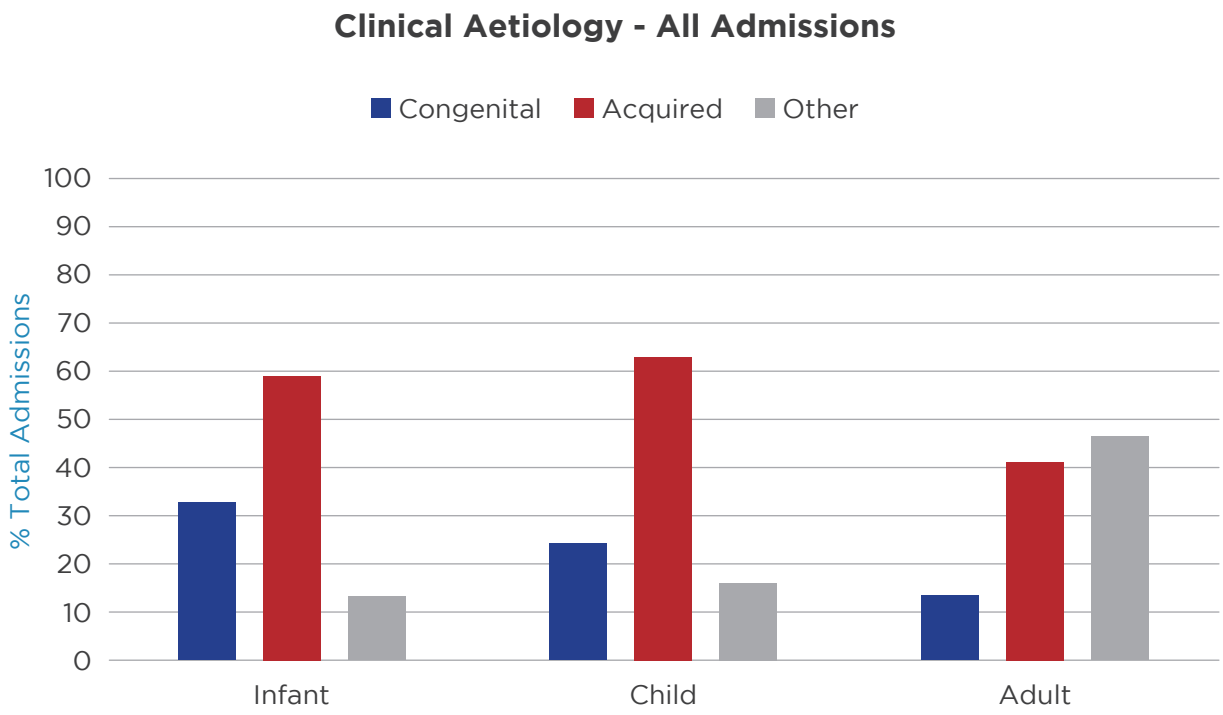


Figure 7: Principal Clinical Diagnosis – All Admissions

		Number of Admissions (% Total age group admissions)		
		Infant	Child	Adult
Congenital	Aqueduct Stenosis	50 (15.6)	79 (10.3)	89 (5.0)
	Chiari	2 (0.6)	16 (2.1)	27 (1.5)
	Chiari/Spina Bifida	16 (5.0)	29(3.8)	56 (3.1)
	Dandy Walker	12 (3.8)	13 (1.7)	15(0.8)
	Other /Not Specified/Not Known	25 (7.8)	48 (6.3)	52 (2.9_
Acquired	Infection	45 (14.1)	78 (10.2)	175 (9.9)
	Haemorrhage	128 (40.0)	146 (19.1)	329 (18.5)
	Tumour	15 (4.7)	256 (33.5)	227 (12.8)
Other	Pseudotumor cerebri	0 (0)	17 (2.22)	139 (7.8)
	Trauma	4 (1.3)	19 (2.5)	49 (2.8)
	Arachnoid Cyst	17 (5.3)	32 (4.2)	37 (2.1)
	Idiopathic Normal Pressure Hydrocephalus	0 (0)	8 (1.0)	462 (26.1)
	Other	21 (6.6)	47 (6.1)	139 (7.8)

Note: Some patients may have more than one clinical diagnosis and diagnoses may change between admissions.

Table 7: Clinical Aetiololgy Subgroups

Procedures Captured by the Registry

The Shunt Registry aims to capture all shunt related procedures including insertion, revision, removal, externalisation, EVD and ETV.

Patients may undergo more than one procedure in a single admission

	Infant	Child	Adult	Total
Insertion	202	241	1064	**1507**
Revision	68	372	551	**991**
Removal	12	32	43	**87**
EVD	16	91	61	**168**
ETV	8	28	34	**70**
Other	22	24		**46**

Table 8: Total Number of Procedures Captured

Legacy Patients

Patients whose first entry into the Shunt Registry is for a shunt revision are known as legacy patients. The date of the primary shunt insertion/s precede the Shunt Registry data capture period. 411 patients have only one revision procedure without a prior or subsequent procedure entered into the Shunt Registry.

Primary Participants

1,507 shunt insertions have been entered into the Shunt Registry.

	Age of Patient		
	Infant (<= 12 months)	Child (>12 months and <18 years)	Adult (>=18 years)
Aqueduct Stenosis	176	224	1045
Chiari	0.24 (0.12 - 0.45)	7.73 (3.43 – 13.26)	63.1 (44.4 – 74.1)
Chiari/Spina Bifida	0.9 :1	1.08:1	0.88:1

Table 9: Age of Patients Undergoing a Shunt Insertion

Multiple Revisions

117 patients were admitted for more than one revision procedure.

Number of Revision Procedures	Number of Patients	Number of Procedures
2	86	172
3	18	54
4	10	40
>=5	3	16
TOTAL	**117**	**282**

Table 10: Multiple Revision Procedures

Time Between Revisions

Over half (54.8%) of primary insertion revisions were undertaken within 90 days of the shunt being inserted. The median number of days for insertion to revision was 14, first to second revision was 69.5, third to fourth revision was 88 and fourth to fifth was 55.

Revision times (days) and interquartile ranges are shown below (Figure 8).

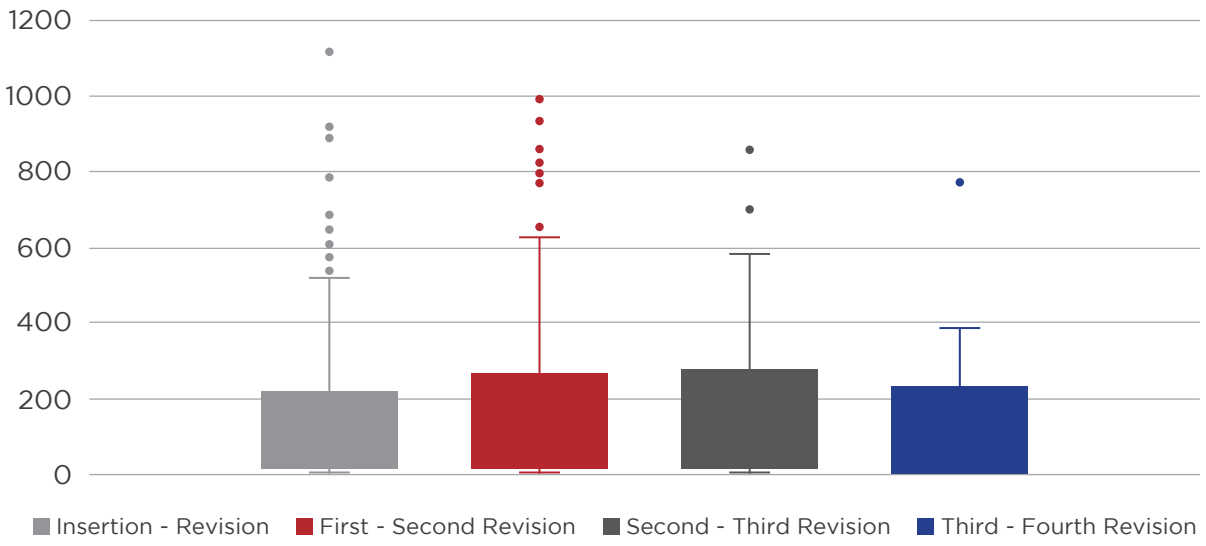


Figure 8: Days Between Procedures

Multiple Admissions

In total, the Shunt Registry has captured 2,858 procedures for 2,202 unique patients.

405 patients have been admitted more than once with 19 patients being admitted between five and thirteen times within four years. 25.8% of infants were admitted more than once within a year.

	Admissions	Unique Patients	Number of Patient Admissions				
			1	2	3	4	>=5
Infant	320	228	154	39	12	6	3
Child	765	492	348	93	37	12	9
Adult	1773	1482	1287	146	34	10	7
	2858	**2202**	**1789**	**278**	**83**	**28**	**19**

Table 11: Multiple Admissions according to Age Group

Operation Details

Duration of Surgery

When reported, the majority of both insertion surgery in all age groups was completed between 31 and 90 mins.

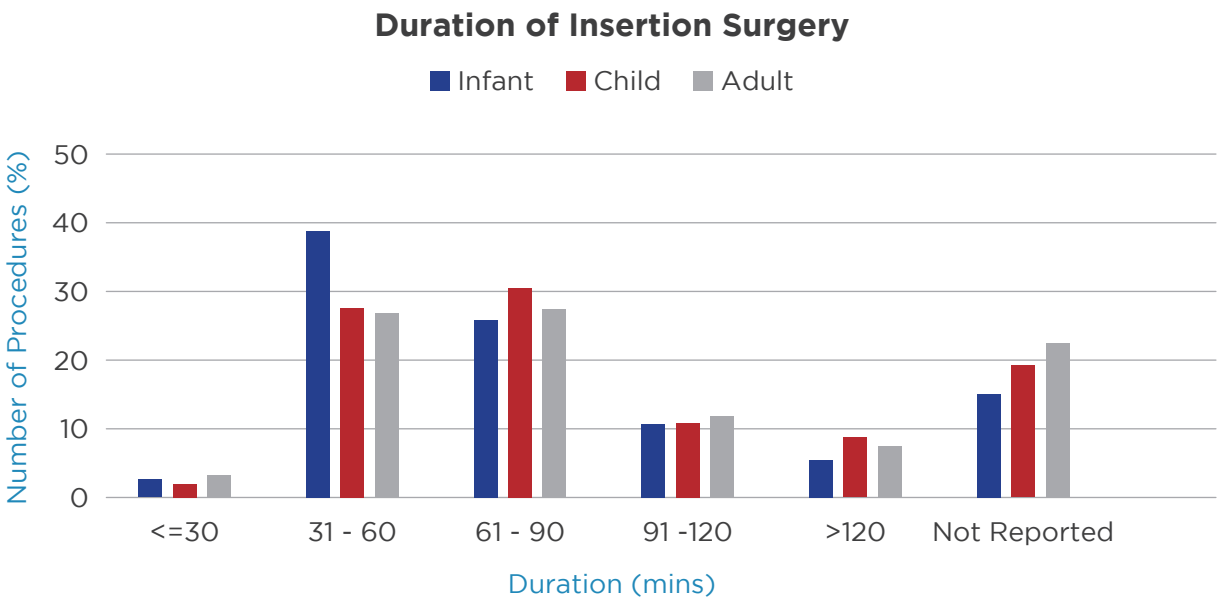


Figure 9 : Duration of Insertion Surgery

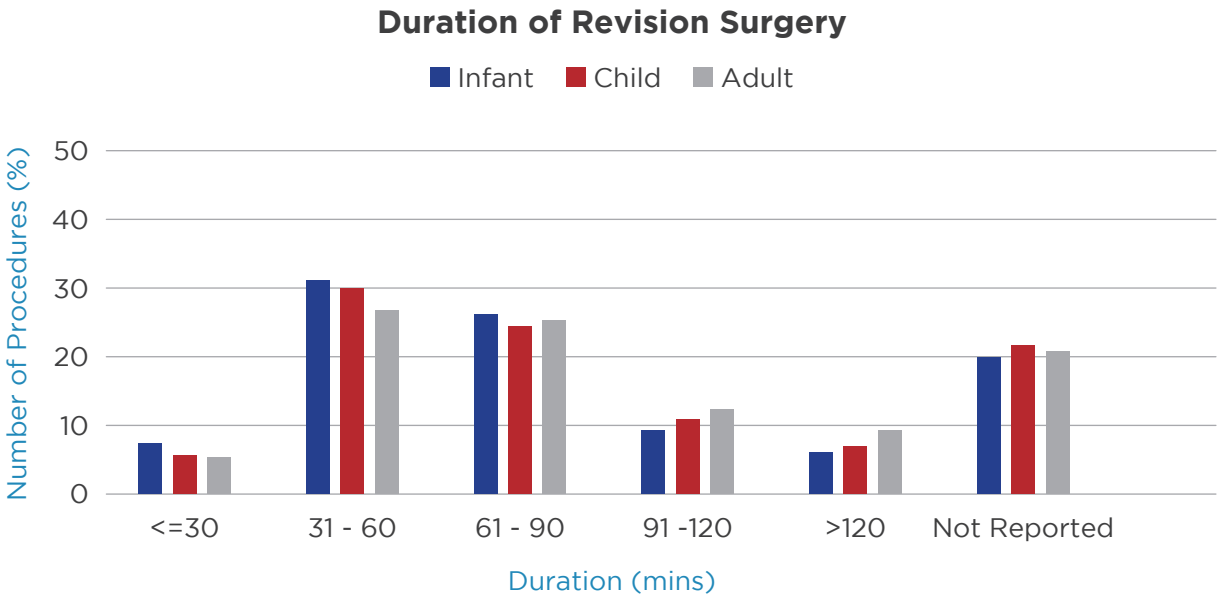


Figure 10: Duration of Revision Surgery

Shunt Revision – Reason for Failure

Complications of shunt surgery include infection, blockage of one or both catheters and /or the valve, underdrainage, catheter misplacement or fracture.

	Infant	Child	Adult	Total
Infection	3	6	16	**25**
Blockage Underdrainage	51	223	336	**610**
Overdrainage	2	37	56	**95**
Disconnection	3	37	49	**89**
Catheter Misplacement	8	10	45	**63**
Fracture		22	20	**42**
No reason found/ Not entered	6	42	62	**110**

Table 12: Reason for Shunt Failure

Conclusion

The establishment of the Shunt Registry enables the unprecedented longitudinal data collection of patients undergoing CSF shunt fluid surgery throughout the public and private hospital sector throughout Australasia. Whilst the Registry has not yet reached its full potential, it has demonstrated the capability to report based on evidence based clinical practice.

Since the inception, site engagement in the Shunt Registry has increased steadily and the Shunt Registry has received strong support from patients, neurosurgeons and support staff who have been fundamental to the success. As the Shunt Registry continues to develop and mature, we are committed to delivering more comprehensive reports to guide best clinical practice and processes and to ultimately improve health outcomes for patients.

References

[1] B. R. H. C. B. S. Hanak BW, "Cerebrospinal Fluid Shunting Complications in Children.," Pediatr Neurosurg. Epub 2017, vol. 52, no. 6, pp. 381-400, 2 Mar 2017.

[2] J. W. C. J. M. P. V. &. S. H. Stone, "Revision rate of pediatric ventriculoperitoneal shunts after 15 years," Journal Of Neurosurgery: Pediatrics, vol. 11, no. 1, pp. 15-19, 2013.

[3] R. H. S. H. P. J. J. A. c. Fernández-Méndez R, "Current epidemiology of cerebrospinal fluid shunt surgery in the UK and Ireland (2004-2013)," J Neurol Neurosurg Psychiatry, vol. July, no. 90(7), pp. 747-754, 2019.

[4] A. F. a. O. B. Pham, "Treating pediatric hydrocephalus in Australia: a 3-year hospital-based cost analysis and comparison with other studies," Journal of Neurosurgery:Paediatrics, vol. 11, no. 4, pp. 398-401, 2013.

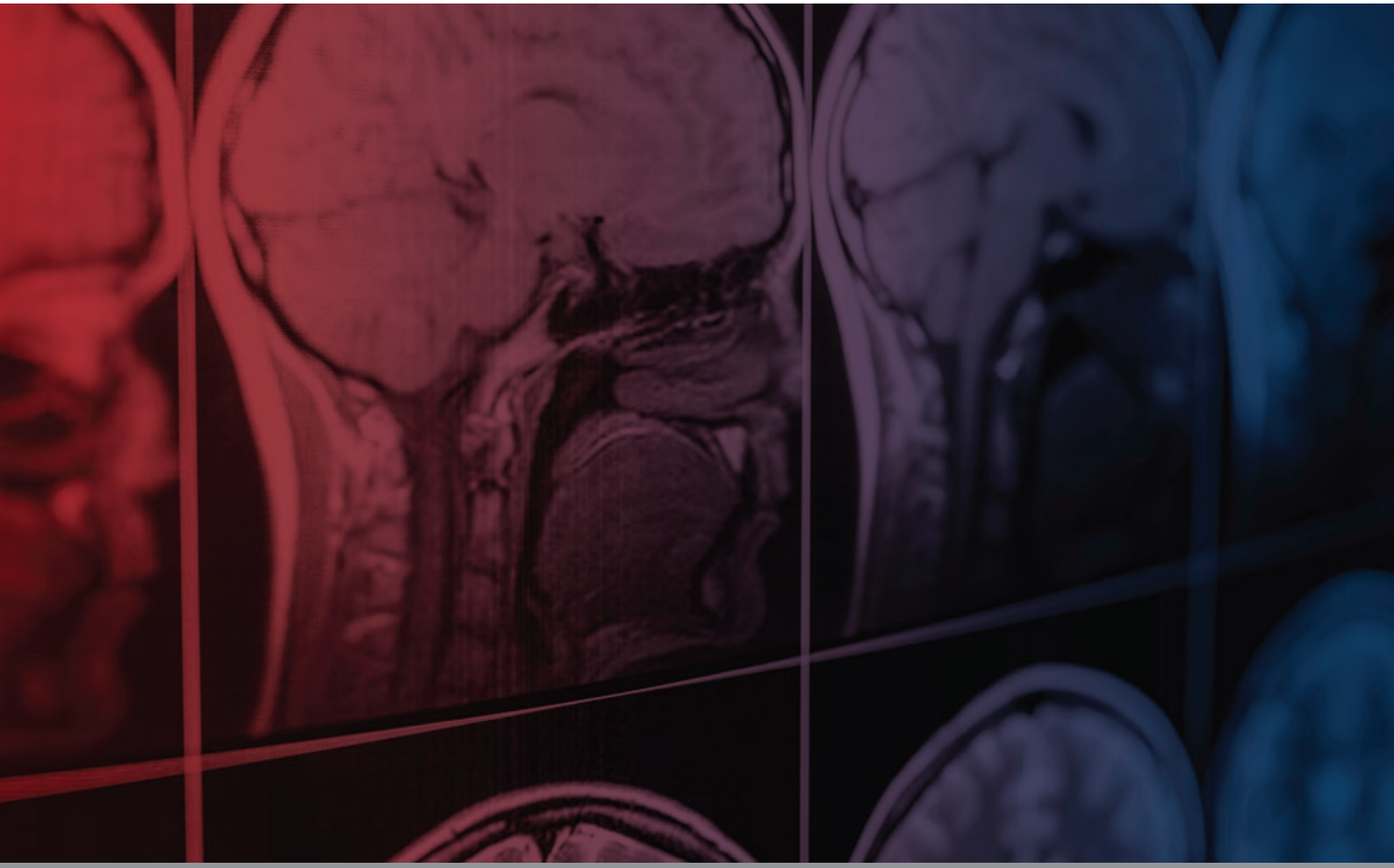
[5] P. D. M. T. S. H. G. B. N. C. N. A. Bir SC, "Epidemiology of adult-onset hydrocephalus: institutional experience with 2001 patients," Neurosurg Focus, vol. 41, no. 3, p. E5, 2016.

[6] Australian Commission on Safety and Quality in Health Care, "Framework for Australian Clinical Quality Registries," 2014.

[7] A. C. o. S. a. Q. i. Health, "Operating Principles and Technical Standards for Australian Clinical Quality Registries," 2018.

[8] H. R. a. A. J. John Douglas Pickard, "UK Shunt Registry Draft report," The Society of British Neurological Surgeons, 2017.

[9] "METeOR home," 2019. [Online]. Available: https://meteor.aihw.gov.au/content/index.phtml/itemId/181162.



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