The Australasian Shunt Registry

What is a Shunt Registry

Record or database of shunt or shunt related procedures for patients in Australasia

Interactive tool for neurosurgeons

Why have a Registry

- Heterogeneous patient group
  - Age
  - Pathology
  - Shunt Systems
  - Surgical Practice
- Analysis needs large numbers

Aim

To provide a tool for the collection, storage and analysis of data in relation to shunt and hydrocephalus related procedures performed in Australasia for the benefit of patients and providers of neurosurgical services.

Aims

- Specific aims of the ASR are to:
  - Provide information on the nature and indication for procedures
  - Assess survival & performance of shunt systems & components
  - Allow confidential self audit of individual neurosurgeons & units
  - Allow collection of data for general & specified research projects
  - Provide accurate data for evidence based management decisions

Data Recorded

- Patient demographics
- Clinical information / Aetiology
- Operation details
- Shunt details / Type / Site / Product details
- Shunt revisions / Indications
- Antibiotic usage

Consent

- NHMRC Guidelines for Ethical Review of Quality Assurance Activities
  - Consent is a key issue
  - Compliance with National Privacy Principle
  - A form of consent is needed
  - Perhaps HREC approval

Consent

- AOA NJR
  - Opt out consent
  - Patient information form
  - Toll free number
  - National Privacy Commisioner

Data Collection

- Method: form based
- Timing
- Responsibility
- Motivation
- Audit

Data Management & Analysis

- Protection Patient & Surgeon Confidentiality
- NHMRC Guidelines for the Protection of Privacy in the Conduct of Medical Research
- Commonwealth Qualified Priviledge Scheme

- Off site data backup and storage

Data Management & Analysis

- Options
  - Clinician run system
  - Data management and Analysis Centre, University of Adelaide, Dept Public Health
  - Other third party

Data Management & Analysis

- Ability to generate a custom-made database
- Awareness and compliance with regulations
- Experience in management and analysis
- Experienced & educated data entry personnel
- Statistical expertise
- Production of reports

Returns May1995-December 2002

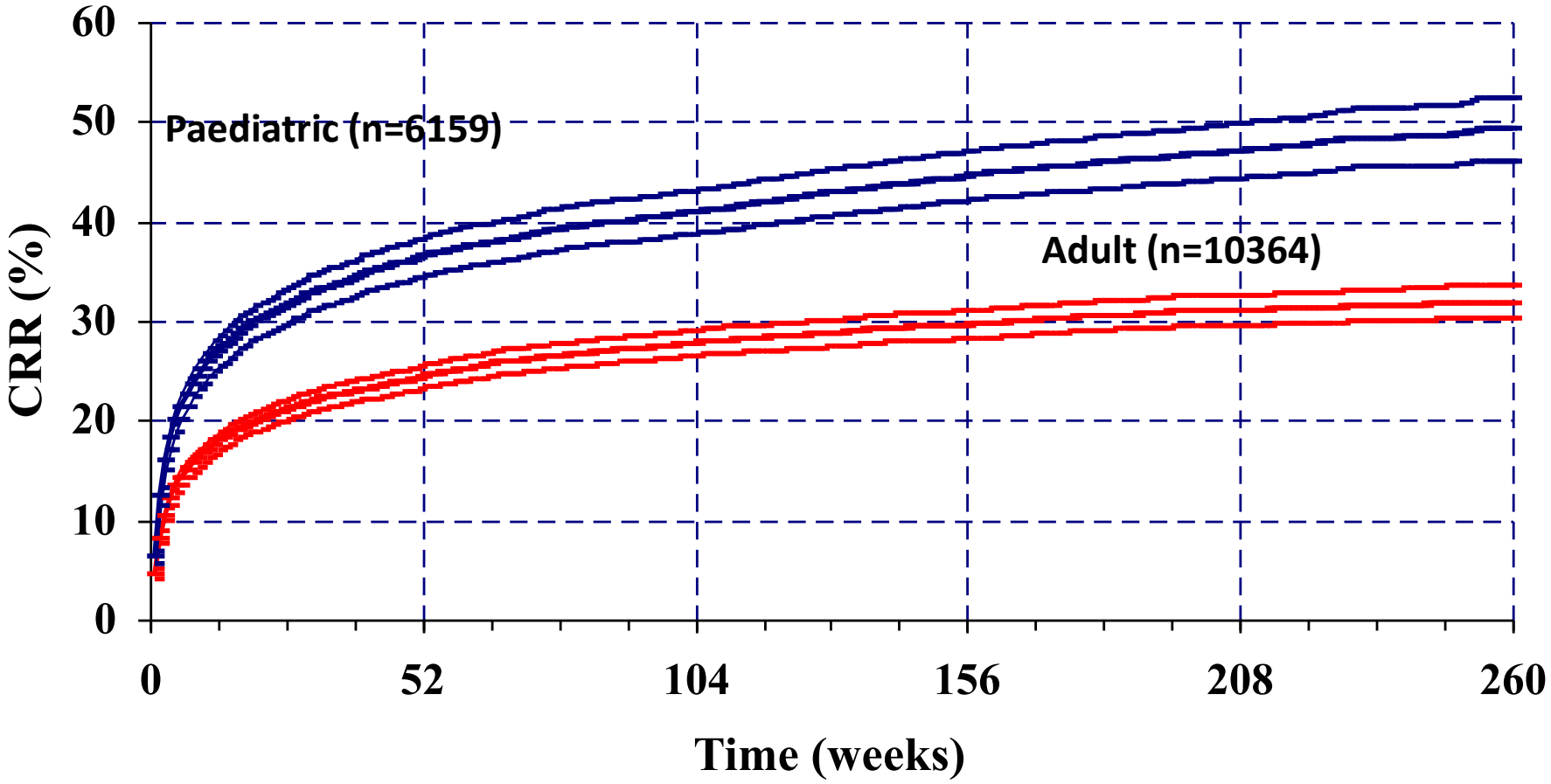
Centre	Returns
Frenchay Hospital, BRISTOL	1744
Addenbrooke's Hospital, CAMBRIDGE	1594
LEEDS General Infirmary	1563
Radcliffe Infirmary, OXFORD	1272
Queen's Medical Centre, NOTTINGHAM	1268
Southern General Hospital, GLASGOW	1247
Wessex Neurosurgical Centre, SOUTHAMPTON	971
Beaumont Hospital, DUBLIN	969
Walton Hospital, LIVERPOOL	935
NEWCASTLE General Hospital	898
University Hospital of Wales, CARDIFF	863
Derriford Hospital, PLYMOUTH	734
King's College Hospital, LONDON	708
Royal MANCHESTER Children's Hospital,	615
Royal Victoria Hospital, BELFAST	560
Others	2549

Centre	Returns
Atkinson Morley's Hospital, LONDON	551
Hope Hospital, SALFORD	457
National Hospital, Queen Square, LONDON	435
BIRMINGHAM Children's Hospital	424
Hurstwood Park Neurosurgical Centre, SUSSEX	411
Queen Elizabeth Hospital, BIRMINGHAM	407
HULL Royal Infirmary	400
Alder Hey Children's Hospital, LIVERPOOL	394
North Staffordshire Hosp. STOKE-ON-TRENT	392
MIDDLESBOROUGH General Hospital	375
Royal Hallamshire Hospital, SHEFFIELD	333
University Hospital, CORK	278
London Hospital, LONDON	275
Western General Hospital, EDINBURGH	239
Wlsgrave Hospital, COVENTRY	239

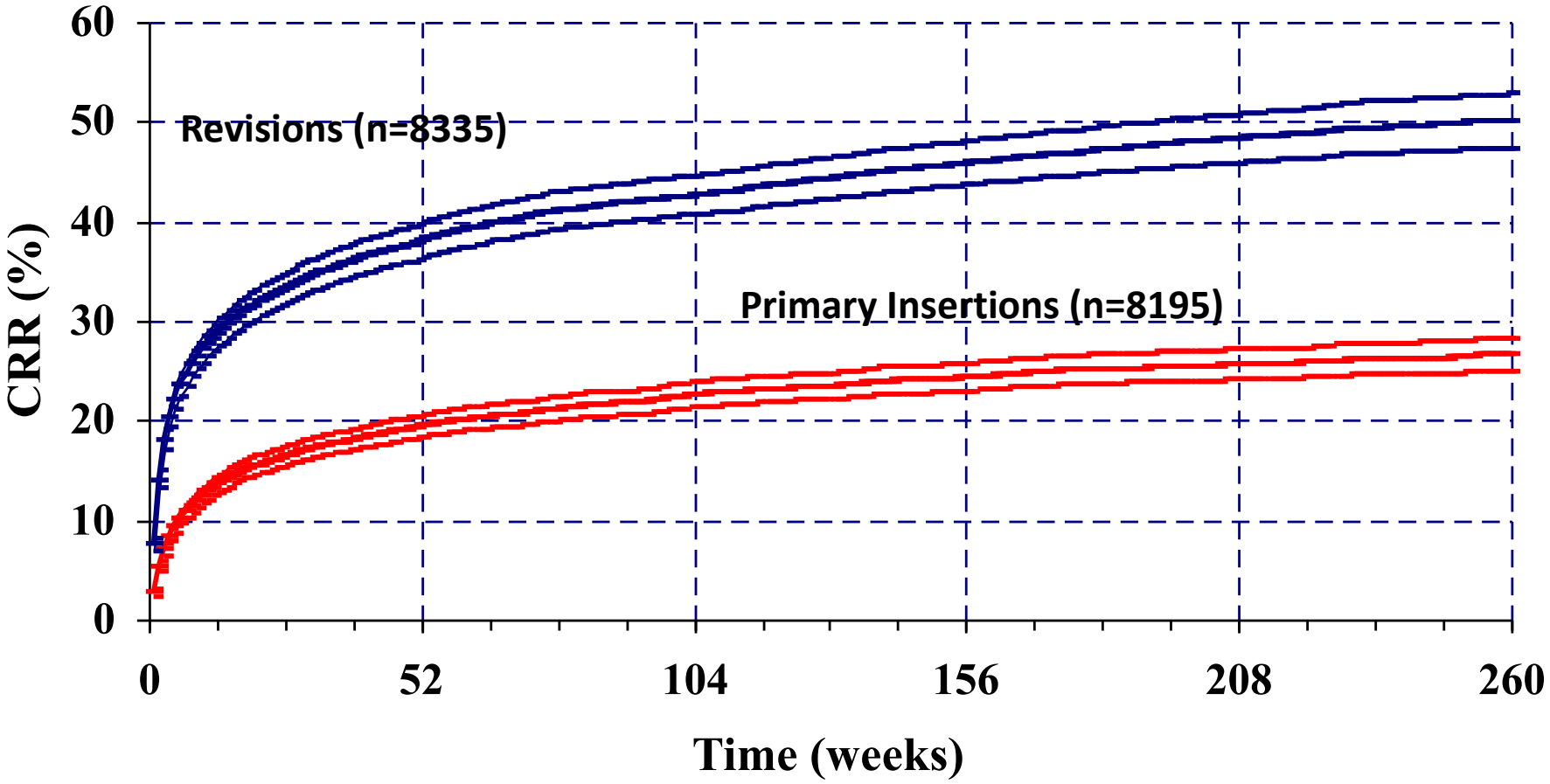
TOTAL 24116

(Patients 16316)

Cumulative Revision Rate (Kaplan-Meier)



Cumulative Revision Rate (Kaplan-Meier)



Reasons for Revision

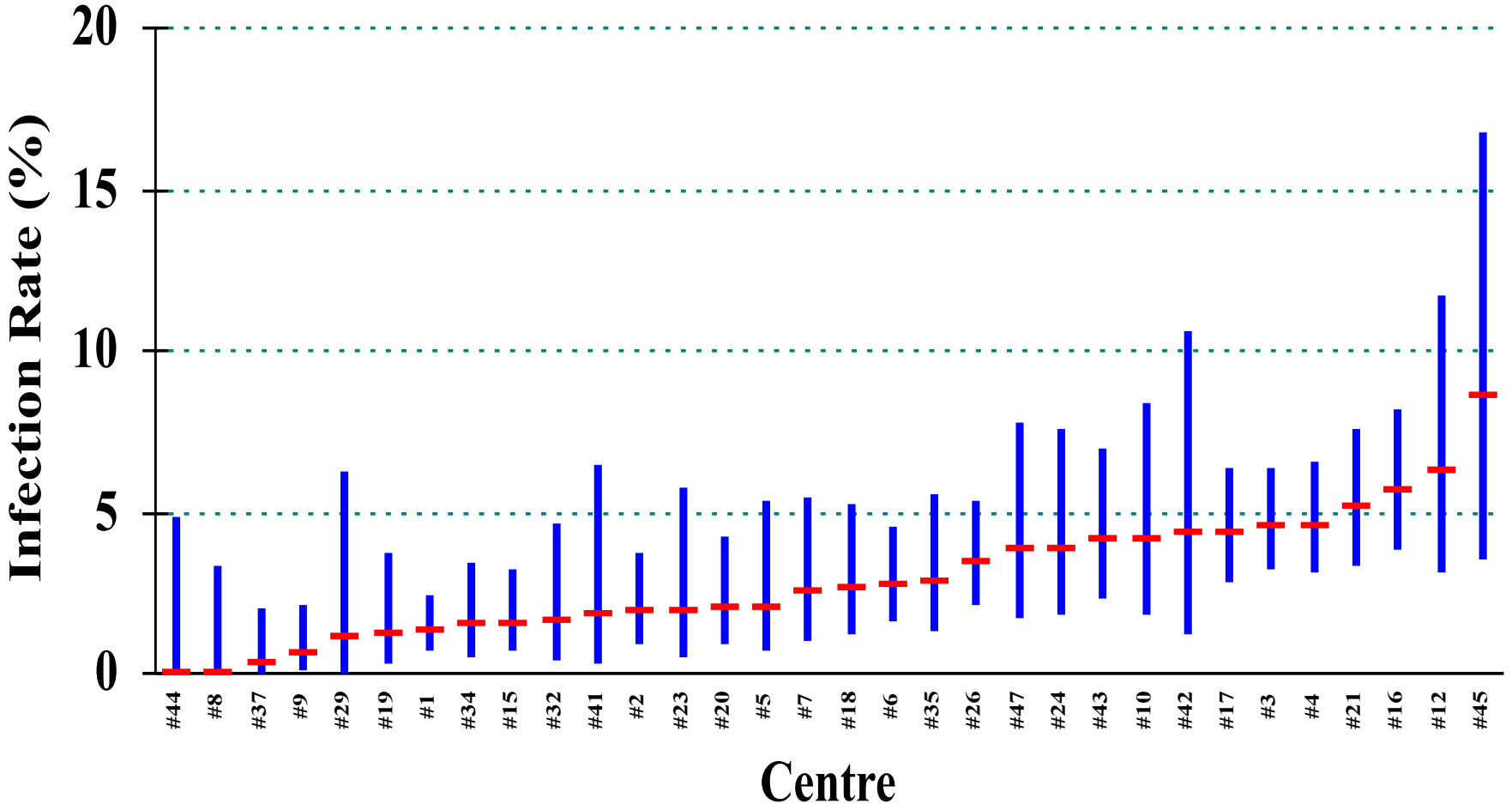
	Age < 1	1 - 16	17-69	>70	TOTAL
Underdrainage	49.4	57.1	61.4	56.0	58.4
Infection	34.6	12.2	13.6	15.1	14.9
Disconnection	10.0	13.2	13.6	16.2	13.2
Fracture	0.9	7.5	3.3	1.5	4.8
Migration	3.0	5.7	4.2	3.9	4.7
Overdrainage	2.1	4.3	3.9	7.3	4.0

Why have a shunt registry?

- Quality assurance activity
  - How well do shunts perform
  - Measure own performance against others
    - Infection / Revision rates
  - Identify underperforming shunt systems

- Research Vehicle
  - Basis for multicentre clinical trials
  - Compare practices and new technology

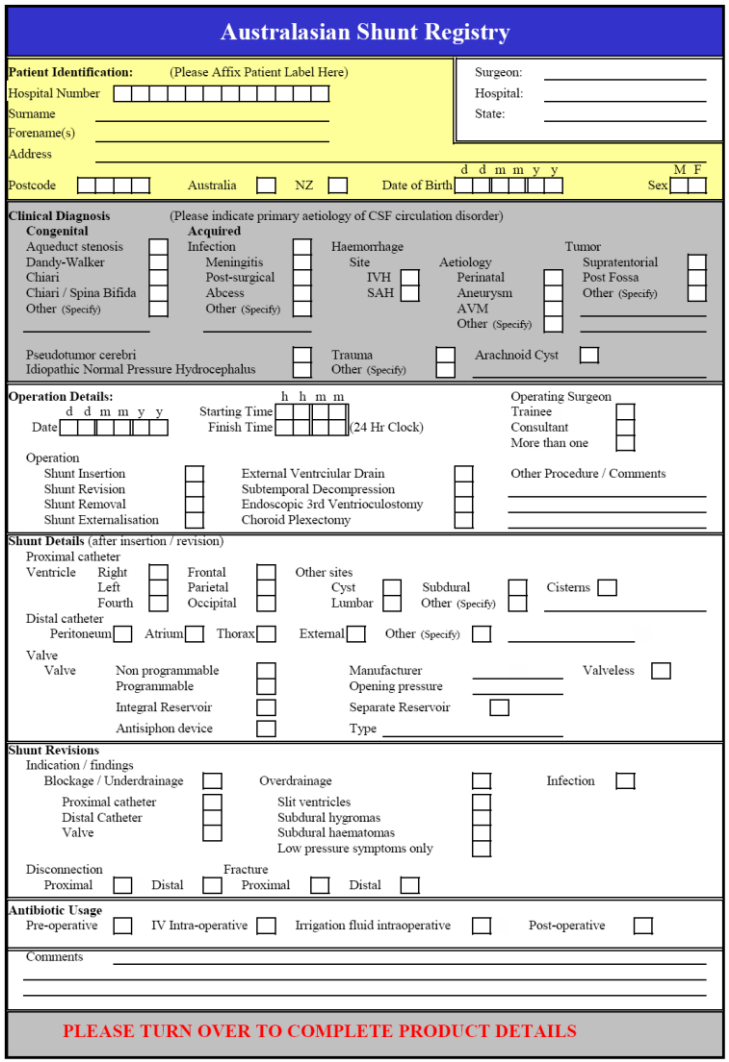
Shunt Registries



What are the Problems?

- Privacy
  - Need to capture failures and revisions
  - Cannot be completely anonymous
  - Need for consent = registry failure
- Participation
  - Surgeons concerned about use of data; apathy
  - Commitment from professional bodies
- Costs and Resources

Australian Shunt Registry



Australasian Shunt Registry

Patient Identification: (Please Affix Patient Label Here)
Hospital Number
Surname
Forename(s)
Address
Postcode Australia NZ Date of Birth d d m m y y Sex M F

Surgeon:
Hospital:
State:

Clinical Diagnosis (Please indicate primary aetiology of CSF circulation disorder)

Congenital
Aqueduct stenosis
Dandy-Walker
Chiari
Chiari / Spina Bifida
Other (Specify)

Acquired
Infection: Meningitis, Post-surgical, Abcess, Other (Specify)
Haemorrhage — Site: IVH, SAH — Aetiology: Perinatal, Aneurysm, AVM, Other (Specify)
Tumor: Supratentorial, Post Fossa, Other (Specify)

Pseudotumor cerebri
Idiopathic Normal Pressure Hydrocephalus
Trauma
Other (Specify)
Arachnoid Cyst

Operation Details:
Date d d m m y y
Starting Time h h m m
Finish Time (24 Hr Clock)

Operating Surgeon: Trainee, Consultant, More than one

Operation
Shunt Insertion
Shunt Revision
Shunt Removal
Shunt Externalisation
External Ventricular Drain
Subtemporal Decompression
Endoscopic 3rd Ventriculostomy
Choroid Plexectomy
Other Procedure / Comments

Shunt Details (after insertion / revision)
Proximal catheter
Ventricle: Right, Left, Fourth — Frontal, Parietal, Occipital
Other sites: Cyst, Lumbar, Subdural, Other (Specify), Cisterns
Distal catheter
Peritoneum, Atrium, Thorax, External, Other (Specify)
Valve
Valve: Non programmable, Programmable, Integral Reservoir, Antisiphon device
Manufacturer, Opening pressure, Valveless, Separate Reservoir, Type

Shunt Revisions
Indication / findings
Blockage / Underdrainage: Proximal catheter, Distal Catheter, Valve
Overdrainage: Slit ventricles, Subdural hygromas, Subdural haematomas, Low pressure symptoms only
Infection
Disconnection: Proximal, Distal
Fracture: Proximal, Distal

Antibiotic Usage
Pre-operative IV Intra-operative Irrigation fluid intraoperative Post-operative

Comments

PLEASE TURN OVER TO COMPLETE PRODUCT DETAILS

?