What can we learn from registries?

- Epidemiological data
- Revision rates and causes
- Infections and causes
- Device problems
- Benchmarking
- Early identification of problems
- Research and education

Update on the Australasian Shunt Registry

- Real collaboration between the NSA and HSA
- Over 2200 procedures registered
- 99% of hospitals registered
- Only 6 % of patients opt –out
- 37 % are revisions

Current epidemiology of cerebrospinal fluid shunt surgery in the UK and Ireland (2004–2013)

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Methods A retrospective, multicentre, registry-based study was conducted based on 10 years' data from the UK Shunt Registry, including primary and revision shunting procedures reported between 2004 and 2013. Incidence rates of primary shunts, descriptive statistics and shunt revision rates were calculated stratified by age group, geographical region and year of operation.

Results 41 036 procedures in 26 545 patients were submitted during the study period, including 3002 infants, 4389 children and 18 668 adults. Procedures included 20 947 (51.0%) primary shunt insertions in 20 947 patients, and 20 089 (49.0%) revision procedures. Incidence rates of primary shunt insertions

Epidemiology

- Infants
  - Perinatal IVH
  - Malformations (AS)
- Children
  - Tumours
  - Post –haemorrhagic
- Adults
  - Tumours
  - Post-haemorrhagic
  - NPH

Causes of hydrocephalus

Underlying diagnosis for primary shunt†, n (%)			
Malformations‡	934 (33.9)	411 (16.3)	1125 (7.4)
Perinatal intraventricular haemorrhage	973 (35.3)	160 (6.3)	94 (0.6)
Tumour (benign, malignant, unspecified)	152 (5.5)	1022 (40.5)	3750 (24.6)
Post-haemorrhagic (AVM, SAH, unspecified)	28 (1.0)	48 (1.9)	2473 (16.2)
Idiopathic normal pressure hydrocephalus	0 (0)	0 (0)	2173 (14.2)
Idiopathic intracranial hypertension	10 (0.4)	122 (4.8)	1160 (7.6)
Infection (meningitis, cerebral abscess, unspecified)	184 (6.7)	108 (4.3)	472 (3.1)
Cyst (colloid, arachnoid, unspecified)	84 (3.0)	124 (4.9)	522 (3.4)
Trauma	30 (1.1)	55 (2.2)	525 (3.4)
Acquired other	127 (4.6)	168 (6.7)	1242 (8.1)
Idiopathic other	22 (0.8)	26 (1.0)	162 (1.1)
Unknown (diagnosis not specified)	212 (7.7)	279 (11.1)	1565 (10.3)

Revisions

- 90 day revision rates
  - Infants 22%
  - Children 19%
  - Adults 13%
- 1 year revison rates
  - Infants 31%
  - Children 25%
  - Adults 17%

Reasons for revision

1. Underdrainage
2. Infection
3. Overdrainage
4. Mechanical failure

Reasons for revision

90-day revision rates, n (%)§	591 (21.9)	462 (18.6)	1919 (12.8)
Reasons for primary shunt revision¶, n (%):			
Underdrainage	317 (64.9)	199 (66.3)	759 (57.2)
Shunt infection	81 (16.5)	35 (11.7)	158 (11.9)
Disconnection	25 (5.1)	12 (4.0)	93 (7.0)
Migration	17 (3.4)	6 (2.0)	101 (7.6)
Overdrainage	7 (1.4)	24 (8.0)	101 (7.6)
Fracture	8 (1.6)	5 (1.6)	30 (2.2)
Wound infection	3 (0.6)	1 (0.3)	8 (0.6)
More than one reason	30 (6.1)	18 (6.0)	75 (5.6)
Primary shunt revisions that included shunt replacement with external ventricular drain	55 (5.5)	21 (2.6)	106 (3.3)

Issues with UKSR

- Average case ascertainment 79.5%
- Reasons for revision missing:-
  - in 42.4% overall
  - 57.9% among first revisions
- Its all about recruitment and the quality of the data!

Australasian shunt registry

- Dedicated data manager
- Ethics approval for each site and each state
- Feedback to each unit compared to group.
- De-identified surgeon specific data
- Device monitoring

Future funding

- Established 2013 with seed funding of $150 000 from Commonwealth Department of Health and Ageing
- No further government funding.
- Supported since then by NSA
- Annual cost of ~ $110 000
- Cost of 1 shunt revision due to infection ~ $80 000

Future funding

- Government
- Industry
- HSA
- Philanthropy