Challenges faced by registries

Prof Karen Smith

VACAR Chair

Director Centre for Research and Evaluation

CI AUS-ROC

ambulance.vic.gov.au

Value of Registries

The most pressing areas for registry development are high cost areas of medicine with known variation in processes and outcomes that may indicate inappropriate care or inefficient use of limited resources
(Evans et al MJA 2011)

Powerful tool for describing healthcare, including the complications and benefits of therapies

Drive a **quality agenda** and foster a performance culture

Support more **effective**, **efficient** and **appropriate** care

Clinical trials often **exclude patients** at higher risk of poor outcomes, so estimation of illness burden or intervention effects may be subject to enrolment bias

Knowing that performance is being measured is **motivational**

Inexpensive, relatively simple to maintain, and more often reflect the true clinical situation

Provision of meaningful data to clinicians **encourages engagement**

Monitor whether care is delivered in line with **best practice**

Reduce costs associated with clinical trials

May **drive poorer performing areas to improve** performance
(if OHCA survival could be increased to the highest performing community throughout the US, it is estimated that 15,000 premature deaths could be prevented annually [Nichol et al JAMA 2008])

Monitor **equity** of access to care

Verify if real practice is in keeping with recommendations from **guidelines**

Economic value of clinical quality registries

**Australian Commission on Safety and Quality in Health Care
Nov 2016**

▶ Examined 5 Australian clinical quality registries

▶ Each of the 5 clinical quality registries improved clinical practice at a relatively low cost, leading to a significant net positive return on investment

▶ Benefit to cost ratios ranged from 2:1 to 7:1

▶ Minimum expected benefit to cost ratio would be 4:1 if full national coverage were achieved by all 5 clinical quality registries

▶ Also likely to be more individual practitioner, cultural and systems levels benefits not captured in study

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

November 2016

Economic evaluation of clinical quality registries

Final report

Monash University and Health Outcomes Australia have prepared this report on behalf of the Australian Commission on Safety and Quality in Health Care.

- The Australian Resuscitation Outcomes Consortium (Aus-ROC)

Centre of Research Excellence (CRE) funded by the National Health and Medical Research Council (NHMRC)
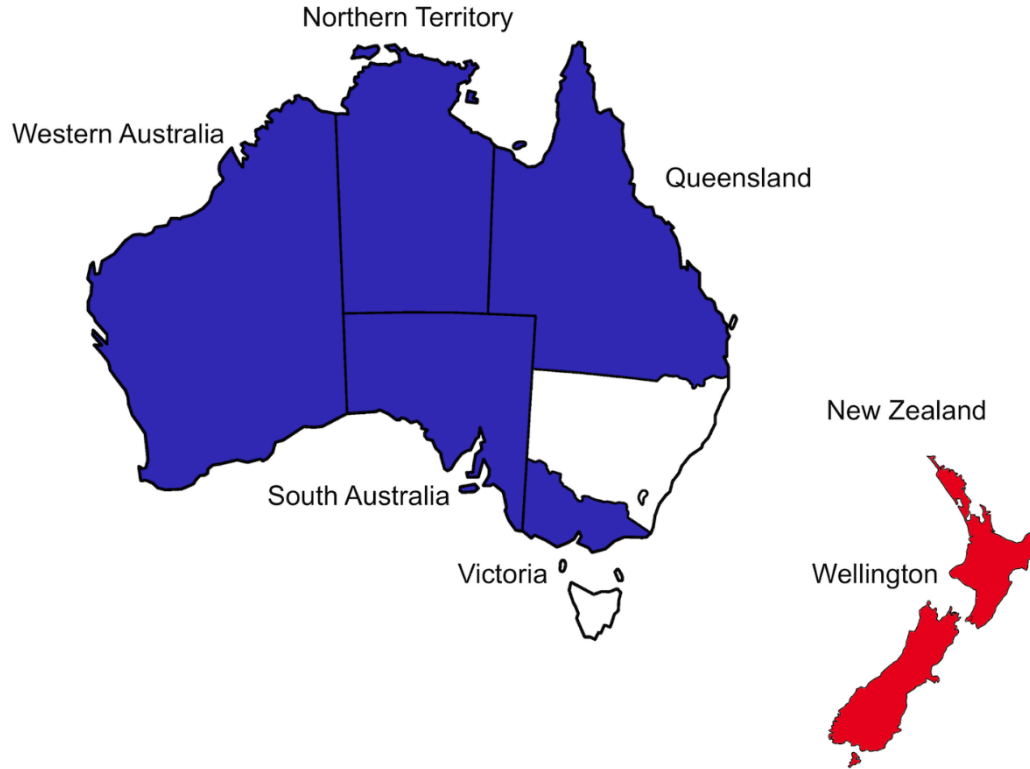
Mission: to provide infrastructure and project support for clinical trials and outcome-oriented research in the area of out-of-hospital cardiac arrests

- Major objective

**Develop an Australian and New Zealand cardiac arrest registry,
or Epidemiological-registry (i.e. Epistry)**

Aus-ROC Australian and New Zealand Epistry

Capture population: 19.5 million

Aus-ROC Australian and New Zealand Epistry

TABLE 1. *Summary data related to ambulance service characteristics*

	Australia					New Zealand	
	SAAS	AV	SJAWA	QAS	SJANT†	SJNZ	WFA
Service area population	1 685 714[10]	5 841 667[10]	2 573 389[10]	4 722 447[10]	210 000	4 018 370[11]	491 380[11]
Geographical area (km^2)	984 179.8[12]	227 495.5[13]	2 526 417.9[14]	1 725 825.9[15]	1 353 163.9[16]	261 521.9[17]	8130.1[18]
Population density (persons per km^2)	1.71	25.68	1.02	2.74	0.18	15.37	60.44
Employment type							
Full time	784 (33%)	2578 (63%)	655 (18%)	3083 (80%)	152 (88%)	1168 (52%)	226 (55%)
Part time	211 (9%)	240 (6%)	57 (1%)	182 (5%)	2 (1%)	97 (4%)	64 (16%)
Casual	70 (3%)	172 (4%)	0 (0%)	273 (7%)	8 (5%)	455 (20%)	30 (7%)
Volunteer	1286 (55%)	1103 (27%)	2968 (81%)	323 (8%)	10 (6%)	536 (24%)	92 (22%)
Total of number of paramedics with:							
BLS-only‡	1469 (64%)	30 (1%)	2968 (82%)	235 (8%)	48 (28%)	1288 (59%)	47 (37%)
ALS	657 (29%)	2473 (83%)	655 (18%)	2697 (87%)	113 (66%)	633 (29%)	56.5 (44%)
Intensive care training	173 (7%)	488 (16%)	8 (0%)	161 (5%)	11 (6%)	262 (12%)	25 (19%)

Beck B, *et al.* 'A description of the ambulance services participating in the Aus-ROC Australian and New Zealand out-of-hospital cardiac arrest Epistry'. *Emergency Medicine Australasia*, 2016; 28:673-683.

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Challenges

- **Definitions**
  - Cardiac arrest (eg bystander CPR but ROSC on EMS arrival, <1 minute CPR by EMS)
  - Resuscitation commenced by EMS (some registries exclude early termination)
- **Case capture**
  - Variable incidence rates- reflective of incomplete capture?
  - Biased sampling?
- **Outcome measures**
  - Hospital discharge versus 30 day survival
  - Using death registry for survival data (incomplete linkage). How test?

Challenges cont

- **Infrastructure**

  - Cost and onus is on contributing organisations in tight health budget

  - Added burden / cost to services (need to see value for cost and effort). Cant be used to the same level as local registries for clinical quality improvement

- **Variation in Quality**

  - May have registries contributing with very tight and extensive quality control measures versus other less mature registries

  - National registry limited ability / visibility to check data

- **Data Governance and access**

  - Limited to host organisation?

- **Authorship**

  - How manage authorship, opportunity to analyse, opportunity to lead and write projects/papers? (ROC have a 29 page document dedicated to this)

Challenges cont

- **Outcomes and benchmarking**

  - How interpret results given the challenges faced and the inability to QC in detail?

  - Analysis performed by member that not close to data / interpretation issues?

  - Results can gain attention of Board/ Gvt – need proper data limitation explanations

  - How risk adjust to allow meaningful benchmarking? – this is a key question

  - Recent grant:

    - Establish a robust risk adjustment strategy for comparing and benchmarking outcome data across services

    - Determining what level of variation across services is explained by potentially modifiable variables

    - Quantifying the likely survival gains if modifiable factors were optimised across Australia / NZ

- **Research and priority setting**

  - Similar issues as to authorship inclusiveness – how agree on priorities?

  - How manage when local registry research projects and national registry research projects overlap too much?

Thank you

Prof Karen Smith

✉ Karen.Smith@ambulance.vic.gov.au

@vacar_av

🐦 @karensmith_av