Australian Resuscitation Outcomes Consortium (Aus-ROC) out-of-hospital cardiac arrest ‘epistry’

A NHMRC Centre of Research Excellence (CRE) in Clinical Research, #1029983

Janet Bray
on behalf of the Aus-ROC Investigators
Sept 2013

Individual ambulance service’s registries/databases contribute data
Aus-ROC specific aims

• undertake large multi-centre clinical trials (e.g. RINSE)
• examine system-based strategies to improve the efficiency and effectiveness of pre-hospital emergency care for OHCA in urban and rural environments.
• build capacity in pre-hospital emergency care research across Australia through graduate research and post-doctoral training.
• establish an Australia-wide OHCA ‘epistry’ (epidemiologic registry) to monitor and report on the population-based effects of changes in pre-hospital resuscitation policy and practice.

This presentation will..

• Introduce the purpose and structure of the NHMRC Aus-ROC Epistry

• Outline the process and challenges in the establishment of the Epistry so far
What is a cardiac arrest?

**Estimates Crude OHCA incidence in Australia**

Based on incidence of ~90 per/100,000

- NSW: 6561
- VIC: 5060
- QLD: 4104
- WA: 2187
- SA: 1488
- TAS: 450
- NT: 210
- ACT: 336

Incidence: ~20,396 OHCA/year

~7,546 received bystander CPR (~37%)
~9,178 EMS treated (~43%)
~917 survivors (5% all; ~9% EMS treated)
Leading Causes of Death in United States
Extrapolated from www.cdc.gov and Nichol JAMA 2008

- Cancer
- Heart Disease ex OHCA
- OHCA
- Stroke
- Chronic Respiratory Injury
- Alzheimer
- Diabetes
- Influenza and Pneumonia
- Renal
- Septicemia

Annual Number of Deaths

Table 4. Incidence and Outcome of EMS-Treated Out-of-Hospital Cardiac Arrest²

Table 5. Incidence and Outcome of Ventricular Fibrillation³


Abbreviation: EMS, emergency medical services.
²All rates were unequal across cities at P < .001.
³All rates were unequal across cities at P < .001.
Out-of-hospital cardiac arrest (OHCA)
-poor survival outcomes

<table>
<thead>
<tr>
<th></th>
<th>Perth (WA) 2008</th>
<th>Vic 2008</th>
<th>US/Canada¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>All arrests (n)</td>
<td>1,058</td>
<td>4,986</td>
<td>19,584</td>
</tr>
<tr>
<td>Rate per 100,000 population (crude)</td>
<td>66.0</td>
<td>93.8</td>
<td>95.7</td>
</tr>
<tr>
<td>Survival EMS assessed</td>
<td>3.6%</td>
<td>5.4%</td>
<td>1.1 to 8.1%</td>
</tr>
<tr>
<td>Survival EMS treated</td>
<td>8.4%</td>
<td>12.4%</td>
<td>3.0 to 16.3%</td>
</tr>
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</table>


Regional variation in Victoria

Adult survival in 2011

<table>
<thead>
<tr>
<th></th>
<th>Metro</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>to hospital</td>
<td>35%</td>
<td>28%</td>
</tr>
<tr>
<td>to discharge</td>
<td>14%</td>
<td>8%</td>
</tr>
</tbody>
</table>

http://www.ambulance.vic.gov.au
Differences in survival in OHCA..

- Different definitions and case ascertainment
- Different case-mix (e.g. age, pathophysiology)
- Better prehospital and inhospital (post-resuscitation) clinical care
- Better organisation of local emergency medical services

OHCA

- Is a major public health problem with a high case fatality (>90%)
- Regional variation exist and can be extensive
- Survival outcomes have not improved, despite decreases in the incidence of coronary artery disease and 50 years since the advent of cardiopulmonary resuscitation (CPR)

We need to do something different if we want to see changes in OHCA survival outcomes...

- CRE
- Epistry
Importance of OHCA Epistry

• Without a reliable uniform data the effectiveness of different EMS systems and interventions cannot be compared.
• Participation in an OHCA registry enables medical providers and EMS systems to compare patient populations, interventions, and outcomes and identifies opportunities to improve quality of care and ascertain whether resuscitation is provided according to evidence-based guidelines.

Aus-ROC Epistry Aims

1. Establish a comprehensive ongoing data infrastructure to facilitate the design, implementation and interpretation of Aus-ROC trials.

2. Define the incidence and outcome of OHCA, including quality of life after hospital discharge.

3. Describe the relationships between resuscitation performance and EMS structure.

4. Evaluate the relationships between outcome and patient, EMS, regional, and periodic factors.
Epistry Management Committee

Steering Committee
Chair: Peter Cameron

Management Committee
Chair: Judith Finn

Epistry Management Committee (EMC)
Chair: Ian Jacobs

Aus-ROC Epistry Population Coverage

55% Aus & 100% NZ population
-includes metropolitan and rural populations

8 ambulance services varying stages
✓ VIC, WA (Perth & 80% rural) & SA – ready
➢ NT, ACT & TAS – almost ready to start
➢ NZ & Wellington – starting
- NSW & QLD – may start in the future
Acronym?

- Australian and New Zealand Cardiac ARrest Epistry (ANZ-Care)
- Australian and New Zealand Registry Out-of-hospital Cardiac ARrest (ANZ-ROCAR)

Epistry data governance

- Epistry management committee
- Ethics approval- overarching (Monash HREC)
- Data governance document
- MOU
Aus-ROC Epistry
issues in set-up

- Funding
- Data harmonisation
- EMS structures
- Data transfer and access

Aus-ROC CRE funding

- Postdoctoral Fellows
  – 2 Vic; 1 WA; 1 SA
- PhD students
  – 2 Vic; 2 WA; 1SA
- Part-time Director (Judith Finn)
- Part-time Executive Officer (Mimi Morgan)
- Direct research costs
  – No specific project funding**
  – No Epistry funding
Aus-ROC ‘Epistry’ Staff

Ideally

• Registry Manager
• Registry Data analyst

Currently

• Chief Investigators & Director overseeing
• Research Fellow & Executive Officer coordinating the set-up

‘UTSTEIN’: Utstein-style definitions and reporting templates

Cardiac arrest and cardiopulmonary resuscitation outcome reports: update and simplification of the Utstein templates for resuscitation registries. A statement for healthcare professionals from a task force of the international liaison committee on resuscitation (American Heart Association, European Resuscitation Council, Australian Resuscitation Council, New Zealand Resuscitation Council, Heart and Stroke Foundation of Canada, InterAmerican Heart Foundation, Resuscitation Council of Southern Africa)*


Pediatric Critical Care Fellowship, Children’s Hospital of Philadelphia, Department of Anesthesiology and Critical Care, 34th St. and Civic Center Blvd. Sixth Floor, Room 6120C, Philadelphia, PA 19104-4309, USA

Received 27 September 2004, accepted 27 September 2004
Core variables

- EMC compared existing registries variables:
  - core variable list
    - 46 variables ideal; 24 core
    - Patient factors (e.g. age, sex)
    - Arrest factors (e.g. presumed cause, location)
    - EMS factors (e.g. resuscitation attempted, response time)
    - Outcomes (e.g. survived event, survived hospital)
  - Revealed variation—some definitions and coding.
    - e.g. location of arrest
Example

• Location of arrest important predictor of outcome

• Utstein: “Location of arrest is the specific location where the event occurred or the patient was found.” Subcategories useful:
  1) Place of residence (e.g., home, apartment, back yard of a home)
  2) Public place (e.g., street, city park, shopping centre, sports stadium, airport, railway station etc)
  3) Other (e.g., hotel room, private office, long-term care facility)

<table>
<thead>
<tr>
<th>VIC</th>
<th>WA</th>
<th>SA</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 possible codes</td>
<td>4 possible codes</td>
<td>Not currently collected. Possible to collect for patients who survive initial event</td>
</tr>
<tr>
<td>Home = any residence</td>
<td>Home = patient’s residence</td>
<td></td>
</tr>
</tbody>
</table>

Data standardisation

• Key Outcome Measure – survival to hospital discharge:
  – Ambulance Victoria
    • since 1999 (rural and metro) – hospital and at 12m (since 2010)
  – St John Ambulance (WA)
    • since 1996 (metro only)
    • linkage to ED+HMD+DEA - hospital
  – South Australian Ambulance Service (SAAS)
    • since 2009 (not as extensive data)
    • no hospital outcome presently (has ethics)
Data standardisation

- Existing sites with datasets
  - variables - uniform definition
  - accept some differences
- New sites without datasets
  - developing data dictionary and/or spreadsheet
- Case ascertainment varies between sites and will need to be initially checked and monitored

Ambulance services

- Differences in ambulance services are potentially important: e.g. different emergency call taking
- Survey to describe key relevant differences in ambulance services participating in Aus-ROC Epistry
  - compare differences
  - important reference for publications
Data Transfer, Storage and Access

- De-identified by ambulance services
- Transferred via Secure File Transfer Protocol (SFTP)
- Re-coded at Monash
- Stored in database on Monash Server
- Access via analytical console

External access restricted

Secure File Transfer Protocol (SFTP)

Welcome to Monash University's secure file storage environment. Files placed here are held in accordance to the Health Records Act (2010) and Privacy Act (1988).

Files removed from here are the responsibility of the user for compliance to these Acts.

For assistance contact Clinical Informatics & Data Management Unit (CIDMU), Pht: (03) 9903 0050.
Data transfer

Secure File Transfer - SFTP

File was successfully uploaded.

Data Access

Access to the Aus-ROC OHCA Registry data is guided by strict protocols and procedures to ensure that privacy and other ethical principles are maintained at all times.

Access to the data is subject to the Specific Access Guidelines:

1. Only Aus-ROC staff at Monash University (who have specific specific access guidelines) and study participants will have direct access to the Aus-ROC OHCA Registry data.
2. All use of the Aus-ROC OHCA Registry data, in whatever context, must receive prior approval from the Aus-ROC Orthopaedics Ethics Committee and, in instances where hospital or other health care providers are involved, require institutional ethics committee approval.
3. Any material to be published using Aus-ROC OHCA Registry data must be reviewed by the Aus-ROC Orthopaedics Ethics Committee for endorsement and, before it is released for publication.
4. Under no circumstances will individual units of data be released.
5. Only requests that meet Specific Access Guidelines 1 and 4 (below) will be provided free of charge, whereas a large number of such requests are made. These requests will be reviewed periodically. The provision of data for all other requests (specific access guidelines 2-8) will be subject to a fee-for-service basis. See Fees For Provision of Data (July 2003) for an explanation of these.
6. All third party requests for access to data must be submitted in writing. Requests will be evaluated according to the Specific Access Guidelines. As a general rule, requests for data under Specific Access Guidelines 3 and 4 will take 2-4 weeks to complete. Data cannot be supplied within 2 weeks of a request. All other requests must be first made to the Aus-ROC Director, who will then assess such requests in consultation with the next Aus-ROC Registry Management Committee meeting. If the request is held quarterly and data cannot be extrapolated until approved, then the Aus-ROC Registry Management Committee will consider a specific meeting to consider specific data requests. Once approval has been received, it will take 2-4 weeks to supply the data.
7. All data requests must be submitted in writing to a data request form (located at the bottom of this document) or posted to: Aus-ROC Executive Officer, Department of Epidemiology and Preventive Medicine, Monash University, Alfred Centre, Level 5, 84 Commercial Road, Melbourne, VIC 3004.
Aus-ROC Epistry - extension

- CPR quality (Q-CPR)
- Neurological outcomes
- In-hospital management
  - Emergency department data
  - Intensive care unit data
- Long-term outcomes
  - Morbidity
  - Mortality
- Effect of comorbidity on survival outcomes
- Quality of Life

Kaplan Meir Survival Curve
for all OHCA survivors Perth 1996-2010 (n=457)

During study period
n=143  (31%) died

Median survival
11.77 years

Mean survival
9.6 ± sd=0.3 years
95% CI 9.0 to 10.3 years
Clinical paper

Cardiac arrest outcomes before and after the 2005 resuscitation guidelines implementation: Evidence of improvement?

C. Deasy\textsuperscript{a, b, c, 1}, J.E. Bray\textsuperscript{a, 1}, K. Smith\textsuperscript{a, 1}, R. Wolfe\textsuperscript{b, 1}, J.R. Harris\textsuperscript{a, 1}, S.A. Bernard\textsuperscript{a, b, c, 1}, P. Cameron\textsuperscript{b, c, 1}

\textsuperscript{a} Ambulance Manuals, Australia
\textsuperscript{b} Royal Australasian College of Surgeons, Australia
\textsuperscript{c} Alfred Hospital, Australia

Variation in out-of-hospital cardiac arrest resuscitation and transport practices in the Resuscitation Outcomes Consortium: ROC Epistry—Cardiac Arrest

Dana Zive\textsuperscript{a, 1, 2}, Kent Koppel\textsuperscript{a, 3, 4}, Terri Schmidt\textsuperscript{a, 5, 6}, Jan Stell\textsuperscript{a, 7}, Gena Sears\textsuperscript{a}, Lois Van Ottingham\textsuperscript{a}, Ahamed Idirs\textsuperscript{a}, Shannon Stephens\textsuperscript{a}, Mohamed Daya\textsuperscript{a}, the ROC Investigators

\textsuperscript{a} Virginia Health Sciences (Virginia), Department of Emergency Medicine, Blacksburg, VA, United States
\textsuperscript{b} University of Washington Clinical Field Center, Resuscitation Outcomes Consortium, Seattle, WA, United States
\textsuperscript{c} East Research, Seattle, WA, United States
\textsuperscript{d} Clark County Public Health Department, Clark County, OR, United States
\textsuperscript{e} University of Kentucky, Department of Emergency Medicine, University of Kentucky, Lexington, KY, United States
\textsuperscript{f} Washington Hospital Research Institute, Otsu, Shiga, Japan
\textsuperscript{g} University of British Columbia, Vancouver, BC, Canada

Increased survival after EMS witnessed cardiac arrest. Observations from the Resuscitation Outcomes Consortium (ROC) Epistry—Cardiac arrest

David Hostler\textsuperscript{a, 1}, Elizabeth G. Thomas\textsuperscript{a}, Scott S. Emerson\textsuperscript{a}, James Christenson\textsuperscript{a}, Ian G. Stiell\textsuperscript{a}, Jon C. Rittenberger\textsuperscript{a}, Kyle R. Gorman\textsuperscript{a}, Blair L. Bigham\textsuperscript{a}, Clifton W. Callaway\textsuperscript{a}, Gary M. Vilko\textsuperscript{a}, Tammy Beaudoin\textsuperscript{a}, Sheldon Cheskes\textsuperscript{a}, Alan Craig\textsuperscript{a}, Daniel P. Davis\textsuperscript{a}, Andrew Reed\textsuperscript{a}, Ahamed Idirs\textsuperscript{a}, Graham Nichol\textsuperscript{a, 1}, The Resuscitation Outcomes Consortium Investigators

\textsuperscript{a} University of Pittsburgh, Department of Emergency Medicine, 3501 Forbes Avenue, Suite 405, Pittsburgh, PA 15213, United States
\textsuperscript{b} University of British Columbia, Vancouver, BC, Canada
\textsuperscript{c} University of Ottawa, Department of Emergency Medicine, Ottawa, ON, Canada
\textsuperscript{d} University of Ottawa, Fire Services, Ottawa, ON, Canada
\textsuperscript{e} University of Tennessee, Knoxville, TN, United States
\textsuperscript{f} University of California, San Diego, CA, United States
\textsuperscript{g} University of California, San Diego, CA, United States
\textsuperscript{h} University of California, San Diego, CA, United States
\textsuperscript{i} University of Alabama at Birmingham, Department of Emergency Medicine, Birmingham, AL, United States
\textsuperscript{j} University of Texas Southwestern Medical Center, Dallas, TX, United States
\textsuperscript{k} University of Toronto, University Health Network, Toronto, ON, Canada
\textsuperscript{l} University of Florida, Department of Emergency Medicine, Jacksonville, FL, United States
\textsuperscript{m} University of Washington, Seattle, WA, United States
In Summary

• The Aus-ROC Epistry will bring together core data from Ambulance Service cardiac arrest registries across Australia and New Zealand

• Provide an opportunity to:
  – Compare processes and survival outcomes
  – Provide infrastructure to plan & monitor trials
  – Generate hypotheses about candidate interventions

Goal: Improve patient outcomes from OHCA

Louise Owen and daughter – the ‘big picture’

• A ‘typical’ School day as a teacher in Grafton in 1990
• 30 years old mother of one (Grace)
• 26 weeks pregnant
• Sudden Cardiac Arrest
• Alarm raised by students + CPR performed by colleagues
• Defibrillation by Ambulance Officers 8 minutes later
• Transferred to Brisbane Hospital
• Katy born by Caesarian section – 13 weeks premature – but healthy

• Louise continues to be a strong advocate for resuscitation practice, training and research

Photo from www.surgeons.org/surgical_news
Louise is a cardiac arrest survivor and has over 20 years of CPR training experience.

She is a longstanding advocate of cardiac arrest survival in Australia having survived a cardiac arrest while pregnant with her daughter, also a survivor.

She is the head of training and education for Cardiac Responder.

janet.bray@monash.edu
www.ausroc.org.au

http://www.youtube.com/watch?v=ILxjxfB4zNk