<table>
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<th><strong>Establishing the Aus-ROC Australian and New Zealand Out-of-hospital Cardiac Arrest Epistry</strong></th>
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<td><strong>Date Submitted by the Author:</strong></td>
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</tbody>
</table>
| **Complete List of Authors:** | Beck, Ben; Monash University, Department of Epidemiology and Preventative Medicine  
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| **Secondary Subject Heading:** | Emergency medicine |
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Establishing the Aus-ROC Australian and New Zealand Out-of-hospital Cardiac Arrest Epistry

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Number of tables: 2

Number of figures: 1

References:

Number of references: 27
ABSTRACT

Introduction: Out-of-hospital cardiac arrest (OHCA) is a global health problem with low survival. Regional variation in survival has heightened interest in combining cardiac arrest registries to understand and improve OHCA outcomes. While individual OHCA registries exist in Australian and New Zealand ambulance services, until recently these registries have not been combined. The aim of this protocol paper is to describe the rationale and methods of the Australian Resuscitation Outcomes Consortium (Aus-ROC) out-of-hospital cardiac arrest (OHCA) epidemiological-registry (Epistry).

Methods and analysis: The Aus-ROC Epistry is designed as a population-based cohort study. Six ambulance services in Australia (Ambulance Victoria, South Australian Ambulance Service, St John Ambulance Western Australia and Queensland Ambulance Service) and New Zealand (St John New Zealand and Wellington Free Ambulance) currently contribute data to the Epistry. All OHCA attended by ambulance, regardless of aetiology or patient age, are included in the Epistry. The catchment population is approximately 19.3 million persons, representing 63% of the Australian population and 100% of the New Zealand population. Data are collected using Utstein-style definitions. Information incorporated into the Epistry includes demographics, arrest features, ambulance response times, treatment and patient outcomes. The primary outcome is ‘survival to hospital discharge’, with ‘return of spontaneous circulation’ (ROSC) as a key secondary outcome.

Ethics and dissemination: Ethics approval was independently sought by each of the contributing registries. Over-arching ethics for the Epistry was provided by Monash University HREC (Approval No. CF12/3938 – 2012001888). A population-based OHCA registry capturing the majority of Australia and New Zealand will allow risk-adjusted outcomes to be determined, to enable benchmarking across ambulance providers, facilitate the identification of system-wide strategies associated with survival from OHCA, and allow monitoring of temporal trends in process and outcomes to improve
patient care. Findings will be shared with participating ambulance services and the academic community.

STRENGTHS AND LIMITATIONS

- The Aus-ROC Epistry is a population-based OHCA registry with a capture region encompassing the majority of Australia and all of New Zealand.
- The Epistry provides an ability to define consistent primary and secondary outcome measures to compare the effects of regional and ambulance service variations and understand factors associated with improved survival from OHCA.
- Combining data from multiple regions has inherent challenges, including variation in the variables collected by each of the participating ambulance services.
INTRODUCTION

Out-of-hospital cardiac arrest (OHCA) is a global health problem.\(^1\) Despite over 50 years since the advent of cardiopulmonary resuscitation,\(^2\) survival remains low with reported rates between 0.6% and 25%.\(^3\) Recognition of the variation in OHCA survival rates between regions has heightened interest in the development of multi-centre cardiac arrest registries to understand and improve OHCA outcomes.

Individual OHCA registries have been established by ambulance services in most Australian states and across the whole of New Zealand. However, until recently combining these registries has been hindered by a lack of infrastructure to host the data and to ensure a consensus of definitions and standardisation. As illustrated by the success of international groups, such as the Resuscitation Outcomes Consortium (ROC),\(^4\) the combining of registries across a larger region facilitates: the understanding of regional differences in the OHCA incidence and outcomes; the influence of different ambulance service structures; and the patient, ambulance service and period factors associated with survival.\(^5-7\)

AIMS AND OBJECTIVES OF THE PROJECT

The Australian Resuscitation Outcomes Consortium (Aus-ROC)\(^8\) was established as a National Health and Medical Research Council (NHRMC) Centre of Research Excellence in 2011 to increase research capacity aimed at improving OHCA survival and outcomes. One of the major objectives of this consortium was to develop an Australian and New Zealand cardiac arrest epidemiological registry (Epistry), to enhance and inform coordinated OHCA outcomes research and evaluation. This paper describes the rationale and methods of the Aus-ROC Epistry.

METHODS/DESIGN

Study design
The Aus-ROC Epistry is designed as a population-based cohort study. Six established cardiac arrest registries, four in Australia and two in New Zealand, contribute data to the Epistry (Figure 1). All six cardiac arrest registries are maintained by ambulance services: Ambulance Victoria, SA Ambulance Service, St John Ambulance Western Australia, Queensland Ambulance Service, St John New Zealand and Wellington Free Ambulance. Approximately 19.3 million persons are served by these ambulance services (Table 1), thus the Epistry represents approximately 63% of the Australian population (total population of 23.5 million) and 100% of the New Zealand population (total population of 4.5 million).

Table 1: Description of the six participating Aus-ROC Regions.

<table>
<thead>
<tr>
<th>Region</th>
<th>Ambulance Service</th>
<th>Service area population</th>
<th>Geographic area (ha)</th>
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<tr>
<td>South Australia, Australia</td>
<td>SA Ambulance Service</td>
<td>1,685,714(^9)</td>
<td>98,417,966(^11)</td>
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<tr>
<td>Victoria, Australia</td>
<td>Ambulance Victoria</td>
<td>5,841,667(^9)</td>
<td>22,749,552(^12)</td>
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<td>Western Australia, Australia</td>
<td>St John Ambulance Western Australia</td>
<td>2,573,389(^9)</td>
<td>252,641,786(^13)</td>
</tr>
<tr>
<td>Queensland, Australia</td>
<td>Queensland Ambulance Service</td>
<td>4,722,447(^9)</td>
<td>172,582,593(^14)</td>
</tr>
<tr>
<td>Australian Registries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wellington, New Zealand</td>
<td>St John New Zealand</td>
<td>4,018,370(^10)</td>
<td>26,152,195(^15)</td>
</tr>
<tr>
<td>Wellington Free Ambulance</td>
<td></td>
<td></td>
<td>813,005(^16)</td>
</tr>
<tr>
<td>New Zealand Registries</td>
<td></td>
<td>4,509,750</td>
<td>26,965,200</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>19,332,967</td>
<td>573,357,097</td>
</tr>
</tbody>
</table>

Note: Australia population = 23,490,736, Australia geographic area = 758,848,540.5 ha,\(^12\) New Zealand population = 4,509,750,\(^10\) New Zealand geographic area = 26,965,200 ha.\(^15\)

Inclusion criteria

All OHCA attended by ambulance, regardless of aetiology, are included in the Epistry.

Variables

Data across all participating sites are collected in accordance with Utstein-style definitions,\(^17\) although some variation in the coding of these items exists. Recoding of each variable is conducted.
to ensure uniformity in the variables collected. Data includes information on the OHCA event, demographics, arrest features, response times, treatment and outcome. Variables were identified by consensus among representatives from participating ambulance services (Table 2). All variables are collected by each of the six participating ambulance services.

Table 2: Mandatory variables included in the Aus-ROC Epistry

<table>
<thead>
<tr>
<th>Group</th>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case overview</td>
<td>Unique Aus-ROC case identifier</td>
</tr>
<tr>
<td></td>
<td>Event date</td>
</tr>
<tr>
<td></td>
<td>X coordinate of event</td>
</tr>
<tr>
<td></td>
<td>Y coordinate of event</td>
</tr>
<tr>
<td>Demographics</td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td>Age qualifier</td>
</tr>
<tr>
<td></td>
<td>Sex</td>
</tr>
<tr>
<td></td>
<td>Location of arrest</td>
</tr>
<tr>
<td>Arrest features</td>
<td>Witnessed arrest</td>
</tr>
<tr>
<td></td>
<td>Bystander CPR</td>
</tr>
<tr>
<td></td>
<td>First arresting rhythm</td>
</tr>
<tr>
<td></td>
<td>Aetiology of arrest</td>
</tr>
<tr>
<td>Dates and times</td>
<td>Date and time call received</td>
</tr>
<tr>
<td></td>
<td>Date and time arrive at scene (first)</td>
</tr>
<tr>
<td></td>
<td>Date and time depart scene (transporting ambulance)</td>
</tr>
<tr>
<td></td>
<td>Date and time arrive hospital (transporting ambulance)</td>
</tr>
<tr>
<td>Treatment</td>
<td>Ambulance service resuscitation attempt</td>
</tr>
<tr>
<td></td>
<td>Ambulance service defibrillation</td>
</tr>
<tr>
<td></td>
<td>Defibrillation before ambulance service</td>
</tr>
<tr>
<td></td>
<td>Total number of shocks</td>
</tr>
<tr>
<td></td>
<td>Airway (final)</td>
</tr>
<tr>
<td></td>
<td>Mechanical CPR</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Any ROSC</td>
</tr>
<tr>
<td></td>
<td>Scene outcome</td>
</tr>
<tr>
<td></td>
<td>Survived event (ROSC on hospital handover)</td>
</tr>
<tr>
<td></td>
<td>Died</td>
</tr>
<tr>
<td></td>
<td>Discharged alive</td>
</tr>
<tr>
<td></td>
<td>Date of discharge/death</td>
</tr>
<tr>
<td></td>
<td>Discharge disposition</td>
</tr>
<tr>
<td></td>
<td>Receiving hospital (PCI capability)</td>
</tr>
</tbody>
</table>

The primary outcome measure is ‘survival to hospital discharge’, with ‘return of spontaneous circulation’ (ROSC) as a key secondary outcome. Neurological outcome and long-term quality of life measurements are not presently collected across all sites, and thus this measure is not currently included in the Epistry.
Ethical considerations

Ethics approval was independently sought by each of the contributing registries. Over-arching ethics for the Epistry was provided by Monash University HREC (Approval No. CF12/3938 – 2012001888).

Data from each of the contributing registries will be provided in re-identifiable form with a unique identifier should the need arise to cross-check individual cases.

Data management and governance

The Epistry is coordinated and located at the Aus-ROC administrative base in the School of Public Health and Preventive Medicine at Monash University, Australia. Each participating ambulance service is responsible for regulating case ascertainment, data capture and quality control. Data upload is web-based and is stored on a secure server at Monash University. Data is then recoded by Epistry staff at Monash University for consistency with the Epistry data dictionary and then combined to form the Epistry.

An Epistry Management Committee (EMC) was established to develop processes and protocols, and oversee all ongoing aspects of the Epistry governance. The committee comprises representatives from each of the contributing ambulance services and Aus-ROC investigators. The Epistry consensus governance document guides the committee on the agreed use of the Epistry data; whilst maintaining data security and ethical principles.

Statistical analyses

Based on previously reported incidence of OHCA in our region, we estimate that the Epistry will capture approximately 14,000 OHCA patients annually. We anticipate using descriptive statistics to summarise baseline characteristics and survival outcomes. Annual crude and age-sex-adjusted incidence rates will be calculated using population figures from the Australian Bureau of Statistics and Statistics New Zealand. Logistic regression will be used to investigate factors associated with key outcome measures with ambulance services as random effects.
Reporting

Publically-available reports will be generated on an annual basis, in which ambulance services will be de-identified. As a component of quality improvement, benchmarking reports will be confidentially provided to each of the participating ambulance services comparing their risk-adjusted outcomes with the combined outcomes of the other ambulance services participating in the Aus-ROC Epistry. Findings will also be reported in peer-reviewed publications.

DISCUSSION

The Aus-ROC Epistry was established with the aim of understanding regional, ambulance service and treatment factors associated with improved OHCA survival and outcomes. The scope of the Epistry will enable a range of important research questions to be answered, including understanding regional variations in outcome, the impact of variations in the provision of treatment for OHCA between ambulance services, temporal changes in incidence and outcome and the impact of changes in clinical guidelines and clinical trials, as well as increased clinical trial efficiency. The Epistry will allow risk-adjusted outcomes to be determined, to enable benchmarking across providers and identification of system-wide strategies associated with survival for OHCA patients in Australia and New Zealand.

Variations have been identified in the incidence and outcomes of OHCA across geographical regions in Australia\(^{18,19}\) and internationally.\(^{20-22}\) To improve outcomes for these patients, there is a need to identify the underlying causes of these variations, which may include differences in the underlying risk of OHCA, and ambulance service structure, function and resuscitation practices; or simply case definitions. The Epistry will serve as a framework to understand this variation and the underlying factors. The longitudinal nature of the Epistry enables pre-post studies to assess the effect of changes in practice, such as examining whether OHCA patient survival improves following the implementation of Guideline updates.\(^{23}\) The Epistry will also facilitate the evaluation of clinical trials
by providing infrastructure to capture and combine prehospital and in-hospital data across multiple regions in a standardised manner. It is intended to eventually broaden the telephone assessment of quality-of-life (using validated instruments) of OHCA survivors that is conducted by the Victorian Ambulance Cardiac Arrest Registry and in Aus-ROC clinical trials, and use this information to study patient-centred outcomes, as well as economic evaluation of resuscitation interventions.

The Aus-ROC Epistry has been modelled on the successful ROC Epistry. In comparison to ROC who rely on data from 264 emergency medical service agencies, one of the strengths of Aus-ROC is the contribution of data from only six ambulance services. Individually, these ambulance services cover large geographical areas and populations, and represent both metropolitan and rural regions, facilitating understanding of variability in the ambulance service systems and the impact that such variability has on patient outcomes. When compared to other multi-centre registries that capture smaller proportions of their relevant population, the capture population of the Epistry represents the majority of Australia and New Zealand and is therefore more likely to be representative of the broader population. With significant heterogeneity in the reporting of OHCA outcomes, another strength of the Aus-ROC Epistry is the ability to define consistent primary and secondary outcome measures to compare the effect of regional and ambulance service variations. Similarly, having a consistent and uniform denominator when defining incidence and survival in OHCA enables valid comparisons across regions.

The sensitive nature of OHCA data, particularly for ambulance services, presents challenges when establishing multi-centre cardiac arrest registries. These challenges include data ownership, access security and use. In establishing the Epistry, memorandums of understanding were developed between the lead academic institution and each of the participating ambulance services. These agreements, combined with the Epistry governance document, provide clear guidelines on the ownership, use and dissemination of Epistry data.
Combining data from multiple regions has inherent challenges. Variation existed in the variables collected by each of the participating ambulance services, which reduced the number of core variables that were collected for the Epistry. However, it is hoped that over time, all participating sites will be able to collect additional variables, such as ‘neurological outcome’. A survey of the participating ambulance services is currently underway to evaluate variation in the treatment and provision of service between Epistry sites. This survey will also collect data on case ascertainment and quality control measures within each of the participating sites. Aus-ROC also has a vision to extend the current network of participating ambulance services to include all Australian ambulance services and thus capture the prevalence of OHCA in the entire Australian population – as is currently possible for New Zealand.

SUMMARY

The Aus-ROC Epistry is a population-based OHCA registry with a capture region encompassing the majority of Australia and all of New Zealand. Combining OHCA data from six sites will facilitate an understanding of the factors that are associated with improved survival from OHCA and will allow monitoring of temporal trends in process and outcome. Furthermore, the Epistry provides infrastructure to enhance the coordination of clinical trials and improve collaboration between ambulance services, thus increasing capacity to improve outcomes of OHCA patients in Australia and New Zealand.

CONTRIBUTIONS

BB drafted the manuscript and all other authors reviewed and approved the manuscript.

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The Australian Resuscitation Outcomes Consortium (Aus-ROC) is a National Health and Medical Research Council (NHRMC) Centre of Research Excellence (#1029983) (https://www.ausroc.org.au/).

COMPETING INTERESTS

None declared.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the late Prof Ian Jacobs whose contribution to the science of resuscitation is immeasurable. It was Prof Jacob's vision to establish the Aus-ROC Epistry and it is through his hard work and dedication that the Epistry is now operational. The Aus-ROC Epistry will act as one of Prof Jacob's many legacies.

The authors would also like to thank the registry staff in each of the participating ambulance services for their contribution.
REFERENCES


FIGURES

Figure 1: Map of Aus-ROC Epistry highlighting the captured regions in Australia and New Zealand (shown in colour).
APPENDIX 1

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Professor Judith Finn, Monash University and Curtin University, Australia

Professor Peter Cameron, Monash University, Australia

Professor Stephen Bernard, The Alfred Hospital, Australia

Associate Professor Karen Smith, Ambulance Victoria, Australia

Professor Peter Thompson, Sir Charles Gairdner Hospital, Australia

Professor Andrew Tonkin, Monash University, Australia

Professor Hugh Grantham, Flinders University, Australia

Professor Peter Morley, The Royal Melbourne Hospital, Australia

Associate Professor Tony Walker, Ambulance Victoria, Australia

Professor Antonio Celenza, University of Western Australia, Australia

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Dr Ben Beck, Monash University, Australia

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Dr Madoka Inoue, Curtin University, Australia

Dr Cindy Hein, SA Ambulance Service, Australia

Ms Meredith Morgan, Monash University, Australia

Mr Brian Stafford, Consumer Representative

Mr Jeff Waters, Consumer Representative
Figure 1: Map of Aus-ROC Epistry highlighting the captured regions in Australia and New Zealand (shown in colour).
Establishing the Aus-ROC Australian and New Zealand Out-of-hospital Cardiac Arrest Epistry

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l. University of Washington-Harborview Center for Prehospital Emergency Care, University of Washington, Seattle, WA, United States of America

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Faculty of Medicine, Nursing and Health Sciences

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<td>Queensland, Australia</td>
<td>Queensland Ambulance Service</td>
<td>4,722,447</td>
<td>172,582,593</td>
</tr>
<tr>
<td><strong>Australian Registries</strong></td>
<td></td>
<td><strong>14,823,217</strong></td>
<td><strong>121,809,304</strong></td>
</tr>
<tr>
<td>New Zealand (excluding Wellington)</td>
<td>St John New Zealand</td>
<td>4,018,370</td>
<td>26,152,195</td>
</tr>
<tr>
<td>Wellington, New Zealand</td>
<td>Wellington Free Ambulance</td>
<td>491,380</td>
<td>813,005</td>
</tr>
<tr>
<td><strong>New Zealand Registries</strong></td>
<td></td>
<td><strong>4,509,750</strong></td>
<td><strong>26,965,200</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>19,332,967</strong></td>
<td><strong>573,357,097</strong></td>
</tr>
</tbody>
</table>

Note: Australia population = 23,490,736, Australia geographic area = 758,848,540.5 ha, New Zealand population = 4,509,750, New Zealand geographic area = 26,965,200 ha.

Demographic and socioeconomic characteristics of each of the regions in Australia and New Zealand are shown in Appendix 2 and Appendix 3, respectively. Australian regions participating in the Epistry demonstrated similar characteristics to those of the broader Australian population. While some regions not currently participating in the Epistry demonstrated variations in the proportion of the population who were Aboriginal and Torres Strait Island peoples and those living in ‘major cities’, these regions (Australian Capital Territory, Northern Territory and Tasmania) had small total populations that reflected a combined 4.9% of the Australian population.
Differences in the classification of geographical regions did not facilitate comparisons between Australia and New Zealand. Alternate metrics may be required when making comparisons of rurality between the two countries.

Inclusion criteria

All OHCA attended by ambulance, regardless of aetiology, are included in the Epistry. All deaths attended by ambulance are classified as OHCA and thus included in the Epistry.

Data capture

Capture of OHCA cases varies between ambulance services. A combination of electronic queries of patient care records (PCRs), manual sorting through PCRs, staff standardised reporting and dispatch codes are used to identify OHCA cases. For those ambulance services that use electronic queries, subsequent manual searches are conducted by all services to maximise case capture. Hospital outcomes data is commonly obtained through linkage with hospital records and state-based death registries. In one region, hospital outcomes are obtained through linkage with the state Department of Health data.

Variables

Data across all participating sites are collected in accordance with Utstein-style definitions, although some variation in the coding of these items exists. Recoding of each variable is conducted to ensure uniformity in the variables collected. Data includes information on the OHCA event, demographics, arrest features, response times, treatment and outcome. Variables were identified by consensus among representatives from participating ambulance services (Table 2). All variables are collected by each of the six participating ambulance services.

Table 2: Mandatory variables included in the Aus-ROC Epistry

<table>
<thead>
<tr>
<th>Group</th>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case overview</td>
<td>Unique Aus-ROC case identifier</td>
</tr>
<tr>
<td></td>
<td>Event date</td>
</tr>
<tr>
<td></td>
<td>Longitude coordinate of event</td>
</tr>
</tbody>
</table>
The primary outcome measure is ‘survival to hospital discharge’, with ‘return of spontaneous circulation’ (ROSC) as a key secondary outcome. These measures are considered ‘core’ outcomes according to the Utstein template. While neurological outcome and long-term quality of life measurements are important patient-centred outcomes, they are not presently collected across all sites, and thus these measures are not currently included in the Epistry.

**Ethical considerations**

Ethics approval was independently sought by each of the contributing registries. Over-arching ethics for the Epistry was provided by Monash University HREC (Approval No. CF12/3938 – 2012001888).

Data from each of the contributing registries will be provided in re-identifiable form with a unique identifier should the need arise to cross-check individual cases.
Data management and governance

The Epistry is coordinated and located at the Aus-ROC administrative base in the School of Public Health and Preventive Medicine at Monash University, Australia. Each participating ambulance service is responsible for regulating case ascertainment, data capture and quality control. Data upload is web-based and is stored on a secure server at Monash University. Data is then recoded by Epistry staff at Monash University for consistency with the Epistry data dictionary and then combined to form the Epistry.

An Epistry Management Committee (EMC) was established to develop processes and protocols, and oversee all ongoing aspects of the Epistry governance. The committee comprises representatives from each of the contributing ambulance services and Aus-ROC investigators. The Epistry consensus governance document guides the committee on the agreed use of the Epistry data; whilst maintaining data security and ethical principles.

Statistical analyses

Based on previously reported incidence of OHCA in our region, we estimate that the Epistry will capture approximately 14,000 OHCA patients annually. We anticipate using descriptive statistics to summarise baseline characteristics and survival outcomes. Annual crude and age-sex-adjusted incidence rates will be calculated using population figures from the Australian Bureau of Statistics and Statistics New Zealand. Logistic regression will be used to investigate factors associated with key outcome measures with ambulance services as random effects.

Reporting

Publicly-available reports will be generated on an annual basis, in which ambulance services will be de-identified. As a component of quality improvement, benchmarking reports will be confidentially provided to each of the participating ambulance services comparing their risk-adjusted outcomes.
with the combined outcomes of the other ambulance services participating in the Aus-ROC Epistry. Findings will also be reported in peer-reviewed publications.

**DISCUSSION**

The Aus-ROC Epistry was established with the aim of understanding regional, ambulance service and treatment factors associated with improved OHCA survival and outcomes. The scope of the Epistry will enable a range of important research questions to be answered, including understanding regional variations in outcome, the impact of variations in the provision of treatment for OHCA between ambulance services, temporal changes in incidence and outcomes and the impact of changes in clinical guidelines and clinical trials, as well as increased clinical trial efficiency. The Epistry will allow risk-adjusted outcomes to be determined, to enable benchmarking across providers and identification of system-wide strategies associated with survival for OHCA patients in Australia and New Zealand.

Variations have been identified in the incidence and outcomes of OHCA across geographical regions in Australia\textsuperscript{21,22} and internationally.\textsuperscript{23–25} To improve outcomes for these patients, there is a need to identify the underlying causes of these variations, which may include differences in the underlying risk of OHCA, and ambulance service structure, function and resuscitation practices; or simply case definitions. For example, other multi-centre cardiac arrest registries have investigated regional variation in: the incidence and outcomes of OHCA,\textsuperscript{23,26,27} temporal trends in survival,\textsuperscript{6} rates of bystander CPR,\textsuperscript{28} treatment and transport practices,\textsuperscript{7} and the association between receiving hospital characteristics and survival.\textsuperscript{29} The Epistry will serve as a framework to address similar questions and identify factors associated with regional variation in survival. The longitudinal nature of the Epistry enables pre-post studies to assess the effect of changes in practice, such as examining whether OHCA patient survival improves following the implementation of Guideline updates.\textsuperscript{30} The Epistry will also facilitate the evaluation of clinical trials by providing infrastructure to capture and combine prehospital and in-hospital data across multiple regions in a standardised manner. It is intended to
eventually broaden the telephone assessment of quality-of-life (using validated instruments) of 
OHCA survivors that is conducted by the Victorian Ambulance Cardiac Arrest Registry and in Aus-
ROC clinical trials, and use this information to study patient-centred outcomes, as well as economic 
evaluation of resuscitation interventions.

The Aus-ROC Epistry has been modelled on the successful ROC Epistry. In comparison to ROC who 
rely on data from 264 emergency medical service agencies, one of the strengths of Aus-ROC is the 
contribution of data from only six ambulance services. Individually, these ambulance services cover 
large geographical areas and populations, and represent both metropolitan and rural regions, 
facilitating understanding of variability in the ambulance service systems and the impact that such 
variability has on patient outcomes. When compared to other multi-centre registries that capture 
smaller proportions of their relevant population, the capture population of the Epistry represents 
the majority of Australia and New Zealand and is therefore more likely to be representative of the 
broader population. With significant heterogeneity in the reporting of OHCA outcomes, another 
strength of the Aus-ROC Epistry is the ability to define consistent primary and secondary outcome 
measures to compare the effect of regional and ambulance service variations. Similarly, having a 
consistent and uniform denominator when defining incidence and survival in OHCA enables valid 
comparisons across regions.

The sensitive nature of OHCA data, particularly for ambulance services, presents challenges when 
establishing multi-centre cardiac arrest registries. These challenges include data ownership, access 
security and use. In establishing the Epistry, memorandums of understanding were developed 
between the lead academic institution and each of the participating ambulance services. These 
agreements, combined with the Epistry governance document, provide clear guidelines on the 
ownership, use and dissemination of Epistry data.

Combining data from multiple regions has inherent challenges. Variation existed in the variables 
collected by each of the participating ambulance services, which reduced the number of core
variables that were collected for the Epistry. However, it is hoped that over time, all participating
sites will be able to collect additional variables, such as ‘neurological outcome’ and other
resuscitation practices and interventions. A survey of the participating ambulance services is
currently underway to evaluate variation in the treatment and provision of service between Epistry
sites. This survey will also collect data on case ascertainment and quality control measures within
each of the participating sites. Aus-ROC also has a vision to extend the current network of
participating ambulance services to include all Australian ambulance services. While four Australian
ambulance services not currently participating in the Epistry have been invited to contribute data
(NSW Ambulance, St John Ambulance Northern Territory, ACT Ambulance, Ambulance Tasmania),
these service-based OHCA registries are in various stages of development. It is hoped that these
registries will be able to contribute data in the future and thus the Epistry will capture the
prevalence of OHCA in the entire Australian population – as is currently possible for New Zealand.

SUMMARY

The Aus-ROC Epistry is a population-based OHCA registry with a capture region encompassing the
majority of Australia and all of New Zealand. Combining OHCA data from six sites will facilitate an
understanding of the factors that are associated with improved survival from OHCA and will allow
monitoring of temporal trends in process and outcome. Furthermore, the Epistry provides
infrastructure to enhance the coordination of clinical trials and improve collaboration between
ambulance services, thus increasing capacity to improve outcomes of OHCA patients in Australia and
New Zealand.

CONTRIBUTIONS

BB, JB, KS, TW, HG, CH, MT, AS, TS, BD, AS, MB, EB, KP, PC, GN, JF were all involved in the study
design. BB drafted the manuscript and all other authors reviewed and approved the manuscript.
FUNDING

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COMPETING INTERESTS

None declared.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the late Prof Ian Jacobs whose contribution to the science of resuscitation is immeasurable. It was Prof Jacob’s vision to establish the Aus-ROC Epistry and it is through his hard work and dedication that the Epistry is now operational. The Aus-ROC Epistry will act as one of Prof Jacob’s many legacies.

The authors would also like to thank the registry staff in each of the participating ambulance services for their contribution.
REFERENCES


Figure 1: Map of Aus-ROC Epistry highlighting the captured regions in Australia and New Zealand (shown in colour).
Figure 1: Map of Aus-ROC Epistry highlighting the captured regions in Australia and New Zealand (shown in colour).

169x126mm (300 x 300 DPI)
APPENDIX 1

Australian Resuscitation Outcomes Consortium (Aus-ROC) Steering Committee Members

Professor Judith Finn, Monash University and Curtin University, Australia

Professor Peter Cameron, Monash University, Australia

Professor Stephen Bernard, The Alfred Hospital, Australia

Associate Professor Karen Smith, Ambulance Victoria, Australia

Professor Peter Thompson, Sir Charles Gairdner Hospital, Australia

Professor Andrew Tonkin, Monash University, Australia

Professor Hugh Grantham, Flinders University, Australia

Professor Peter Morley, The Royal Melbourne Hospital, Australia

Associate Professor Tony Walker, Ambulance Victoria, Australia

Professor Antonio Celenza, University of Western Australia, Australia

Professor Andrew Forbes, Monash University, Australia

Professor Graham Nicol, University of Washington, United States of America

Professor Gavin D Perkins, Warwick University, United Kingdom

Dr Janet Bray, Monash University, Australia

Dr Lahn Straney, Monash University, Australia

Dr Ben Beck, Monash University, Australia

Dr Teresa Williams, Curtin University, Australia

Dr Madoka Inoue, Curtin University, Australia

Dr Cindy Hein, SA Ambulance Service, Australia

Ms Meredith Morgan, Monash University, Australia

Mr Brian Stafford, Consumer Representative

Mr Jeff Waters, Consumer Representative
APPENDIX 2

Demographic and socioeconomic characteristics of Australian states. Data are segregated by those regions currently participating and those not currently participating in the Aus-ROC Epistry.

<table>
<thead>
<tr>
<th>Regional Characteristic</th>
<th>VIC</th>
<th>SA</th>
<th>WA</th>
<th>QLD</th>
<th>NSW</th>
<th>ACT</th>
<th>NT</th>
<th>TAS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (%)</td>
<td>49.5</td>
<td>49.6</td>
<td>50.6</td>
<td>49.9</td>
<td>49.7</td>
<td>49.8</td>
<td>52.7</td>
<td>49.8</td>
<td>49.8</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>37.3</td>
<td>39.8</td>
<td>35.8</td>
<td>36.6</td>
<td>37.8</td>
<td>34.6</td>
<td>31.6</td>
<td>37.3</td>
<td></td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander Peoples (%)</td>
<td>0.7</td>
<td>1.9</td>
<td>3.1</td>
<td>3.6</td>
<td>2.5</td>
<td>1.5</td>
<td>26.8</td>
<td>4.0</td>
<td>2.6</td>
</tr>
<tr>
<td>Total born overseas (%)</td>
<td>31.4</td>
<td>26.7</td>
<td>37</td>
<td>26.3</td>
<td>31.4</td>
<td>28.6</td>
<td>25.4</td>
<td>16.4</td>
<td>30.2</td>
</tr>
<tr>
<td>Average wage and salary income ($)</td>
<td>50,276</td>
<td>46,551</td>
<td>57,365</td>
<td>49,863</td>
<td>53,917</td>
<td>60,987</td>
<td>54,082</td>
<td>43,521</td>
<td>51,923</td>
</tr>
<tr>
<td>Unemployment rate (%)</td>
<td>5.4</td>
<td>5.7</td>
<td>4.7</td>
<td>6.1</td>
<td>5.9</td>
<td>3.6</td>
<td>5.3</td>
<td>6.4</td>
<td>5.6</td>
</tr>
<tr>
<td>Population of capital city (% of state)</td>
<td>75.8</td>
<td>77.3</td>
<td>78.3</td>
<td>48.1</td>
<td>64.2</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Note that there is no segregation of Canberra (the capital city of the Australian Capital Territory (ACT)) and the state of ACT according to the Australian Bureau of Statistics (ABS). ** The Remoteness Areas are a geographical standard of relative remoteness provided by the ABS. All data sourced from the Australian Bureau of Statistics.\(^1^7,1^8\) VIC – Victoria, SA – South Australia, WA – Western Australia, QLD – Queensland, NSW – New South Wales, ACT – Australian Capital Territory, NT – Northern Territory, TAS – Tasmania.
### APPENDIX 3

**Demographic and socioeconomic characteristics of New Zealand regions.**

<table>
<thead>
<tr>
<th>Regional Characteristic</th>
<th>New Zealand (excluding Wellington)</th>
<th>Wellington Region</th>
<th>New Zealand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (%)</td>
<td>48.7</td>
<td>48.3</td>
<td>48.7</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>*</td>
<td>37.2</td>
<td>38.0</td>
</tr>
<tr>
<td>Maori population (%)</td>
<td>14.3</td>
<td>12.4</td>
<td>14.1</td>
</tr>
<tr>
<td>Total born overseas (%)</td>
<td>23.6</td>
<td>24.0</td>
<td>23.6</td>
</tr>
<tr>
<td>Median income ($)</td>
<td>*</td>
<td>32,700</td>
<td>28,500</td>
</tr>
<tr>
<td>Unemployment rate (%)</td>
<td><img src="http://bmjopen.bmj.com/site/about/guidelines.xhtml" alt="" />3.6</td>
<td>3.9</td>
<td>3.6</td>
</tr>
</tbody>
</table>

**2006 NZ Census - Urban/rural profile areas**

<table>
<thead>
<tr>
<th>Regional Characteristic</th>
<th>New Zealand (excluding Wellington)</th>
<th>Wellington Region</th>
<th>New Zealand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main urban area (%)</td>
<td>69.7</td>
<td>88.6</td>
<td>71.8</td>
</tr>
<tr>
<td>Satellite urban area (%)</td>
<td>3.4</td>
<td>1.7</td>
<td>3.2</td>
</tr>
<tr>
<td>Independent urban area (%)</td>
<td>11.6</td>
<td>6.0</td>
<td>11.0</td>
</tr>
<tr>
<td>Rural area with high urban influence (%)</td>
<td>3.3</td>
<td>1.3</td>
<td>3.1</td>
</tr>
<tr>
<td>Rural area with moderate urban influence (%)</td>
<td>4.2</td>
<td>1.3</td>
<td>3.8</td>
</tr>
<tr>
<td>Rural area with low urban influence (%)</td>
<td>6.0</td>
<td>0.9</td>
<td>5.5</td>
</tr>
<tr>
<td>Highly rural/remote area (%)</td>
<td>1.8</td>
<td>0.1</td>
<td>1.6</td>
</tr>
</tbody>
</table>

* Note that median values for age and income could not be obtained for New Zealand (excluding Wellington). All data sourced from Statistics New Zealand. ** The urban/rural profile areas are geographical classifications provided by Statistics New Zealand. Data for urban/rural profile areas is drawn from the 2006 New Zealand Census.\(^9\)