**Resuscitation registers: how many active registers are there and how many collect data on paediatric cardiac arrests?**

**Booth:** Identifying national resuscitation registers

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**ABSTRACT**

**Background**

Cardiac arrest, particularly in children, often has a poor outcome and international guidelines highlight significant gaps in the evidence base for effective resuscitation. Whilst randomised controlled trials for some interventions can be justified, they are not appropriate for many aspects of resuscitation. Therefore, guidelines must use other sources of data such as epidemiological evidence from cardiac arrest registries, to improve the efficacy of resuscitation.

The aim of our study was to identify existing national cardiac arrest registries and document key information about the registries, including whether they contain data on paediatric arrests.

**Methods**

Key bibliographic databases were searched for papers about or using data from cardiac arrest registries. Two reviewers independently screened the search results for relevant papers. A list of registers named in the papers was compiled and information obtained from the papers and the websites of registers where possible.

**Results**

Twenty three active national or large regional cardiac arrest registries were identified. These included five international collaborations and 10 registries that cover a population of at least 10 million people. Twelve registries are based in Europe, five in North America, four in Asia and two in Australasia. The registries vary in their organisation, but the majority (20) defer to the Utstein reporting guidelines for cardiac arrest. Registries covered populations between 0.4 and 174.5 million and contained between 100 and 605,505 records. Sixteen collected data on out-of-hospital arrests only; three in-hospital arrests only; and four included both. For ten registers the number of paediatric arrests was available and ranged from 56 to 3,900.

**Conclusions**

To our knowledge this report contains the most complete list of active national and large regional cardiac arrest registries. Register data support current guidelines on effective resuscitation however, even the largest registries include relatively small numbers, particularly of paediatric events. A less fragmented approach has the potential to improve the utility of registration data for the benefit of patients.

Abstract word count: 315/350

**INTRODUCTION**

There is evidence of improvement in the survival of paediatric in hospital cardiac arrest (IHCA). Between 2000 and 2009, the risk adjusted survival rate of resuscitation for children in the American Heart Association's Get With The Guidelines-Resuscitation program increased from 42.9% to 81.2%[[1](#_ENREF_1)]. However, despite finding an improvement in the delivery of care including increased rates of bystander cardiopulmonary resuscitation and survival of out-of-hospital cardiac arrest (OHCA) in adults, there is limited evidence of any increase in survival from paediatric OHCA [[2-6](#_ENREF_2)]. At the five yearly reviews undertaken by the International Liaison Committee on Resuscitation (ILCOR) significant gaps in the availability of evidence to support guideline development have been repeatedly identified in North America or Australia [[7](#_ENREF_7), [8](#_ENREF_8)]. In particular there is a paucity of evidence to support paediatric resuscitation guidelines [[9](#_ENREF_9)]. A number of factors including the unpredictability of cardiac arrest and rarity in children make it difficult to conduct randomised control trials of the resuscitation process. The ILCOR guidelines therefore draw on data from other sources of evidence including the cardiac arrest registries, for example, Get With The Guidelines©– Resuscitation. Although the use of cohort data from registries has the potential to provide valuable evidence to inform practice we could not find a summary of currently active registries internationally. We therefore set out to identify active national and large regional registers and to identify those that include paediatric data.

**METHOD**

We searched two bibliographic databases, MEDLINE and Embase, to identify papers that reported on or used data from patient registries or audit programmes that collected information on cardiac arrest and/or resuscitation outcomes for patients of any age. The same search strategy was repeated in MEDLINE, Embase and PubMed using specific terms to filter for paediatric related articles. The search strategies can be found in Appendix 1. The database searches were undertaken in November 2016 by KW, an experienced information specialist. The results were downloaded to two separate EndNote x7 libraries.

The Cochrane Library and the Registry of Patient Registries were hand searched using key words (resuscitation; cardiac arrest; registry; register). In addition, a key word search in the Google Advanced Search function was undertaken and the first three pages of results reviewed.

The titles and abstracts of both sets of search results were independently screened by two researchers to identify articles reporting on a national or large regional cardiac arrest register, or research articles that used data from such a register. We excluded articles relating to local registers, registers gathering information on cardiac arrest but not as the main focus (e.g. trauma registers, intensive care registers and sports associated cardiac arrest registers) and registers set up specifically for a research project (e.g. SOS-KANTO). We also excluded registers no longer collecting data. Full text articles were obtained and checked for relevance independently by two authors with discrepancies resolved through discussion. Details of the register name, country, whether it included OHCA and/or IHCA, and any specification regarding age for inclusion, were extracted from the articles.

Where more than one article referred to the same register, the extracted data were merged to form a list of cardiac arrest registers. Internet searches using the names of the identified registers were performed. The websites of those found were interrogated to confirm information collected and identify missing details such as data collection requirements, coverage, web address, and to confirm whether the register was active.

**RESULTS**

The database searches without age restriction identified 2498 records; the searches with the filter for paediatrics located 935 records. Hand searching identified one register, the Australian Resuscitation Outcomes Consortium (Aus-ROC) OHCA register.

Of the 3434 identified records, 254 were thought to contain information about a register that collected data on cardiac arrest, including 73 on paediatric cardiac arrest. A list of 52 possible registries was produced from the identified papers. The internet searches for further information identified multiple names for some of the registers, reducing the list to 44. A further 21 were excluded: nine as they were inactive, two because they were created solely for research purposes, and 10 as they were not IHCA or OHCA registries. We identified 22 national or large regional active cardiac arrest registers (Table 1).

The registries are primarily located in Europe (12) and North America (4); four were identified in Asia and two in Australasia. Websites were found for 14 of the active registers.

TABLE 1 HERE

***Registry administration***

The registries vary in their organisation, administration and leadership. Four are led by collaborations between institutions, five by medical societies, three by government departments, two by universities, two by hospitals, two by emergency medical services, and one is led by an independent organisation. For three the information could not be found (Table 1). The scope for data collection for the registers ranges from data collected by the only hospital in the country (Malta) to international collaborations of registers such as the European Registry of Cardiac Arrests (EuReCa). EuReCa combines data from national registries of 27 European countries. The coverage ranges between 3-100% of the individual countries included and is estimated to cover 34% of the overall population of the 27 countries. There are a further three international collaborations; Pan-Asian Resuscitation Outcomes Study, Australian Resuscitation Outcomes Consortium (Aus-ROC) and Pediatric Cardiac Arrest European Registry in Emergency Services.

***Registry inclusion criteria:*** Sixteen registries collect data exclusively on OHCA, three on IHCA and four include both. Twenty include patients of all ages, one excludes those younger than 28 days, one excludes those younger than 14 years and one excludes adults. Two registers included paediatric cardiac arrest exclusively.

***Data Collected:*** The majority (19) refer to the Utstein reporting guidelines for cardiac arrest in the design of their data collection. Eleven registries follow up patients until discharge, four follow up until discharge or 30 day survival, one has a follow up at six months, one follows up to between six and 11 months, and three include one year survival. Data on follow up were not found for three registers.

***Size:*** The registries collect data from medical services that provide care to populations varying between 0.4 and 174.5 million people. The largest two cover a total population of 174 and 127 million. Five cover between 50 to 100 million and three 10 to 50 million people. There are eight registries covering populations less than 10 million and for four the data were not found, and two of these are multi-national so likely to cover large populations. One registry includes over 100,000 episodes of cardiac arrest in all ages, eight include between 50,000 and 100,000, and a further six between 10,000 and 50,000. Data for the number of paediatric arrests is available for nine registries; two include between 2,000 and 4,000, the rest include less than a thousand episodes.

***Register based research publications:*** Of the 254 research publications identified in the bibliographic searches a review of titles identified 70 (28%) using or reporting on paediatric data (Table 2).

TABLE 2 HERE

**DISCUSSION**

***Registries Identified***

We identified 22 active cardiac arrest registries. These include nine registries that cover a population of at least 10 million and international collaborations in North America, Europe and Asia. Although two dedicated paediatric registries were identified and most other registers included all ages, relatively little paediatric data could be identified overall. From our searches the largest register by number of records contained was the North American Cardiac Arrest Registry to Enhance Survival (CARES), containing 200,000 episodes of cardiac arrest in total and 3,900 records of paediatric cardiac arrest. We did identify the Resuscitation Outcomes Consortium (ROC), which contained large numbers of records (179,310 cardiac arrests, 2,800 in paediatrics) but was excluded from the analysis as the database ceased recruiting patient data in 2016. We are aware that other registries may exist but have not published, for example the JAAM-OHCA and JSEM-IHCA registries in Japan have recently started collecting data and plan to publish in the future.

***Limitations***

Our literature search may not have identified all active national or large regional registries. This may be due to those registries not publishing data and we recognise that there may be data used for audit that was not accessible to the literature search. The addition of searches using a paediatric filter and in PubMed as well as MEDLINE and Embase was because we were aware that some relevant records had not been identified in the ‘all ages’ searches. The ‘missing’ studies and others were found in the paediatric specific searches. Where available, we collected current information about data in the register. For the others we used the information provided in the publications to obtain the information, depending on when the data for the study were accessed and/or when the paper was published, the information for these registers is likely to underestimate the current total data held in the registry.

We limited inclusion to active national and larger regional registries (for example states in the USA). Registers collecting data at a single site were excluded unless these were national registers. Our searches highlighted a range of related registries, some of which contain varying amounts of data on cardiac arrests. These were excluded as cardiac arrest data was not their main focus, but they may still contain useful information to help inform practice. In the absence of any international overview of where and how cardiac arrest data is being collected, we concentrated our efforts on identifying active dedicated registries. Further work to identify where and what related data is collected may be worth considering.

***Potential value of registry data***

Whilst there is evidence that survival following IHCA and OHCA is improving[[10](#_ENREF_10), [11](#_ENREF_11)], studies including data on paediatric and younger adults show limited evidence of the same trend for OHCA [[5](#_ENREF_5), [6](#_ENREF_6), [12-15](#_ENREF_12)]. Existing registries have allowed numerous research studies to use registry data to enable identification of variable survival rates both regionally[[16](#_ENREF_16)] and globally[[17](#_ENREF_17)], development of a standardised mortality ratio for comparing healthcare settings and specific quality deficiencies[[18](#_ENREF_18)].

ICLOR has repeatedly identified fundamental gaps in the evidence that underlies our resuscitation guidelines. This includes the question of whether an airway – breathing – circulation, a circulation –airway – breathing approach or chest compression only approach should be advised. The prospect of a future randomised controlled trial answering this is unrealistic. There are examples of registry data contributing to the evidence base of effective resuscitation[[19](#_ENREF_19)]. However, the small numbers of paediatric data collected by individual registries and limited collaborations across continents mean that in their current form, these too are unlikely to answer this question. If we are to seriously attempt to answer the questions of ILCOR we need to consider the expansion and collaboration of current registries. Steps to consider include compulsory reporting for cardiac arrest[[20](#_ENREF_20)], the expansion of existing registries and international collaboration. Interestingly, there has been a suggestion that the duration of participation of hospitals with registries is significantly associated with improved survival from in hospital cardiac arrest events[[21](#_ENREF_21)]. There is also potential to benefit from registries focussed on collecting data for other purposes, but which tangentially include information related to cardiac arrests which could support this effort[[22](#_ENREF_22), [23](#_ENREF_23)].

**CONCLUSION**

To the best of our knowledge this report contains the most comprehensive list of cardiac arrest registries and the only one to detail the collection of paediatric data. Whilst there is evidence of successful, large, international registries and collaborations, the current fragmented approach limits the utility of registry data. The widespread collection of a standardised dataset on cardiac arrest causes, resuscitation efforts and outcomes, short, medium and long term would provide vital missing epidemiological data that could greatly enhance scientific knowledge and improve outcomes for patients worldwide.

**Declaration of Conflicts of Interest**

IM and NS are members of the ILCOR taskforce.

IM, NS, JH, AB, KL, AM and KW declare they have no conflicts of interest to disclose.

**Role of the Funding Source**

The authors have not received any funding for undertaking this work.

**Ethics and Patient Consent**

These were not required for this study.

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**Table 1 Active national or large regional cardiac arrest registries**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Registry name****Web link** | **Location** | **Lead organisation** | **Data reporting method** | **Coverage** | **Popn.****(million)** | **IHCA****OHCA** | **Ages included** | **Latest follow up time point** | **Year launched** | **Total number of records** | **Number of paediatric records** |
| All Japan Utstein Registry | Japan | G | All EMS | All Japan | 127.3 | OHCA | All | Discharge | 2005 | 55721 |  |
| Andalusian Registry of Out-of-hospital Cardiac Arrest | Spain | EMS | All EMS | Regional EMS of Andalusia | 8.4 | OHCA | All | 6 months | 2008 | 9000 |  |
| Australian Resuscitation Outcomes Consortium (Aus-ROC) <https://www.ausroc.org.au/epistry/>  | Australia and New Zealand | U (Monash) | Volunteering institutions | Excludes NSW, ACT and Tasmania | 19.3 | OHCA | All | Discharge | 2014 |  |  |
| Cardiac Arrest Registry in the Canary Islands | Spain |  | Compulsory registration |  | 2.1 | Both |  |  | 2008 |  |  |
| CARES, Cardiac Arrest Registry to Enhance Survival <https://mycares.net/>  | USA | G (Federal), U (Emory), MS (AHA) | Volunteering institutions | 13 state-wide registries and parts of 23 states | 80 | OHCA | All | Discharge | 2004 | 200000 | 3900 |
| Danish Cardiac Arrest Registry<http://genoplivning.dk/> | Denmark | MS (Danish RC), U (Copenhagen University), EMS | All EMS | All regional EMS services in Denmark | 5.6 | OHCA | All | 1 year survival | 2001 | 45269 | 348 |
| European Registry of Cardiac arrest (EuReCa) [www.eureca-one.eu/](http://www.eureca-one.eu/%20%20)   | EU | MS (ERC) | National registries | National registries include 34% of the population in 27 countries | 174.5 | OHCA | All | Discharge / 30 day survival | 2007 | 10682 |  |
| German Resuscitation Registry<http://www.reanimationsregister.de/> | Germany | MS (DGAI) | Volunteering institutions | 164 preclinical and 148 hospital based – 10% of German population | 9 | Both | All | 1 year survival | 2007 | 94400 |  |
| Get with the Guidelines – Resuscitation Registry[www.heart.org/](http://www.heart.org/) | USA | MS (AHA) | Volunteering institutions | At least 190 hospitals |  | IHCA | All | Discharge | 2010 | 35000 | 3647 |
| Japan National Registry of Cardio-Pulmonary Resuscitation (JNRCPR) | Japan | Hospital (TMCMC) | Volunteering institutions | 14 children’s and university hospitals | 50 | IHCA | 0-18 | Discharge/ 30 day survival | 2009 | 514 | 514 |
| King County Cardiac Arrest Surveillance System<http://www.kingcounty.gov> | King County, WA, USA | G (King County) | All EMS | All of King County | 1.93 | OHCA | All | Discharge | 1976 | 23920 | >56 |
| National Cardiac Arrest Audit (NCAA) <http://resus.org.uk/> | UK | MS (UK RC), Charity (ICNARC) | Volunteering institutions | 188 participating hospitals |  | IHCA | Excludes neonates | Discharge | 2009 | 70661 | 931 |
| National Emergency Department Information System for Cardiac Arrest (NEDIS-CA) | South Korea |  | Volunteering institutions | 29 emergency departments |  | OHCA | All | Discharge | 2008 | 10000 |  |
| National Quality Registry for Cardiopulmonary Resuscitation[www.kvalitetsregister.se/](http://www.kvalitetsregister.se/) | Sweden | G | All EMS and volunteering hospitals | 95% of emergency hospitals and all ambulance services | 9.6 | Both | All | 3-5months and 6-11 months | 1990 | 87827 |  |
| Out of Hospital Cardiac Arrest Outcomes<http://www2.warwick.ac.uk/>  | UK | U (Warwick) | All EMS | All NHS ambulance services in UK | 64.1 | OHCA | All | Discharge | 2014 | 78729 |  |
| Out-of-hospital cardiorespiratory arrest in Spain (OHSCAR) | Spain |  | Volunteering EMS | 19 regional EMS | 46 | OHCA | All | Discharge | 2013 | 8997 | 160 |
| Pan-Asian Resuscitation Outcomes Study (PAROS) [www.scri.edu.sg](http://www.scri.edu.sg) | 9 Asian countries | MS (Asian EMS) | Volunteering institutions | 837 hospitals covering a fifth of the population | 89 | OHCA | All | Discharge / 30 day survival | 2010 | 66,000 |  |
| Pediatric Cardiac Arrest European Registry in Emergency Services (E-PEDCARE) | 7 European Countries | MS (REPEM) | Volunteering institutions | 66 participating hospitals in 7 countries |  | Both | Paediatric | Discharge | 2014 | 101 | 101 |
| Registre électronique des Arrêts Cardiaques (ReAC) <http://registreac.org> | France | Association (ReAC) | All EMS | > 90% of EMS in France including overseas territories and dependents | 66 | OHCA | All | Discharge / 30 day survival | 2011 | 73047 |  |
| Registry for Out-of-Hospital Cardiac Arrests in Malta | Malta | Hospital | Volunteering institution | Only government run ED in Malta | 0.4 | OHCA | > 14 years |  | 2011 | 100 |  |
| Save Hearts in Arizona Registry OHCAhttp://azdhs.gov  | Arizona, USA | G (Sate of Arizona) and U (Arizona) | Volunteering institutions | 80% of population of Arizona | 5.1 | OHCA | All | Discharge | 2004 | 13000 |  |
| Victorian Ambulance Cardiac Arrest Registry <http://ambulance.vic.gov.au/>  | Victoria State, Australia | EMS | All EMS | All EMS in Victoria State | 5.8 | OHCA | All | 1 year survival | 1999 | 85000 | 209 |

Key: ACT, Australian Capital Territory; AHA, American Heart Association; Asian EMS, Asian Emergency Medical Services Council; Danish RC, Danish Resuscitation Council; DGAI, Deutsche Gesellschaft für Anästhesiologie & Intensivmedizin; EMS Emergency Medical Services; ERC, European Resuscitation Council; G, government; ICNARC, Intensive Care National Audit and Research Centre; IHCA, in hospital cardiac arrest; MS, Medical society; NHS, National Health Service; NSW, New South Wales; OHCA, Out of hospital cardiac arrest; REPEM, Research in European Paediatric Medicine; TMCMC, Tokyo Metropolitan Children’s Medical Centre); U, university; UK RC, UK Resuscitation Council.

**Table 2 Number of publications per register**

|  |  |
| --- | --- |
|  | **Database searches** |
| **Registry** | **Adult related publications** | **Paediatric related publications (indicated in title)** |
| All Japan Utstein Registry | 16 | 11 |
| Andalusian Registry of Out-of-hospital Cardiac Arrest | 2 | 1 |
| Australian Resuscitation Outcomes Consortium (Aus-ROC) | 3 | 0 |
| Cardiac Arrest Registry in the Canary Islands | 1 | 0 |
| CARES, Cardiac Arrest Registry to Enhance Survival | 25 | 12 |
| Danish Cardiac Arrest Registry | 15 | 2 |
| European Registry of Cardiac arrest (EuReCa) | 3 | 0 |
| German Resuscitation Registry | 7 | 0 |
| Get with the Guidelines - Resuscitation Registry | 31 | 30 |
| King County Cardiac Arrest Surveillance System | 0 | 1 |
| National Cardiac Arrest Audit (NCAA) | 4 | 0 |
| National Emergency Department Information System for Cardiac Arrest (NEDIS-CA) | 2 | 1 |
| National Quality Registry for Cardiopulmonary Resuscitation (Sweden) | 17 | 2 |
| Out of Hospital Cardiac Arrest Outcomes (UK) | 1 | 0 |
| Out-of-hospital cardiorespiratory arrest in Spain (OHSCAR) | 4 | 1 |
| Pan-Asian Resuscitation Outcomes Study (PAROS) | 3 | 0 |
| Pediatric Cardiac Arrest European Registry in Emergency Services (E-PEDCARE) | 0 | 1 |
| Registre électronique des Arrêts Cardiaques (ReAC) | 4 | 1 |
| Registry for Out-of-Hospital Cardiac Arrests in Malta | 3 | 0 |
| Save Hearts in Arizona Registry OHCA | 1 | 0 |
| Japan National Registry of Cardio-Pulmonary Resuscitation (JNRCPR) | 0 | 4 |
| Victorian Ambulance Cardiac Arrest Registry (VACAR) | 28 | 4 |
|  | 173 | 70 |

**Supplementary file 1: Search strategies**

In reviewing the results of the initial searches a number of additional relevant terms were identified. These were incorporated into a revised and updated search. Both search strategies are presented here.

**MEDLINE and EMBASE search strategy Run 13th September 2016**

Database: Embase <1974 to 2016 September 13>

Database: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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1 Registries/ (62471)

2 (register$ or registry or registries).ti,ab. (201196)

3 1 or 2 (209622)

4 \*heart arrest/ (11330)

5 3 and 4 (718)

6 cardiopulmonary arrest$.ti,ab. (1785)

7 heart arrest$.ti,ab. (218)

8 6 or 7 (2000)

9 3 and 8 (88)

10 cardiac arrest regist$.ti,ab. (267)

11 resuscitation registr$.ti,ab. (70)

12 heart attack registr$.ti,ab. (6)

13 5 or 9 or 10 or 11 or 12 (965)

**MEDLINE and EMBASE search strategies revised and rerun 4th December 2016**

Database: Embase <1974 to 2016 December 4>

Database: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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1 Registries/ or clinical audit/ (127185)

2 (register$ or registry or registries or audit$).ti,ab. (465935)

3 1 or 2 (485887)

4 \*heart arrest/ (24709)

5 3 and 4 (1377)

6 cardiopulmonary arrest$.ti,ab. (2866)

7 heart arrest$.ti,ab. (539)

8 6 or 7 (3401)

9 3 and 8 (170)

10 (cardiac arrest adj (regist$ or audit$)).ti,ab. (455)

11 (resuscitation adj (registr$ or audit$)).ti,ab. (118)

12 (heart attack adj (registr$ or audit$)).ti,ab. (7)

13 5 or 9 or 10 or 11 or 12 (1781)

14 Registries/ or clinical audit/ (127185)

15 (register$ or registry or registries or audit$).ti,ab. (465935)

16 14 or 15 (485887)

17 \*heart arrest/ (24709)

18 \*resuscitation/ (53605)

19 16 and (17 or 18) (3333)

20 (cardiopulmonary adj (arrest$ or resuscitat$)).ti,ab. (17006)

21 heart arrest$.ti,ab. (539)

22 20 or 21 (17512)

23 16 and 22 (993)

24 (cardiac arrest adj (regist$ or audit$)).ti,ab. (455)

25 (resuscitation adj (registr$ or audit$)).ti,ab. (118)

26 (heart attack adj (registr$ or audit$)).ti,ab. (7)

27 19 or 23 or 24 or 25 or 26 (3765)

28 27 not 13 (1984)