Collaboration in pre-hospital care research: the pan asian resuscitation outcomes study

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Abstract

The Pan-Asian Resuscitation Outcomes Study (PAROS) Clinical Research Network is a unique, low-cost, self-funded model of a collaborative research network in the Asia-Pacific region formed in 2010. Currently, research into pre-hospital and emergency care in the Asia-Pacific region is largely inadequate and poorly coordinated owing to the marked variations in Emergency Medical Services (EMS) systems and outcomes reporting. With conditions such as Out-of-Hospital Cardiac Arrest (OHCA) being one of the leading causes of death worldwide, the dearth in the understanding of trends and research in pre-hospital and emergency care underscores the urgent need for more collaborative research in this area. By creating a platform to connect serious researchers, PAROS Clinical Research Network fosters an environment conducive for intellectual exchanges and for research ideas to be shared and implemented. This article describes the enablers pertaining to governance, frameworks and people in the formation and development of the PAROS Clinical Research Network. The Network has concentrated on building a supportive environment through having proper governance structure, efforts to harmonize the data dictionary for the registry, supportive frameworks that promote ethical and proper collection and use of data, and efforts in seeking opportunities to educate and equip its members with relevant knowledge and research capabilities. These descriptions are presented to provide a research framework for others in the field and to increase international collaboration for research in pre-hospital and emergency care.

Key words
● Research Network ● Pre-hospital ● Emergency Care ● Collaboration ● Out-of-hospital Cardiac Arrest ● Asia-Pacific

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Out-of-hospital cardiac arrest (OHCA) is a leading healthcare concern. The ever-increasing and progressively aging population is expected to contribute to the increasing strain on emergency medical services (EMS) systems and healthcare infrastructures for emergency medical conditions including OHCA.

Today, published OHCA incidences and outcomes vary greatly around the globe. OHCA survival-to-discharge rate for Asia stands at a dismal 2% as compared to 6%, 9%, and 11% for North America, Europe, and Australia respectively (Berdowski et al, 2010). Even when available, data from most of the Asia-Pacific region has been largely inadequate and uncoordinated unlike the Cardiac Arrest Registry to Enhance Survival (CARES) in the United States, the Canadian Ontario Prehospital Advanced Life Support (OPALS) network and the Resuscitation Outcomes Consortium (ROC) of North America. These regional registries have produced research impacting policies and serve as models for the Asia-Pacific region. Without a similar regional effort in the Asia-Pacific region to capture and measure OHCA outcomes, it is difficult to systematically deduce ways to improve survival in a part of the world where OHCA survival rates are one of the lowest globally. Owing a large part to the inherently complex and uncontrolled environment of pre-hospital and emergency care, the lack of integrated understanding of the markedly different Emergency Medical Services (EMS) systems in the Asia-Pacific region, and varying outcomes reporting adds to the challenge to derive meaningful outcomes data from numerous sources and interpret them.

The desire to establish an OHCA registry for the Asia-Pacific region prompted a group of pre-hospital and emergency care providers to form a working group in 2009. When exploring the possibilities of establishing a pre-hospital and emergency care collaborative research group in the Asia-Pacific region, in 2010, the Pan-Asian Resuscitation Outcomes Study (PAROS) Clinical Research Network

was formally established with the aim to:

- Understand OHCA as a disease in the Asia-Pacific region;
- Deepen the understanding of the heterogeneity in the pre-hospital systems in the Asia-Pacific region;
- Provide international benchmarking and study of best practices;
- Impact community awareness and change attitudes towards OHCA;
- Improve OHCA survival by systemic and community level interventions.

This article describes the enablers in the formation and development of the PAROS Clinical Research Network. The goal is to provide a research framework for others in the field and to increase international collaboration for research in pre-hospital and emergency care.

METHOD

The establishment of the registry was reviewed as a study that met the criteria for minimal risk research and approved by the respective institutional review boards that have jurisdiction over the participating EMS sites. Depending on the appropriate ethics review model in each country, some regions/countries allow the use of outcomes of a single institutional review board for data collected from a region or from multiple centres. Each participating site is responsible for obtaining and maintaining the IRB approvals for the study. A register of all IRB approvals is kept by the Trial Coordinating Centre.

The formation and development of the PAROS Clinical Research Network is the result of consistent efforts to ensure that the Network conducts only quality research relevant to improving resuscitation outcomes, while building a research-friendly environment for the like-minded to carry out intellectual debates. The Network focused on enablers targeted at three levels—governance, systems/frameworks, and passionate people who share the same vision of improving outcomes in pre-hospital and emergency care.

A. Governance

Constitution

The PAROS Clinical Research Network adopted a constitution with an Executive Committee at its inception in 2010, comprising a chairman, three

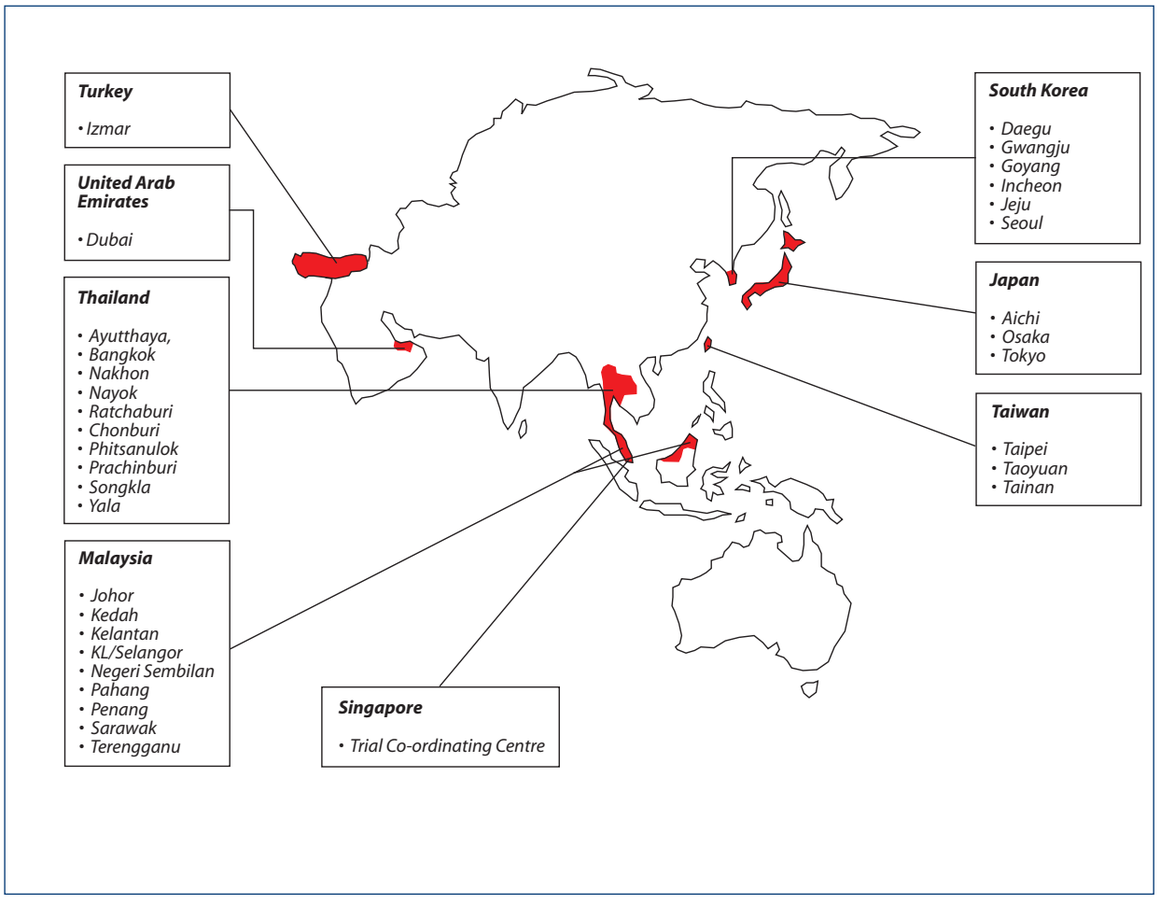

Figure 1. Map of PAROS participating sites

Table 1: Characteristics of participating EMS sites

Country	Regions (population base)	EMS system type	No. of participating hospitals	Level of providers
Korea	6 (20mn)	Single-tier	232	Basic & intermediate life support
Singapore	1 (5mn)	Single-tier	7	Basic & intermediate life support
Taiwan	3 (8mn)	Single-tier	45	Intermediate & Advanced life support
Japan	3 (24mn)	Single-tier	346	Basic & Advanced life support
Thailand	9 (10mn)	Single-tier	13	Basic & Advanced life support
Malaysia	10 (10mn)	Single-tier	10	Basic life support
Turkey	1 (4mn)	Single-tier	47	Basic life support
United Arab Emirates	1 (2mn)	Single-tier	11	Basic & Advanced life support

* The data from this table are based on a survey of all participating EMS systems.

co-chairmen and two nominated representatives per participating country to allow representation of issues unique to each country and to facilitate implementation. The Executive Committee is elected for a three-year term. The Network is currently chaired by Assoc. Prof Marcus Ong from Singapore, and co-chaired by Assoc. Prof Sang Do Shin from South Korea, Prof Hideharu Tanaka from Japan, and Assoc. Prof Matthew Ma from Taiwan. The Chairman and three Co-Chairmen also hold the executive authority for conflict resolution should potential conflicts arise within the Network.

Today, the PAROS CRN has now grown into a consortium of eight participating countries–Japan,

Table 2. List of approved studies in progress (organized by publications committees)

OHCA (Publications Committee Chairman: Assoc. Prof Marcus Ong)
- Paediatric OHCA Resuscitation Outcomes
- Regional Variation in Outcomes of Witnessed Ventricular Fibrillation (VF) OHCA in Asia
- Impact of Supraglottic Airways and Endotracheal Intubation on Outcomes Following OHCA
- Outcomes from Manual versus Mechanical Chest Compressions at the Emergency Department Setting for OHCA – a Pan-Asian Perspective

EMS Systems (Publications Committee Chairman: Assoc. Prof Sang Do Shin)
- Comparison of EMS Systems
- EMS Systems – "End-of-Life" Issues
- Incidence of VF in Asian OHCA
- Classify Urban/Suburban/Rural Sites for OHCA Research Across PAROS Countries

EMS Survey (Publications Committee Chairman: Prof Hideharu Tanaka)
- Pan-Asian Study of EMS Performance Indicators
- EMS Education and Training
- Non-Cardiac OHCA in PAROS
- Asia EMS Survey on Ambulance Design and Safety Specifications

ED Survey (Publications Committee Chairman: Assoc. Prof Matthew Ma)
- Adherence of Early Goal-Directed Therapy (EGDT)
- ED Overcrowding in Asia
- Re-exploration of EMS Response Time to the Survival of OHCAs in Asia
- Factors Affecting Neurologic Outcomes of OHCA Patients with Percutaneous Coronary Intervention

Korea, Malaysia, Singapore, Taiwan, Thailand, Turkey, and United Arab Emirates (*Figure 1*). The characteristics of the participating regions and countries are found in *Table 1*. The eight participating countries present a potential patient population of 83 million—a huge population base useful for the characterization of populations and population-based studies. This systemic diversity can help to deepen the understanding of issues and systems in pre-hospital and emergency care on both local and international levels.

Publications committees

The Network views publications as an integral part of sharing the research findings, whether from the research done within the Network, or with other research groups within the research community. With this in mind, four publications committees were formed within the Network to introduce an in-built peer-review system and to instil a pro-research environment for budding research ideas. The four committees are organized by themes—OHCA, EMS Systems, Emergency Department (ED) Survey, EMS Survey.

At least twice a year, members can propose new study proposals which will be evaluated by the Publications Committees. This provides room for individual research ideas to bloom and an avenue for constructive feedback to be exchanged. The further organization of Publications Committees members into writing groups also help to create momentum and leverage on members with stronger language capabilities. To date, the Network has approved 16 studies ranging from termination of resuscitation, training, performance indicators, compliance of therapies, to secondary analyses of the PAROS registry. A table of the approved studies currently in progress can be found in *Table 2*.

B. Supportive systems and frameworks

Harmonized database and data capture systems

To measure the outcomes in a meaningful way and for comparisons across countries or regions, the PAROS Clinical Research Network developed a harmonized data dictionary based on the Utstein Style Template (Cummins et al, 1991; Jacobs et al, 2004). The list of variables, categorized as core and non-core determined by consensus, can be found in *Table 3*. Only countries that have given their commitment to contribute at least data of the core data variables can be considered a PAROS participating country. From October 2010, new countries interested in participating must also demonstrate to the PAROS Executive Committee their ability to meet this minimum criterion. A single data collection form based on the harmonized definitions was also designed to use in all participating countries. Where data was collected in a non-English language, participating countries perform back-translation to replicate the form in their own language, or have members versed in both languages transcribe and validate the data provided. In order for the collected data to eventually have population-based applications, country representatives on the PAROS Executive Committee work with their respective hospitals and agencies in EMS to include all OHCA cases conveyed by EMS or presenting at emergency departments.

To cater to the needs of participating regions or countries with and without existing data capture systems, two methods of capturing data were used—direct entry online via an online data capture system called ePAROS, or an export field entry which allows exported data from existing databases to auto-populate the registry. ePAROS is a user-friendly data capture system adapted from CARES. Access to this electronic mode of data collection is offered at no cost to the data personnel of the participating countries—allowing data to be collected in a cost-effective manner in limited resourced environments. Where export field entry is used, iterative rounds of data matching, clarifications on the provided data, and alignment with the PAROS data dictionary is carried out with the epidemiologist based at the Trial Coordinating Centre before any data is migrated to the ePAROS registry. The list of regions employing the two different methods is shown in *Table 4*.

Systemic compatibilities with the CARES system also allows for potential cross-continent comparisons that will bring exciting possibilities for exchange of ideas to improve survival.

Data quality assurance framework

Although united by good faith and trust, the Network is conscious that such intangibles though laying the foundation for research collaboration are, in themselves, inadequate to rigorously ensure accuracy and completeness of the contributed data. To ensure that data integrity is maintained in the data contributed by each participating country or region, a data quality assurance plan was developed for the registry. The document details the roles and responsibilities of the parties involved in the process, procedures for quality checks to ensure accuracy and completeness of data, and the recommended timelines applicable. The implementation of this framework endeavors to establish an accountability framework and a transparent approach to the expectations and the recommended corrective actions.

Table 3. List of PAROS variables (core and non-core)

S/N	VARIABLE	CORE	NON-CORE
	Emergency Medical Services (EMS) agency		
1	Mode of transport	●	
2	Date of incident	●	
3	Location of incident		●
4	Location type		●
5	Date of birth / Age	●	
6	Gender	●	
7	Race		●
8	Medical history		●
9	Time call received at dispatch centre	●	
10	Time first responder dispatched		●
11	Time ambulance dispatched		●
12	Time first responder arrived at scene		●
13	Time ambulance arrived at scene	●*	
14	Time EMS arrived at patient side	●*	
15	Time ambulance left scene	●	
16	Time ambulance arrived at ED	●	
17	Estimated time of arrest		●
18	Arrest witnessed by	●	
19	Bystander CPR	●	
20	First CPR initiated by		●
21	Bystander AED applied		●
22	Resuscitation attempted by EMS / Private ambulance	●	
23	First arrest rhythm	●	
24	Time CPR started by EMS / Private ambulance		●
25	Time AED applied by EMS / Private ambulance		●
26	Pre-hospital defibrillation	●	
27	Defibrillation performed by		●
28	Mechanical CPR device used by EMS / Private ambulance		●
29	Advanced airway used by EMS / Private ambulance		●
30	Drug administered by EMS / Private ambulance		●
31	Return of spontaneous circulation at scene / en-route	●	
32	CPR discontinued at scene / en-route		●
33	Final status at scene	●	
34	Cause of arrest (only for cases pronounced dead at scene by EMS)	●	
35	Level of destination hospital		●
36	Destination hospital		●
37	Patient's status at ED arrival	●	
	Hospital [Emergency Department (ED)]		
38	Date of arrival at ED	●	
39	Time of arrival at ED		●
40	Patient status on arrival at ED - Pulse and / or Breathing		●
41	Cardiac rhythm on arrival at ED		●
42	ED defibrillation performed		●
43	Mechanical CPR device used at ED		●
44	Advanced airway used at ED		●
45	Drug administered at ED		●
46	Return of spontaneous circulation at ED	●	
47	Emergency PCI performed		●
48	Emergency CABG performed		●
49	Hypothermia therapy initiated		●
50	ECMO therapy initiated		●

Table 3. List of PAROS variables (core and non-core) (continued)

S/N	VARIABLE	CORE	NON-CORE
51	Cause of arrest	●	
52	Reason for discontinuing CPR at ED		●
53	Outcome of patient	●	
54	Patient status	●	
55	Date of discharge or death		●
56	Patient neurological status on discharge or at 30th day post-arrest		●
57	EQ-5D Health Dimensions - Mobility		●
58	EQ-5D Health Dimensions - Self-care		●
59	EQ-5D Health Dimensions - Usual activities		●
60	EQ-5D Health Dimensions - Pain / discomfort		●
61	EQ-5D Health Dimensions - Anxiety / depression		●
62	EQ-5D Visual Analog Scale (VAS)		●

Data use framework

Recognizing the sensitivities surrounding the use of identifiable data, the use of identifiable data is restricted to the linking of data belonging to a single case. All unique patient identifiers will be permanently removed from the PAROS registry before use so as to protect the confidentiality and privacy of the subjects. Only study sites will maintain separate study logs that will enable tracing of individual case hospital outcomes and allow verification of data as needed.

Data drawn from the PAROS Clinical Research Network can only be used after written approval from the PAROS Publications Committees and the request should come in the form of a research proposal with the involvement of at least one member. This ensures that any data released for research have been evaluated scientifically, and limited to the approved use and the minimum necessary.

Funding model

The PAROS Clinical Research Network uses a low-cost, self-funded funding model. Each participating country is responsible for administering its own data collection process. Data for the registry are input via secured channels to an internet-based electronic data capture system hosted by the Trial Coordinating Centre located at the Singapore Clinical Research Institute in Singapore. The Trial Coordinating Centre is supported by grants from the Singapore Clinical Research Institute, Singapore Health Services, and the National Medical Research Council (Singapore).

Table 4. List of participating regions by county

COUNTRY	PARTICIPATING REGION
Regions using Batch Download from National Registries	
Japan	Aichi, Osaka, Tokyo
Korea	Daegu, Gwangju, Goyang, Incheon, Jeju, Seoul
Taiwan	Taipei, Taoyuan, Tainan
Regions using Electronic Capture System	
Malaysia	Johor, Kedah, Kelantan, Kuala Lumpur / Selangor, Negeri Sembilan, Pahang, Penang, Sarawak, Terengganu
Singapore	Singapore
Thailand	Ayutthaya, Bangkok, Nakhon Nayok, Ratchaburi, Chonburi, Phitsanulok, Prachinburi, Songkla, Yala
Turkey	Izmir
United Arab Emirates	Dubai

Trial Coordinating Centre – Singapore Clinical Research Institute

As the Trial Coordinating Centre for PAROS Clinical Research Network, the Singapore Clinical Research Institute (SCRI) hosts the ePAROS, functions as the custodian of data for PAROS Clinical Research Network, and works closely with the Network on issues ranging from developing enabling frameworks, guidelines, bulletins, organization of investigators meetings and relevant educational events, maintenance of website, to the provision of epidemiological and statistical support. As an academic research organization dedicated to enhancing the standards of human clinical research, it fosters multi-institutional research by supporting and utilizing frameworks and platforms established to develop the people, processes, and systems needed to effectively execute this common goal.

C. People

Affiliations

The PAROS Clinical Research Network is affiliated to the Asian EMS Council, an advocate for pre-hospital care and EMS in Asia that focuses on creating opportunities for education and training. Both the Network and the Asian EMS Council are affiliated to the Asian Relations Ad Hoc Committee of the National Association of EMS Physicians (NAEMSP). PAROS CRN has also forged ties with the CARES, a research initiative based in Atlanta, USA, showcasing collaboration with parties beyond the region.

Education and communications

As a young Network, the PAROS Clinical Research Network is committed to building up the research capabilities of its members. Besides working with the Asian EMS Council for educational events that increase the understanding of the varying pre-hospital systems in the region, the Network also independently organizes workshops centred on literature review and manuscript-writing. This combination helps members broaden their horizons and gain appreciation of the different systems, and foster an environment conducive for intellectual exchanges and for research ideas to be shared and implemented beyond local settings. The organization of investigators meetings are often suitably held in conjunction with a regional or international educational conference. Timing meetings with such conferences also help to encourage participation in face-to-face exchanges—a boon to strengthening ties within the Network, which in turn drives progress.

As a means to engage members, the Network also issues a bulletin at least once every six months to keep members updated on the activities of the Network, and disseminate new information pertaining to the registry or studies conducted under the auspices of the Network. Every investigators meeting, held at least twice a year, also functions as an opportune time for members to update on progress to date, upcoming activities and plans, and reiterate or review timelines when necessary.

SUMMARY

This effort is a unique, low-cost, self-funded model of a collaborative research network. By creating a platform to connect serious researchers, PAROS Clinical Research Network fosters an environment conducive for intellectual exchanges and for research ideas to be shared and implemented. The Network has concentrated on building a supportive environment through having proper governance structure, efforts to harmonize the data dictionary for the registry, supportive frameworks that promote ethical and proper collection and use of data, and relentless effort to always seek educational opportunities to educate and equip its members with relevant knowledge and research capabilities.

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