



PAROS DATA AGREEMENT

This Data Agreement provides guidelines on the use of data within the Pan-Asian Resuscitation Outcomes Study (PAROS) Clinical Research Network (CRN). By virtue of becoming a registered member of this Network [Executive Committee (EXCO) and/or General], the member has agreed that all guidelines stipulated in this Agreement shall be complied with without exception. As the default custodian of data for PAROS CRN, the Singapore Clinical Research Institute Pte Ltd (SCRI) also agrees to comply with this Agreement.

By receiving data originating from PAROS CRN, the relevant party agrees to not use or disclose them other than that permitted or required by this Agreement, in addition to the applicable local laws, regulations, and guidelines.

The Chairman of PAROS CRN (i.e. “the Chairman”), in consultation with the PAROS EXCO, reserves the right to amend this Agreement from time to time.

(A) Contributing Data

Any registered member of the Network *must* contribute a core data set, whether directly or indirectly, depending on the whether they are from an Emergency Medical Services (EMS) agency or a hospital. For an institution with a hospital-based EMS, or a combined registry, core data variables expected of both the EMS agency and hospital would apply. This core data set (endorsed by PAROS EXCO) would include:

Emergency Medical Services (EMS) agency	Hospital [Emergency Department (ED)]
i. Mode of transport	i. Date of arrival at ED
ii. Date of incident	ii. Return of spontaneous circulation at ED
iii. Date of birth / Age	iii. Cause of arrest
iv. Gender of patient	iv. Outcome of patient
v. Time call received at dispatch centre	v. Patient status
vi. Time ambulance arrived at scene ¹	
vii. Time EMS arrived at patient side ¹	
viii. Time ambulance left scene	
ix. Time ambulance arrived at ED	
x. Arrest witnessed by	
xi. Bystander CPR	
xii. Resuscitation attempted by EMS / Private ambulance	
xiii. First arrest rhythm	
xiv. Pre-hospital defibrillation	
xv. Return of spontaneous circulation at scene / en-route	
xvi. Final status at scene	
xvii. Cause of arrest	
xviii. Patient’s status at ED arrival	

¹ Each country would declare whether “Time ambulance arrived at scene” and/or “Time EMS arrived at patient side” would be core to them and they will be bound by this expectation.



Contribution of data to PAROS CRN database beyond this core data set, subject to availability in the member country, is highly encouraged. See [Annex A](#) for a complete listing of the PAROS CRN variables.

(B) De-identification and Cleaning Up of Data

In PAROS CRN, identifiable data refers to data that identifies or can be reasonably used to identify the patient (e.g. name, address, contact information, identification number, etc). It does not include country, state/province/prefecture of origin, and postal code. De-identified data refers to data stripped of all unique patient identifiers.

The main purpose of capturing identifiable data is to facilitate linking of data (independently entered by an EMS agency and a hospital) belonging to a single case. Once linked, the data would be cleaned up by addressing errors and/or incomplete data fields. Subsequently, the administrator of the PAROS CRN database² would perform the de-identification process by *permanently* removing all unique patient identifiers in the database.

Any data extracted from PAROS CRN (whether between network members, or between network member(s) and non-member(s)) can only be done in the de-identified format.

(C) Data Ownership

Data contributed to the PAROS CRN belongs to the Network, with the SCRI as the default custodian of these data.

i) Members of PAROS CRN whose institution(s) have contributed directly (cases from source to PAROS CRN without intermediaries) or indirectly (cases contributed to a registry from which data was later provided to PAROS CRN) to the Network will continue to own their portion of source data and they are free to use them in a way they deem appropriate as long as they are not collaborating with any other site(s) (whether PAROS or non-PAROS). Any use of data drawn from PAROS CRN beyond that contributed by one's own institution(s) would require an approval [see Part (D)].

ii) Non-members of PAROS CRN do not and cannot own any data in PAROS CRN. If they wish to use data extracted from PAROS CRN's database, they must obtain approval before using them for the approved purpose(s)/project(s) [see Part (D)].

(D) Requesting for Data

Data drawn from PAROS CRN (partial or all) cannot be used without first obtaining the relevant written approval from PAROS CRN, unless these data were solely contributed from source by that user. Data drawn from PAROS CRN for use with one or more collaborating site(s) for publication must also seek written approval from PAROS CRN. Written approvals, instead of verbal or other forms of approvals, should be used.

² As of September 2010, the administrator of PAROS CRN database is Ms Shahidah.



Any request of data extracted from PAROS CRN (partial or all) must come in the form of a research proposal and at least one PAROS CRN member must be involved in this proposal. This research proposal will be reviewed by one of the four Publications Committees³ (PCs), depending on the subject nature of the proposal. The relevant PC would evaluate and decide whether or not to grant approval to the proposal requesting for access to data extracted from PAROS CRN. Proposals will be evaluated based on scientific merits and feasibility of obtaining the data, and the reviewing party may request for additional information/input to aid the evaluation (including consulting the PAROS CRN Network Epidemiologist and/or data personnel). If a decision cannot be reached at the level of a PC, the proposal will be escalated to PAROS CRN EXCO, and Chairman of PAROS CRN (or designee) will make the final decision.

Any proposer holding more than one position in different institutions cannot use data extracted from PAROS CRN across those institutions without first seeking approval (in the form of a research proposal) from the reviewing PC and/or Chairman.

(E) Using & Disclosing Data

Data from PAROS CRN should only be used in accordance to their permitted/approved use. They must not be circulated freely. Any further use from that previously consented would require additional written approval.

All written approvals by a PC Chairman or Chairman of PAROS CRN must be made known to SCRI before SCRI can release data for specific project(s)/purpose(s). Any disclosure of data set(s) should be limited to the minimum necessary.

Where the sharing or use of data (belonging to PAROS CRN) involves a third party (non-members of PAROS CRN), the partnering PAROS CRN member must ensure that the third party complies with this Agreement.

(F) Data Security & Rights to Audit

Contributors, recipients and custodian of the data have a joint responsibility in ensuring the data provided to, extracted from or stored on behalf of PAROS CRN are kept secure at all times. As the default custodian of the data for PAROS CRN, SCRI agrees to use appropriate safeguards to prevent wrongful use or disclosure.

Where a breach in data security (e.g. wrongful disclosure) has been detected, all responsible parties should undertake the responsibility to inform to the Chairman and take reasonable steps to limit the extent of the breach. The Chairman reserves the right to appoint a designee to audit the relevant records and practices related to the use and disclosure of the data originating from PAROS CRN so as to ensure compliance of the contributors, recipients and custodian of the data with the terms of this Agreement.

³ The four Publications Committees are Out-of-Hospital Cardiac Arrest (OHCA), Emergency Medical Services (EMS) Systems, Emergency Department (ED) Survey and EMS Survey.



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(G) Acknowledging PAROS CRN

The use of any data requested from PAROS CRN (whether by a single member, between PAROS members, or between PAROS member(s) and non-member(s)) must accord due acknowledgement to PAROS CRN.

(H) Miscellaneous

Upon the termination of PAROS membership, for any reason, the recipients of the data (outgoing member(s) and associated non-member(s)) shall return all extracted data to the Chairman (or designee) or destroy all data received from the PAROS CRN. In the event that the return or destruction of the data is not feasible, recipients of those data should inform the Chairman and limit further uses and/or disclosures. All contributed data to the Network would remain with the Network and outgoing parties cannot request for those data to be withdrawn from the Network's database. The Chairman reserves the right to guide the relevant outgoing parties to take reasonable steps to seek rectification, including termination of PAROS membership.



Annex A

LIST OF PAROS CRN VARIABLES (CORE & 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 (<i>optional</i>)		●
4	Location type		●
5	Date of birth / Age	●	
6	Gender	●	
7	Race (<i>optional</i>)		●
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	● ⁴	
14	Time EMS arrived at patient side	● ⁴	
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 (<i>only for cases pronounced dead at scene by EMS</i>)	●	
35	Level of destination hospital		●
36	Destination hospital		●
37	Patient's status at ED arrival	●	

⁴ Each country would declare whether #13 and/or #14 would be core to them and they will be bound by this expectation.



S/N	Variable	Core	Non-Core
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		●
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)		●