CARES Data Sharing User Guide

CARES
Cardiac Arrest Registry
to Enhance Survival

INDEX

What is CARES?

In 2004, the Centers for Disease Control and Prevention (CDC) established the Cardiac Arrest Registry to Enhance Survival (CARES) in collaboration with the Department of Emergency Medicine at the Emory University School of Medicine. CARES was developed to help communities determine standard outcome measures for out-of-hospital cardiac arrest (OHCA), by linking the three sources of information that define the continuum of emergency cardiac care: 911 dispatch centers, emergency medical services (EMS) providers, and receiving hospitals. Participating EMS systems can compare their performance to de-identified aggregate statistics, allowing for longitudinal benchmarking capability at the local, regional, and national level.

CARES began data collection in Atlanta, with nearly 1,500 cases captured in 2006. The program has since expanded to include 30 state-based registries (Alabama, Alaska, California, Colorado, Connecticut, Delaware, Florida, Hawaii, Illinois, Kentucky, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Utah, Vermont, Washington and Wisconsin) plus 50 community sites in 16 additional states, representing a catchment area of approximately 170 million people or 51% of the US population. To date, the registry has captured over 800,000 records, with more than 2,200 EMS agencies and over 2,500 hospitals participating nationwide.

Who owns CARES data?

CARES is a secure and confidential data management system that allows EMS agencies and hospitals to monitor their performance and compare themselves against state and national benchmarks. Local EMS agencies and hospitals have ownership of their own data. CARES is committed to maintaining the confidentiality of EMS agency and hospital data; therefore, all data is shared in a de-identified, aggregate format. Fields that could identify a patient, EMS agency, or hospital are removed from research datasets, and publications shall not separately identify participating EMS agencies, hospitals, or their contributed data. Data sharing applications and agreements are proposal-specific and limited to each individual project.

What is a CARES case?

EMS agencies are instructed to include all out-of-hospital cardiac arrests (OHCAs) of non-traumatic etiology where the patient: 1) receives resuscitative efforts from First Responders or EMS, or 2) is defibrillated prior to the arrival of a 911 Responder. CARES includes OHCA patients of all ages.

The following are not considered CARES cases: 1) Unworked/untreated cardiac arrests where resuscitative efforts were not initiated or terminated due to rigor, lividity, decomposition, injuries incompatible with life, Do Not Resuscitate directive, and/or obvious signs of death, 2) Stillborn neonates/perinatal newborns, born without signs of life, 3) Private EMS transport that did not involve 911 dispatch (i.e. interfacility transport), and 4) Cardiac arrests of traumatic etiology.

How is CARES data collected?

The CARES software (https://mycares.net), developed and maintained by Physio-Control, Inc., links three sources to describe each OHCA event: 1) 911 call center data, 2) EMS data, and 3) hospital data. The registry evaluates OHCA events of non-traumatic etiology that involve persons who received resuscitative efforts, including CPR and/or defibrillation. EMS initiates a CARES record and can submit data in two ways: using a data-entry form on the CARES website, or via upload from an agency's electronic patient-care record (ePCR) system. When the patient survives to the hospital with ongoing resuscitation, CARES requests outcome data from the receiving facility.

What kind of data does CARES collect?

Data collection within CARES is based on the Utstein-style definitions – a standardized template of uniform reporting guidelines for clinical variables and patient outcomes that was developed by international resuscitation experts[1].

From 2005-2012, only patients with a presumed cardiac etiology were included in CARES. However, in alignment with the Utstein guidelines and ILCOR recommendation, the registry's inclusion criteria were modified in January 2013 to include all patients with non-traumatic OHCA. As such, data analysis is restricted to the 2013-2021 dataset, which includes more than 700,000 records.

Mandatory data elements collected from EMS providers include demographics (i.e. name, age, date of birth, incident address, sex, and race/ethnicity), arrest-specific data (i.e. location type of arrest, witness status, and presumed etiology), and resuscitation-specific data (i.e. information regarding CPR initiation and/or AED application, defibrillation, initial arrest rhythm, return of spontaneous circulation [ROSC], field hypothermia, and pre-hospital survival status).

EMS providers are also able to enter a number of optional elements, which further detail arrest interventions (i.e. usage of mechanical CPR device, ITD, 12 Lead, automated CPR feedback device, and advanced airway; administration of drugs; and diagnosis of STEMI).

The CARES form also includes a number of optional time elements, including estimated time of arrest, initial CPR, defibrillatory shock, sustained ROSC, and termination of resuscitative efforts. Supplemental data elements collected from the 911 call centers include the time that each 911 call was received, the time of dispatch for both first responder and EMS providers, and arrival time at the scene.

Data elements collected from receiving hospitals include emergency department outcome, provision of therapeutic hypothermia/TTM, hospital outcome, discharge location, and neurological outcome at discharge (using the Cerebral Performance Categories [CPC] Scale). Receiving facilities may also complete optional elements outlining hospital procedures, including coronary angiography, CABG, and stent or ICD placement.

The CARES dataset is geocoded on an annual basis, using Centrus Desktop Geocoder, and linked to a number of census-tract level variables including: median household income, median age, race/ethnicity, unemployment rate, poverty status, urbanicity, and educational attainment.

The CARES forms (required elements only, and required and supplemental elements) are located in Appendix A.

How can I access CARES data?

Inquiries about the national dataset should be directed to Rabab Al-Araji (ralaraj@emory.edu), CARES Epidemiologist. Inquires about state-specific projects should be directed to the respective CARES State Coordinator (contact information: https://mycares.net/sitepages/contactus.jsp).

Researchers who want to analyze state or national aggregate data must submit a research proposal to the CARES Data Sharing Committee. Each unique project requires a separate proposal submission. The CARES Data Sharing Application is located in Appendix B. Once completed, the application will be distributed to committee members for review. Feedback will be provided within four weeks of submission.

The goals of the national and state Data Sharing Committees are as follows:

- To promote accurate and scientifically sound presentations and papers from the CARES program.

[1] *Resuscitation*. 2015 Nov;96:328-40.

- To oversee the use of the data belonging to EMS agencies and hospitals and protect agency and hospital confidentiality.
- To ensure that all involved parties have consented to the use of their data, or, if the research or analysis is de-identified, cumulative data, that it is approved by a committee.
- To ensure participation and support from all stakeholders.
- To avoid duplication of effort and data mining.

The committee evaluates the proposal for scientific merit and makes recommendations. If there are no concerns or issues raised, the researcher will be informed that their proposal has been approved. Any comments or suggestions from the committee will be shared with the lead investigator.

How much does CARES data cost?

CARES charges 5% of the total project award amount when the research or study is funded from sources external to the researcher's institution. However, there is no charge to access the CARES National Dataset if the research or study is funded from internal sources at the researcher's institution. Examples of external funding sources include but are not limited to:

- The National Institutes of Health
- Agency for Healthcare Research and Quality
- American Heart Association
- Industry

An overview and FAQ document can be found on the National Dataset Fee FAQ Document (Appendix F).

My project has been approved. What are the next steps?

An overview of the required steps can be found in the Data Sharing Checklist (Appendix C).

Step 1: Non-Disclosure Agreement & IRB approval

Prior to receipt of the CARES dataset, the lead researcher must sign a Non-Disclosure Agreement for Information Recipients stating they will not share the dataset or expand the analysis beyond the scope of the proposal. The signed NDA should be sent to the CARES Data Sharing Coordinator for final execution by Emory University. A fully executed copy will be returned once available.

Lead authors must obtain IRB approval from their institutions within 3 months of receiving the dataset for analysis. A copy of the IRB approval must be shared with the CARES Data Sharing Coordinator.

Step 2: Dataset review webinar

After approval of the proposal by the Data Sharing Committee, the CARES Data Sharing Coordinator will provide the requested de-identified dataset specific to the study proposal. The Data Sharing Coordinator will schedule a webinar with the study investigators and affiliated statistical staff to review the dataset and answer questions about interpretation of the CARES elements.

I'm ready to start my data analysis. What should I consider?

Data element definitions and coding considerations (including information about location type, bystander CPR, PAD, and patient outcome) are found in Appendix D. Additional information can be found in the CARES Data Dictionary (https://mycares.net/sitepages/dataelements.jsp).

Details regarding the dataset structure and relationships between CARES questions are found in Appendix E.

Step 3: Send descriptive data tables for review prior to further analysis

Descriptive data tables should be shared with the CARES Data Sharing Coordinator for review prior to further analysis. This will allow for feedback regarding inclusion/exclusion criteria, data element interpretation, and coding in advance of more sophisticated analyses.

Authorship

Authors who participate in the writing of a manuscript should do so in accordance with the International Committee of Medical Journal Editors guidelines (JAMA 1997; 277(11): 927-934).

All abstracts/manuscripts written using CARES data will use the following format to list authorship:

- Individual authors will be listed first.
- All abstracts/manuscripts should include the words "and the CARES Surveillance Group" in the authorship line following the individual authors (e.g. Schwamm L, George M, Matters M, and the CARES Surveillance Group).

The "Acknowledgement" section of all manuscripts should reference the CARES participating sites by providing the web link https://mycares.net/sitepages/map.jsp.

Abstracts

Abstract or presentation proposals must be followed up with a submission within *three months* of the date that the dataset is provided.

Abstracts for presentations at scientific meetings should be sent to the Data Sharing Committee for approval prior to submission. Committee members will review the abstract to determine whether it is accurate and scientifically sound. The committee will respond to the investigators within *two weeks* of submission for abstracts. Under very limited circumstances, a researcher may call for an expedited review of an abstract. Requests for an expedited review should be submitted to the committee with justification for the need to expedite the review. Failure of the researcher to complete the work in a timely manner and/or failure to determine deadlines prior to beginning the project DOES NOT justify expedited review.

A copy of accepted abstracts should be sent to the CARES Data Sharing Coordinator for the record.

Manuscripts

Manuscripts must be submitted for review within *nine months* of the date that the dataset is provided.

Draft manuscripts should be sent to the Data Sharing Committee for approval prior to journal submission. Committee members will review the manuscript to determine whether it is accurate and scientifically sound. The committee will respond to the investigators within *four weeks* of submission for manuscripts. Under very limited circumstances, a researcher may call for an expedited review. Requests for an expedited review should be submitted to the committee with justification for the need to expedite the review. Failure of the researcher to complete the work in a timely manner and/or failure to determine deadlines prior to beginning the project DOES NOT justify expedited review.

The CARES Data Sharing Coordinator should be notified with each journal submission and peer review, in order to track projects.

A copy of accepted publications should be sent to the CARES Data Sharing Coordinator for the record.

Appendix A: CARES Forms

CARES Required Elements:

Part A. Demographic Information

1. Street Address (Where Arrest Occurred)

2. City | 3. State | 4. Zip Code | 5. County

6. First Name | 7. Last Name

8. Age ☐ Days ☐ Months ☐ Years

9. Date of Birth ☐ DOB Unknown

10. Gender
☐ Male ☐ Female ☐ Non-Binary ☐ Female-to-Male, Transgender Male ☐ Male-to-Female, Transgender Female

11. Race/Ethnicity
☐ American-Indian/Alaska Native ☐ Asian ☐ Black/African American ☐ Hispanic/Latino ☐ Native Hawaiian/Pacific Islander ☐ White ☐ Unknown

Part B. Run Information

14. Date of Arrest

15. Incident #

16. Fire/First Responder

17. Destination Hospital

☐ No First Responder dispatched

Part C. Arrest Information

18. Location Type
☐ Home/Residence
☐ Public/Commercial Building
☐ Street/Highway
☐ Nursing Home
☐ Healthcare Facility
☐ Place of Recreation
☐ Industrial Place
☐ Transport Center
☐ Other _____

19. Arrest Witness Status
☐ Unwitnessed
☐ Witnessed by Bystander
☐ Witnessed by 911 Responder

20. Presumed Cardiac Arrest Etiology
☐ Presumed Cardiac Etiology
☐ Trauma
☐ Respiratory/Asphyxia
☐ Drowning/Submersion
☐ Electrocution
☐ Exsanguination/Hemorrhage
☐ Drug Overdose
☐ Other _____

Resuscitation Information

21. Resuscitation Attempted by 911 Responder (or AED shock given prior to EMS arrival)
☐ Yes
☐ No

22. Who Initiated CPR
☐ Not Applicable
☐ Bystander
☐ Family Member
☐ Healthcare Provider (non-911 Responder)
☐ First Responder
Did Law Enforcement initiate CPR?
☐ Yes
☐ No
☐ EMS Responder (transport EMS)

25. Was an AED Applied Prior to EMS Arrival
☐ Yes, with defibrillation
☐ Yes, without defibrillation
☐ No

26. Who First Applied the AED
☐ Bystander
☐ Family Member
☐ Healthcare Provider (non-911 Responder)
☐ Law Enforcement First Responder
☐ Non-Law Enforcement First Responder

27. Who First Defibrillated the Patient
☐ Not Applicable
☐ Bystander
☐ Family Member
☐ Healthcare Provider (non-911 Responder)
☐ Law Enforcement First Responder
☐ Non-Law Enforcement First Responder
☐ EMS Responder (transport EMS)

First Cardiac Arrest Rhythm of Patient and ROSC Information

29. First Arrest Rhythm of Patient
☐ Ventricular Fibrillation
☐ Ventricular Tachycardia
☐ Asystole
☐ Idioventricular/PEA
☐ Unknown Shockable Rhythm
☐ Unknown Unshockable Rhythm

30. Sustained ROSC (20 consecutive minutes) or present at end of EMS care
☐ Yes, but pulseless at end of EMS care (or ED arrival)
☐ Yes, pulse at end of EMS care (or ED arrival)
☐ No

31. Was Hypothermia Care Provided in the Field
☐ Yes
☐ No

32. End of Event
☐ Effort ceased due to DNR
☐ Pronounced in the Field
☐ Pronounced in the ED
☐ Ongoing Resuscitation in ED

Part E. Hospital Section

47. ER Outcome
☐ Died in the ED
☐ Admitted to hospital
☐ Transferred to another acute care facility from the ED

48. Was hypothermia care/TTM initiated or continued in the hospital
☐ Yes ☐ No

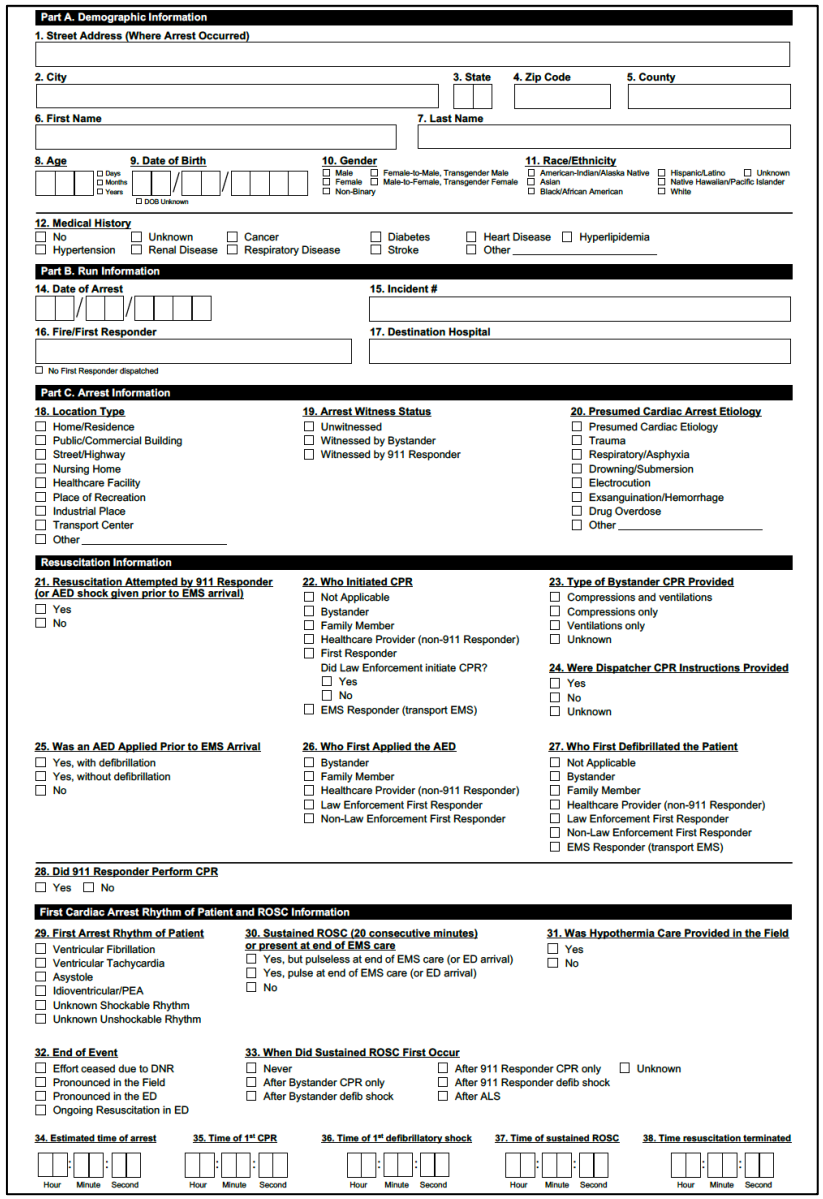
49. Hospital Outcome
☐ Died in the hospital
☐ Discharged alive
☐ Patient made DNR
Choose one of the following:
☐ Died in the hospital
☐ Discharged alive
☐ Transferred to another acute care hospital
☐ Not yet determined
☐ Transferred to another acute care hospital
☐ Not yet determined

50. Discharge from the Hospital
☐ Home/Residence
☐ Rehabilitation Facility
☐ Skilled Nursing Facility/Hospice

51. Neurological Outcome at Discharge from Hospital
☐ Good Cerebral Performance (CPC 1)
☐ Moderate Cerebral Disability (CPC 2)
☐ Severe Cerebral Disability (CPC 3)
☐ Coma, vegetative state (CPC 4)

CARES
Cardiac Arrest Registry
to Enhance Survival

CARES Required & Supplemental Elements:



Part A. Demographic Information

1. Street Address (Where Arrest Occurred)
2. City
3. State
4. Zip Code
5. County
6. First Name
7. Last Name
8. Age — ☐ Days ☐ Months ☐ Years ☐ DOB Unknown
9. Date of Birth
10. Gender — ☐ Male ☐ Female ☐ Non-Binary ☐ Female-to-Male, Transgender Male ☐ Male-to-Female, Transgender Female
11. Race/Ethnicity — ☐ American-Indian/Alaska Native ☐ Asian ☐ Black/African American ☐ Hispanic/Latino ☐ Native Hawaiian/Pacific Islander ☐ White ☐ Unknown
12. Medical History — ☐ No ☐ Unknown ☐ Cancer ☐ Diabetes ☐ Heart Disease ☐ Hyperlipidemia ☐ Hypertension ☐ Renal Disease ☐ Respiratory Disease ☐ Stroke ☐ Other

Part B. Run Information

14. Date of Arrest
15. Incident #
16. Fire/First Responder — ☐ No First Responder dispatched
17. Destination Hospital

Part C. Arrest Information

18. Location Type — ☐ Home/Residence ☐ Public/Commercial Building ☐ Street/Highway ☐ Nursing Home ☐ Healthcare Facility ☐ Place of Recreation ☐ Industrial Place ☐ Transport Center ☐ Other
19. Arrest Witness Status — ☐ Unwitnessed ☐ Witnessed by Bystander ☐ Witnessed by 911 Responder
20. Presumed Cardiac Arrest Etiology — ☐ Presumed Cardiac Etiology ☐ Trauma ☐ Respiratory/Asphyxia ☐ Drowning/Submersion ☐ Electrocution ☐ Exsanguination/Hemorrhage ☐ Drug Overdose ☐ Other

Resuscitation Information

21. Resuscitation Attempted by 911 Responder (or AED shock given prior to EMS arrival) — ☐ Yes ☐ No
22. Who Initiated CPR — ☐ Not Applicable ☐ Bystander ☐ Family Member ☐ Healthcare Provider (non-911 Responder) ☐ First Responder; Did Law Enforcement initiate CPR? ☐ Yes ☐ No ☐ EMS Responder (transport EMS)
23. Type of Bystander CPR Provided — ☐ Compressions and ventilations ☐ Compressions only ☐ Ventilations only ☐ Unknown
24. Were Dispatcher CPR Instructions Provided — ☐ Yes ☐ No ☐ Unknown
25. Was an AED Applied Prior to EMS Arrival — ☐ Yes, with defibrillation ☐ Yes, without defibrillation ☐ No
26. Who First Applied the AED — ☐ Bystander ☐ Family Member ☐ Healthcare Provider (non-911 Responder) ☐ Law Enforcement First Responder ☐ Non-Law Enforcement First Responder
27. Who First Defibrillated the Patient — ☐ Not Applicable ☐ Bystander ☐ Family Member ☐ Healthcare Provider (non-911 Responder) ☐ Law Enforcement First Responder ☐ Non-Law Enforcement First Responder ☐ EMS Responder (transport EMS)
28. Did 911 Responder Perform CPR — ☐ Yes ☐ No

First Cardiac Arrest Rhythm of Patient and ROSC Information

29. First Arrest Rhythm of Patient — ☐ Ventricular Fibrillation ☐ Ventricular Tachycardia ☐ Asystole ☐ Idioventricular/PEA ☐ Unknown Shockable Rhythm ☐ Unknown Unshockable Rhythm
30. Sustained ROSC (20 consecutive minutes) or present at end of EMS care — ☐ Yes, but pulseless at end of EMS care (or ED arrival) ☐ Yes, pulse at end of EMS care (or ED arrival) ☐ No
31. Was Hypothermia Care Provided in the Field — ☐ Yes ☐ No
32. End of Event — ☐ Effort ceased due to DNR ☐ Pronounced in the Field ☐ Pronounced in the ED ☐ Ongoing Resuscitation in ED
33. When Did Sustained ROSC First Occur — ☐ Never ☐ After Bystander CPR only ☐ After Bystander defib shock ☐ After 911 Responder CPR only ☐ After 911 Responder defib shock ☐ After ALS ☐ Unknown
34. Estimated time of arrest (Hour : Minute : Second)
35. Time of 1st CPR (Hour : Minute : Second)
36. Time of 1st defibrillatory shock (Hour : Minute : Second)
37. Time of sustained ROSC (Hour : Minute : Second)
38. Time resuscitation terminated (Hour : Minute : Second)

Part D. Pre-Hospital Interventions

39. Mechanical CPR device used — ☐ Yes ☐ No; If Yes, please specify: ☐ Load Distributing Band (AutoPulse) ☐ Active Compression Decompression (LUCAS Device) ☐ Mechanical Piston ☐ Other
40. Automated CPR feedback device used — ☐ Yes ☐ No
41. Advanced airway successfully placed in the field — ☐ Yes ☐ No ☐ Used existing tracheostomy; If Yes, please specify: ☐ Combitube ☐ King Airway ☐ LMA ☐ Oral/Nasal ET ☐ Other
42. ITD used — ☐ Yes ☐ No; If Yes, select how: ☐ Bag valve mask ☐ Combitube ☐ King Airway ☐ LMA ☐ Oral/Nasal ET ☐ Other
43. Were drugs administered — ☐ Yes ☐ No; If Yes, select drugs given: ☐ Epinephrine ☐ Atropine ☐ Calcium Chloride ☐ Lidocaine ☐ Naloxone ☐ Other ☐ Amiodarone ☐ Bicarbonate ☐ Dextrose ☐ Magnesium Sulfate ☐ Vasopressin
44. Vascular access — ☐ None ☐ IV ☐ IO
45. 12 Lead — ☐ Yes ☐ No
46. STEMI — ☐ Yes ☐ No ☐ Unknown

Part E. Hospital Section

47. ER Outcome — ☐ Died in the ED ☐ Admitted to hospital ☐ Transferred to another acute care facility from the ED
48. Was hypothermia care/TTM initiated or continued in the hospital — ☐ Yes ☐ No
49. Hospital Outcome — ☐ Died in the hospital ☐ Discharged alive ☐ Patient made DNR; Choose one of the following: ☐ Died in the hospital ☐ Discharged alive ☐ Transferred to another acute care hospital ☐ Not yet determined ☐ Transferred to another acute care hospital ☐ Not yet determined
50. Discharge from the Hospital — ☐ Home/Residence ☐ Rehabilitation Facility ☐ Skilled Nursing Facility/Hospice
51. Neurological Outcome at Discharge from Hospital — ☐ Good Cerebral Performance (CPC 1) ☐ Moderate Cerebral Disability (CPC 2) ☐ Severe Cerebral Disability (CPC 3) ☐ Coma, vegetative state (CPC 4)

Hospital Procedures

52. Why was hypothermia care/TTM not initiated or continued in the hospital — ☐ Awake/Following commands ☐ DNR/Family request ☐ Unwitnessed cardiac arrest ☐ Unshockable rhythm ☐ No TH program in place ☐ Other ☐ Unknown
53. Date and Time of Discharge/Death (Hour : Minute)
54. Was the final diagnosis acute myocardial infarction — ☐ Yes ☐ No ☐ Unknown
55. Coronary Angiography Performed — ☐ Yes ☐ No ☐ Unknown; If Yes, provide date and time (Hour : Minute)
56. Was a cardiac stent placed — ☐ Yes ☐ No ☐ Unknown
57. CABG performed — ☐ Yes ☐ No ☐ Unknown
58. Was an ICD placed and/or scheduled — ☐ Yes ☐ No ☐ Unknown
59. Hospital Medical Record Number

Hospital Comments

Response and Treatment Times

	Hour	Minute	Second
60. Time call received at dispatch center			
61. Time First Responder dispatched			
62. Time First Responder en route			
63. Time First Responder arrived at scene			
64. Time Ambulance dispatched			
65. Time Ambulance en route			
66. Time Ambulance arrived at scene			
67. Time EMS arrived at patient side			
68. Time Ambulance left scene			
69. Time Ambulance arrived at ED			

General Comments

Appendix B: CARES Data Sharing Proposal Form

Thank you for your interest in the Cardiac Arrest Registry to Enhance Survival (CARES). To initiate a research project utilizing CARES data, please complete the application below and submit electronically to Rabab Al-Araji at ralaraj@emory.edu.

The proposal will be reviewed by the CARES Data Sharing Committee within 4 weeks to determine that it is scientifically sound and that the scope of the analysis is reasonable. If the committee approves the proposal:

- CARES staff will conduct a webinar to review the data elements and answer questions prior to providing the researcher with the de-identified dataset.
- The researcher must sign a Non-Disclosure Agreement stating they will not share the dataset or expand the analysis beyond the scope of the proposal.
- Abstracts for presentations at scientific meetings should be submitted within 3 months of receipt of the dataset. Abstracts must be sent to the CARES Data Sharing Committee for review 2 weeks in advance of submission.
- Publication manuscripts should be submitted within 9 months of receipt of the dataset. Manuscript drafts must be sent to the CARES Data Sharing Committee for review 4 weeks in advance of submission.

More detailed information about the CARES Data Sharing Policy and Guidelines can be found at: https://mycares.net/sitepages/datashare.jsp.

Primary Contact Information

Name: _____

Title: _____

Hospital/University/Company: _____

Street Address: _____

City, State, Zip: _____

Phone: _____

Email: _____

Project name/Working title:
Lead investigator:
Target Conference:
Target Journal:

A) Funding

Is this project funded? If yes, please review the CARES National Dataset Fee Document for more information (Appendix F).
If so, is the funding internal to your institution or externally funded?
If externally funded, what entity or organization is the source of the funding?
What is the total expected award amount?
Please include any other detail(s) that you feel is relevant:

B) Study Investigators

Name	Institution	Email (required)
1.		
2.		
3.		
4.		
5.		
6.		
7.		

8.		

C) Main objective, aim, or hypothesis

D) Background/Rationale

E) Methods

Specific outcome(s) of interest:
Explanatory variables of interest:
Study population (inclusion/exclusion criteria):

Analysis plan (*with power calculations and plans for obtaining statistical/epidemiological expertise, if relevant*):

F) Relevant references

FOR USE BY CARES:

Date submitted: CARES DSC deadline: Date approved:	**DSC Feedback/Comments:**

Appendix C: Data Sharing Checklist

- ☐ Sign CARES Non-Disclosure Agreement for Information Recipients

- ☐ Complete dataset review webinar with CARES Data Sharing Coordinator

- ☐ Submit IRB approval letter to CARES Data Sharing Coordinator within 3 months of receipt of dataset

- ☐ Send descriptive data tables to CARES Data Sharing Coordinator for review prior to further analysis

- ☐ Submit **abstracts** for presentations at scientific meetings within **3 months** of receipt of dataset
    - Send abstract to CARES for committee review *2 weeks* in advance of submission
    - Include "and the CARES Surveillance Group" in the authorship line following the individual authors
    - Include CARES logo on poster

- ☐ Submit **publication** manuscripts within **9 months** of receipt of dataset
    - Send manuscript to CARES for committee review *4 weeks* in advance of submission
    - Include "and the CARES Surveillance Group" in the authorship line following the individual authors
    - In Acknowledgements section, reference the CARES participating sites by providing the web link: https://mycares.net/sitepages/map.jsp.
    - Send to CARES for re-review if the manuscript is revised based on peer review process

- ☐ Send a copy of accepted abstract or manuscript to CARES Data Sharing Coordinator

Appendix D: Data Element Definitions

CARES Case Definition:
A CARES case is a non-traumatic out-of-hospital cardiac arrest event where resuscitation is attempted by a 911 responder (CPR and/or defibrillation). This includes patients that received an AED shock by a bystander prior to the arrival of 911 responders.

Location Type:
Type of location where the patient arrested. CARES location types are generally grouped into the following:

- Home/Residence: Home/Residence
- Nursing Home or Healthcare Facility: Nursing Home; Healthcare Facility
- Public: Public/Commercial Building; Street/Highway; Place of Recreation; Industrial Place; Transport Center; Other

Pediatric age categories:
When analyzing the pediatric CARES dataset, we recommend utilizing the following age categories:
<1 year (infants), 1-5 years (toddlers), 6-12 years (school age), and 13-18 years (adolescents).
For some studies, there may only be a small number of subjects in each group. In these cases, groups may be combined. However, infants (<1 year) should always be analyzed as a unique subgroup. Stillborn neonates/perinatal newborns born without signs of life, are not CARES cases and do not need to be entered into the registry.

Bystander - A bystander, family member, healthcare provider (non-911 responder).

First Responder – Personnel who respond to the medical emergency in an official capacity as part of an organized medical response team but are not the designated transporter of the patient to the hospital.

Emergency Medical Services (EMS) - Personnel who respond to the medical emergency in an official capacity (i.e. respond to the 911 call) as part of an organized medical response team and are the designated transporter of the patient to the hospital.

Bystander CPR – Cardiopulmonary resuscitation initiated by a bystander, family member, or healthcare provider (non-911 responder).

Bystander CPR Rate:
We recommend excluding 911 Responder witnessed events as well as those that occurred in a nursing home/healthcare setting from bystander CPR rate calculations, as these are scenarios where a trained medical professional would most likely be performing CPR.

Exclude "Arrest Witness Status = 911 Responder Witnessed" AND "Location Type = Nursing Home; Healthcare Facility" from numerator and denominator.

Numerator: Who Initiated CPR = bystander, family member, healthcare provider (non-911 responder)

AED Application:
"Was an AED applied prior to EMS arrival" denotes AED application by a lay person or First Responder prior to the arrival of EMS, regardless of whether defibrillation occurred. "Yes, with defibrillation", and "Yes, without defibrillation" are both affirmative responses to this question.

PAD Rate:
When the outcome of interest is the use of an AED by a bystander, we recommend excluding 911 Responder witnessed events as well as those that occurred in a healthcare facility or nursing home, as these are scenarios where a trained medical professional would most likely be applying an AED or monitor. AEDs are rarely used during cardiac arrests occurring in residential locations; therefore, we recommend excluding arrests that occurred in a non-public location and evaluating the public access defibrillation (PAD) rate.

Exclude "Arrest Witness Status = 911 Responder Witnessed" AND "Location Type = Nursing Home; Healthcare Facility; Home/Residence" from numerator and denominator.

Numerator: Who first applied the AED = bystander, family member, healthcare provider (non-911 responder)

Who first defibrillated the patient? – Used to determine the frequency of defibrillatory shocks among bystanders and responders. "Not Applicable" is selected when defibrillation did not occur.

First Arrest Rhythm - First cardiac rhythm present when a monitor/defibrillator or AED is attached to a patient.

Sustained ROSC - Return of Spontaneous Circulation (ROSC) is defined as the restoration of a palpable pulse or a measurable blood pressure. Sustained ROSC is deemed to have occurred when chest compressions are not required for 20 consecutive minutes and signs of circulation persist. "Yes", "Yes, but pulseless at end of EMS care", and "Yes, pulse at end of EMS care" are all affirmative responses to this question.

Survived to hospital admission - Includes patients for whom ER Outcome = Admitted to hospital.

Survived to hospital discharge - Includes patients for whom Hospital Outcome = Discharged Alive or Patient Made DNR = Discharged Alive.

Good Cerebral Performance – CPC 1; Patient is conscious, alert, able to work and lead a normal life.

Moderate Cerebral Performance – CPC 2; Patients is conscious and able to function independently (dress, travel, prepare food), but may have hemiplegia, seizures, or permanent memory or mental changes.

Utstein Patients - Those who had a bystander witnessed arrest and presented in a shockable rhythm. To view CARES Utstein patients, select the following:

- Arrest Witness Status = Bystander Witnessed
- First Rhythm Type = Shockable

Utstein Bystander Survival - Survival among patients whose cardiac arrest was witnessed by a bystander, were in a shockable rhythm, and received some bystander intervention (CPR and/or AED application).

Appendix E: CARES Database Structure

The table below includes details about the CARES dataset structure, including the data elements and responses, and relationships between CARES questions. Light grey shading indicates the supplemental/optional CARES data elements.

Header	Title on CARES Form	Responses	Description/Comments
Run ID	N/A		Unique record identifier generated by CARES software.
EMS Agency ID	N/A		Unique EMS agency identifier generated by CARES. Included in CARES dataset when needed for analysis.
Date of Arrest	Date of Arrest		
Age (Years)	Age/Age Modifier		Patient age, in years. Days and months have been converted accordingly.
Gender	Gender	Male Female Female-to-Male, Transgender Male Male-to-Female, Transgender Female Non-Binary	Transgender and Non-Binary are new answer choices as of 2021.
Race/Ethnicity	Race/Ethnicity	American-Indian/Alaskan Asian Black/African American Hispanic/Latino Native Hawaiian/Pacific Islander White Unknown	Race is "Unknown" for approximately 25% of CARES cases, due to the fact that a number of communities do not collect this information. This field changed from single- to multi-select in 2021.
Medical History	Medical History	No Unknown Cancer Diabetes Heart Disease Hyperlipidemia Hypertension Renal Disease Respiratory Disease Stroke Other	
Destination Hospital ID	N/A		Unique hospital identifier generated by CARES. Included in CARES dataset when needed for analysis.
Location Type	Location Type	Home/Residence Public/Commercial Building Street/Hwy Nursing Home Healthcare Facility Place of Recreation Industrial Place Transport Center Other	
Arrest Witness Status	Arrest Witness Status	Unwitnessed Witnessed by Bystander Witnessed by 911 Responder	
Presumed Cardiac Arrest Etiology	Presumed Cardiac Arrest Etiology	Presumed Cardiac Etiology Trauma Respiratory Drowning Electrocution Drug Overdose Exsanguination/Hemorrhage Other	From 2005-2012, CARES only required arrests of presumed cardiac etiology to be entered. In January 2013, our case definition expanded to include all non-traumatic worked arrests. Analyses using CARES data MUST include all non-traumatic etiologies. Drug Overdose and Exsanguination/Hemorrhage are new answer choices as of January 2017. Prior to this, these etiologies were coded as Other.

Header	Title on CARES Form	Responses	Description/Comments
Resuscitation Attempted	Resuscitation Attempted by 911 Responder (or AED shock given prior to EMS arrival)	Yes No	CARES requires that cardiac arrest events where resuscitation was attempted be entered into the registry. DOAs/unworked arrests are not CARES cases and are therefore removed from datasets.
Initiated CPR	Who Initiated CPR	Not Applicable Bystander Family Member Healthcare Provider (non-911 Responder) First Responder EMS Responder (transport EMS)	
Did Law Enforcement initiate CPR	Did Law Enforcement initiate CPR	Yes No	This field is applicable only if “Initiated CPR” = First Responder.
Type of Bystander CPR Provided	Type of Bystander CPR Provided	Compressions and ventilations Compressions only Ventilations only Unknown	This field is applicable only if Initiated CPR = Bystander, Family Member, or Healthcare Provider (non-911 Responder). The ‘Unknown’ answer choice was added in 2021.
Dispatcher CPR instructions provided	Were Dispatcher CPR instructions provided?	Yes No Unknown	The question is not applicable if the arrest was witnessed by a 911 Responder.
Was an AED applied prior to EMS arrival	Was an AED applied prior to EMS arrival	Yes, with defibrillation Yes, without defibrillation No	
Who First Applied the AED	Who First Applied the AED	Bystander Family Member Healthcare Provider (non-911 Responder) Law Enforcement First Responder Non-Law Enforcement First Responder	This field is applicable only if "Was an AED applied prior to EMS arrival" = "Yes with defibrillation" or "Yes without defibrillation".
Who First Defibrillated the Patient	Who First Defibrillated the Patient	Not Applicable Bystander Family Member Healthcare Provider (non-911 Responder) Law Enforcement First Responder Non-Law Enforcement First Responder EMS Responder (transport EMS)	This question includes Not Applicable as a response, for cases where no shock was given. This question is not specific to AEDs, but applies to defibrillation with any device.
Did 911 Responder perform CPR	Did 911 Responder perform CPR	Yes No	
First Monitored Rhythm	First Arrest Rhythm of Patient	Ventricular Fibrillation Ventricular Tachycardia Asystole Idioventricular/PEA Unknown Shockable Rhythm Unknown Unshockable Rhythm	First cardiac rhythm present when a monitor/defibrillator or AED is attached to a patient. Unknown Shockable or Unknown Unshockable are included for situations where the device lacked recording ability.
First Rhythm Type	N/A	Shockable Non-Shockable	Categorizes First Monitored Rhythm as Shockable (VF, VT, Unknown Shockable) or Nonshockable (Asystole, Idioventricular/PEA, Unknown Unshockable).
Sustained ROSC	Sustained ROSC (20 consecutive minutes) or present at end of EMS care	Yes Yes, but pulseless at end of EMS care Yes, pulse at end of EMS care No	

Header	Title on CARES Form	Responses	Description/Comments
When did sustained ROSC first occur	When did sustained ROSC first occur	Never After Bystander CPR Only After Bystander defib shock After 911 Responder CPR only After 911 Responder defib shock After ALS Unknown	
Was hypothermia care provided in the field	Was hypothermia care provided in the field	Yes No	
Mechanical CPR device Used	Mechanical CPR device Used	Yes No	
Mechanical CPR device Used detail	If "Yes", please specify:	Load-Distributing Band (AutoPulse) Active Compression Decompression (LUCAS Device) Mechanical Piston Other	Applicable when Mechanical CPR device Used = Yes.
Automated CPR feedback device used	Automated CPR feedback device used	Yes No	
Advanced Airway successfully placed in the field	Advanced Airway successfully placed in the field	Yes No Used existing tracheostomy	The 'Used existing tracheostomy' answer choice was added in 2021. This field also changed from single- to multi-select in 2021.
Advanced Airway detail	If "Yes", please specify:	Combitube King Airway LMA Oral/Nasal ET Other	Applicable when Advanced Airway successfully placed in the field = Yes.
ITD Used	ITD Used	Yes No	
ITD Used detail	If "Yes", please specify:	Bag valve mask Combitube King Airway LMA Oral/Nasal ET Other	Applicable when ITD Used = Yes.
Were drugs administered	Were drugs administered	Yes No	
Drugs administered detail	If "Yes", please specify:	Epinephrine Atropine Amiodarone Bicarbonate Calcium Chloride Dextrose Lidocaine Magnesium Sulfate Naloxone Vasopressin Other	Applicable when Were drugs administered = Yes. The Calcium Chloride and Magnesium Sulfate answer choices were added in 2021.
Vascular access	Vascular access	None IV IO	
12 Lead	12 Lead	Yes No	

Header	Title on CARES Form	Responses	Description/Comments
STEMI	STEMI	Yes No Unknown	
End Of The Event	End Of The Event	Dead in Field Pronounced Dead in ED Effort Ceased due to DNR Ongoing Resuscitation in ED	CARES does not require that field DNRs be entered into the registry. DNRs are not CARES cases and are therefore removed from datasets.
Emergency Room Outcome	Emergency Room Outcome	Died in the ED Admitted to hospital Transferred to another acute care facility from the ED	This is the second data element which can indicate that the patient died in the ED (see "End of the Event"). If patient was admitted to the hospital, the following hospital questions (Hypothermia Care & Hospital Outcome) are applicable.
Survived to Hospital Admission	N/A	Yes No Missing	This data element indicates whether the patient survived to hospital admission, and maps responses from "End of the Event" and "ER Outcome".
Hospital Outcome	Hospital Outcome	Died in the hospital Discharged Alive Patient made DNR Transferred to another acute care hospital Not yet determined	If the patient died in the hospital, the record is complete. If they are "Discharged Alive" then the following hospital questions (Discharge from the Hospital and Neuro Outcome) are applicable.
Patient made DNR outcome	Patient made DNR outcome	Died in the hospital Discharged Alive Transferred to another acute care hospital Not yet determined	If "Hospital Outcome = Patient made DNR", then the hospital user is prompted to enter the final patient outcome from a drop-down menu.
Survived to Hospital Discharge	N/A	Yes No Missing	This data element indicates whether the patient survived to hospital discharge, and maps responses from "Survived to Hospital Admission", "Hospital Outcome", and "Patient made DNR Outcome".
Discharge From The Hospital	Discharge From The Hospital	Home/Residence Rehabilitation Facility Skilled Nursing Facility/Hospice	
Neurological Outcome	Neurological Outcome at Discharge from Hospital	Good Cerebral Performance (CPC1) Moderate Cerebral Disability (CPC2) Severe Cerebral Disability (CPC3) Coma, vegetative state (CPC4)	
CPC Score	N/A	CPC 1/2 CPC 3/4 Missing	This data element maps neurological outcome to CPC Score, grouping CPC 1 and 2, and CPC 3 and 4. We recommend that CPC 1 and 2 be grouped together as a positive neurological outcome.
Hospital - Was hypothermia care/TTM initiated/continued	Was hypothermia care initiated or continued in the hospital	Yes No	This field is applicable only if ER Outcome = Admitted to hospital.
Original Emergency Room Outcome	N/A		
Transfer Hospital ID	N/A		Unique transfer hospital identifier generated by CARES. Included in CARES dataset when needed for analysis.
Hospital (Trans) - Was hypothermia care initiated/continued	N/A		This field is applicable only if the patient was transferred and admitted to a secondary receiving facility.

Header	Title on CARES Form	Responses	Description/Comments
Why was hypothermia care not initiated or continued in the hospital?	Why was hypothermia care not initiated or continued in the hospital?	Awake/Following commands DNR/Family request Unwitnessed cardiac arrest Unshockable rhythm No TH program in place Other	This supplemental hospital element was added in 2016.
Date of Discharge/Death	Date and time of Discharge/Death	MM/DD/YY	This supplemental time stamp was added in 2018.
Time of Discharge/Death	Date and time of Discharge/Death	HH:MM	This supplemental time stamp was added in 2018.
Final Diagnosis Myocardial Infarction	Was the final diagnosis acute myocardial infarction	Yes No Unknown	
Coronary Angiography Performed	Coronary Angiography Performed	Yes No Unknown	
Coronary Angiography Date	If "Yes", please provide date and time:	MM/DD/YY	This field is applicable only if Coronary Angiography Performed = Yes.
Coronary Angiography Time	If "Yes", please provide date and time:	HH:MM	This field is applicable only if Coronary Angiography Performed = Yes.
Was a cardiac stent placed	Was a cardiac stent placed	Yes No Unknown	
CABG Performed	CABG Performed	Yes No Unknown	
ICD placed and/or scheduled	Was an ICD placed and/or scheduled	Yes No Unknown	
Estimated Time Of Arrest	Estimated Time Of Arrest	HH:MM:SS	
Time of 1st CPR	Time of 1st CPR	HH:MM:SS	
Time of 1st Defibrillation	Time of 1st Defibrillatory Shock	HH:MM:SS	
Time of sustained ROSC	Time of sustained ROSC	HH:MM:SS	This supplemental time stamp was added in 2021.
Time Resuscitation Terminated	Time resuscitation terminated	HH:MM:SS	This supplemental time stamp was added in 2021.
Call Received At Dispatch Center	Time call received at dispatch center	HH:MM:SS	
FR Dispatched	Time First Responder dispatched	HH:MM:SS	
FR En Route	Time of First Responder en route	HH:MM:SS	
FR On Scene	Time First Responder arrived at scene	HH:MM:SS	
Ambulance Dispatched	Time Ambulance dispatched	HH:MM:SS	
Ambulance En Route	Time for Ambulance en route	HH:MM:SS	
Ambulance On Scene	Time Ambulance arrived at scene	HH:MM:SS	
EMS At Patient Side	Time EMS arrived a patient's side	HH:MM:SS	
Ambulance Left Scene	Time Ambulance left scene	HH:MM:SS	
Ambulance Arrived At ED	Time Ambulance arrived at ED	HH:MM:SS	

Appendix F: National Dataset Fee FAQ

Fees of Accessing the CARES National Dataset
FAQ

Overview

- As of January 2020, new research projects that receive funding from external sources will be charged a data fee for accessing the national dataset.
- The intent of this fee is not to inhibit access to the CARES national dataset. However, when external funds are awarded for a study, that CARES can recoup some of its costs in supporting the research process

What projects are charged a fee?

- There is no charge to access the CARES National Dataset if the research or study is funded from internal sources at the researcher's institution.
- CARES charges 5% of the total project award amount when the research or study is funded from sources external to the researcher's institution.
- Examples of external funding sources include but are not limited to:
    - The National Institutes of Health
    - Agency for Healthcare Research and Quality
    - American Heart Association
    - Industry

How do I notify CARES of my project receiving/not receiving funding?

- The CARES National Data Sharing application includes questions pertaining to the funding status of the study. Please complete the application as accurately as possible.
- If the funding status changes after the application is completed and submitted to CARES, please notify the CARES Epidemiologist, Rabab Al-Araji (rabab.al-araji@emory.edu) as soon as possible.

What happens if my project receives an extension?

- If your project receives an extension and is externally funded, a 5% fee will be charged to the additional award amount.

How do I make a payment to CARES?

- Once CARES is notified that a project is externally funded, CARES will request that the below information be completed.
    - Invoice Information:
        - Researcher Name:
        - Project Name:
        - Funding Source:
        - Total Award Amount:
        - Primary Invoice Contact Name:
            - Email:
            - Phone
        - Secondary Invoice Contact Name:
            - Email:
            - Phone:
        - Physical Address
- As soon as this information is submitted to CARES, an invoice will be generated and returned to the researcher. CARES asks that payment via check be received within 30 days.

Additional Questions?

- Please contact:
    - CARES Epidemiologist, Rabab Al-Araji, MPH (rabab.al-araji@emory.edu)