





PENNSYLVANIA CARES

This tool kit is free to EMS Agencies interested in implementing the Pennsylvania CARES program. The materials have been developed to provide step-by-step instructions for implementing a program and useful materials to assist you in that process. This and other toolkits may also be found at http://mycares.com

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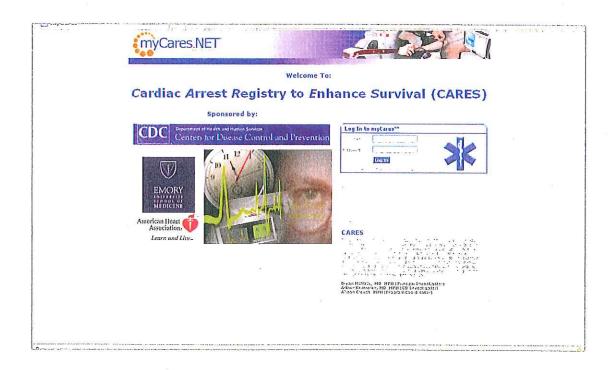


Pennsylvania CARES Overview

An ongoing registry of cardiac arrest is the major tool to improve cardiac arrest survival. While cardiac arrest resuscitation comprises only a small fraction of all EMS calls, such events are an excellent surrogate to quantify overall EMS system performance. Cardiac arrest activates the entire EMS system, from community bystanders through hospital care. The tools in this kit will enable an individual agency to be enrolled in the Cardiac Arrest Registry to Enhance Survival (CARES) and begin surveillance of out-of-hospital cardiac arrest and EMS performance.

The goal of the CARES program is to establish a model for unifying all essential data elements to evaluate care for out-of-hospital cardiac arrest. The CARES system builds this model by working with EMS agencies, hospitals, and computer aided dispatch (CAD) systems. These sources enable efficient data collection that is essential for improving cardiac arrest care. The collection and reporting system is provided by a restricted-access, secure, internet database developed by Sansio/Scanhealth, Inc. and managed locally by CARES program staff. All participants can view their own statistics and de-identified, community-aggregate statistics.

Pennsylvania CARES is 1 of 7 sites in a national effort to monitor cardiac arrest and improve survival. Thanks to a grant from the Medtronic Foundation, Pennsylvania is launching a statewide effort to collect OHCA data using the CARES platform modified for each state. This will be referred to as Pennsylvania CARES.



Introduction

Upwards of 350,000 persons suffer out-of-hospital cardiac arrest (OHCA) and receive attempted resuscitation each year in the United States, making OHCA a leading cause of death among adults.

Nationally, few communities actively monitor and report their survival rates from OHCA. The range of survival in these communities for ventricular fibrillation is anywhere from 2% to 50%. This difference is striking since the approach to the care of these patients is uniform and there is no evidence that patients in one part of the country are different biologically from another.

The **CARES** (Cardiac Arrest Registry to Enhance Survival) Program is a collaborative effort to reduce mortality and improve care. Using the Utstein style of statistics for OHCA, **CARES** is capable of identifying and tracking all cases of cardiac arrest in a defined geographic area. The ultimate goals of **CARES** is to help local EMS administrators and medical directors identify who is affected, when and where cardiac arrest events occur, which elements of the system are functioning properly, which elements need more work, and how changes can be made to improve emergency cardiac care, and in turn cardiac arrest outcomes.

CARES is a secure, Web-based data management system in which participating communities enter local data and generate their own reports. This reduces time involved in registering events, tracking patient outcomes with hospitals, and calculating response intervals. Multiple reporting features can be generated and monitored continuously through secure online access by **CARES** participants and allow for longitudinal, internal benchmarking.

Presently, the odds of surviving an episode of out-of-hospital cardiac arrest in the United States vary by a factor of 10 to 20, depending on the community in which it occurs. Such extreme disparities indicate a real opportunity to increase survival by identifying specific areas where care can be improved. **CARES** enables communities to rigorously assess all aspects of OHCA care. Just as important, CARES enables a community or system to track changes in care so that effective progress can be measured.

Please refer to the **CARES** website (https://mycares.net) for additional program information. Contact the **Pennsylvania CARES** coordinator for additional information: Kathryn.Tucker@uphs.upenn.edu or call # (215) 746-4630

Key Players

Any **EMS agency**-public and private-that transports a CA patient



Communication Centers



Hospitals



Resources needed: computer and internet



EMS Agencies

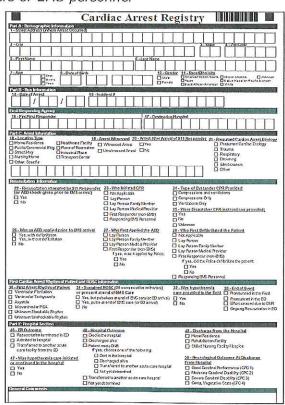
Working with CARES staff, EMS agencies develop an all-inclusive plan for identifying cardiac arrest in their system. Because each system is unique it is necessary to brainstorm methods for identification of each and every cardiac arrest.



Inclusion criteria:

- Out-of-Hospital non-traumatic cardiac arrest
- Patient assessed by organized EMS personnel
- Patient received either:
 - o External defibrillation by lay responders or EMS personnel
 - Chest compression by EMS personnel

These criteria identify which events initiate a CARES entry. Typically 1-2 people at each agency assure case identification and data entry. Data entry is supported by a complete data dictionary. The CARES Coordinator is available for support and troubleshooting. Data are submitted via desktop data entry or batch uploads.

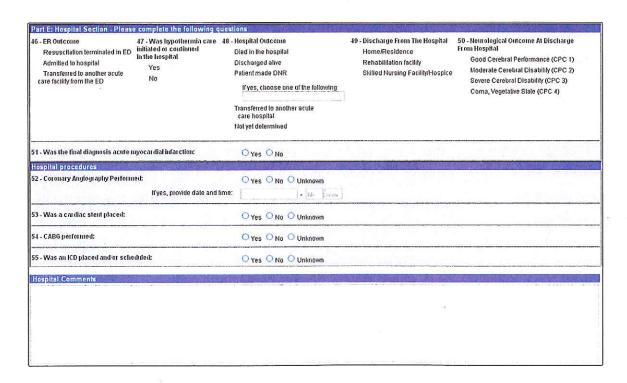


Hospitals

A professional and collaborative relationship with the hospital is an important component because it enables complete follow-up of patients transported to the hospital. Communication with the hospital orients them to the project and CARES website, addresses any HIPAA concerns, and defines the plan for coordinated follow-up. An automatic email to the hospital contact is generated when a case is entered into CARES as arriving at the hospital.

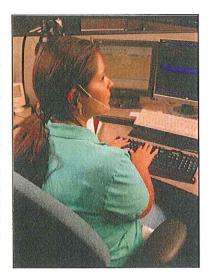


The hospital contact is a key person identified at each local receiving hospital and has their own log-on to the CARES website. The hospital contact logs into the website periodically, typically weekly or monthly, to view cases requiring follow-up. Hospital contacts only access patients that have been transported to their facility. Patient identifiers are a needed component for hospitals to identify patients needing follow-up. Hospital questions include emergency department outcome, disposition location, important procedures and interventions, and neurological status at time of discharge using the Cerebral Performance Category Score. Completion of the CARES information requires only a few minutes for patients who die in the hospital and a few additional minutes for those who survive. CARES staff is available to work with hospital to explain the activity and help address challenges in finding patients and entering outcomes.



CAD System

Successful resuscitation depends in part on timely care. Accurate measures of when care is delivered is critical to understanding patient outcome. Different systems have different sources to capture clock times. Sometimes these times are available from EMS, other times through the use of computer-aided dispatch (CAD). The CAD information can assure accurate times corresponding to the atomic, universal clock. This information can be available through paper records or may be electronically exported/imported to EMS and even to the CARES website. CAD records are matched to a case based on date, approximate time, location, all event information identified by EMS during the initial CARES report. CARES staff works with each agency to help identify the best approach to capture essential time elements.



Response and Treatment Times		
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Time Ambulance dispatched	hly mto	
Time for Ambulance en route	[hh][mm][::	
Time First responder arrived at scene	Taka marriar 155	
Time Ambulance arrived at scene	hh lim les	
Time EMS arrived at patient side	tib (mm) es	
Time Ambulance left scene	hh mm s	
Time Ambulance arrived at ED	lih mm is	

What about HIPAA?



- The CARES system uses a secure Web database with restricted access for authorized users.
- Has software that collects and links data sources to create a single de-identified record for each event.
- Uses a simple HIPAA-compliant methodology to protect confidentiality.
- CARES is a public health activity as described by 45 CFR § 164.512(b) and is authorized by sections 301(a) and 317(k)(2) of the Public Health Service Act.
- The CDC considers this to be a quality improvement intervention and public health surveillance activity, for which disclosure of protected health information by covered entities is authorized by 45 CFR § 164.512(b) of the Privacy Rule.
- When the case has been audited and is free from any errors or questions, identifiers are then 'scrubbed' from the case by CARES staff.

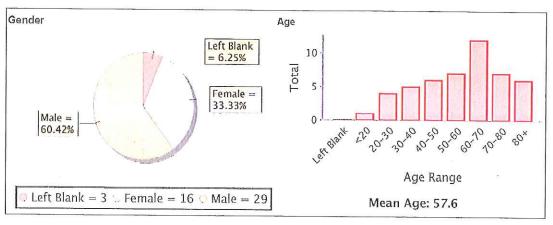
In conclusion: CARES is HIPAA compliant.

Review

The CARES database allows for real time self made reporting features. CARES cases are audited individually and manually to ensure accuracy and data integrity. CARES staff will work with Agency personnel to assure a constructive, positive process.

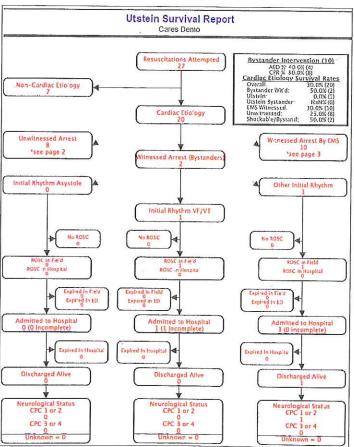
Reporting features can then be used to develop system improvement. Data are to six and the days of the day

Reporting features can then be used to develop system improvement. Data can be filtered and compiled in many different ways to create meaningful reports.



Reports

Utstein is the recognized international standard for reporting out-of-hospital cardiac arrest survival. The Utstein recommendations are an attempt to develop and present consensus definitions so that systems can reasonably assess their performance and identify areas for improvement.



Steps for Implementation

- Contact Pennsylvania CARES Coordinator: Kat Tucker at Kathryn.Tucker@uphs.upenn.edu or (215) 746-4630
- Identify all EMS agencies that care for and/or transport cardiac arrests among that geographic area.
- · Identify all receiving hospitals.
- Complete EMS Agency Application the CARES Coordinator can help.
- Communicate and work with system stakeholders, such as CAD, ambulance companies, hospitals, medical directors, etc.
- The PA CARES Coordinator will work with you to:
 - Approach local hospitals to inform them of CARES and seek buy-in.
 - Identify a contact person at each hospital.
 - Set up a log-in for data entry personnel, any one needing access to reports, and hospital contacts. Each person will have a log-in unique to their needs (i.e. data entry only, reports only, hospital only).
 - A mechanism and plan to obtain 100% case identification.
 - Set a start date to begin entering cases.
- Begin entering cases. As cases accrue begin running reports ...

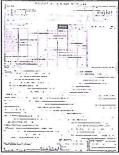


Case Timeline Example Case of a Cardiac Arrest

Step 1- Cardiac Arrest event occurs in the field and receives care by EMS personnel.



Step 2- EMS agency collects incident report forms and patient care records from the EMTs and Paramedics that responded and treated the patient. EMS-liaison, identified data entry person, gathers this information along with CAD times.



Step 3- Necessary information is completed on the CARES paper form and data is entered into mycares.net. When the patient is transported to the hospital, the receiving hospital is chosen from the drop down list. An automatic email is sent to the hospital's CARES contact.



Step 4- For patients transported, the hospital's CARES contact logs in to CARES, identifies the patient based on identifiers provided by EMS, reviews the medical record, and answers the questions related to the hospital care and outcome of the patient.

Note: Step 4 does not occur when the patient dies in the field and does not require any hospital information.



Step 5- The case is audited by CARES. When all of the information is complete, is logical, and there are no further questions, the case is then 'scrubbed' of all identifiable data. This data will now be included in regional and national reports.



Articles

The following is a proof-of-concept article for the CARES system and can be used as a resource regarding the rationale, design, and scope of CARES.

EMERGENCY MEDICAL SERVICES/CONCEPTS

CARES: Cardiac Arrest Registry to Enhance Survival

From the Department of Emergency Medicine, Emory University School of Medicine, Atlanta, GA.

Bryan McNally. MD, MPH
Allen Stokes, BS, EMT-P
Allison Crouch, MPH
Arthur L. Kellermann, MD, MPH
For the CARES Surveillance
Group*

Despite 3 decades of scientific progress, rates of survival from out-of-hospital cardiac arrest remain low. The Cardiac Arrest Registry to Enhance Survival (CARES) was created to provide communities with a means to identify cases of out-of-hospital cardiac arrest, measure how well emergency medical services (EMS) perform key elements of emergency cardiac care, and determine outcomes through hospital discharge. CARES collects data from 3 sources—911 dispatch. EMS, and receiving hospitals—and links them to form a single record. Once data entry is completed, individual identifiers are stripped from the record. The anonymity of CARES records allows participating agencies and institutions to compile cases without informed consent. CARES generates standard reports that can be used to characterize the local epidemiology of cardiac arrest and help managers determine how well EMS is delivering out-of-hospital cardiac arrest care. After pilot implementation in Atlanta, GA, and subsequent expansion to 7 surrounding counties, CARES was implemented in 22 US cities with a combined population of 14 million people. Additional cities are interested in joining the registry. CARES currently contains more than 13,000 cases and is growing rapidly. [Ann Emerg Med. 2009;54:674-683.]

Provide feedback on this article at the journal's Web site, www.annemergmed.com.

0196-0644/\$-see front matter Copyright © 2009 by the American College of Emergency Physicians. doi:10.1016/j.annemergmed.2009.03.018

Letters of Support



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control

October 20, 2008

To Whom it May Concern:

The Centers for Disease Control and Prevention (CDC) is an agency of the Department of Health and Human Services and is a public health authority as defined by the Health Insurance Portability and Accountability Act (HIPAA), Standards for Privacy of Individually Identifiable Health Information; Final Rule (Privacy Rule)[45 CFR § 164.501]. Pursuant to 45 CFR § 164.512(b) of the Privacy Rule, covered entities may disclose protected health information to public health authorities "... authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to. the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions " The definition of public health authority includes " . . . an individual or entity acting under a grant of authority from or contract with such public agency . . . " [45 CFR § 164.501]. The Section of Prehospital and Disaster Medicine in the Department of Emergency Medicine at the Emory University School of Medicine (Emory) is acting under a cooperative agreement with the CDC to carry out the CARES (Cardiac Arrest Registry to Enhance Survival) Program. The purpose of the CARES Program is to help local communities identify and track cases of cardiac arrest and identify opportunities for improvement in the treatment of out-of-hospital cardiac arrest. Through this grant of authority, Emory may function as a public health authority under the Privacy Rule for purposes of this project.

CARES is a public health activity as described by 45 CFR § 164.512(b) referenced previously and is authorized by sections 301(a) and 317(k)(2) of the Public Health Service Act. The information being requested represents the minimum necessary to carry out the public health purposes of this project pursuant to 45 CFR § 164.514(d) of the Privacy Rule. The Privacy Rule provides that covered entities "... may rely, if such reliance is reasonable under the circumstances, on a requested disclosure as the minimum necessary for the stated purposes when making disclosures to public officials that are permitted under 45 CFR § 164.512, if the public official represents that the information requested is the minimum necessary for the stated purposes(s)."

The Principal Investigator for the CARES Program is Dr. Bryan McNally at the Emory University School of Medicine. If you have questions or concerns please contact Dr Bryan McNally at bmcnall@emory.edu or call 404-712-2772.

Sincerely,

Paula W. Yoon Paula W. Yoon, ScD, MPH

Division for Heart Disease and Stroke Prevention Centers for Disease Control and Prevention



Centers for Disease Control

October 20, 2008

Bryan McNally, MD, MPH
Assistant Professor of Emergency Medicine
Section of Prehospital and Disaster Medicine
Department of Emergency Medicine
Emory University School of Medicine
531 Asbury Circle – Annex, Suite N340
Atlanta, Georgia 30322

Dear Dr McNally:

This letter serves as verification of a grant of authority from the Centers for Disease Control and Prevention (CDC) for you to conduct the public health activities described here, acting as a public health authority pursuant to the Standards for Privacy of Individually Identifiable Health Information promulgated under the Health Insurance Portability and Accountability Act (HIPAA) [45 CFR Parts 160 and 164)]. Under this rule, covered entities may disclose, without individual authorization, protected health information to public health authorities "... authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions ... "The definition of a public health authority includes "... an individual or entity acting under a grant of authority from or contract with such public agency"

The Section of Pre-hospital and Disaster Medicine in the Department of Emergency Medicine at the Emory University School of Medicine is acting under a cooperative agreement with the CDC to conduct the CARES (Cardiac Arrest Registry to Enhance Survival) Program which is authorized by sections 301(a) and 317(k)(2) of the Public Health Service Act. The purpose of the CARES Program is to help local communities identify and track cases of cardiac arrest and identify opportunities for improvement in the treatment of out-of-hospital cardiac arrest. The CDC grants this authority to Emory University School of Medicine for purposes of this project. Further, the CDC considers this to be a quality improvement intervention and public health surveillance activity, for which disclosure of protected health information by covered entities is authorized by 45 CFR § 164.512(b) of the Privacy Rule.

Sincerely,

Paula W. Yoon, ScD, MPH

Paula W. yosh

Division for Heart Disease and Stroke Prevention Centers for Disease Control and Prevention



November 21, 2011

To Whom It May Concern:

The mission of the Pennsylvania HeartRescue Project is to improve survival in Pennsylvania from out-of-hospital cardiac arrest by 50 percent over the next five years by developing a statewide infrastructure to provide state-of-the-art care at the scene, en route to the hospital and in the hospital. Saving lives is the central objective of the PA Department of Health and the HeartRescue Project.

No data or information submitted by participating EMS Agencies and hospitals will be used in the future for purposes other than improving care for cardiac arrest victims. The HeartRescue Project is prohibited from utilizing any data for assessment or analysis of individual personnel or department performance.

The HeartRescue Project will collect data in collaboration with an established data collection system, the Cardiac Arrest Registry to Enhance Survival (CARES) registry. The Pennsylvania Department of Health in coordination with the and Bureau of Emergency Medical Services is supportive of the CARES registry and the HeartRescue Project as a public health program and is exempt from HIPAA regulations.

"The Privacy Rule permits covered entities to disclose Public Health Information, without authorization, to public health authorities or other entities who are legally authorized to receive such reports for the purpose of preventing or controlling disease, injury, or disability ([45 CFR 164.512(b)]; [45 CFR 164.512(b)(1)(iii)]; [45 CFR 164.512(b)(1)(ii)])".

Data will be entered into the secure Cardiac Arrest Registry to Enhance Survival (CARES) database, sponsored by the Centers for Disease Control, the American Heart Association and Emory University, by each participating EMS Agency and hospital. All data will be managed and maintained by each CARES site and the designated Pennsylvania CARES State Coordinator(s).

Data entered into the CARES registry and audited is aggregated so that individual protected health information and provider information is not available. The data maintained for the HeartRescue Project have been identified as confidential data and is not available to the public. Only de-identified information will be reported.

Bureau of EMS | Room 606 Health & Welfare Bldg | 625 Forster Street | Harrisburg, PA 17120-0701

PA Heart Rescue Project

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The Pennsylvania Department of Health supports the HeartRescue Project and the data collected through the CARES registry. We encourage you to participate in this important initiative to improve health and clinical outcomes in the State of Pennsylvania and our nation. Thank you for your commitment to emergency health care in our Commonwealth and its citizens.

Sincerely,

Martin Raniowski
Deputy Secretary for
Health Planning
and Assessment

Sincerely,

Douglas Kupas, MD Commonwealth EMS Medical Director Sincerely,

Joseph W. Schmider, Director Bureau of Emergency Medical Scrvices

Notes

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