Cardiac Arrest Registry to Enhance Survival (CARES)

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INTRODUCTION

Out-of-hospital cardiac arrest (OHCA) is the leading cause of death among adults in the United States and Western countries. It is estimated that approximately 400,000 deaths occur every year. Most of these deaths are due to a fatal heart rhythm disturbance called ventricular fibrillation. Nationally, only about 35 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 35%, a striking difference, 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 of the Centers for Disease Control and Prevention (CDC), the American Heart Association (AHA) and the Emory University Department of Emergency Medicine, Section of Prehospital and Disaster Medicine. The CDC and the AHA are working together to reduce the death rate from heart disease and stroke by 25% from the years 2000-2010. One of the CDC’s initiatives is to develop a model national registry to accurately measure our progress in the treatment of OHCA.

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 and which elements are not, and how changes can be made to improve cardiac arrest outcomes. CARES utilizes an internet database system that reduces time involved in registering events, tracking patient outcomes with hospitals, and response intervals associated with First Responder and EMS response. 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. Disparities in outcome this extreme are unacceptable and are what the CARES project will be able to identify and allow communities to improve upon. As more communities participate in CARES, confidential, external benchmarking can occur between similar systems across the United States. CARES is expanding to several other cities within the next year. These cities include Atlanta (GA) - including Georgia EMS Region III, Kansas City (MO), Anchorage (AK), Raleigh-Durham (NC), Austin and Houston (TX), Cincinnati and Columbus (OH), Nashville (TN), Louisville (KY), Boston (MA), Tucson (AZ), and San Francisco (CA).

The CARES Reference Manual provides a comprehensive review of the implementation, operations, and reporting of CARES. Please use this manual as a resource and guide for furthering your understanding of CARES, and please do not hesitate to contact the CARES staff for additional questions and updates.

Thank you for your interest in the CARES Program and your consideration of participating in the program in an effort to improve out-of-hospital cardiac arrest survival in your community. Please visit https://mycares.net for more information.
Cardiac Arrest Registry to Enhance Survival (CARES)
OPERATIONAL OVERVIEW

**Overview**
The goal of the CARES program is to establish a model of unifying all essential data elements from three, independent sources, which currently record fractured data of a single, cardiac arrest event. The CARES system is building this model by establishing a relationship with emergency medical services (EMS) agencies, hospitals, and computer-aided dispatch (CAD) systems. Through these sources, access to specific data elements and participation allow for understanding of data flow and the ability to develop an efficient and automatic data collection and outcome reporting system. The collection and reporting system is provided by a restricted-access, secure, internet database developed by Sansio/Scanhealth, Inc. and managed locally by the CARES program staff. All participants can view their individual statistics and de-identified, community-aggregate statistics.

**EMS agencies**
EMS providers initiate a CARES event based on criteria set forth initially by the project coordinator and the data dictionary. A contact person at each EMS agency (CARES liaison) ensures adherence to the criteria and provides routine communication with the project coordinator for issues, concerns, and questions. The data can be submitted in three ways: completion of the CARES form, direct entry into the website database, or exporting electronic data from field software programs.

**Hospitals**
Hospitals receive notification to provide outcome data through an email, which is automatically generated by the database. These four basic questions include emergency department outcome, hospital outcome, disposition location, and neurological status at time of discharge. Through establishing a relationship with the hospital, orientation to the project and website was conducted, HIPAA concerns were addressed, and adequate identification of patients within their system was obtained.

**CAD system**
CAD data is collected through automatic export/import and/or direct entry into the website database. Once contact and agreement is made with each CAD system administrator, three time elements (Call Received, Dispatch, and Arrival) for the EMS and First Responder are sent and/or entered after matching the event based on date, approximate time, and location of the event. In various combinations, multiple CAD systems provide response times for EMS and First Responders. All event and First Responder information is identified by EMS during the initial CARES report.

**Review**
The CARES database is monitored daily by the project staff, which continues to address key issues. These include CARES form and dictionary revisions for EMS and hospital users, updates in website data entry and report formats, identifying and meeting with additional communities for program participation, summary analysis of pitfalls and solutions for project ‘tool kit’, and advising agencies with system improvement in areas related to the CARES program.
Importance of Data Elements and Linkage to CARES

CAD System
- Provides accurate response intervals by using:
  - 911 Call Received
  - First Responder dispatch
  - EMS dispatch
  - First Responder arrival
  - EMS arrival

EMS
- Likely phase of survival
- Date and time of event
- Location type
- Bystander interventions
- Etiology of event
- Rhythm analysis (Utstein)
- IDs CAD, First Resp, and Hospitals involved w/ event

Patient Care Report
- Optically scannable form*
- Desktop data entry
- Laptop electronic patient care report entry **

Hospital
- Survival to Discharge
- Report transferred patients
- Neurological status

CARES Event
- Cardiac Arrest
- Integrates each identified occurrence
- Streamlines data collection process
- Provides meaningful outcome statistics in report format
- Reports include survival rates, demographics, response times and bystander intervention
- Allows for both confidential internal/external benchmarking
- Query tool to ensure compliance with data reporting methods

Computer Interface
- Manual entry
- Automatic computer entry by data extract

* Scannable form self populates the registry
** Direct interface between electronic patient care report and CARES registry
Administrators of the CARES program have Agency, Regional, and/or Aggregated data. May "Message" other users securely within the site.
Welcome To:

Cardiac Arrest Registry to Enhance Survival (CARES)

Sponsored by:

CDC
Department of Health and Human Services
Centers for Disease Control and Prevention

Emory University School of Medicine
American Heart Association

Log In to myCares™

Username: 
Password: 
Log In

Did you forget your password?

More information on CARES

CARES

The Cardiac Arrest Registry to Enhance Survival (CARES) was initiated in October 2004 as a cooperative agreement between the Center for Disease Control and Prevention (CDC) and the Department of Emergency Medicine at Emory University School of Medicine to identify incidents of prehospital cardiac arrest. The CARES Program is designed to consolidate all essential data elements of a prehospital cardiac arrest event in an efficient manner. With this standardized collection system, participants can track ongoing system performance in several, tailored reports. If you have any questions about this program, please send an email to cares@emory.edu.
# Cardiac Arrest Registry

## Part A: Non - HealthEMS™ Users start here, otherwise skip to part B

1. **First Responding Agency**
2. **Hospital Destination**
3. **Dispatch Times**

### Arrest Information

<table>
<thead>
<tr>
<th>Location Type</th>
<th>Walters Witnessed</th>
<th>Arrest After Arrival of EMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home/Residence</td>
<td>Witnessed Arrest</td>
<td>Yes</td>
</tr>
<tr>
<td>Public Building</td>
<td>Unwitnessed Arrest</td>
<td>No</td>
</tr>
<tr>
<td>Street/Hwy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Farm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mine/Quarry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Industrial Place</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician Office/Clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jail</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational Inst.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Arrest Information

<table>
<thead>
<tr>
<th>Time of 1st CPR</th>
<th>Time of ROSC</th>
<th>CPR Stopped/Termination Time</th>
<th>Time of 1st Defibrillation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Resuscitation Information

<table>
<thead>
<tr>
<th>Was an AED Used During Resuscitation</th>
<th>Who First Applied Monitor/Defibrillator, AED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>No</td>
<td>Bystander</td>
</tr>
<tr>
<td>AED Present but not Used</td>
<td>Bystander Family Member</td>
</tr>
<tr>
<td>AED Malfunctioned</td>
<td>First Responder Fire/Police AED</td>
</tr>
</tbody>
</table>

### First Cardiac Arrest Rhythm of Patient and ROSC Information

<table>
<thead>
<tr>
<th>First Arrest Rhythm of Patient</th>
<th>ROSC</th>
<th>Out of Hospital Disposition</th>
<th>End of the Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventricular Fibrillation</td>
<td>Yes</td>
<td>Resuscitation not initiated</td>
<td>Dead in Field</td>
</tr>
<tr>
<td>Ventricular Tachycardia</td>
<td>No</td>
<td>at scene due to obvious</td>
<td>Pronounced Dead in ED</td>
</tr>
<tr>
<td>Asystole</td>
<td></td>
<td>signs of death, DNR,</td>
<td>Ongoing Resuscitation in ED</td>
</tr>
<tr>
<td>Idioventricular/PEA</td>
<td>Yes</td>
<td>resuscitation considered</td>
<td></td>
</tr>
<tr>
<td>Unknown Shockable Rhythm</td>
<td>No</td>
<td>futile, or resuscitation</td>
<td></td>
</tr>
<tr>
<td>Unknown Unshockable Rhythm</td>
<td></td>
<td>is not required</td>
<td></td>
</tr>
</tbody>
</table>

### First Cardiac Arrest Rhythm Strip (Apply with ScotchTape on Top and Sides)
Demographics
Sample Data

Gender
Male = 63.64%
Female = 36.36%

Age
Age Range
Mean Age: 62.4

Location Type | Count
---|---
Home/Residence | 106 - 68.8%
Hospital | 17 - 11.0%
Other | 8 - 5.2%
Public Building | 8 - 5.2%
Street/Hwy | 7 - 4.5%
Educational Institution | 4 - 2.6%
Nursing Home/Assisted Living Center | 3 - 1.9%
Recreation/Sport Facility | 1 - 0.6%
911 to EMS Dispatch
Sample Data

Run Volume

Response Time (Min.)

Unknown = 12

> 90 Sec = 10

<= 90 Sec = 118

<= 90 Sec = 118  > 90 Sec = 10
Unknown = 12
When Atlanta's emergency medical system needed rescuing, Mayor Shirley Franklin started performing CPR — in more ways than one.

In 2003, she started issuing orders that have resulted in lifesaving changes to Atlanta's emergency system. She began looking for ways to hold emergency crews more accountable, and last year she ordered all 8,000 city employees — including herself — to be trained in cardiopulmonary resuscitation.

"All you need to do is save one life and it's worth it," Franklin says. "It's miraculous."

Thanks to those efforts and a program created in Atlanta by Emory University and the Centers for Disease Control and Prevention, the city is saving more residents who collapse of sudden cardiac arrest. Since September 2005, the survival rate for such patients in Atlanta has jumped from less than 3% to 15%. That's well above the 6% to 10% survival rate for most cities that was identified in a 2003 analysis by USA TODAY.

Atlanta's success has made it, and the program it's following, a template for cities trying to improve cardiac-arrest survival rates, an often murky set of figures complicated by communication problems among government agencies.

Several cities — including Houston, Anchorage, Austin, Cincinnati, Kansas City, Mo., Raleigh, N.C., and Tucson — are following in Atlanta's footsteps by signing up for the Emory/CDC program. It allows cities to use its Internet database to combine data from 911 dispatch centers, paramedic run reports and hospital discharge records to reveal more about the performance of EMS units — widely viewed as a key step in improving cardiac survival rates. Many cities have no system to effectively track such rates.

A few cities in the program or planning to join it were identified in the USA TODAY report four years ago as having particularly good systems for tracking emergency crews' performance. Those include Houston, Kansas City, Tucson, Boston, Nashville and San Francisco. Other cities taking part or planning to — such as Atlanta, Austin and Columbus, Ohio — were identified as having less-than-stellar systems for tracking cardiac survival rates.

The program — known as Cardiac Arrest Registry to Enhance Survival, or CARES — is a five-year, $1.5 million CDC project launched three years ago. It was partly inspired by the USA TODAY investigation, which found that emergency medical systems in most of the nation's 50 largest cities were fragmented, inconsistent and slow.

Why the focus on cardiac arrest survival rates and not those from something else, such as car accidents or cancer? Cities use cardiac arrest survival rates as a key measure of EMS performance because such victims typically live or die depending on the care they get in the first minutes after collapse, unlike other emergencies in which survival hinges more on hospital care.

"The system has to deliver in order to save a cardiac arrest victim," says Arthur Kellermann, an emergency physician at Emory University School of Medicine. "If it can deliver in a consistent manner for cardiac arrest victims, there is every reason to expect that it will deliver for trauma victims, asthma victims, women in labor."

More than 250,000 people die outside of hospitals each year when their hearts stop beating. Many are reaching the natural end to battles with disease, but others are healthy when struck by
an electrical short circuit of the heart called ventricular fibrillation. "V-fib" can be caused by anything from a blocked coronary artery, to a ball striking the chest, to changes in the heart muscle from an infection.

In 2003, USA TODAY found disparities in emergency medical care across the nation, and said cities that carefully track their EMS performance save many more lives. In most cases, such cities also make a point of teaching residents CPR by, among other things, sending firefighters into homes, churches or businesses to train people.

The reason: If a bystander or acquaintance can quickly perform CPR when a person is stricken with cardiac arrest, they can buy the victim precious time before emergency personnel arrive. Businesses also are encouraged to have defibrillators and people trained to use them so victims can be shocked if rescue crews can't arrive quickly.

Bryan McNally, the emergency physician from Emory Healthcare who heads CARES, told an EMS conference in February that the impetus for the program included USA TODAY's finding that a lack of data regarding EMS responses to cardiac arrest victims is a "major obstacle to improving pre-hospital emergency cardiac care."

Atlanta's huge challenge

Franklin says she learned from USA TODAY's report that Atlanta was losing more than 10 times as many cardiac arrest victims as cities such as Boston, Seattle and Rochester, Minn. The newspaper's analysis ranked cities' EMS efforts in three tiers, with Atlanta's in the bottom tier of cities that had no idea how many lives their rescue units were — or were not — saving.

"Shirley Franklin was furious to see Atlanta as a 'Class C' city," Kellermann says. "She felt it should be in the first tier."

When Franklin took a closer look, what she saw was grim.

From August 2005 through March 2006, her city saved only one person considered by doctors to be among the "most saveable" victims of sudden cardiac arrest. They were deemed saveable because people saw them collapse, and what the victims needed was to be treated quickly with a defibrillator shock to restore their heart's rhythm.

USA TODAY found that in such cases, life and death usually is decided within six minutes of an attack. If the heart is not restarted by then, brain damage can be so severe that the victim is not likely to wake up, even if he or she survives.

"It became really clear to us when we looked at the statistics that the availability of trained personnel close by when somebody is experiencing cardiac arrest can save a life," Franklin says.

She vowed to do more to help the city improve, including enrollment in CARES.

It's paying off. From September 2005 through July 2007, months in which the city has tracked its performance using CARES, 10 of 66 cardiac arrest victims in the "most saveable" category survived with normal brain function.

Atlanta's 15% survival rate is a dramatic improvement, but still well behind leading cities such as Boston, where the survival rate for such cardiac patients is 38%.

One patient's good fortune
The response to save 69-year-old Ronald Williams on May 21 shows how the Atlanta area's system is still moving too slowly to save a life without help from bystanders.

Williams, of Tucker, Ga., was undergoing a stress test in his cardiologist's office when his heart went into V-fib. The medical staff called for help, began CPR and delivered a shock with a defibrillator.

The call for help went first to a 911 center, then to fire department rescuers from Sandy Springs, an Atlanta suburb. By the time paramedics reached Williams and delivered a second shock with their defibrillator, nine minutes had passed since he had gone into arrest.

Williams says he's lucky he was in his doctor's office. "It could have happened anywhere," says the retired aerospace technician, whose blocked arteries were cleared in a hospital after he was revived.

Jing Fang, a physician and researcher in CDC's Division for Heart Disease and Stroke Prevention who is technical director for CARES, says the program ultimately should help save more people like Williams.

Using the system's database, city leaders can track how many cardiac arrest victims their crews tried to save, how many of the victims had their hearts restarted in the field, and how many went home from the hospital with good brain function. The leaders also can see how many victims got help before rescuers arrive. By seeing how each part of the system performed, EMS leaders say they can determine what improvements are needed.

The CARES program allows cities to tell how their crews are performing compared with others in their region and, soon, to the other cities participating nationally.

Some cities that are struggling to determine their cardiac arrest survival rates are not in CARES. In Dallas, officials see CARES as "valuable and laudable," but they are creating their own system to track cardiac arrest survival, says Marshal Isaacs, medical director for the city's fire and rescue units. He says the system could be in place next year.

In Chicago, Philadelphia, El Paso and San Diego, medical directors report having problems getting hospitals to share data on patient survival rates. Jim Dunford, medical director for San Diego's EMS, says a law is needed to force cooperation.

"How can it be that the No. 1 killer of Americans remains heart disease and we still can't accurately measure outcome from cardiac arrest?" he asks.

El Paso's EMS medical director, James "Randy" Loflin, says his city is unable to track survival rates because "hospitals tell us they can't share survival data due to HIPAA," a federal law that protects patient privacy. CARES was designed to share data while complying with the law, McNally says.

'Community response' is key

When Atlanta started crunching its cardiac arrest survival numbers, it became clear that when rescue crews reached a patient, there often were people standing around, unsure how to help.

Only 7% of the city's cardiac arrest victims were getting CPR from bystanders when the CARES program was introduced. Houston, Tucson and other cities that save the most lives in such situations have raised their CPR rates for bystanders through training programs and by having
911 dispatchers give simplified CPR instructions over the phone. Chest compressions alone — even without mouth-to-mouth breathing — can buy minutes for a cardiac arrest victim until rescuers arrive.

"It's not just about streamlining or improving the professional response, it's also about the community response," McNally says. "What is happening before the ambulance or first responders get there? Are people doing CPR?"

When Franklin told city employees to get CPR training, she says, "each of us took a pledge that we would train others."

Atlanta's bystander CPR rate has more than doubled to more than 17%. To give an idea of how far Atlanta has to go to catch up with cities that save the most lives, McNally cites bystander CPR rates of 30% to 40% and higher in places such as Seattle and Boston.

"A lot of us think … the only solution is a doctor," Franklin says. "Having a trained workforce is part of the solution."
Four years ago, in a special report headlined "Six minutes to live or die," USA TODAY reporter Robert Davis documented how emergency medical services in most of the nation's 50 largest cities were fragmented, inconsistent and slow.

He described case after case in which heart attack victims who might have been saved in one city died or suffered brain damage in another, simply because CPR wasn't delivered within that critical six minutes.

Davis discovered a critical difference between successful cities, most notably Seattle, which had a remarkable "save" rate of 45% in the year studied (2001), and those like Atlanta, which had no idea how poorly it was doing and only later discovered that it saved an abysmal 3%. Most important, Davis found that the top performers had systems that any city could replicate. In failing cities, meanwhile, emergency services were chaotically managed with little accountability.

Though good journalism can point the way toward saving lives, change requires official action and commitment. In a follow-up story this week, Davis reported how Atlanta Mayor Shirley Franklin responded. The city's performance has improved fivefold since 2005. Franklin's actions should be a template for lagging cities such as Washington, New York, Nashville, Los Angeles and Chicago.

The two key ingredients:

* Accountability. A system that works overcomes the all-too typical problem illustrated by the case of baggage handler Andrew Redyk, 64, who died at Los Angeles International Airport after he had a heart attack in 2001. Emergency crews took almost half an hour to reach him, but officials couldn't know that from their data. It listed the response time as six minutes.

Atlanta is now one of a handful of cities participating in the Cardiac Arrest Registry to Enhance Survival (CARES), launched three years ago by Emory University and the Centers for Disease Control and Prevention.

CARES is a central database that collates information from 911 centers, paramedic run reports and hospital discharge records. The database provides the kind of tracking that can help leaders see problems. CARES designates officials to be responsible for entering the data and pushes them to complete it. City officials can track how their emergency services are doing and compare them with other cities that have signed up.

In Chicago, Philadelphia, El Paso and San Diego, by contrast, medical directors report problems getting hospitals to share information on survival rates.

* Leadership. Franklin is aggressively pushing solutions when weaknesses are identified. One example borrowed from Seattle: training more ordinary citizens in CPR, boosting the chances that
bystanders can help before medical teams arrive. Last year, Franklin ordered all 8,000 city employees, including herself, to be trained in CPR. She has more than doubled the rate at which bystanders give help, from 7% to 17%.

Cities like Seattle or Houston, with the highest "save" rates, go even further, finding creative ways to ingrain CPR training in people's lives. These include CPR training in schools, making CPR mandatory for some professions and streamlining training. Their bystander CPR rates exceed 40%.

And, of course, successful cities force coordination, ending turf fights like those that commonly exist between emergency services and fire departments.

The bottom line is that if other cities follow Atlanta's template, improvements are guaranteed. Lives can be saved — more than 1,000 each year in the nation's biggest cities. As Franklin noted, "All you need to do is save one life, and it's worth it. It's miraculous."