

# **CARES**

## **Frequently Asked Questions - EMS**

### **1. What is CARES?**

CARES stands for the Cardiac Arrest Registry to Enhance Survival. CARES 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. The ultimate goal of **CARES** is to improve survival from sudden cardiac death. The registry is designed 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.

### **2. What does participating in CARES involve?**

CARES asks that there is an EMS contact at each participating agency. This contact serves as the local CARES administrator for the agency and will oversee CARES operations. The EMS contact is the liaison between the EMS agency and CARES staff throughout participation with CARES. The EMS contact will work closely with CARES staff to determine the most appropriate methods for starting data collection and program implementation and will monitor data collection for the EMS agency and participating hospitals.

### **3. How does data get into CARES?**

There are three methods of data entry into the CARES database. 1) The CARES dataset can be entered via desktop computer by the CARES EMS contact or the EMS field providers/supervisors. 2) The CARES dataset can be automatically extracted from the electronic Patient Care Report which then auto-populates the CARES registry. 3) The CARES dataset can be completed in paper format and then optically scanned to populate the registry.

### **4. How does CARES collect hospital outcomes?**

CARES encourages voluntary participation from hospitals where the participating EMS agency transports cardiac arrest patients. A CARES contact person needs to be identified at each participating hospital. The only requirement for a contact is that he/she has access to hospital records to obtain outcome data. The hospital dataset consists of four simple questions and is only required for worked arrests of cardiac etiology where the EMS crew indicates there was ongoing resuscitation in the emergency department. We ask that the CARES data use agreement is signed at each facility to acknowledge confidentiality of data exchange. The hospital contact will be given access to the CARES website (<https://mycares.net>) and can enter hospital outcomes at their convenience.

### **5. Is the CARES website secure?**

Sansio, the CARES website vendor, uses Secure Socket Layer (SSL) encryption technology in transmitting Protected Health Information to their servers to help ensure the integrity and privacy

of the Protected Health Information provided to them via the Internet. Encryption involves systematically scrambling numbers and letters, so that even if someone managed to intercept the information, they would not be able to decode the information. In order to take advantage of this encryption technology, customers need to have an Internet browser that will support 128-bit encryption. Physically, data is protected by a state-of-the-art electrical backup system, a series of uninterruptible power sources, redundant data storage, and redundant pathways to access data. The entire system is protected by cutting edge fire protection, and off-site data archiving to assure data integrity even in the event of a catastrophe.

#### **6. Does CARES use identifiable patient information?**

Yes, CARES requires the use of a patient's name and date of birth to link the EMS record with the hospital outcomes. The name and DOB are provided via the EMS dataset. Hospitals are not required to give CARES the patient identifiers as this information is already included in the EMS record. Once a record is determined to be complete by CARES staff, the record is de-identified, or 'scrubbed', of patient name and DOB. The CARES data use agreement was created to ensure all data is held confidential and under restricted access in the CARES website.

#### **7. How does HIPAA apply?**

The disclosure and use of protected health information (PHI) in connection with CARES is permissible under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) under the regulation issued at 45 C.F.R. § 164.512(b)(1)(i). The regulation authorizes a public health authority to collect or receive PHI, without individual patient authorization, for the purpose of preventing or controlling disease, injury or disability, including the conduct of public health surveillance. The CDC and organizations acting under the CDC's authority are considered public health authorities under the regulation. For your convenience, I have attached a copy of the letter from the CDC that reflects the CDC's grant of authority to the Emory University School of Medicine to function as a public health authority under 45 CFR § 164.512(b) in carrying out the CARES Program.

Each institution's IRB must make its own determination as to what type of review, if any, should be provided to the CARES Program. The Emory IRB has reviewed this study, and in particular the CDC's letter granting the Emory University School of Medicine to act on behalf of the CDC, as a public health authority, in collecting this information. In view of this letter, the Emory University IRB has determined that the CARES Program constitutes a public health activity and does not constitute "research" as defined under the regulations at 45 CFR Part 46 ("Common Rule"), and therefore does not require IRB review.

#### **8. Who has access to the data?**

The participating EMS agency has access to all of the EMS and hospital data for their patients. EMS agencies do not have access to data from other participating agencies. Hospital contacts can view but not edit the EMS dataset for patients transported to their facility. CARES staff has access to all EMS and hospital data for monitoring and de-identification purposes.

#### **9. What is the data used for?**

CARES data helps 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. Using the CARES software, the EMS agency will have the ability to generate ‘real-time’ Utstein Survival Reports, EMS and First Responder response interval reports, as well as demographic reports. The EMS agency can use this data to inform system changes that will improve outcomes for cardiac arrest patients. CARES will allow for confidential internal benchmarking for the participating EMS agency and, in the near future, there will also be an opportunity for external regional and national benchmarking to occur in a de-identified manner.

**10. How do I obtain more information about CARES?**

More information is available to anyone via the CARES website ([mycares.net](http://mycares.net)). Visit the CARES homepage and select the ‘More information on CARES’ link. Also, feel free to contact one of the CARES Program Coordinators for more information.