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 encourages voluntary participation from hospitals where the participating EMS Agency transports cardiac arrest patients. The hospital dataset consists of four simple questions and are only required for worked arrests of cardiac etiology where the EMS crew indicates there was ongoing resuscitation in the emergency department. The hospital contact will be given access to the CARES website (https://mycares.net) and can enter hospital outcomes at their convenience.

3. 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.

4. Does CARES use identifiable patient information?
Yes, CARES requires the use of a patient’s name and date of birth. Hospitals are not required to give CARES the patient identifiers as this information is already included in the EMS record. However, a patient’s name and DOB is connected with the hospital outcomes as this is the only means of linking the EMS record with the hospital outcomes. 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.
5. How does HIPAA apply?
CARES was approved and considered exempt from further review by the Emory University IRB. CARES is considered to be a quality improvement/assurance program conducted by a covered entity and is thus considered “healthcare operations.” Therefore CARES is not subject to Privacy Rule requirements for research activities or patient authorization. In general, the Privacy Rule permits the use or disclosure of patient information for a registry if the registries are supporting public health activities and/or registries developed for health care operations of health care providers, such as QA/QI. In an effort to ensure confidentiality, a data use agreement can be instituted and approved by all participating hospitals if necessary, however is not required.

6. Who has access to the data?
Each participating hospital has access to their data and only their data. Therefore, hospitals do not have the ability to view data from other area hospitals. The CARES software has the ability to export data for all CARES patients that have been transported to your facility into excel. Other than the hospital contact at your facility, the only other people who can access the data are system administrators at the participating EMS agency and CARES staff.

7. What is the data used for?
Hospital outcomes data is critical in monitoring survival for out-of-hospital cardiac arrests. Not only will the hospital outcomes help determine the survival rate for cardiac arrests in your community, but will also allow for confidential internal benchmarking for the participating EMS agency. 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 arrests. In the near future, there will be an opportunity for external regional and national benchmarking to occur in a de-identified manner.

8. How is a hospital contact notified of when to enter data?
When a CARES patient has been transported to a receiving facility, the CARES website will generate a generic email to be sent to the specified hospital contact. No patient information is sent in the email but the email serves as a reminder to log-in to the website when it is most convenient for the contact. The hospital contact is asked to wait until the patient has been discharged (or expired) to enter hospital outcomes so they will have sufficient information to answer all four questions.

9. How does a hospital participate in CARES?
A CARES contact person needs to be identified at each hospital. The only requirement for a contact is that he/she has access to hospital records to obtain outcome data. Once a contact person is identified, CARES staff will schedule a brief online demonstration of the data entry process and provide the contact person with their individual username and password for the CARES website.

10. How do I obtain more information about CARES?
More information is available to anyone via the CARES website (mycares.net). Visit the CARES homepage and select the ‘More information on CARES’ link. Also, feel free to contact any one of the CARES Program Coordinators.