

EVALUATION OF THE CARDIAC ARREST REGISTRY TO ENHANCE SURVIVAL
(CARES)

EVALUATION REPORT

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
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EXECUTIVE SUMMARY

The Centers for Disease Control and Prevention (CDC), in collaboration with the American Heart Association, began funding Emory University 2004 to develop and coordinate the Cardiac Arrest Registry to Enhance Survival (CARES) Program. CDC contracted with Battelle to conduct an evaluation to gain a better understanding of program relationships, implementation and outcomes of the CARES program, and to demonstrate the value of CARES.

Methods

The evaluation addressed the following topics and questions.

1. *Relationships:*
 - a. How does Emory assess the support provided by CDC/Division for Heart Disease and Stroke Prevention (DHDSPP)?
 - b. How do the CARES agencies assess the support provided by Emory?
2. *Implementation:*
 - a. How has CARES been implemented and how does the implementation vary among agencies?
 - b. What are the logistical, political, and motivational barriers and facilitators to implementation?
 - c. What strategies have agencies developed to facilitate implementation?
3. *Outcomes:*
 - a. What are the accomplishments of CARES and how are data being used?
4. *Lessons Learned:*
 - a. What are the lessons learned across CARES agencies that inform future planning? What are potential future directions for CARES?

To answer these questions, the evaluation relied on the following data sources:

- **Program documents**, including applications, protocols, training manuals, progress reports, presentation slides, and draft reports and publications.
- A **focus group**, composed of CARES site representatives.
- **Key informant interviews**, with electronic Patient Care Record (ePCR) CARES vendors, CDC/DHDSPP staff, and current and past Emory CARES staff.
- **Case studies** of CARES sites. The sites were selected based in part on recommendations from Emory and the out-of-hospital cardiac arrest (OHCA) case volume noted in the registry.

Findings and Recommendations

The key findings and recommendations of the CARES program evaluation are listed below by thematic category.

Relationships

The evaluation gathered information to assess CDC/DHDSP support to Emory and Emory's support to CARES sites. Specific areas of interest were CDC's provision of financial and technical support and potential needs for CDC's support in the future. Aspects of Emory's support that were explored were the types of technical assistance (TA) often requested by CARES sites, satisfaction levels with the TA and related products or tools provided by Emory, and recruitment strategies. The relationship between Emory and CDC, as well as between Emory and CARES agencies, was shown to be positive and an asset to the program.

CDC may consider strengthening its support to Emory by assisting in the development of a feasible and effective audit system, statistical analysis of CARES data, provision of full-time IT support, and identification of state contacts for potential CARES sites.

Program Implementation

Information from all five data sources was gathered and compiled to address the process of implementing CARES, including key steps or models toward recruitment, data collection and management, and variations or adaptations across agencies. Logistical, political, and motivational barriers and facilitators of implementation were also identified. Findings indicated that CARES agencies implemented a few key program model components but with variability. These components were 1) having a point of contact to champion implementation, 2) establishment of hospital agreements to obtain access to data, 3) ePCR data collection from EMS workers, 4) data entry into the CARES registry, and 5) quality assurance or management of data in collaboration with Emory.

Noted barriers to implementation were challenges with the initial recruitment of hospitals to the registry and the additional work burden on hospital staff, inconsistent methods for collecting 911 and EMS response times, and limited funding for IT upgrades and potential expansion of the registry. Respondents mentioned the sharing of data through reports, limiting the number of persons entering data, automating alert or reminder systems, data confidentiality, and utilizing existing relationships for recruitment as facilitators to implementation.

Recommendations for consideration for future program implementation efforts—specifically regarding recruitment, data collection, data entry, and data management—were offered to CDC, Emory, CARES agencies, and vendors.

Considerations for CDC include:

- Collaborating with Emory to update the CARES brochure to include a description of existing research on OHCA for hospitals and EMS workers.
- Classifying sudden OHCA as a mandatory reportable condition or including a CARES-like OHCA data collection system in the Healthy People 2020 initiative.

Considerations for Emory University include:

- Identifying a method to manage the existing CARES agencies while continuing to expand the registry. Potential methods include, but are not limited to, developing a system to track EMS agency interest and infrastructure, recruiting entities near existing CARES

agencies, expanding the number of staff at Emory working on CARES, identifying a CARES champion, and developing a CARES media campaign.

- Developing and implementing additional training formats with supplemental materials for implementing all aspects of the registry.
- Improving the collection of CARES data by working with other EMS registries, consulting with data vendors in the planning phases when considering changes, streamlining use of ePCR automation across all CARES agencies, and standardizing data-collection methods, including inclusion and exclusion criteria of cases.
- Automating the audit process to reduce the burden on Emory and CARES agencies. This can be done with improved programming and assistance with developing statistical data checks and sampling cases to review.

Considerations for CARES agencies include:

- Establishing a hospital champion to advocate for CARES among physicians and nurses and utilizing Emory products during recruitment.
- Recruiting large hospitals first.
- Considering the experiences of other CARES agencies, selecting an ePCR vendor who has previous experience implementing CARES, and ensuring that the ePCR vendor works closely with the billing vendor.
- Campaigning for better communications systems for data collection and requesting that CAD and ePCR data are integrated.
- Automating data entry systems and limiting entry of hospital data to one staff person.

Considerations for vendors include:

- Continuing to support CARES and ensuring that related data elements are included as a part of their ePCR product.
- Improving the data-collection and data-entry processes.

Outcomes

Respondents were asked to provide their perspectives on the accomplishments and goals attainment related to strengthened collaborations, feasibility of the implementation process, and TA provided to utilize CARES data for performance improvement. The findings showed that respondents noted creating beneficial relationships both within and outside the EMS community; gaining access to data from three different systems, ePCR, CARES web database and optical scanning of paper records; and increasing the number of participants recruited and maintained in CARES as accomplishments of the program. It was also noted that the CARES registry has created an awareness of the need to standardize data collection in the EMS community. Data captured and reviewed by agencies has been utilized to identify training needs, monitor performance, create benchmark reports to compare performance to other agencies, gain political and financial support, monitor OHCA events, and for information sharing. The following recommendations for the above findings were proposed for Emory in response to the findings:

- Enhance the myCARES.net reporting system to allow agencies to make comparisons, create graphical representations of the data, conduct geo mapping, provide countywide reports, export data in the Excel file format and design ad hoc reports. It was also

suggested that Emory consider providing additional data reports as a part of their standard reporting system.

- Extend reporting functions to hospital staff so they can access reports on data entered. Allowing access to reports may lead to future engagement and interest in the data collection process.
- Add additional outcomes and data elements to the data collection system to afford EMS agencies the opportunity to utilize the data for purposes external to CARES or for program improvement.

Potential Future Directions

Key informants noted that it is advantageous for CARES to expand its current model to a state-wide approach. CARES is currently piloting a state-level model of implementation in which state coordinators take over some of Emory staff roles, such as the audit function. This model will allow for expansion of CARES that cannot be currently accommodated by three Emory CARES coordinators. This expansion may lead to the collection of a more nationally representative sample, as well as various challenges around data collection, data auditing, data confidentiality, and financial sustainability.

Future directions for consideration include the utility of CARES data to determine effective strategies for improving cardiac response times, as well as expansion or improvement of CARES data collection, as all current agencies expressed that they plan to continue participating in CARES. A potential recommendation for consideration by Emory is to form partnerships with external organizations to secure additional funding in order to sustain the CARES program and maintain its current relationships with the agencies. Emory may also consider expanding its reach to underserved areas or internationally.

1. INTRODUCTION

In collaboration with the Centers for Disease Control and Prevention (CDC) Division for Heart Disease and Stroke Prevention (DHDSP) and the American Heart Association (AHA), Emory University's Department of Emergency Medicine received funding (see Appendix A for funding allocations) to develop and coordinate the Cardiac Arrest Registry to Enhance Survival (CARES) program beginning in 2004. Overall, the CARES program seeks to:

- Save more lives from out-of-hospital cardiac arrest (OHCA).
- Strengthen collaboration between 9-1-1 centers, first responders, emergency medical services (EMS) agencies, and hospitals.
- Provide a simple, confidential process for assessing patient outcomes in compliance with the Health Insurance Portability and Accountability Act (HIPAA).
- Offer technical assistance (TA) to help community leaders identify and prioritize opportunities to improve EMS performance.

More information about CARES, including the data elements that each site collects, can be found at <https://mycares.net>.

1.1 Evaluation Purpose

The primary purpose of the CARES evaluation was to provide CDC with information to gain a better understanding of the relationships between CDC, Emory, and CARES sites, how the CARES program is implemented, outcomes of the program, and lessons learned for the future.

1.2 Organization of the Report

In this report, we present the evaluation methods (Section 2), a detailed description of the findings and recommendations organized according to topic areas (Section 3), and a summary of all recommendations organized by audience (Section 4).

2. EVALUATION METHODS

The evaluation used a qualitative methods design with four data collection modes: (1) document reviews, (2) focus groups, (3) key informant interviews, and (4) case studies. A logic model showing the inputs, activities, outputs, and outcomes to which the CARES program aspired is presented in Figure 1. Below we elaborate on the model.

- *Inputs:* CDC funding, the international Utstein criteria, and promotion of the utility of a patient-level registry for OHCA to aid communities in tracking their performance, identifying areas of improvement, and improved survival rates for OHCA.

- *Activities:* Emory University designed and operates the centralized CARES database. Emergency medicine experts selected the 37 required data elements currently being collected in CARES. (Additional variables were added to the data collection template in January 2011.) Emory recruits EMS providers, who in turn recruit the hospitals where the agency transports cardiac arrest patients.

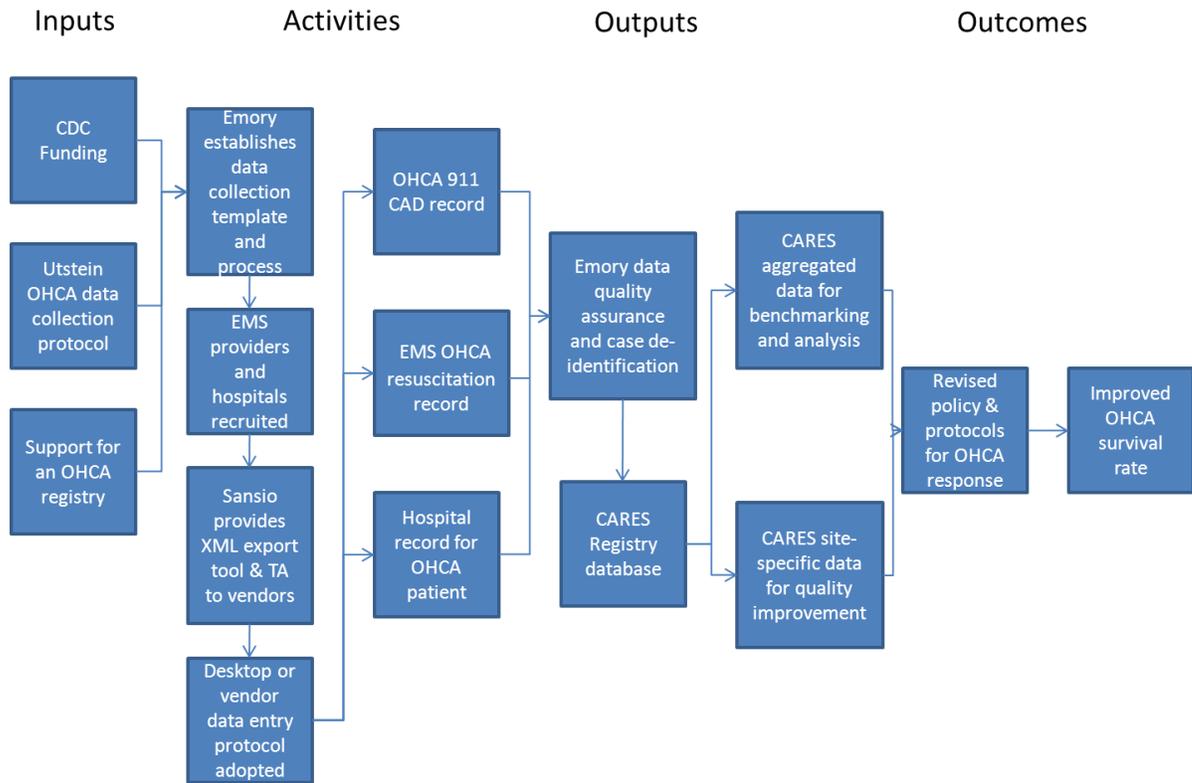
Emory also contracted with Sansio, a private company with experience in software development for EMS data capture, to deliver a secure web-based data management system in which EMS provider organizations enter their local EMS OHCA information and generate their own reports. The variation in EMS provider technology and resources necessitated that Sansio support three different methods of EMS data entry: desktop computer data entry directly into the CARES web database; automatic data extraction from an existing vendor electronic Patient Care Record (ePCR) products; or optical scanning of paper data records.

Hospital outcomes are obtained for cardiac arrest patients classified by the EMS provider as receiving ongoing resuscitation at the hospital. A hospital contact person enters the outcomes data for the patient into the CARES website. The CARES web-based system reminds hospitals of any outstanding cases that need hospital outcomes data entered.

Data uniformly collected from three sources—911 computer-aided dispatch (CAD), EMS, and hospitals—are linked, checked for data quality, and de-identified before being entered into the CARES database. The registry database is shown in the diagram as an output. The actual linkage of the three sources of data relies on matching date, time, and address of 911 CAD and EMS data, as well as matching name and date of birth to both EMS and hospital data.

- *Outputs:* De-identified data can be reviewed and analyzed by agencies, and reports can be generated on the myCares.net website.
- *Outcomes:* Reports and analyses generated by Emory and CDC, as well as from the myCares.net website, are used for program improvement by EMS agencies and to inform OHCA policies and protocols. A potential long-term outcome is the improvement of OHCA survival rates. An additional outcome collected is neurological status at hospital discharge.

Figure 1: CARES Logic Model



2.1 Evaluation Topics

The evaluation was designed to examine the following four overarching categories and related questions.

1. *Relationships:*
 - a. How does Emory assess the support provided by CDC/DHDSF?
 - b. How do the CARES agencies assess the support provided by Emory?
2. *Implementation:*
 - a. How has CARES been implemented and how does the implementation vary among agencies?
 - b. What are the logistical, political, and motivational barriers and facilitators to implementation?
 - c. What strategies have agencies developed to facilitate implementation?
3. *Outcomes:*
 - a. What have been the accomplishments of CARES and how are data being used?
4. *Lessons Learned:*
 - a. What are the lessons learned across CARES agencies that inform future planning? What are potential future directions for CARES?

Evaluation topics and subtopics that fit within these broad categories are shown in Appendix B.

2.2 Data Sources

Qualitative data were collected for the evaluation from the following data sources: CARES program-related documents provided by CDC and Emory; a focus group held in Atlanta composed of seven CARES site representatives; key-informant telephone interviews with five ePCR CARES vendors, five CDC/DHDSP staff, and four current or past Emory CARES staff; and case studies of nine CARES agencies.

Exhibit 1 displays how Battelle used the data sources to address the evaluation topics. Each evaluation topic was informed by a combination of sources and each source is described below.

Exhibit 1. Evaluation Topics by Data Source

Evaluation Topic	Data Sources				
	Atlanta Focus Group	Key Informant Interviews		Document Review	Case Studies
		CDC/DHDSP and Emory	Vendors		
Assessment of CDC/DHDSP support to Emory		X		X	
Assessment of Emory support to CARES participants	X	X	X	X	X
Implementation process	X	X	X	X	X
Logistic, motivational, and political aspects	X	X	X		X
Accomplishments of the program	X	X	X	X	X
Data use	X	X		X	X
Lessons learned that inform future planning	X	X	X		X
Potential future directions	X	X	X		X

2.2.1 Document Review

Battelle reviewed program-specific documents from Emory and CDC to inform the evaluation findings. Key information from the document review and discussions with Emory and CDC were compiled into an Excel file that provided characteristics about the CARES participants.

2.2.2 CARES Atlanta Focus Group

Selection of the seven agencies for the Atlanta focus group was based on the volume of OHCA cases processed by the agency on average each month, when the agencies joined CARES, the geographic location of the agency, type of data entry system used (desktop or vendor), and whether Emory staff regard the participant as a “champion” agency.

Topics for the discussion included successfully implementing CARES, facilitators and barriers to implementation, future visions of CARES, and recommendations for program improvement. A meeting agenda and the focus group guide are included in Appendix C.

2.2.3 Key Informant Interviews

Battelle conducted interviews with five CDC/DHDSP and four current and past Emory CARES staff to understand the context of the program and challenges in establishing it, as well as the provision and receipt of financial and technical support. These interviews were conducted by telephone. The contact script and key informant guides for the Emory and CDC/DHDSP interviews are included in Appendix D.

To understand the vendor perspective on the challenges and benefits associated with adding CARES data elements to their ePCR products, and the assistance they have received from Sansio and Emory University, Battelle staff conducted a brief interview of five vendors who have incorporated CARES data elements into their ePCR products. The contact script, participant information sheet, and vendor interview guide are included in Appendix E.

2.2.4 Case Studies

Administration. Recommendations from Emory staff, coupled with the volume of OHCA cases, were used to identify the nine CARES agencies for case studies. Battelle staff contacted the medical directors or agency administrators associated with each agency by email and/or phone to request their participation in completing a brief email survey and a one-hour telephone interview, and in identifying staff for a semi-structured telephone interview.

These interviews provided an overview of each agency and allowed for cross-agency comparisons during the analysis stage. Each interview covered common topics, such as implementation of CARES, use of CARES data, assessment of TA, barriers and facilitators for initiating and implementing CARES in the community, lessons learned, and ideas and recommendations about future directions. The case study administration contact script, email survey, and interview guide are included in Appendix F.

Staff. To build on information from the medical directors/agency administrators and to learn more about the data entry process, Battelle staff also conducted one-hour semi-structured telephone interviews with other key CARES staff associated with six of the nine case study agencies. Respondents included CARES agency EMS staff responsible for CARES data entry and audit and hospital staff responsible for CARES hospital outcome data. With one exception, all staff interviews with more than one staff member were group interviews. Each telephone interview included topics such as challenges and lessons learned, staff training needs, TA needs, accomplishments of CARES, and future directions for CARES. The staff case study participant information sheet and the interview guide are included in Appendix G.

2.3 Data Analysis

To inform evaluation findings, an Excel spreadsheet was created containing agency characteristics noted from the document review.

Focus group and interview recordings were transcribed and imported into NVivo 8 for coding and analysis. Given the limited number of transcripts involved, a single analyst coded all of the documents. A copy of the codebook is provided in Appendix F.

Prior to the coding and analysis of the qualitative data, Battelle staff created a summary report for the Atlanta Focus Group. This report described the data collection effort, including the methods and high-level findings. The summary report is provided in Appendix G. Similarly, Battelle created a case study summary report for each of the nine case studies. Specific CARES agencies were not identified in these summary reports; case studies were labeled as Case Study 1, Case Study 2, etc. Each summary report was shared with the medical director, and minor corrections were made to some of the summaries based on the medical director's feedback. The case summaries may be found in Appendix H.

3. FINDINGS AND RECOMMENDATIONS

The following sections summarize the main themes that emerged from all the data sources around four overarching evaluation categories—relationships, implementation, outcomes, and future directions. Associated lessons learned and recommendations are integrated within each of these sections.

3.1 Relationships

The evaluation gathered information from all five data sources to assess CDC/DHDSP support to Emory and Emory's support to CARES sites. Specific areas of interest were CDC's provision of financial and technical support and potential needs for CDC's support in the future. Aspects of Emory's support that were explored were the types of TA often requested by CARES sites, satisfaction levels with the TA and related products or tools provided by Emory, and recruitment strategies.

3.1.1 CDC/DHDSP Support to Emory

CDC funds Emory University indirectly through a cooperative agreement to coordinate and manage the CARES program. Under this agreement, CDC/DHDSP staff provide TA and partner with Emory University to analyze the CARES data and to produce manuscripts and presentations. Both located in Atlanta, GA, CDC and Emory communicate regularly through in-person meetings or teleconference calls and e-mails to discuss current issues or collaborate on publications.

Emory CARES staff indicated that CDC was helpful, supportive, and a resource for materials. They noted the benefit of utilizing the knowledge at CDC and described that they were more familiar with CDC staff and their areas of expertise since the relationship began. Noted examples of TA provided by CDC were geo-mapping, developing manuscripts, and providing programmatic support materials.

“... the response you get [from Emory CARES staff] is what you need. You get a response; you get it fairly quickly, and they answer your question.”
-CARES Agency Administrator

Types of technical support CDC could provide to Emory in the future are: 1) assistance with refining the statistical analysis approach for CARES data as the data set grows, 2) geo-mapping, 3) information technology (IT) support of the CARES data entry system, and 4) navigating state relationships or identifying contacts at the state level to facilitate statewide expansion of CARES.

If additional funds become available for CARES in the future, Emory identified the following priority needs: 1) to support the expansion of CARES to more sites, including state-wide expansion, and 2) to fund a full-time IT support position to handle fixes and updates to the data collection system.

3.1.2 Emory Support to CARES Agencies

CDC assesses the level of support from Emory to be high, with staff readily available and responsive to CARES agencies' needs. CARES agencies described Emory staff as friendly, responsive to questions, and easily accessible by mail or phone. Other ways Emory provided support to CARES agencies included:

Collaboration and Communication. Respondents provided a number of examples of how Emory regularly communicated with CARES agencies and facilitated collaboration between CARES sites and hospitals and data vendors. Emory assisted CARES agencies with setting up data use agreements with hospitals and addressing HIPAA or other legal concerns that hospitals may have. At times Emory CARES staff made in-person visits to help facilitate this collaboration.

Emory CARES staff reviewed all CARES cases and communicated with the agencies to resolve inconsistencies and missing data and to verify cardiac etiology. They also facilitated communication between agencies and their ePCR vendor and Sansio to develop a CARES data extract program.

Training and Technical Assistance. Staff members at the CARES agencies received training from Emory to understand the CARES website and the data collection process. CARES agencies indicated that they require the most TA during the initial planning and the data entry phases of the project. The majority of CARES administrators reported satisfaction with the TA Emory provides and stressed the importance of the availability of Emory CARES staff to answer questions.

Respondents also identified helpful TA products and tools that Emory staff provided: reports, presentation tables, and documents on the CARES website. The data dictionary and hospital

recruitment documents were mentioned as the most useful products. Two hospital staff mentioned they were not aware of any TA products.

3.2 Implementation

Information from all five data sources was gathered and compiled to address the process of implementing CARES including key steps or models towards recruitment, data collection and management, as well as variations or adaptations across agencies. Logistical, political, and motivational barriers and facilitators of implementation were also identified.

Emory works with EMS agencies to develop an implementation model that fits their community's configuration of EMS agencies and hospitals and that utilizes existing ePCR data collection. The case studies illustrate nine different ways of implementing CARES. Agencies vary in terms of what type of agency takes the lead (fire department, hospital, county), the number of EMS agencies and hospitals involved, the ePCR product that is used, how pre-hospital and hospital data are collected and entered into the registry, and the agency review process for CARES cases. This flexibility in how CARES can be implemented is an advantage in terms of the rapid uptake of CARES in many different types of settings.

3.2.1 CARES Implementation: Key Components and Variations of the Model

Interviewees emphasized the necessity for CARES implementation to be tailored for the structure of the local EMS system. Indeed, each of the nine case study agencies had implemented CARES in a slightly different manner (see Appendix H). Each case differed in terms of the size of the area served and annual volume of cardiac arrest cases. Nevertheless, each of the agencies, with Emory staff help, developed a model with the following components:

- Acting lead agency and administrator willing to champion the implementation and serve as the primary point of contact for Emory.
- Hospital agreement and participation of nurse(s) or other staff to obtain patient outcome data.
- Collection of ePCR data from EMS workers.
- Entry of ePCR and hospital outcomes data into the CARES registry.
- Agency and hospital staff to perform data quality checks and respond to Emory's audits concerning missing or questionable data.

In the following section we describe the strategies used to implement each of these components.

Lead Agency and Administrator. Several types of agencies served as the CARES lead agency in a community: fire department, county EMS department, and hospital. Typically, the administrator is the medical director for the county, who is not necessarily employed by the lead agency. In one case, the medical director served the role of a medical consultant only, and another agency staff person served as the CARES administrator role.

The functions of the CARES administrator included:

- Work with hospitals to satisfy Institutional Review Board (IRB) requirements.

- Champion for CARES in the community.
- Conduct quality assurance on CARES cases and respond to Emory audit questions.
- Serve as primary contact and coordinator for CARES.
- Follow up with hospitals for outcomes data.

A noted lesson learned by the respondents was the important role the CARES agency administrator played as a champion of CARES in the community. In addition to recruiting hospitals and coordinating the EMS agencies, agency administrators regularly present CARES findings at EMS and physician meetings, provide data for politicians and the media, and advocate for training in the community and for an improved 911 communication system.

Hospital Agreement and Participation. One of the key benefits of joining CARES was being able to obtain hospital outcomes data for their OHCA patients. Prior to CARES, only two of the nine case study agencies had outcomes data on those patients surviving beyond admittance to the emergency department (ED).

The number of hospitals recruited by each of the case study agencies varied, with most agencies recruiting fewer than 10 hospitals; one agency was able to recruit 16 hospitals. At five of the case study agencies, the CARES agency administrator recruited hospitals for participation in CARES. The agency administrators scheduled meetings with hospital representatives and hospital committees (such as EMS advisory or physician committees) to provide information about CARES and establish agreements to collect data. Meetings often involved multiple types of hospital representatives, such as the chief medical officer, hospital administrators, ED representatives, nursing, and physician leadership.

Agency characteristics, such as infrastructure to support data collection or having a champion for CARES in the community, may play a role in the agency’s interest in or ability to participate in CARES. As an Emory key informant said,

“We can make this happen in a community, but the thing that prevents certain communities from coming onboard in terms of actually operationalizing CARES is basically the responsiveness of the person or persons that are going to work with this directly—whether it be the medical director and/or the point person that we’ve identified that’s going to be the primary contact for CARES. When there is not a good line of communication or people, to think that this happens magically by itself, I think is a misperception.”

ePCR EMS Data Collection. All of the CARES agencies use some kind of ePCR data collection system, such as an electronic tablet that EMS workers complete after a patient has been transported to the ED.

Five commercial vendors used by the case study agencies have CARES data elements in their ePCR product and some agencies developed their own ePCR. The ePCR systems were collecting OHCA data prior to CARES, and by design CARES capitalized on existing data collection

efforts. CARES data elements also overlap with data elements used by other registries, such as the National Emergency Medical Services Information System (NEMSIS).

Not all of the electronic systems capture all of the CARES data elements. Data vendors and CARES agency respondents most often mentioned that CARES setup or updates took time and were not a high priority for vendors. Only one vendor had incorporated the January 2011 CARES elements into its ePCR product. Several vendors mentioned that CARES could be a higher priority if there were a greater number of CARES customers. Additionally, ePCR vendors have development schedules planned well in advance, so it is difficult to address changes to CARES within 90 days. Agencies using ePCRs that do not collect all of the CARES elements either leave those elements as missing or have a staff person (or hospital quality improvement nurse) complete those elements based on field notes and audio or video recordings. ePCR vendors discussed integration with NEMSIS as a facilitator to setting up or updating CARES data elements as a part of their ePCR product.

The ePCR data-collection systems vary as to whether the CARES data elements are grouped together or interspersed throughout the set of ePCR fields. Some ePCR systems use logic and data mapping to extract the information needed for CARES from existing data fields, while other systems have a separate CARES screen to answer all CARES questions. The separate screen of CARES questions may duplicate questions asked as part of the standard ePCR product. To reduce the number of data errors, some CARES agency staff conducted trainings or refreshers with EMS workers involved in CARES data collection through brief instruction documents, monthly case reviews, PowerPoint presentations, newsletters, and in-service meetings. In some cases this training is incorporated as part of the regular training provided for EMS workers.

Data Entry into Registry. Sansio, the vendor hosting CARES, provides a standard XML export tool to all vendors. Some vendors have written code to use with the export tool so that CARES data can be extracted automatically from the ePCR database and exported to the CARES registry. Customers may then choose to either use the extract program or have staff manually enter the ePCR CARES elements in the registry through the myCares.net website. The automatic extract program streamlines the process. However, some agencies either cannot use it because it's not supported by their vendor, or have chosen not to use the process. Reasons for not using the automated process include inconsistencies or errors created by the extract program that need to be manually corrected later and the desire to provide up-front quality control on how cases are classified as OHCA and how data elements are interpreted.

Often, agency staff who are involved in the manual entry of CARES data elements do not see the hospital outcomes data, nor do the hospital nurses see the data elements collected from the ePCR. However, one case study agency reported that one of the hospital quality improvement nurses enters all of the outcomes data from several hospitals, as well as the ePCR CARES data elements, into myCares.net. Currently all of the CARES hospitals rely on desktop data entry. In one case, outcomes data from the hospitals are sent as an Excel file and the CARES administrator enters the data into the database.

Many of the CARES agency staff reported being trained by Emory on CARES and the use of the myCares.net website for data entry. Emory CARES staff have trained agencies during in-person visits or by using LiveMeeting. These trainings involved the CARES agency administrator,

agency staff involved in the entry or review of CARES data, and hospital staff entering outcomes data. A few agencies utilize staff members on light duty to help with data entry so CARES training is always ongoing due to frequent staffing changes. New staff members taking over the responsibility of CARES duties are typically trained by their predecessor. Three agencies reported using the data dictionary during training for staff involved in entering information into myCares.net.

CARES agency staff and Emory key informants most often mentioned the need to automate steps in the CARES data entry process as a lesson learned. Automatically pulling all CARES data from an ePCR system allows information to be collected without additional burden on EMS workers or agency staff. One CARES Administrator also mentioned wanting to automate the extraction of hospital outcomes data to CARES.

Quality Assurance and Auditing. The Emory data audit consists of checking each case for missing data, data inconsistencies or illogical combinations, and cases that are of questionable cardiac etiology. The audit did not include any statistical data checks to identify outliers or suspicious patterns. Once Emory staff identify a problem, they email the agency or hospital to ask for clarification and data checking.

Respondents indicated wide variability in the process used to determine if a case is of cardiac etiology. Some ePCRs automatically identify cardiac cases and send them to the registry, while other agencies have a staff person review data and field notes to identify the cases with a cardiac etiology. Staff noted that they are looking forward to an updated ePCR that would automate the process for them. Even the automatic identification of cases may be handled differently by the different vendors. Some agencies verified coroner's reports, as well as other hospital data, to reclassify CARES cases that are not of cardiac etiology. Some assume cardiac etiology unless otherwise documented as trauma, respiratory arrest and drowning, electrocution, or drug overdose. The process used to determine cardiac etiology needs to be consistent across CARES agencies in order for the data to be standardized. One CARES administrator was unsure if he would recommend other EMS agencies to participate in CARES due to being unable to accurately compare across agencies when different procedures are followed to determine cardiac etiology.

CARES and Emory respondents listed automating the audit process most often as a way to reduce burden. As the number of CARES agencies and cases in the registry increases, the burden of the current audit process will increase. Correcting the data errors and communicating with Emory outside of myCares.net creates additional burden on the agencies. Additional programming of the website could improve the efficiency of communication and alleviate the burden.

3.2.2 Logistical, Political, and Motivational Barriers to Implementation

Participants in the focus groups, case studies, and key informant and vendor interviews were all asked to share their perceived challenges and barriers to implementing the CARES program. Key findings around this subtopic that emerged included hospital recruitment and staff participation, accurate collection of specific time-bound data elements, and funding.

Hospital Recruitment and Participation. CARES agencies encountered challenges during the initial recruitment of hospitals to participate in the registry. For example, delays due to hospital concerns around signing data use agreements and Institutional Review Board (IRB) approval, identifying hospital staff to take responsibility of CARES data entry, and staff retention.

Although some CARES agency administrators described the process of establishing data use agreements with hospitals as simple and straightforward, five respondents described it as a challenge. One agency noted challenges with navigating hospital bureaucracy and obtaining IRB approval for establishing data use agreements.

After hospitals are recruited, it was necessary to identify one or more contacts to be accountable for retrieving and entering the outcomes data. Respondents frequently mentioned the importance of the hospital contact and steps they took, such as noting the schedules and best times to call the helpful hospital contacts to obtain outcomes data.

CARES data entry is usually added onto existing responsibilities of hospital staff, which can cause delays in receiving data. As one ED nurse explained, ED nurses are dealing with trauma, so retrieving and entering data for patients who have either died or been transferred elsewhere is a lower priority.

Another barrier mentioned was the inefficient hospital system that required nurses to check multiple sources for data, often not readily accessible from the nurse's computer, increasing the time needed to retrieve patient outcomes data. Field data errors in the patient's date of birth, patient name, or hospital name also added time to data collection.

Administrators also pointed out that turnover in hospital staff and leadership requires the agency to remind the hospitals of their prior commitment to CARES.

Recording Accurate Response Times. There are many challenges and inconsistencies to capturing accurate 911 and EMS response times. The result is that CARES agencies are not confident comparing response times.

- The different systems used to collect this information are not integrated. For example, if the fire department arrives first on the scene, but the ambulance transports the patient to the hospital, an ambulance worker will complete the report, noting the time the ambulance arrived. This record may not include when the fire department arrived and any treatment provided to the patient.

“Those contacts are not imitable, and then unfortunately the more hospitals you deal with, the more opportunities there are for there to be a drift or change in personnel. You’re continually trying to establish connections ...”

- CARES Agency Administrator

- Communities are unable to track the time for a cell phone call to get through to 911. Many cell phone 911 calls go to the highway patrol first, the highway patrol transfers the call to EMS, at which point the time is recorded.
- If the 911 call lines are busy, the time is not accurately recorded, because there is no tracking of how long it takes before the 911 caller speaks to an emergency dispatch operator.

“That’s the time from the initial dialing of 911 to the time of dispatch of the first responder. Those times can vary from a few seconds to many, many, ... minutes. They’re not well measured; clocks are not synchronized; CAD’s are not connected; phone systems are not connected to CAD’s; people don’t know, and 911 and EMS are two widely separated silos.”

- CARES Agency Administrator

Lack of Funding. CARES agencies, data vendors, and Emory respondents identified funding and resource limitations as a challenge to CARES implementation. CARES agencies are not compensated for time spent implementing CARES, and these agencies have limited resources due to budget cuts and community financial challenges.

Staff are implementing CARES in addition to their regular duties and sometimes on their own time. Lack of funding as a barrier was specifically associated with the following topics:

- **IT upgrades.** CARES data vendors are not compensated for making changes to their ePCR product or working with Sansio and agencies to develop or improve the export programs. Consequences of insufficient IT funding for Sansio and the data vendors are increased burden of data collection, data entry, and auditing, as more manual work is required to compensate for the lack of, or faulty, automation. Lack of funding for the vendors also means the export programs have not yet been developed or are in need of additional work.
- **Expansion.** Resource limitations at Emory also impact the program’s ability to support further growth of the registry or initiate new TA forums for agencies. EMS agencies interested in participating in CARES are placed on a waiting list, and some EMS agencies are discouraged because they’re unable to join CARES at this time.

3.2.3 Logistical, Political and Motivational Facilitators to Implementation

Respondents also identified a number of facilitators or approaches taken that made implementation easier such as sharing of data reports, designation of one data entry person and case alert system, confidentiality, recruitment strategies, and existing relationships.

Cardiac Arrest Data Reports. CARES agency respondents discussed lessons learned using CARES data. Many respondents stressed the importance of sharing the data with EMS workers and other CARES EMS agency or hospital staff involved in data collection. Sharing data with staff allowed them to understand why data are being collected and provided a mechanism to give feedback on staff performance.

Access to CARES data and reports also allowed EMS agencies to share data and survival rates with stakeholders such as EMS leadership and local politicians. As explained by one Emory respondent,

“From the political process we believe that communities—medical directors, agency directors—are trying to share their metrics and the reference point with the leadership in their community and the politicians to show how they’re doing their job.”

Data Entry. Restricting the number of staff entering CARES data reduced the need for training and improved consistency and quality of data. This strategy was particularly effective when the ePCR data were not automatically exported to CARES and when there was a large number of participating hospitals.

One case study agency assigned one person to enter both field and hospital data. Even though hospital contacts submitted the outcomes data to this individual, it was still easier to maintain consistency by having one person entering the cases rather than keeping all of the hospital contacts trained. The agency plans to adopt a new ePCR product that can export data to CARES. Once that is in place, this person will no longer need to enter the field data. Agencies found it easier to have one dedicated hospital contact enter data than to spread the responsibility.

Three agencies reported using a case alert system. Some ePCR data vendors have set up alert systems so the CARES administrator or data collection manager automatically receives an email or text message when a case has been identified as OHCA and eligible to be entered into CARES. These alert systems allow for immediate follow-up with data entry staff to ensure the CARES data have been fully entered.

Data Confidentiality. CARES provides de-identified data so EMS agencies are comfortable with the data confidentiality and have confidence their data will not be shared without permission. As one CARES agency staff person remarked,

“I would say that the political aspects, one of the first things that they want to ensure is that they have full access to their own data and that CARES will not be sharing that with any outside source without their permission and knowledge. I think that CARES does a phenomenal job, and really even goes above and beyond to make sure, you know, of the confidentiality piece and making sure that everybody is comfortable, I think, is a huge aspect.”

Effective Recruitment Strategies. Emory’s in-person visits to interested EMS agencies and speaking with the EMS agency, hospitals, and other community stakeholders about CARES, facilitated recruitment. These strategies were further supported by the Emory Principal Investigator’s efforts to promote CARES through conference presentations, connections in the physician community, and calling potential EMS agencies directly to discuss CARES.

Other effective strategies included showing EMS agencies the ease of using myCares.net to query data. Some agencies mentioned this as a reason for joining CARES. Also, word-of-mouth recruitment from existing CARES EMS agencies allowed potential EMS agencies to understand the data collection process from an existing CARES agency. A few EMS agencies reported encouraging hospitals to participate in CARES by announcing that they would no longer transport OHCA cases to non-participating hospitals. This strategy was noted as more appropriate in urban areas where there was a wide selection of hospitals.

Existing Relationships. Existing collaborative relationships among agencies and hospitals in the community facilitated initiation and implementation of CARES. Administrators with hospital ties participated in physician meetings at the hospitals where they were able to share the benefits of CARES. A few administrators worked with physician associates at hospitals with fewer cardiac arrest cases to retrieve outcomes data. One case study agency cited the tight-knit EMS community as a factor in easily obtaining agency and hospital participation. Similarly, if an agency established a relationship with one or more hospitals in the area, it was easier to recruit the remaining hospitals.

“If you have ten hospitals in the community and if you can get six of them—usually the bigger ones first because they often drive the behavior—then you’ll get the last four.”
- CARES Respondent

3.3 Outcomes

Key informants, focus group participants, and case study administrators and staff were asked to describe the accomplishments of CARES and how registry data are generally used. Respondents were asked to provide their perspectives on the accomplishments and goals attainment related to mortality reductions, strengthened collaborations, feasibility of the implementation process, and TA provided to utilize CARES data for performance improvement. Findings for this evaluation topic area fell into two categories:

- Program outcomes
- Registry outcomes

3.3.1 Program Outcomes

The majority of respondents mentioned gaining access to data from three different systems, creating beneficial relationships, both within and outside the EMS community, as well as the number of participants recruited and maintained in CARES, as accomplishments of the program.

Access to Data. CARES provided an opportunity for participating EMS agencies and hospitals to collect standardized OHCA data elements across two silo systems, allowing communities to use this information for program improvement and decision making. Access to reliable data was facilitated by support and TA from Emory to reduce data confidentiality concerns, a streamlined standardized data collection across three systems, and data audits and feedback on 100% of registry cases by Emory.

Strengthening of Relationships. Two EMS agencies reported a closer relationship with the hospitals as an added benefit of CARES. A CARES focus group respondent discussed how

collaboration on CARES led to the creation of a new EMS liaison position at local hospitals. A case study administrator said collaboration with hospitals on CARES has opened the door to obtaining other kinds of outcomes data.

Growth and Sustainability of Registry. CDC and Emory key informants cited the number of EMS agencies currently participating in CARES and the 100% retention rate as an accomplishment. Since CARES was first initiated, Emory has been able to expand the registry from 5 agencies in the Atlanta area contributing data in 2005 to 70 agencies participating in 2010. More agencies have expressed interest in joining CARES, and a statewide model is being piloted in four states.

3.3.2 Registry Outcomes

Respondents noted that the CARES registry has created awareness in the EMS community regarding the need to collect cardiac arrest data and the benefit of the data to the community. The majority of CARES Administrators said they review the CARES data, particularly the pre-packaged reports such as the Utstein report, available through myCares.net. The frequency of review varied by agency from every month to every few months or quarterly, depending on the number of cases. EMS agencies reported utilizing CARES data in the following ways.

Identify Training Needs. Data are used to identify training needs for the community as well as EMS staff. For example, administrators have compared their agency's statistics related to bystander CPR with other agencies, and based on the results, successfully advocated for public awareness campaigns, workplace training, and changes to the 911 protocol to increase bystanders' use and effectiveness of CPR.

Monitor Performance and Program Improvement. The most common use of the data was to monitor performance and track program improvement. Agencies used CARES data to track improvements related to interventions, such as chest compression re-training for EMS workers, modifying 911 instructions and dialogue, and adding AEDs in workplaces. At one agency, a number of system improvements and provider trainings were undertaken to increase OHCA survival. Survival rates for bystander-witnessed ventricular fibrillation increased from 32% to 52%. Another agency published the results of its protocol changes that impacted OHCA survival in a peer-reviewed journal. Agency staff also mentioned how outcomes data are used to acknowledge the work of EMS personnel in saving lives.

Benchmark Reports to Compare Performance. Although most case study agencies collected cardiac arrest data prior to CARES, only a few had access to, or used, hospital outcomes data.

“What CARES then will give us, always, is a way of benchmarking against other communities and seeing if our trends are just national trends or statewide trends, or if it’s something that we’re actually doing here. We’ll always be a member because of that.”
- CARES Agency Administrator

“It helps us with the program we’ve put together to address community CPR CPR training, because now we know kind of where they are. ... it allows us to know that’s going on. If we weren’t tracking that, we would have no idea.”
- CARES Agency Administrator

The data available prior to CARES were hard to use in an analysis because there was no comparison point other than previous agency performance. The CARES benchmarking reports allow agencies to compare their performance against other agencies, as well as against the national benchmark statistic. This comparison gives agencies a perspective on what is possible.

To Obtain Political and Financial Support. Many agencies also shared CARES data with stakeholders to demonstrate that the EMS agency is doing its job, to advocate for resources, or to be accountable to taxpayers. Stakeholders included other CARES agency staff, EMS agencies or advisory boards, the fire department, city quality improvement committee, hospital physicians committee, or the Mayor.

In addition, CDC and Emory respondents shared the ways they utilized CARES data.

Monitor OHCA Events. CDC uses CARES data to monitor the number of OHCA cases. A CDC key informant said:

“CDC primarily uses it to monitor out-of-hospital cardiac arrests cases. We don’t really have a national system, so we rely on this CARES network to get a feel for how prevalent these events are and what some of the issues are surrounding it.”

Emory conducts data analyses to produce the national CARES report for CARES agencies. CDC’s statistical unit also conducts analyses to post survival data trends and maps on the CDC website.

Publications and Presentations. CDC and Emory collaborated on publications for peer-reviewed journals, such as the *Journal of the American Medical Association (JAMA)*, and recently published a CARES report for the *Morbidity and Mortality Weekly Report (MMWR)*. Emory also presented CARES information at the National Association of EMS Physicians (NAEMSP) conference.

3.4 Potential Future Directions

CARES is currently piloting a state-level model of implementation, in which state coordinators take over some of the Emory staff roles, such as the audit function. This model will allow for expansion of the program that cannot be currently accommodated by three Emory CARES coordinators. CDC and Emory find this model of expansion advantageous to CARES and participating EMS agencies. An Emory key informant mentioned that expanding at the state level could lead to collecting a more nationally representative sample and allow more to be done with the data. CARES EMS agencies also described a state-level model as beneficial, in terms of providing more comparable data. However, CARES EMS administrators and focus group participants mentioned potential challenges of expanding to the state level, including:

- Difficulty of ensuring consistent methodology for data collection across the state.
- Difficulty of auditing a large number of cases.
- Loss of a neutral, third party audit and thus loss of trust in comparison data.

- Challenges with obtaining data agreements and participation from a large number of hospitals.
- Logistics of maintaining data confidentiality for each participating community within the state.
- Financial ability to maintain a government-funded state coordinator position.

Future directions of CARES at participating agencies mentioned by respondents included different ways they would like to use CARES data, as well as expansion or improvement of CARES data collection. All agencies expressed that they plan to continue participating in CARES.

Use CARES Data To Improve Response. CARES agencies will continue to use data as a tool to measure results of efforts to improve cardiac arrest response. CARES agencies want to use data to compare the protocols used (compressions, ventilations, medications, etc.) and survival rates across communities to determine effective strategies. A strategy could also include establishing uniform resuscitation centers at hospitals offering in-hospital post-resuscitative care found to be effective. Data will also be used to launch community awareness and cardiac arrest CPR initiatives.

Geo-mapping. A few respondents shared an interest in conducting geographic information system (GIS) mapping of AEDs and cardiac arrests.

CARES Expansion. An interest was expressed in expanding CARES across local metropolitan areas or across the state to increase the benefit of participation. Others expressed the desire to add additional EMS agencies in their area to have more complete OHCA data for their city or county.

System Improvements. One suggestion was for CARES agency staff to meet others using the same ePCR product to discuss best practices or standards for the ePCR product.

4. SUMMARY RECOMMENDATIONS

In this section we highlight the main conclusions from the evaluation and offer recommendations for the CARES program for all primary stakeholders: CDC, Emory, CARES EMS agencies and vendors.

Centers for Disease Control and Prevention

CDC may consider the following recommendations to further support Emory in their efforts.

Collaborate with Emory to:

- Develop a more feasible and efficient audit process, including
 - statistical data check strategy to identify irregular data patterns or compare frequency

distributions across agencies to identify abnormal variations with the data.

- sampling plan for case review.
- Strengthen statistical analysis expertise.
- Support a full time IT position to maintain and update the CARES data collection system.
- Create a CARES brochure describing the existing research on OHCA for hospitals and EMS workers to assist with recruitment of hospitals.
- Identify appropriate contacts for a potential state model of CARES.

CDC may consider the following recommendation to move toward a more sustainable program.

Classify OHCA as a Reportable Condition: One suggestion was to work toward making sudden cardiac arrests a mandatory public health reportable condition or including the collection of OHCA data in a system such as CARES in the Healthy People 2020 initiative. Communities would be required to collect this type of information and there would be more buy-in from EMS workers entering the data. The large customer base for vendors would be influential.

Emory University

As the lead developer and coordinator of CARES, the majority of recommendations are directed to Emory University. These suggestions covered a number of areas such as implementation, including recruitment and data processes, outcomes, future directions, and sustainability of the program.

Implementation

- **Recruitment:** The recruitment of agencies and hospitals to CARES has been a success. The future challenge is to manage the number of existing CARES agencies while continuing to grow the registry. Possible recommendations include:
 - Use a system to track EMS agency interest and infrastructure and to group agencies by state.
 - Recruit agencies located near existing CARES agencies to take advantage of participating hospitals and to gain access to regional registry data.
 - Recruit agencies using ePCR vendors with successful CARES extract programs.
 - Gradually recruit agencies to help Emory staff provide the programmatic and analytic support needed for new agencies, while maintaining support for existing CARES agencies.
 - Identify a CARES champion. The Emory Principal Investigator has been essential to the recruitment of EMS agencies for CARES through conferences or word of mouth from other CARES participants, increasing interest in CARES and the numbers on the waiting list.
 - Develop an active CARES marketing campaign.
- **Training:** The training Emory provides to agency and hospital staff is efficient and effective. In order to ensure consistency, particularly with staff turnover and increasing numbers of agencies and hospitals, additional training formats and materials are needed. For example:
 - Provide annual refresher trainings to agency and hospital staff.
 - Ask agencies to share training dates and reminders with other agencies.
 - Consider including “test” cases to verify that all CARES agencies and hospitals are handling data in the same manner.

- Train agency IT and data entry staff on CARES terminology.
 - Provide technical support for searches and queries on the CARES website.
 - Develop a Frequently Asked Questions document on CARES variables for EMS workers.
 - Support a CARES agency discussion group log.
- **Data Collection:** Recommendations to improve the collection of CARES data include:
- Work with NEMESIS and other registries and research studies to overlap as many data elements as possible. Provide data vendors with the overlap of CARES and NEMESIS elements and justification for CARES elements that do not overlap with NEMESIS.
 - Consult data vendors early in the process when considering changes to CARES and allow about a year lead time for making any changes.
 - Establish ePCR automation at all CARES EMS agencies. One suggestion is to incentivize (non-financially) vendors for being CARES compliant.
 - Set consistent standardized data collection methods. For example,
 - Identify who will collect data.
 - Provide standard protocols or methods for the collection (for example, the order and wording of data elements), entry, and review of data across agencies for consistency.
 - Reduce the variation in how the CARES elements are collected in ePCRs.
 - Standardize the process to determine cardiac etiology across CARES agencies.
 - Make the inclusion and exclusion of cases more consistent.
 - Work with vendors to automate the identification of cases in a similar fashion and train agency staff to use the same algorithm.
 - Preserve the original data for greater consistency across agencies by using a data or comment field to indicate that additional data (such as a coroner's report) would change or not change the original decision of cardiac etiology. This will also allow for statistical analysis of the degree to which arrest cases of cardiac etiology may be overestimated and to what extent the survival rate may be impacted.
- **Data Entry:** Develop or disseminate different training methods and materials helpful for CARES agency staff or EMS workers entering data, including:
- Develop a frequently asked questions list for CARES data entry staff with definitions of data elements most commonly misunderstood, or provide clearer definitions in the data dictionary.
 - Use pop-up help boxes within the CARES data entry system to provide definitions.
 - Provide CARES training documentation to first responders.
 - Provide a CARES training manual with telephone or email assistance.
 - Provide a data dictionary to keep at stations for data entry staff.
- **Data Audit Process:** Automating the audit process was the most frequently mentioned recommendation to reduce burden for both Emory and CARES agencies in preparation for potential growth of the registry. This process could be streamlined if Emory and Sansio had additional resources to improve the programming, and if Emory received assistance with developing statistical programming data checks and sampling cases to review. Possible audit automation improvements include:
- Flag cases requiring review in myCares.net as a part of the agency's CARES dashboard.
 - Track cases already changed or reviewed by the agency within myCares.net. This feature would allow EMS agencies to review cases over time without having to manually record which cases they have already finalized and to maintain an audit trail of changes.
 - Enable all audit communication to occur within myCares.net, enabling Emory and CARES agency staff to communicate regarding specific audit questions within the website.

- Program myCares.net to conduct automated checks.
- Include validation rules in myCares.net to prevent data entry errors such as skipping critical data elements or logic inconsistencies.
- Limit misspellings by providing drop-down boxes or auto-fill for data such as addresses.
- Provide an easy way to enter a custom date range in the CARES search function.
- Include a search by ID function to easily locate cases.

Program and Registry Outcomes

- **Enhancement of myCares.net Reports:** The myCares.net reports are widely used, but the CARES data have even greater potential. Administrators and staff provided a number of suggestions for how to improve the reports.
 - Provide the ability to compare similar agencies (e.g., size, type of location) in a blinded fashion.
 - Create more reports in graphical format (for example, bar or line graphs) for EMS agencies to share with stakeholders.
 - Conduct geographic mapping of CARES data for each locality or each agency participating in CARES.
 - Provide countywide data reports.
 - Export CARES data to Excel, allowing EMS agencies to conduct additional data analyses or create custom Excel charts or graphs. Having CARES data available in Excel format helps EMS agencies use the data for purposes other than the reports available in myCares.net.
 - Design ad hoc reports with flexible selection options within myCares.net for EMS agencies to run at their convenience. Reports of interest include: 1) performance over time within different time periods such as quarterly or yearly; and 2) Utstein rates by different variables such as age, location, or hypothermia treatment.
 - Other suggestions for CARES data reports include: 1) look at the entire community system of care versus the EMS system (in-hospital variables affecting survival may differ in different communities); 2) use an agency-based database to collect outcomes on all cases instead of only cardiac etiology cases; and 3) review cases with a neurologically intact outcome to see what procedures were administered.
- **Extend Reporting Functions to Hospital Staff:** Currently, hospital staff entering CARES outcomes data do not receive feedback on data entered. Added value to participating hospitals would be to access reports on the outcomes information entered. Examples of reports include the number of patients receiving hypothermia, the number of patients going to the catheterization lab, and the number of patients receiving CPR, along with survival information to provide to hospital administration. This feedback could help foster more engagement in the data collection process.
- **Add Additional Outcomes and Data Elements:** CARES could add other outcomes and data elements to data collection in order for EMS agencies to use the data for multiple purposes or to make further improvements to EMS response to cardiac arrest. Possibilities include other pre- and in-hospital procedures, such as cooling, double defibrillation, advanced airways, and basic life support chest compressions, to monitor effectiveness of procedures. Also data on other medical or traumatic arrests, or acute coronary syndromes, STEMI, or stroke could be useful to participating CARES agencies. However, it's important to acknowledge the balance required between collecting important data elements and not overloading staff with data collection.

Future Directions and Sustainability

- **Develop External Partnerships:** CARES could form partnerships with external organizations to obtain additional funding to help sustain CARES or for other research purposes. Potential partnerships could be with OHCA quality assurance program initiatives or with cardiac arrest device companies. EMS agencies participating in CARES may consider partnering with teaching hospitals, which typically have the infrastructure to conduct research.
- **Program Expansion:** Emory may consider extending the CARES program to underserved areas, such as American Indian or Alaskan Native areas, or to less urban areas in the future. CARES also has the potential to expand internationally and add to the knowledge base. Emory has collaborated with a Pan-Asian group to collect OHCA data and other countries have expressed interest in using a software platform to collect OHCA data.

CARES Agencies

Recommendations for CARES agencies include:

- **Recruitment of Hospitals:**
 - Use Emory products to recruit hospitals.
 - Recruit larger hospitals first.
- **Vendor Selections:** CARES EMS agencies soliciting bids from ePCR vendors should
 - Talk to other CARES EMS agencies with experience with vendors.
 - Consider selecting an ePCR vendor already implementing CARES.
 - Ensure that the ePCR vendor works closely with the billing vendor for a smooth billing transition.
- **Data Collection:**
 - Request that CAD data be integrated with ePCR data so location coordinates and response time data are collected automatically.
 - Use response time data that is automatically extracted and make note of the data limitations. This will enable staff to avoid recalculating response times. Variation across agencies in how response times are adjusted adds more error.
 - Campaign for better communications systems that accurately track cell phone 911 calls.
- **Data Entry:**
 - Automate data entry systems and reduce variation of who is entering the hospital data.
 - Reduce the data collection burden for hospital staff by making improvements in the hospital systems.

Vendors

CARES ePCR vendors plan to continue to support CARES and have related data elements available as a part of their products. A few vendors have planned some possible improvements to the CARES portion of the ePCR product. One vendor is considering changing the ePCR product to have a section dedicated to CARES. This section will be pre-populated with information from the CAD, so EMS workers only need to complete remaining fields. Another vendor is working on including programming logic to require particular CARES questions and improve data quality.

Some specific suggestions for improving the data collection and entry process include:

- Add a text box for EMS agencies to specify location type and etiology when “other” is selected as a response.
- Add another response option for hypothermia treatment to indicate if it was not appropriate for the patient.
- Improve the data entry flow of response and treatment times.
- Keep element boxes for service dates and date of birth in consistent locations to prevent confusion.
- Integrate CARES data elements with NEMSIS data requirements.
- Group CARES elements to aid with interpretation.
- Auto-populate data in the CARES screen to avoid double data entry of CARES elements by EMS workers or the need for agency staff to search paramedic notes or recordings.
- Improve the vendor extract programs so data elements may be automatically sent to the registry rather than entered via desktop data entry.

APPENDIX A: CARES FUNDING ALLOCATIONS

The following outlines the funding amounts allocated by CDC for the CARES project; itemized by fiscal year (FY):

FY 2004 – 2006:	\$599, 957
FY 2007:	\$299,983
FY 2008:	\$299,000 (with \$54,065 of carryover)
FY 2009:	\$500,000
FY 2010:	\$500,000
FY 2011:	\$500,000

APPENDIX B: EVALUATION TOPICS AND SUBTOPICS

Category	Evaluation Topic	Subtopic
Relationships	Assessment of CDC/DHDSP support to Emory	<ul style="list-style-type: none"> • Financial support from CDC • Technical support from CDC • Other support needs
	Assessment of Emory support to CARES participants	<ul style="list-style-type: none"> • Type of technical assistance (TA) needed • Satisfaction with TA provided • Satisfaction with TA products (frequently asked questions, data use agreements, CARES data dictionary, etc.) • Satisfaction with website and other infrastructure support provided • Other support needs from Emory • Recruitment strategies
Implementation	Implementation process	<ul style="list-style-type: none"> • Implementation steps or models <ul style="list-style-type: none"> ○ Recruitment ○ Data collection ○ Data management
	Logistic, political, and motivational aspects	<ul style="list-style-type: none"> • Variation and adaptation across agencies • Barriers and facilitators to implementation and adoption
Outcomes	Accomplishments of the program	<ul style="list-style-type: none"> • Goal attainment including but not limited to: <ul style="list-style-type: none"> ○ Mortality reductions ○ Strengthened collaboration ○ Feasible process implemented ○ TA in utilization of CARES data for performance improvement
	Data use	<ul style="list-style-type: none"> • Use of CARES data to make decisions
Lessons Learned	Lessons learned that inform future planning	<ul style="list-style-type: none"> • Strategies for successful implementation to inform future participants
	Potential future directions	<ul style="list-style-type: none"> • Integration with data vendors • Integration with existing systems (e.g., NEMESIS) • Integration of CARES data changes • Integration with new program initiatives (e.g., state health department integration, reaching the underserved, etc.) • CARES program expansion to state level • Sustainability of CARES • Recruitment

APPENDIX C: CARES AGENCIES ATLANTA FOCUS GROUP MEETING

Agenda

Topic	Approximate Time
Housekeeping and Introductions	Working Breakfast 7:30 AM
Accomplishments of the CARES Program	8:00 AM
Definition(s) of successful implementation	8:30 AM
	Break 10:00 AM
Facilitators and barriers to successful implementation	10:15 AM
What is working well and what needs improvement re: data collection, audit process, data use	Working Lunch 11:30 AM
	Break 1:00 PM
Future directions of CARES and recommendations for program improvement	1:15 PM
	Wrap Up 3:00 PM

Agency Name	Contact	State	Year Began	Data Entry Method
Boston EMS	Sophia Dyer, MD	MA	2007	Desktop
Columbus Fire Department	Shawn Koser	OH	2007	Desktop
Contra Costa County EMS	Pam Dodson	CA	2009	Desktop
Durham County EMS	Kevin Underhill	NC	2009	Desktop
Gwinnet County	Mark Peters	GA	2005	Desktop
Nashville Fire Department	Chief Joaquin Toon	TN	2008	ePCR
REMSA	Adam Heinz	NV	2009	ePCR

CARES Agencies Focus Group Guide
Atlanta, GA
Thursday, January 27, 2011

WORKING BREAKFAST	7:30 AM
<p>Housekeeping Issues</p> <ul style="list-style-type: none"> • Lunch • Flow of day • Recording conversation • Expenses • Checking Out <p>CARES Evaluation Overview</p> <p>Introductions</p> <ul style="list-style-type: none"> • Battelle • CDC • Emory • Participants – name, your agency’s name, your position, how long you have been involved with CARES <p>Please share one accomplishment of CARES at your agency.</p>	
<p>We are interested in learning about the different ways that the CARES program has been implemented and in defining what is successful implementation. We will revisit this definition at the end of the meeting and make any edits if necessary after our discussion. What do <i>you</i> think defines successful implementation?</p> <p style="margin-left: 40px;"><i>Probe:</i> <i>Implementation support (political, financial, administrative)</i> <i>Collaboration (# of participating hospitals, strength of collaboration between agencies/hospitals)</i> <i>Collection and use of data</i> <i>Improved outcomes</i> <i>Role of CDC for success?</i> <i>Role of Emory for success?</i></p> <p>What is the primary goal of implementing CARES at your agency? Does the definition capture this? Is there anything missing?</p> <p>Given this definition, briefly describe where your agency is with implementation.</p>	
BREAK	

CARES Agencies Focus Group Guide

Atlanta, GA

Thursday, January 27, 2011

What are the facilitators to getting to successful implementation?

Probe:

Key partner or champion

Financial support

Staffing or training

What are the barriers to getting to successful implementation?

Probe:

Political will

Logistical issues (recruitment, staff time, training, ease of use)

Data collection issues (software, working with vendor, missing data, quality control process)

Financial support

Are there things that CARES staff could do to help achieve successful implementation?

Probe:

Technical support (support documents, meetings, website)

Are there strategies that you have identified to overcome barriers to successful implementation?

WORKING LUNCH

Data collection

What is working well?

Probe:

Working with ePCR vendors

Data entry system and data entry process

Staffing(availability, time, training)

Quality control steps

Data elements

What needs improvement?

Probe:

ePCR vendors

Desktop data entry (DDE) versus entering into web-based database

Real time data versus data entry at later time

CARES staff involved in data entry

Quality control steps

Staff availability and time

Missing data, quality control process, or staff training needs

CARES Agencies Focus Group Guide
Atlanta, GA
Thursday, January 27, 2011

<p>Data collection continued</p> <p>What needs improvement?</p> <p><i>Probe continued:</i> <i>Data entry system issues</i> <i>[For agencies using vendor] Logistical or technical issues working with vendor</i> <i>Data elements</i></p> <p>What would help improve the data collection process?</p>	
<p>Emory audit process</p> <p>What is working well?</p> <p><i>Probe:</i> <i>Timing of receiving audit results</i> <i>Communication between CARES agencies and Emory</i></p> <p>What needs improvement?</p> <p><i>Probe:</i> <i>Timing of receiving audit results</i> <i>Communication between CARES agencies and Emory</i></p> <p>What would help improve the audit process?</p>	
<p>Data use</p> <p>How are CARES data used?</p> <p><i>Probe:</i> <i>Guide EMS system improvements</i> <i>Improve emergency cardiac treatment</i> <i>Compare EMS system performance at local or national level</i> <i>Determine when and where cardiac events are happening</i> <i>Determine who is affected in community by OHCA</i></p> <p>Are there barriers to using CARES data?</p> <p><i>Probe:</i> <i>Ease of use (software, data exports, reports)</i> <i>Staff time</i></p>	

CARES Agencies Focus Group Guide
Atlanta, GA
Thursday, January 27, 2011

<p>Data use continued</p> <p>Are there kinds of technical assistance that would lessen barriers? If so, what kinds?</p> <p><i>Probe:</i> <i>Functionality of software or MyCARES website</i> <i>Data analysis plans</i> <i>Best practices for use and interpretation of reports</i></p>	
<p>BREAK</p>	
<p>How will your agency maintain the current implementation of CARES in the future?</p> <p><i>Probe:</i> <i>Review facilitators mentioned in morning</i> <i>Review barriers mentioned in morning</i> <i>Implementation support (political, financial, administrative)</i></p> <p>What are the potential future directions of CARES?</p> <p><i>Probe:</i> <i>Statewide expansion</i> <i>Increased collaboration for collecting CARES data</i> <i>Use of CARES data</i></p>	
<p>Reviewing the description we did earlier of successful implementation, are there edits needed after our discussion? If so, what are they?</p>	
<p>WRAP UP</p>	<p>3:00 PM</p>

APPENDIX D: CARES KEY INFORMANT INTERVIEWS, CONTACT SCRIPT AND GUIDES

Contact Script

E-mail subject line: Evaluation of CARES – Key Informant Interview

Hello [name of key informant],

I work for the Battelle Centers for Public Health Research and Evaluation and I'm part of the team conducting the Evaluation of the Cardiac Arrest Registry to Enhance Survival (CARES). As a part of this evaluation, we are conducting interviews with key stakeholders, including CDC staff and Emory CARES staff. We would like to conduct a telephone interview with you to better understand the context of CARES and challenges in establishing the program as well as to help answer evaluation questions related to the provision and receipt of financial and technical support. The telephone interview should take approximately 45 minutes.

Would you be available to participate in a telephone interview in the next two weeks? Please provide me with a few available times and the best number to reach you.

Thank you for your time.

CARES CDC/DHDSP Key Informant Interview Guide

Respondent ID _____

Location or Telephone Number _____

Date and Time Interview Conducted: Date: _____ Start _____ Stop _____

Interviewer: _____ Interview recorded: Yes ___ No ___

Hello. My name is [*Interviewer's Name*] and I work for Battelle Centers for Public Health Research and Evaluation. Battelle was retained by CDC to conduct an evaluation of the CARES program. I appreciate the time you are taking to speak with me. I am interested in learning about the implementation of the CARES program. The purpose of this interview is to help inform the development of program improvement recommendations for current CARES agencies and implementation strategies for future CARES participants.

This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time. We expect that the interview will take about 30-45 minutes.

I will be taking notes, but would like to record the interview to make sure that I accurately capture everything you say. Your name and personal identifiers will not be used in reporting the information.

Do you have any questions before I begin the interview?

May I turn on the recorder?

1. Please briefly describe your current role with the CARES program.

Probe:

Examples of your typical activities; are they:

Mainly administrative or management

Mainly technical

Reviewer/consultant

Mixed

- Has your role with the CARES program changed? If so, in what ways?

2. When did you begin working with the CARES program?

CARES CDC/DHDSP Key Informant Interview Guide

3. From your perspective, what is the primary goal of the CARES program?

Probe:

Near term vs long-term goal(s)

Shifts in goal(s) over time? Basis for shift

4. Since you began working with the CARES program, what have been the major accomplishments in the implementation of the registry?

Probe:

Planned accomplishments?

Unanticipated accomplishments?

5. There are several activities critical to a successful registry such as recruitment, data collection, and data management. I'd like to hear your view of how well you think CARES is being implemented at this time.

Probe:

Recruitment process (# of participants, methods to recruit additional agencies)

Data collection process (ePCR vendors and web-based, level of agency participation in data collection)

Data management and audit process

Mix of models given state expansion project

6. How is CARES registry data currently being used by CDC?

- Are there plans for CDC to use CARES registry data in other ways in the future?

7. How would you characterize CDC's relationship with Emory with regards to the CARES program?

- Since you began working with the CARES program, has the relationship between CDC and Emory changed?
 - If so, how?
- If more financial support was available from CDC for the CARES program, how would you prioritize the use of the extra funds?
- Are there any other types of support that CDC could provide Emory?

CARES CDC/DHDSP Key Informant Interview Guide

8. What is your assessment of the level of technical support provided by Emory for implementing the CARES program?

- What additional technical support from Emory would be helpful to the CARES program?

9. What would you say is the most significant challenge CDC has faced with the CARES program since you've been involved?

Probe:

Financial, political, or staffing

Collaborator relationships

Communication

Media

- Significant challenge faced by Emory?

Probe:

Financial, political, or staffing

Recruitment, data collection, registry management, quality control

Collaborator relationships

Communication

Media

- Significant challenge faced by agencies participating in CARES?

Probe:

Financial, political, or staffing

Communication

EMS Community

- Significant challenge faced by external stakeholders?

Probe:

Financial, political, or staffing

Communication

EMS Community

10. What will be the challenges CDC will face with the CARES Program in the next year?

- In the next 5 years?
- What sort of actions could help address these challenges?

CARES CDC/DHDSP Key Informant Interview Guide

11. What are some potential future directions for the CARES program?
12. In regards to our task, what do you hope is gained from the evaluation of CARES?
 - What types of “strategies from the field” would be useful to CARES participants?
13. How would you like to see the evaluation results (i.e. in what format, how long)?
14. Is there some other aspect of the CARES program implementation that you would like to add to what we have covered?

THANK YOU for taking the time to participate in this interview.

Respondent ID _____

Location or Telephone Number _____

Date and Time Interview Conducted: Date: _____ Start _____ Stop _____

Interviewer: _____ Interview recorded: Yes ___ No ___

Hello. My name is [*Interviewer's Name*] and I work for Battelle Centers for Public Health Research and Evaluation. Battelle was retained by CDC to conduct an evaluation of the CARES program. I appreciate the time you are taking to speak with me. I am interested in learning about the implementation of the CARES program. The purpose of this interview is to help inform the development of program improvement recommendations for current CARES agencies and implementation strategies for future CARES participants.

This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time. We expect that the interview will take about 30-45 minutes.

I will be taking notes, but would like to record the interview to make sure that I accurately capture everything you say. Your name and personal identifiers will not be used in reporting the information.

Do you have any questions before I begin the interview?

May I turn on the recorder?

1. Please briefly describe your current role with the CARES program.

Probe:

Examples of your typical activities; are they:

Mainly administrative or management

Mainly technical

Reviewer/consultant

Mixed

- Has your role with the CARES program changed? If so, in what ways?

2. When did you begin working with the CARES program?

3. From your perspective, what is the primary goal of the CARES program?

Probe:

Near term vs long-term goal(s)

Shifts in goal(s) over time? Basis for shift

4. Since you began working with the CARES program, what have been the major accomplishments in the implementation of the registry?

Probe:

Planned accomplishments?

Unanticipated accomplishments?

5. There are several activities critical to a successful registry such as recruitment, data collection, and data management. I'd like to hear your view of how well you think each of these is being implemented at this time. Let's start with EMS provider recruitment.

- EMS provider recruitment
 - What has worked well with recruitment of EMS providers?
 - What could be improved in the recruitment of EMS providers?
 - What motivates EMS providers to become part of CARES?
 - What are the logistical hurdles that must be overcome to participate in CARES?

Probe: software and hardware issues, training

- What are the political aspects of joining CARES?

Probe: recruiting hospitals, institutional barriers

- How have agencies dealt with the political aspects?

- What are the financial aspects of joining CARES?

Probe: recruiting hospitals, institutional barriers

- How have agencies dealt with the financial aspects?

- Registry data collection

- What is working well in terms of data collection?

Probe: real time data versus data entry later, adding data elements, desktop data entry (DDE) versus an electronic patient care reporting (ePCR) vendor

- What needs improvement in terms of data collection?

Probe: real time data versus data entry later, adding data elements, desktop data entry (DDE) versus an electronic patient care reporting (ePCR) vendor

- Registry management
 - What are the successes with managing the registry?
 - What are the challenges with managing the registry?
- Registry data quality control
 - What is working well in terms of the audit process?
 - What needs improvement in terms of the audit process?
- Use of registry data
 - How is registry data being used by Emory CARES staff to guide EMS system improvements?
 - In what other ways is the registry data being used by Emory CARES staff?

6. How would you characterize Emory's relationship with CDC with regards to the CARES program?

- Since you began working with the CARES program, has the relationship between Emory and CDC changed?
 - If so, how?
- What is your assessment of the level of technical support from CDC for implementing the CARES program?
 - What additional technical support from CDC would be helpful to the CARES program?
- If more financial support was available from CDC for the CARES program, how would you prioritize the use of the extra funds?

- Are there any other types of support that CDC could provide Emory?

7. What would you say is the most significant challenge Emory has faced with the CARES program since you've been involved?

Probe:

Financial, political, or staffing

Collaborator relationships

Communication

Media

- Significant challenge faced by CDC?

Probe: CDC actions or guidelines

Financial, political, or staffing

Recruitment, data collection, registry management, quality control

Collaborator relationships

Communication

Media

- Significant challenge faced by agencies participating in CARES?

Probe:

Financial, political, or staffing

Communication

- Significant challenge faced by external stakeholders?

Probe:

Financial, political, or staffing

Communication

EMS Community

8. What will be the challenges CDC will face with the CARES program in the next year?

- In the next 5 years?
- What sort of actions could help address these challenges?

9. What are some potential future directions for the CARES program?

10. In regards to our task, what do you hope is gained from the evaluation of CARES?

- What types of “strategies from the field” would be useful to CARES participants?

11. How would you like to see the evaluation results (i.e. in what format, how long)?

Probe:

Written report

Executive summary

Tables

Presentation

12. Is there some other aspect of the CARES program implementation that you would like to add to what we have covered?

THANK YOU for taking the time to participate in this interview.

APPENDIX E: CARES VENDOR INTERVIEWS, CONTACT SCRIPT, INFORMATION SHEET, AND GUIDE

Contact Script

E-mail subject line: Evaluation of CARES – ePCR Vendor Interview

Hello [name of CARES Data Vendor],

I work for the Battelle Centers for Public Health Research and Evaluation and I'm part of the team conducting the Evaluation of the Cardiac Arrest Registry to Enhance Survival (CARES) for the Centers for Disease Control and Prevention (CDC). I am contacting you because your company works with CARES participants. If you are willing to participate in this project, we will schedule and conduct a 30-45 minute telephone interview with you. The telephone interview will include topics such as the electronic Patient Care Record (ePCR) product provided by your company for CARES participants, the process of updating the ePCR product with new CARES data elements, and how you work with CARES participants. An information sheet is attached if you'd like further information about the interview.

Would you be available to participate in a telephone interview in the next two weeks? Below are some possible date/time slots for an interview. If none of these times work with your schedule, could you please suggest some available dates and times?

[Day and time 1 – Tailor to vendor's time zone]

[Day and time 2 – Tailor to vendor's time zone]

[Day and time 3 – Tailor to vendor's time zone]

If you are able to participate, I will e-mail you a copy of the questions before the telephone interview. You may review these questions prior to the interview, which may help reduce the time needed for the interview if there is any information that you need to look up.

Thank you for your time.

Vendor Interview Information Sheet

What is the purpose of this study?

We are requesting your participation in a telephone interview as part of an evaluation of the CARES program. This component of the evaluation will help the Centers for Disease Control and Prevention (CDC) understand the electronic Patient Care Record (ePCR) products provided by data vendors for CARES participants, the process of updating CARES data elements as part of data vendors' ePCR products, and how data vendors work with Sansio and CARES participants. Overall, this evaluation will inform recommendations to improve the CARES program for current and future CARES participants.

Who is doing this study?

This study is being conducted for the CDC by Battelle Centers for Public Health Research and Evaluation, a non-profit research company.

What is my role in the study?

You are one of approximately six CARES data vendors that are being asked to participate in a telephone interview. The telephone interview is expected to last about 30-45 minutes. A copy of the interview questions will be provided to you before the interview.

What are the benefits to being part of this study?

There are no direct benefits for participating. However, sharing your opinions and your experiences with the CARES program will help inform the development of program improvement recommendations for current CARES participants and implementation strategies for future CARES participants.

What will happen to the information I share?

All information gathered in this study will be kept confidential and your privacy will be protected. All data will be presented in the aggregate. No information you provide will be associated with your name in any summaries or reports. A summary of information collected from your company and the final comprehensive report will be provided to CDC and Emory University.

Who do I speak to if I have questions about the study?

If you have any questions regarding this study please call Linda Wings, Task Leader, at Battelle Centers for Public Health Research and Evaluation at (206) 528-3151. If you have any questions regarding your rights as a study subject, please contact the Battelle Institutional Review Board at 1-877-810-9530, ext. 500, leave a message including your name and phone number, and your call will be returned as soon as possible.

Vendor Interview Guide

Respondent ID _____

Telephone Number _____

Date and Time Interview Conducted: Date: _____ Start _____ Stop _____

Interviewer: _____ Interview recorded: Yes ___ No ___

Hello. My name is [*Interviewer's Name*] and I work for Battelle Centers for Public Health Research and Evaluation. As was stated in the email sent to you, Battelle was retained by the Centers for Disease Control and Prevention (CDC) to conduct an evaluation of the CARES program. I appreciate the time you are taking to speak with me. This component of the evaluation will help the CDC understand the electronic Patient Care Record (ePCR) products provided by data vendors for CARES participants, the process of updating CARES data elements as part of data vendors' ePCR products, and how data vendors work with Sansio and CARES participants. Overall, this evaluation will inform recommendations to improve the CARES program for current and future CARES participants.

This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time. We expect that the interview will take about 30-45 minutes.

I will be taking notes, but would like to record the interview to make sure that I accurately capture everything you say. Your name and personal identifiers will not be used in reporting the information.

Do you have any questions before I begin the interview?

May I turn on the recorder?

Vendor Interview Guide

Vendor Background

Please provide a brief description of your company.

- When was it founded?
- How many customers does your company have in total?
- How many customers do you have for your company's electronic patient care report (ePCR) product?
- What is the geographic extent of your company's ePCR customers?

ePCR Product

Please provide a brief description of your company's ePCR product.

When was your company's ePCR product first released?

What have been the key dates and milestones in the ePCR product's development since release?

What type(s) of licensing does your company offer?

Probe: Perpetual? Subscription? Other?

Vendor Interview Guide

ePCR Product continued

How often are ePCR product updates provided to customers?

- What is the current version?

How are ePCR product updates provided to customers?

Probe: Via the Internet? CDs? Other?

CARES

How did your company learn about the Cardiac Arrest Registry to Enhance Survival (CARES) (e.g., customer, CARES staff)?

How many CARES customers does your company have?

Do all of your company's CARES customers have their Computer-Aided Dispatch system (CAD) data integrated with ePCR? If no, how many do not?

When were CARES data elements first included as part of your company's ePCR product (Version and Date)?

What has to happen in order to get the process of updating CARES data elements started once your company receives the updates from CARES?

Vendor Interview Guide

CARES continued

What factors influence the priority for updating CARES data elements in your company's ePCR product?

What steps are involved in incorporating CARES data elements into your company's ePCR product?

Of these steps, are there ones that are particularly challenging?

Have you implemented the January 2011 CARES data elements?

If no, why not?

Have you implemented the January 2011 data validation rules?

If no, why not?

Is the documentation CARES Emory staff provides adequate? If not, please describe why not.

Vendor Interview Guide

CARES continued

How many times did your company contact Sansio staff in 2010 with questions about the CARES data elements?

Are edits to CARES data elements included in your company's normal ePCR product releases? If not, why?

Does your company's ePCR product have an automated or scheduled process to send data to CARES?

- If yes, what is the frequency that data is sent?
- If no, please describe the manual process.

What benefits are there to implementing CARES data elements as part of your company's ePCR product for CARES customers?

- Benefits for non-CARES customers?
- Benefits for your product?

Vendor Interview Guide

CARES continued

What tips would you offer to future CARES EMS agencies to make the process smoother for you as the vendor?

What tips would you offer to CARES Emory staff to make the process smoother for you as the vendor?

What do you see as the future for your company's ePCR product and incorporating CARES data elements (e.g., technological changes)?

APPENDIX F: CARES ADMINISTRATION CASE STUDY CONTACT SCRIPT, INFORMATION SHEET, SURVEY, AND INTERVIEW GUIDE

CONTACT SCRIPT

Hello [name of Medical Director],

My name is *interviewer* and I am calling from the Battelle Centers for Public Health Research and Evaluation, a non-profit organization that has been hired under contract by the Centers for Disease Control and Prevention (CDC) to do a project to learn more about CARES. We will be conducting case study interviews with staff from 9 different CARES agencies.

I am contacting you because [AGENCY NAME] has been selected as a case study. If you accept, you will participate in a brief survey to be returned by e-mail or fax and a 60 minute telephone interview. The survey and telephone interview will include topics such as the implementation of CARES at [AGENCY NAME], challenges and lessons learned, technical assistance, and recommendations for future directions. Additionally, we will ask you to recommend 4-5 staff (for example, an EMS representative, hospital representative or other key project staff or stakeholders) to participate in a group telephone interview. The individuals recommended for the group telephone interview should be the staff with the most knowledge about CARES. If the staff members agree to participate, you will provide us with their contact information and we will contact them directly to schedule the group interview.

Are you interested in participating in the case study?

[if No] Thank you for your time.

[if Yes] Great! Before I proceed with scheduling your interview, I'd like to [confirm/ask you for] your e-mail address to send the brief survey.

E-mail address: _____

Thank you. I will be sending you the survey in the next few days. You may complete this survey electronically and return via e-mail or print the survey to complete hardcopy and return via fax. The survey will include the contact information needed to return the survey. We would like the survey to be completed prior to the scheduled interview so we can tailor the interview questions based on your answers.

Are you available to participate in an interview on [date(s) and time(s)]?

[Proceed with scheduling interview based on availability].

Do you have any other questions for me related to this project or the interview process? *[Address questions].*

Thank you very much for your willingness to participate in the project. If you have any further questions about the project, feel free to contact me at [phone number; email address]. I look forward to speaking with you on [Day] at [time].

CARES Administration Case Study Interview Information Sheet

What is the purpose of this study?

We are requesting your participation in a survey and telephone interview as part of an evaluation of the CARES program. This component of the evaluation will help the Centers for Disease Control and Prevention (CDC) understand how different agencies implemented CARES, the pros and cons of each model approach, challenges and facilitators to implementation, recruitment efforts, technical support required, data entry processes, and how data is being used. Overall, this evaluation will inform recommendations to improve the CARES program for current and future CARES participants.

Who is doing this study?

This study is being conducted for the CDC by Battelle Centers for Public Health Research and Evaluation, a non-profit research company.

What is my role in the study?

You are one of approximately nine CARES medical directors that are being asked to participate in a survey and an interview. A brief survey (10 questions) will be e-mailed to you. You may complete this survey at your convenience and return via email or fax. The telephone interview is expected to last about 1 hour. The interview will be conducted by research staff of Battelle Centers for Public Health Research and Evaluation. With your permission, the interview will be audio recorded for use by Battelle research staff only.

What are the benefits to being part of this study?

There are no direct benefits for participating. However, sharing your opinions and your experiences with the CARES program will help inform the development of program improvement recommendations for current CARES participants and implementation strategies for future CARES participants.

What will happen to the information I share?

All information gathered in this study will be kept confidential and your privacy will be protected. Records will be stored in locked offices and password-secured networks to which only study staff will have access. We will permanently erase all audio recordings when the study is over and we will archive program documents and the database containing transcripts with our project records at Battelle. The database, including the transcripts, will be destroyed two years after the contract ends. Neither the audio files nor the transcripts will be shared with CDC. All data will be presented in the aggregate. No information you provide will be associated with your name in any summaries or reports. A summary of information collected from your agency and the final comprehensive report will be provided to CDC and Emory University.

Who do I speak to if I have questions about the study?

If you have any questions regarding this study please call Linda Wings, Task Leader, at Battelle Centers for Public Health Research and Evaluation at (206) 528-3151. If you have any questions regarding your rights as a study subject, please contact the Battelle Institutional Review Board at 1-877-810-9530, ext. 500, leave a message including your name and phone number, and your call will be returned as soon as possible.

CARES Administration Case Study Survey

Please complete the following questions based on your experience with the Cardiac Arrest Registry to Enhance Survival (CARES). The information we request in the survey may at times require you to consult your records or to consult with other staff involved in CARES. The purpose of administering this survey prior to the case study interview is to allow you to look up information at your convenience. When we receive the completed survey, we will use the information to tailor questions and interview topics during our case study interview. Survey responses from all nine case study participants will be compiled and given to CDC without your names or without personal identifiers.

Please complete the survey electronically by XXXX, 2011 and return it via e-mail to Jaime Liesmann at liesmannj@battelle.org. If you prefer to complete the survey hardcopy, you may fax the survey to Jaime at 614-458-0437.

BACKGROUND

1. Did your community have an out-of-hospital cardiac arrest (OHCA) registry before joining CARES? Please click on () your response. Select ONE answer.

Yes No

2. How many emergency medical services (EMS) agencies are there in your jurisdiction? Please click in the grey box to type text.

STAFFING/RECRUITMENT

3. Roughly how many staff members at [AGENCY NAME] are involved in the implementation of CARES? Please click in the grey box to type text.

4. How many hospitals have been recruited to participate in CARES with [AGENCY NAME]? Please click in the grey box to type text.

CARES Administration Case Study Survey

CARES DATA

5. How is the CARES data collected by [AGENCY NAME] being used?
Please click on (☒) your response. Select ALL THAT APPLY.

Use of CARES data

- Compare EMS system performance at local or national level
- Guide EMS system improvements
- Determine when and where cardiac events are happening
- Determine who is affected in the community by OHCA
- Improve emergency cardiac treatment
- Other (Please describe) _____

6. How frequently do you review CARES data?
Please click on (☒) your response. Select ONE answer.

Frequency of CARES data review

- Weekly
- Bi-Weekly
- Monthly
- Bi-Monthly
- Quarterly
- Annually
- Other (Please describe) _____

TECHNICAL ASSISTANCE

7. During which phase or CARES component did you need technical assistance the most?
Please click on (☒) your response. Select ONE answer.

Phase/Component Requiring the Most TA

- Initial planning for CARES
- Recruitment
- Implementing CARES in the field
- Data entry
- Use of data
- Other (Please describe) _____

8. What types of technical assistance products from Emory have been most useful to you during the initiation

CARES Administration Case Study Survey

and implementation of CARES?

Please click on (☒) your response. Select ALL THAT APPLY.

Technical Assistance (TA) Products

- CARES Summary Document
- CARES EMS Dataset
- CARES Data Dictionary
- CARES IRB Approval and Modification
- CARES Hospital Data Use Agreement
- CARES EMS Data Use Agreement
- EMS Frequently Asked Questions
- Hospital Frequently Asked Questions
- Other (Please describe) _____

9. How satisfied are you with the CARES technical assistance provided by Emory?
Please click on (☒) your response. Select ONE answer.

Level of Satisfaction with TA

- Very Satisfied
- Satisfied
- Neither Satisfied nor Dissatisfied
- Dissatisfied
- Very Dissatisfied

CHALLENGES

10. Please briefly describe the main challenge [AGENCY NAME] has faced during the implementation of CARES? Please click in the grey box to type text.

CARES Administration Case Study Interview Guide

Hello. I am *Interviewer* and I work for Battelle Centers for Public Health Research and Evaluation. I appreciate the time you are taking to speak with me. We are interested in learning about the implementation of the Cardiac Arrest Registry to Enhance Survival (CARES) program. [AGENCY NAME], and eight other current CARES agencies, has been selected to participate in case study interviews. CARES administrators and other key CARES staff are being interviewed as a part of the case studies. The purpose of these interviews is to help inform the development of program improvement recommendations for current CARES participants and implementation strategies for future CARES participants.

This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time. We expect that the interview will take about 1 hour. You will not be compensated for this interview.

I will be taking notes, but would like to record the interview to make sure that I accurately capture everything you say. Your name and personal identifiers will not be used in reporting the information.

Do you have any questions before we begin the interview?

May I turn on the recorder? [If agree, begin recording.]

1. Please briefly describe your role with implementing CARES.

2. How is CARES being implemented at [AGENCY NAME]?

Probe:

Model being used for implementation

- How did [AGENCY NAME] determine the initial model of how CARES would be structured and managed?

3. How did [AGENCY NAME] recruit the [REFER TO THE NUMBER OF HOSPITALS PROVIDED IN SURVEY QUESTION 2] hospitals to participate in CARES?

- Is [AGENCY NAME] trying to recruit additional hospitals?
- What are the challenges [AGENCY NAME] faces in recruiting hospitals?

Probe:

Logistical issues such as software and hardware or staff training

Institutional issues such as IRB approval, data use agreements, or HIPAA concerns

Political barriers

Financial barriers

- How does [AGENCY NAME] overcome these challenges?

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4. Please describe the process of entering CARES data at [AGENCY NAME].

Probe:

Desktop data entry (DDE) versus entering into web-based database [REFER TO EMS PROVIDER CHARACTERISTICS]

Real time data versus data entry at later time

CARES staff involved in data entry

Quality control steps

- What influenced [AGENCY NAME]'s decision to use [a data vendor/desktop data entry] for CARES?
- What are the challenges to CARES data entry?

Probe:

Staff availability and time

Missing data, quality control process, or staff training needs

Data entry issues

[For agencies using vendor] Logistical or technical issues working with vendor

- How does [AGENCY NAME] overcome these data entry challenges?
- What improvements could be made to the data entry product used at [AGENCY NAME]?
- How are staff members participating in CARES trained at [AGENCY NAME]?

Probe:

Frequency/length of training

Type of training (presentation, workshop, one-on-one, refresher courses, manual)

Differences in training based on role

- Who conducts the training with the staff?

5. In the survey you indicated that CARES data collected by [AGENCY NAME] are being used to [REFER TO PURPOSES PROVIDED IN SURVEY QUESTION 3]. Can you please describe how CARES data are being used by [AGENCY NAME] for these purposes?

- You stated that CARES data are reviewed by [AGENCY NAME] [REFER TO FREQUENCY PROVIDED IN SURVEY QUESTION 4]. How are CARES data reviewed?
 - Who is involved in this process?

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6. Does [AGENCY NAME] utilize the tailored CARES reports available in myCARES?

- Do these reports meet [AGENCY NAME]'s needs? If no, how could they be improved?
- How frequently are CARES reports reviewed by [AGENCY NAME]?

Probe:

Types of reports viewed most often (statistics, graphs, charts, maps)

- Who is involved in reviewing the reports at [AGENCY NAME]?
- Are CARES data findings shared with agency stakeholders or other community stakeholders? If yes, how is CARES information shared?

Probe:

Types of stakeholders

Format of how data is shared (presentations, press release, publications, informal)

7. You indicated that [AGENCY NAME] needed technical assistance the most for [REFER TO PHASE/COMPONENT PROVIDED IN SURVEY QUESTION 5]. What types of technical assistance did you need from Emory during this phase/component?

- What other types of technical assistance did [AGENCY NAME] need during the initiation or implementation of CARES in your community?

Probe:

TA needed during different phases (recruitment, data entry, use of data)

- You selected [REFER TO TA PRODUCTS PROVIDED IN SURVEY QUESTION 6] as the most useful technical assistance product(s) to [AGENCY NAME] during the initiation and implementation of CARES. How has [AGENCY NAME] used these products?
 - What other types of technical assistance products would be helpful to [AGENCY NAME]?

Probe:

Products helpful during recruitment and initiation of CARES, data collection, and reporting

- In the survey you indicated that you were [REFER TO LEVEL OF SATISFACTION PROVIDED IN SURVEY QUESTION 7] with the technical assistance provided by Emory. Could you briefly describe your reasons for this rating?
 - [For rating of satisfied or below] How can technical assistance be improved?

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- Does the myCARES website provide the information [AGENCY NAME] needs for implementing CARES in your community?
 - What additional information or functionality would be useful to you on the myCARES website?

8. You described [REFER TO MAIN CHALLENGE PROVIDED IN SURVEY QUESTION 8 AND SUMMARIZE BRIEFLY] as the biggest challenge to implementing CARES in your community. Can you provide further detail on how this was a challenge to [AGENCY NAME]?

- How has [AGENCY NAME] overcome or worked to overcome this challenge?
- What have been the challenges to working with other entities in your state to implement CARES?
 - How has [AGENCY NAME] overcome these challenges?

9. What has been most helpful in implementing CARES in your community?

Probe:

Political support

Financial support

Strong collaboration/relationships

Technical assistance

- What facilitates or helps working with other entities in your state to implement CARES?
- What are the advantages to the CARES model of implementation used by [AGENCY NAME]?
- What are the disadvantages to the CARES model of implementation used by [AGENCY NAME]?

10. What have been the major accomplishments at [AGENCY NAME] since the implementation of CARES?

Probe:

Mortality reductions

Strengthened collaboration

Use of CARES data for performance improvement

Full implementation of CARES

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- What does [AGENCY NAME] hope to achieve in the future through the implementation of CARES?

11. What advice would you give to a new community joining CARES?

Probe:

Advice specific to planning, staffing, recruiting, data vendors, data collection, data use

- Would you recommend a particular implementation model for new CARES agencies?
 - Does the model depend on the characteristics of the community?

12. What are some potential future directions for the CARES program?

Probe:

State-wide expansion

Integration with existing systems (e.g., NEMESIS)

Integration with new program initiatives (e.g., state health department integration, reaching the underserved, etc.)

Integration with data vendors

- How does [AGENCY NAME] plan on continuing CARES in the future?

Probe:

Financial support

Stakeholder support

Staffing needs

- What are the challenges to sustaining CARES?
- What assists with sustaining CARES?
- How do you think CARES implementation will change at [AGENCY NAME] over the next five years?

13. Is there some other aspect of the CARES program implementation that you would like to add to what we have not covered?

Thank you for participating in this interview. We appreciate your time.

APPENDIX G: CARES STAFF CASE STUDY INFORMATION SHEET AND INTERVIEW GUIDE

What is the purpose of this study?

We are requesting your participation in a group telephone interview as part of an evaluation of the CARES program. This component of the evaluation will help the Centers for Disease Control and Prevention (CDC) understand the challenges and lessons learned in implementing CARES, accomplishments of the CARES program, and possible future directions for CARES. Overall, this evaluation will inform recommendations to improve the CARES program for current and future CARES participants.

Who is doing this study?

This study is being conducted for the CDC by Battelle Centers for Public Health Research and Evaluation, a non-profit research company.

What is my role in the study?

Staff members that work with approximately eight other CARES agencies will also be asked to participate in group interviews. The group telephone interview is expected to last about 1 hour. The interview will be conducted by research staff of Battelle Centers for Public Health Research and Evaluation. With your permission, the interview will be audio recorded for use by Battelle research staff only.

What are the benefits to being part of this study?

There are no direct benefits for participating. However, sharing your opinions and your experiences with the CARES program will help inform the development of program improvement recommendations for current CARES participants and implementation strategies for future CARES participants.

What will happen to the information I share?

All information gathered in this study will be kept confidential and your privacy will be protected. Records will be stored in locked offices and password-secured networks to which only study staff will have access. We will permanently erase all audio recordings when the study is over and we will archive program documents and the database containing transcripts with our project records at Battelle. The database, including the transcripts, will be destroyed two years after the contract ends. Neither the audio files nor the transcripts will be shared with CDC. All data will be presented in the aggregate. No information you provide will be associated with your name in any summaries or reports. A summary of information collected from your agency and the final comprehensive report will be provided to CDC and Emory University.

Who do I speak to if I have questions about the study?

If you have any questions regarding this study please call Linda Winges, Task Leader, at Battelle Centers for Public Health Research and Evaluation at (206) 528-3151. If you have any questions regarding your rights as a study subject, please contact the Battelle Institutional Review Board at 1-877-810-9530, ext. 500, leave a message including your name and phone number, and your call will be returned as soon as possible.

Hello. I am *Interviewer* and I work for Battelle Centers for Public Health Research and Evaluation. I appreciate the time you are taking to speak with me. We are interested in learning about the implementation of the Cardiac Arrest Registry to Enhance Survival (CARES) program. [AGENCY NAME], and eight other current CARES agencies, has been selected to participate in case study interviews. CARES administrators and other key CARES staff are being interviewed as a part of this case study. The purpose of this interview is to help inform the development of program improvement recommendations for current CARES participants and implementation strategies for future CARES participants.

This interview is voluntary. You have the right not to answer any question, and to stop the interview at any time. We expect that the interview will take about 1 hour. You will not be compensated for this interview.

Since this is a group telephone interview, please state your first name before answering each question so we know who is speaking. Please speak one at a time so we can accurately capture your comments. There may be some questions that do not apply to your role on CARES, so everyone may not be responding to each question.

I will be taking notes, but would like to record the interview to make sure that I accurately capture everything you say. Your name and personal identifiers will not be used in reporting the information.

Do you have any questions before we begin the interview?

May I turn on the recorder? [If agree, begin recording.]

1. Please briefly describe your role with CARES and how long you've been involved with the CARES program.

2. What are the challenges to CARES data entry?

Probe:

Staff availability and time

Missing data, quality control process, or staff training needs

Data entry issues

[For agencies using vendor] Logistical or technical issues working with vendor

- How do you overcome these data entry challenges?
- What improvements could be made to the data entry product used at [AGENCY NAME]?

3. Do you access the myCARES website?

[if YES]:

- What additional information or functionality would be useful to you on the myCARES website?

[if NO]:

- Why not?

4. Are you involved in the review of CARES reports?

[If YES]:

- How often do you review CARES reports?
- Does the content and format of the CARES reports meet your needs?

Probe:

Types of reports viewed most often (statistics, graphs, charts, maps)

- How could the CARES reports be improved?

[if NO]:

- What information, if any, do you receive about how well [AGENCY NAME] is responding to OHCA?

5. Did you receive any training for your role in the CARES program?

[if YES]:

- Who provided the training?
- Was the training provided for your role in CARES sufficient?

[if NO]:

- Would training have been helpful?

6. What types of training would be helpful to current or new staff participating in CARES?

Probe:

Frequency/length of training

Type of training (presentation, workshop, one-on-one, refresher courses, manual)

Differences in training based on role

7. What types of technical assistance do you need to implement CARES in your community?

Probe:

TA needed during different phases (recruitment, data entry, use of data)

- Have you used any technical assistance product(s) developed by Emory?

Probe:

Specific products used (CARES Summary Document, CARES Data Dictionary, CARES IRB Approval and Modification, CARES Hospital Data Use Agreement, CARES EMS Data Use Agreement, EMS Frequently Asked Questions, Hospital Frequently Asked Questions)

- [If yes] Did these CARES technical assistance products meet your needs?
- What types of CARES technical assistance products would be helpful to you?

Probe:

Products helpful during recruitment and initiation of CARES, data collection, and reporting

- How can technical assistance be improved?

8. What is the biggest challenge to implementing CARES in your community?

- How have you overcome or worked to overcome this challenge?

9. What has been most helpful in implementing CARES in your community?

Probe:

Political support

Financial support

Strong collaboration/relationships

Technical assistance

- What political support has helped to implement CARES?
- What has helped with strengthening collaboration in the community to implement CARES?
- What are the advantages to the CARES model of implementation used by [AGENCY NAME]?

- What are the disadvantages to the CARES model of implementation used by [AGENCY NAME]?

10. What have been the major accomplishments of CARES in your community?

Probe:

Mortality reductions

Strengthened collaboration

Use of CARES data for performance improvement

Full implementation of CARES

- Have there been any unanticipated or unexpected outcomes resulting from the implementation of CARES in your community?

Probe:

Positive or negative unanticipated outcomes

- What do you hope to achieve in the future through the implementation of CARES in your community?

11. What advice would you give to a new community joining CARES?

Probe:

Advice specific to planning, staffing, recruiting, data vendors, data collection, data use

- Would you recommend a particular implementation model for new CARES agencies?
 - Does the model depend on the characteristics of the community?

12. What are some potential future directions for the CARES program?

Probe:

State-wide expansion

Integration with existing systems (e.g., NEMESIS)

Integration with new program initiatives (e.g., state health department integration, reaching the underserved, etc.)

Integration with data vendors

13. Is there some other aspect of the CARES program implementation that you would like to add to what we have not covered?

Thank you for participating in this interview. We appreciate your time.