

Centers for Disease Control and Prevention (CDC) Atlanta, GA

October 13, 2020

Bryan McNally, MD, MPH
Executive Director
CARES: Cardiac Arrest Registry to
Enhance Survival
Emory University - Woodruff Health
Sciences Center
Mailstop 1599/001/1BQ
1599 Clifton Road NE
Atlanta, Georgia 30322

Dear Dr. McNally:

The Department of Emergency Medicine at the Emory University School of Medicine is collaborating with the Centers for Disease Control and Prevention (CDC) to conduct the Cardiac Arrest Registry to Enhance Survival (CARES) Program (see attached Memorandum of Understanding (MOU) executed on October 13, 2020). The purpose of CARES is to help local communities identify and track cases of out-of-hospital cardiac arrest (OHCA) and identify opportunities for improvement in the treatment and ultimate survival of such events.

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

Therefore, the CDC considers CARES to be a quality improvement intervention and public health surveillance activity, for which disclosure of protected health de-identifiable health information by covered entities is subject to 45 CFR § 164.512(b) of the Privacy Rule.

Sincerely yours,

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Robert K. Merritt Supervisory Health Scientist Division for Heart Disease and Stroke Prevention National Center for Chronic Disease Prevention and Health Promotion

MEMORANDUM OF UNDERSTANDING

Between

Emory University

AND

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division for Heart Disease and Stroke Prevention

This Memorandum of Understanding (MOU) sets forth the terms and understanding between Emory University (Emory) and Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Division for Heart Disease and Stroke Prevention (DHDSP), for purposes of providing a framework for engaging in activities relating to the Cardiac Arrest Registry to Enhance Survival (CARES) initiative. CDC and Emory may be individually identified in this MOU as "Party" or collectively referred to as "the Parties."

BACKGROUND

Cardiac arrest can strike a seemingly healthy individual of any age, race, ethnicity, or gender at any time in any location, often without warning. Cardiac arrest is the third leading cause of death in the United States, following cancer and heart disease. Four out of five cardiac arrests occur in the home, and more than 90 percent of individuals with cardiac arrest die before reaching the hospital.

In 2015, the National Academy of Science released "Strategies to Improve Cardiac Arrest Survival. A Time to Act", emphasizing the need for a national out-of-hospital cardiac arrest registry in the United States. The report highlighted "the large health burden of cardiac arrest, a national responsibility exists to facilitate dialogue about cardiac arrest that is informed by comprehensive data collection and timely reporting and dissemination of information. Reliable and accurate data are needed to empower states, local health departments, EMS systems, health care systems, and researchers to develop metrics, identify benchmarks, revise education and training materials, and implement best practices."

Without a uniform and reliable method of data collection, communities cannot measure the effectiveness of their response systems, nor can they assess the impact of interventions designed to improve OHCA survival. Participation in an OHCA registry enables communities to compare patient populations, interventions, and outcomes with the goal of identifying opportunities to improve quality

¹ IOM (Institute of Medicine). 2015. Strategies to improve cardiac arrest survival: A time to act. Washington, DC: The National Academies Press.

of care and ascertain whether resuscitation is provided according to evidence based guidelines.

CARES was developed to help communities determine standard outcome measures for out-of-hospital cardiac arrest (OHCA) locally allowing for quality improvement efforts and benchmarking capability to improve care and increase survival. Today, CARES is well positioned to be the National Cardiac Arrest Registry for the United States, developed in 2004 through a collaboration between the Centers for Disease Control and Prevention (CDC) and Emory University School of Medicine's Department of Emergency Medicine. In 2005, Atlanta, Georgia was the first community to begin data collection and has expanded to more than 28 state registries and an additional 50 communities in 13 states nationwide. CARES includes more than 1800 EMS agencies and 2,200 hospitals with a catchment area of 152 million. To date more than 500,000 patients have been entered in the registry. CARES uses an internet database system to register out-of-hospital cardiac arrest events, track patient outcomes with hospitals, and record response intervals associated with First Responder and EMS response. Three sources of data are linked into a single record to adequately describe each out-of-hospital cardiac arrest in CARES: 1) 911 call center data (to provide incident address, dispatch and arrival times), 2) EMS data (to describe presenting cardiac rhythm and treatment methods), and 3) hospital data (to document outcome at discharge). Multiple reporting features can be generated confidentially and monitored continuously through secure online access by CARES participants which allows for longitudinal, internal benchmarking. Local EMS administrators and medical directors can identify when and where cardiac arrest occurs, which elements of their EMS system are functioning properly in dealing with these cases, and what changes can be made to improve outcomes.

In operating the CARES registry, Emory is acting as a "public health authority "as that term is defined at 45 CFR 164.501 of the Health Insurance Portability and Accountability Act (HIPAA) regulations and, as such, Emory is authorized under 45 CFR 164.512 to collect and receive patient identifiable information from health care providers, including EMS providers and hospitals, that participate in the program for the purpose of conducting the CARES public health surveillance program.

PURPOSE

The essence of this MOU is to provide the framework supporting the parties' joint activities relating to the CARES initiative.

The parties acknowledge that this MOU documents and formally recognizes the continuing collaborative relationship between CDC and Emory for the operation of the CARES registry since the CARES registry began in 2004.

The goals of the partnership will be accomplished by undertaking the following activities:

ROLES and RESPONSIBILITIES

It is hereby agreed by and between the partners that this collaboration will support the following roles and responsibilities of each party as follows, and to the extent government resources and appropriations allow:

General:

- The spirit of this MOU demonstrates commitment to work collaboratively to achieve the goals of the CARES initiative.
- In a critical effort to standardize and improve registry data, CDC and Emory will work toward greater harmonization n of the relevant indicators tracking out-of-hospital cardiac arrest.
- CDC and Emory will collaborate on communications and promotion of CARES.

CDC agrees to:

- 1. Provide subject matter expertise on cardiovascular and stroke epidemiology, surveillance, and monitoring.
- 2. Provide subject matter expertise in GIS and mapping, including assisting the CARES team with generating maps.
- 3. Be a member of and actively participate on the CARES Oversight Board.

EMORY agrees to:

- 1. Continue to provide the CDC with de-identified US out of hospital cardiac arrest data for inclusion in their Data Trends and Maps Website, Interactive Atlas of Heart Disease and Stroke, or similar derivative products.
- 2. Continue to provide the CDC with de-identified Global out of hospital cardiac arrest data for future inclusion in their Data Trends and Maps Website, Interactive Atlas of Heart Disease and Stroke, or similar derivative products.
- 3. Provide subject matter expertise on EMS, resuscitation, and cardiac arrest protocols.

USE OFMARKS

Provision of assistance as intended under this MOU does not give EMORY or any of its partners or affiliates a blanket right to use the CDC logo. Permission to use the CDC logo must be obtained from CDC and is determined on a case by case basis. This similarly applies to the use of the Department of Health and Human Services (HHS) logo.

FUNDRAISING/SOLICITATION

EMORY will not use CDC or DHHS marks or slogans, or the existence of this partnership, for fundraising activities. EMORY will not imply that HHS or any component agency endorses any fundraising activities in connection with these activities.

PUBLICITY AND ENDORSEMENTS

EMORY shall not imply that the involvement of HHS or CDC in this is partnership serves as an endorsement of the general policies, activities, or products of EMORY; where confusion could result, publicity should be accompanied by a disclaimer to the effect that no endorsement is intended. EMORY will clear all publicity materialls for events with HHS and CDC to ensure compliance with this paragraph.

INTELLECTUAL PROPERTY

This MOU does not, and is not intended to, transfer to either party any rights in any intellectual property of the other party. HHS and CDC shall maintain full rights to re-use the content and material that it provides for any and all CDC purposes, and/or to share with other collaborators or requestors. Any report, article, or other paper prepared by employees of the Federal Government as part of their official duties is, under the U.S. Copyright Act, a "work of the United States Government" for which copyright protection under Title 17 of the United States Code is not available.

TRADE SECRET OR COMMERCIAL INFORMATION

CDC shall comply with 18 U.S.C. Section 1905, the Trade Secrets Act, and, to the extent applicable law allows, safeguard any EMORY proprietary and confidential information obtained pursuant to activities set forth in this MOU. EMORY shall clearly mark all information, in any format, of a proprietary and confidential nature provided to CDC, as such.

PUBLIC AVAILABILITY

This partnership agreement shall be publicly available.

LEGAL AUTHORITY

This MOU is authorized by Section 301(a) of the Public Health Service Act, 42 U.S.C. 241(a).

FUNDING

In general, each party is expected to bear the costs of its participation in this project. Nothing in this Agreement shall obligate EMORY, HHS, or CDC to any current or future expenditure of resources in advance of the availability of appropriations from Congress. CDC's participation in all aspects of this MOU is subject to availability of funds.

LIABILITY

Each party will be responsible for its own acts and the results thereof and shall not be responsible for the acts of the other party and the results thereof.

GOVERNING LAW

This MOU shall be governed by applicable federal law.

ENTIRETY

This MOU represents the entire agreement of the Parties with respect to the subject matter hereof and supersedes all prior and/or contemporaneous agreements or understandings, written or oral, with respect to the subject matter of this MOU.

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EFFECTIVE DATE

This MOU will become effective on the date of the last signatory to the agreement.

REVISIONS/AMENDMENTS

It is understood and agreed that the Parties may revise or modify this MOU by written amendment hereto, provided such revisions or modifications are mutually agreed upon.

TERMINATION

This MOU is entered into voluntarily by all Parties and may be modified by mutual consent of authorized officials from the EMORY and CDC. This MOU may be terminated by either party with thirty (30) days advance written notice. In the absence of a mutual agreement by authorized officials from the EMORY and CDC to continue to further this partnership, this MOU shall end on September 30, 2023.

Centers for Disease Control and Prevention (CDC)

By: Jobet & Menth
Print Name: Robert K. Merritt, MA, FAHA
Print Title: Acting Director Division for Heart Disease and Stroke Prevention (DHDSP) National Center for Chronic Disease Prevention And Health Promotion (NCCDPHP)
Date: 10/13/2020
Emory University
By:Bryun Maly, Mr. MPH
Print Name:Bryan McNally, MD, MPH
Print Title:Executive Director, CARES
Date:10/13/20