Review

The past, present, and future of the Cardiac Arrest Registry to Enhance Survival (CARES)

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Abstract

Background: The Cardiac Arrest Registry to Enhance Survival (CARES) was created in 2004 in collaboration with the Centers for Disease Control and Prevention (CDC) and Emory University School of Medicine's Department of Emergency Medicine. The registry allows local communities to benchmark their performance, enhance the quality of care, and increase survival rates for out-of-hospital cardiac arrest (OHCA).

Methods/design: CARES enrolls patients who experience a non-traumatic, EMS-treated OHCA. For each case, data is collected from three sources: 911 call center data, EMS data, and hospital data. CARES data is de-identified and stored in a secured web-based cloud platform and maintains confidentiality throughout the process. CARES data is subjected to an internal auditing system that oversees both local and regional levels. The variables in CARES adhere with the Utstein style reporting system and the National EMS Information System (NEMSIS) standard.

Discussion: As of 2023, CARES captures data from a population base of over 178 million people which accounts for 53% of the total U.S. population. Over the past two decades, CARES has consistently been a part of public health surveillance for OHCA and serves as a quality improvement tool to improve cardiac arrest outcomes. Moreover, CARES commits to facilitate observational research on OHCA, continues to modernize its software platform, and comprehensively expands its coverage for the entire U.S.

Keywords: Out-of-hospital cardiac arrest, Emergency Medical Services, Registry, CPR, Epidemiology

Introduction

The Cardiac Arrest Registry to Enhance Survival (CARES) was established in 2004 through a collaboration between the Centers for Disease Control and Prevention (CDC) and Emory University's Department of Emergency Medicine. CARES was created with the purpose of assisting communities in establishing standard outcome measures for out-of-hospital cardiac arrest (OHCA) by connecting the three key sources of data in the emergency cardiac care process: 911 dispatch centers, emergency medical services (EMS) providers, and receiving hospitals. CARES serves as a central OHCA data repository in the U.S. for public health surveillance, quality improvement and observational research related activities.

CARES began data collection in Atlanta, Georgia, with nearly 500 cases captured in 2006.[1] Presently, more than 500 cases are entered daily. As of 2023, CARES includes 34 states and 42 communities in 14 states, representing 53% of the U.S. population (approx-

imately 178 million people). A map of 2023 CARES participants is illustrated in Fig. 1.

In 2022, 147,736 non-traumatic EMS-treated OHCAs were reported to CARES. Bystander CPR was performed on 40.0% of patients and 11.3% of patients received bystander AED application when arresting in a public location. OHCA survival to hospital discharge was 9.3%, with nearly 80% of survivors having a favorable neurological outcome (Supplemental Appendix A1).

Methods

Registry design

CARES employs a national prospective, multicenter observational registry for patients with OHCA. Data collection adheres to the Utstein-style definitions and reporting guidelines for cardiac arrest, by the International Liaison Committee on Resuscitation (ILCOR), guidelines that have become a global standard for OHCA reporting.[2,3]
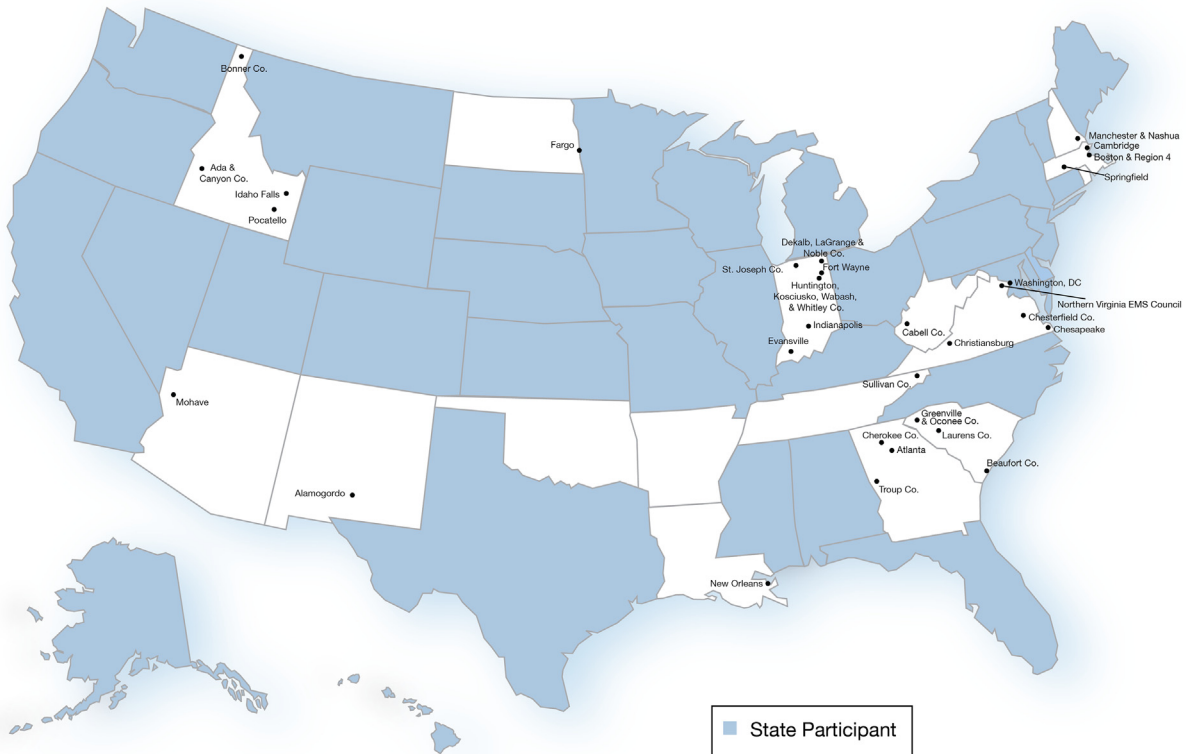
Fig. 1 – CARES 2023 Participation Map.

CARES captures data on all non-traumatic OHCAs where resuscitation is attempted by a 911 responder, who may be either a First Responder (fire, police) or an EMS responder. The resuscitation attempt refers to cases where patients have undergone initiation of CPR and/or defibrillation administered by a 911 Responder. This also includes patients that receive an AED shock by a bystander prior to the arrival of 911 responders. Exclusion criteria includes cardiac arrests where there is no resuscitation attempt upon the arrival of EMS and patients with obvious signs of death such as the presence of rigor mortis or lividity, signs of decomposition or the presence of a valid Do-Not-Resuscitate (DNR) order. Additionally, stillborn neonates/perinatal newborns without signs of life, private EMS transport that did not involve 911 dispatch, cardiac arrests of clear and obvious traumatic etiology, and bystander suspected cardiac arrest where ROSC was achieved without the need for defibrillation or 911 responder CPR are also excluded (Table 1).

Data collection and auditing process

The CARES web-based software (https://mycares.net), links three sources to describe each OHCA event: 1) 911 call center data, 2) EMS data, and 3) hospital data. Data can be submitted through two methods: using the data entry form on the CARES website, or automatically uploading from an agency's electronic patient-care record (ePCR) system. Data is initially linked between three sources by patient's name and date of birth (DOB), which are provided by the EMS agency. Once a record is determined to be complete by CARES staff, the record is de-identified, or "scrubbed", of patient name and DOB. In order for CARES to obtain a waiver for Health Insurance Portability and Accountability Act (HIPAA) consent, two conditions had to be met. 1) Patients' name and DOB needed to be de-identified after the record was fully audited and deemed accurate and complete 2) No contact could be made with a patient or family member after hospital discharge to respect their privacy.

CARES's hospital outcomes are collected by a local CARES contact person who is required by CARES to have access to hospital records to obtain data. CARES data are de-identified, encrypted and compiled by using a HIPAA–compliant, and securely stored in a web-based data management system (Emory-AWS Cloud). Access to the CARES website is restricted to authorized users, who are prohibited from viewing data from another agency or hospital. Hospital contacts can view, but they cannot edit the EMS portion of the CARES form for patients transported to their facility. EMS contacts likewise can view, but they cannot edit the hospital record. The only exception is that Integrated Health Systems have the option to request access to a centralized CARES account which allows them to view data at an institutional level.

CARES maintains a robust internal auditing process to ensure the integrity and accuracy of the data. Prior to gaining access to CARES, local EMS agency contacts undergo standardized training from a CARES Program or State Coordinator, which covers data definitions, the data collection process, and the various features of the CARES website. Various additional measures are implemented to guarantee the integrity and accuracy of the data, including integration of built-in software logic, an audit algorithm for consistent data

Table 1 – CARES inclusion and exclusion criteria.

Inclusion criteria (all of the following)	Exclusion criteria (any of the following)

• Patients of all ages who experience a non-traumatic OHCA
• Patients who are pulseless on arrival of 911 Responder; OR
	• Unworked/untreated cardiac arrests, to include codes that are terminated immediately upon arrival of EMS because the patient is not a viable candidate for resuscitation due to:
	  o Injuries incompatible with life.
	  o The presence of rigor mortis or lividity.
	  o Signs of decomposition.
	  o Presence of a valid DNR.

Patients who become pulseless in the presence of 911 Responder; **OR**	• Stillborn neonates/perinatal newborns, born without signs of life. • Private EMS transport that did not involve 911 dispatch (example: interfacility transport between nursing home and hospital). • Cardiac arrest of clear and obvious traumatic etiology. • Bystander suspected cardiac arrest, where ROSC was achieved without the need for defibrillation or 911 Responder CPR
Patients who have a pulse on arrival of EMS, where a successful attempt at defibrillation was undertaken by a bystander prior to arrival of 911 Responder.	

Abbreviations: CARES, Cardiac Arrest Registry to Enhance Survival; OHCA, out-of-hospital cardiac arrest; DNR, Do Not Resuscitate; ROSC, return of spontaneous circulation.

validation, and a biannual evaluation of population coverage and case ascertainment. Additional information about the CARES auditing process can be found in Supplemental Appendix A1.

CARES variables

CARES data collection follows Utstein-style definitions, a standardized template of uniform reporting guidelines for clinical variables and patient outcomes developed by international resuscitation experts. Mandatory data from EMS providers includes demographics, arrest-specific details, and resuscitation-specific information (Fig. 2). Optional elements cover additional intervention details, time-related information, and data from 911 call centers and receiving hospitals. CARES variables were first developed in 2004 by the CARES team, with input from an ad hoc panel that was convened at the National Association of EMS Physicians (NAEMSP) Annual Meeting.[1] CARES variables have been continuously updated based on new evidence and feedback from end users, State Coordinators, and the CARES Advisory Council. The CARES dataset and data dictionary were last updated in 2023, aligning with the National EMS Information System (NEMSIS v.3.5) and the Utstein template.

Data elements collected from EMS providers include demographics (i.e. name, age, date of birth, incident address, gender, and race/ethnicity), arrest circumstances (i.e. location type of arrest, witness status, and presumed etiology), and resuscitation-specific data (i.e. information regarding CPR initiation and/or AED application, defibrillation, initial arrest rhythm, return of spontaneous circulation [ROSC], field hypothermia, and pre-hospital survival status). EMS providers are also able to enter several optional elements, which further detail arrest interventions (i.e. usage of mechanical CPR device, impedance threshold device [ITD], 12-lead EKG, automated CPR feedback device, and advanced airway; administration of drugs; and diagnosis of ST-elevation myocardial infarction [STEMI]). The

CARES form also includes several optional time elements, including estimated time of arrest, initial CPR, defibrillator shock, sustained ROSC, and termination of resuscitative efforts. Supplemental data elements collected from 911 call centers include the time that the call was received, the time of dispatch for both first responder and EMS providers, and arrival time at the scene. Data elements collected from receiving hospitals include emergency department outcome, provision of therapeutic hypothermia/ targeted temperature management [TTM], hospital outcome, discharge location, and neurological outcome at discharge (using the Cerebral Performance Categories [CPC] Scale). Receiving facilities may also complete optional elements outlining hospital procedures, including coronary angiography, coronary artery bypass grafting [CABG], and stent or implantable cardioverter defibrillator [ICD] placement. The CARES dataset is geocoded on an annual basis and linked to several census-tract level variables including median household income, median age, race and ethnicity, unemployment rate, poverty status, urbanicity, and educational attainment.

Analysis and reporting

Local EMS agencies and hospitals have continuous access to their own data and can generate several reports related to 911 response time intervals; delivery rates of critical interventions such a bystander CPR, dispatcher CPR, and public access defibrillation; patient demographics; and community survival rates.

Once the dataset for each calendar year is finalized, CARES analyzes the national dataset and produces an annual report. This report includes key information about OHCA incidence, patient demographics, arrest etiology, location of arrest, witness status, initial rhythm, CPR provision, AED usage, and patient outcomes. Furthermore, each participating state, EMS agency, and hospital receive several

Fig. 2 – CARES Data Entry Form.

annual reports, enabling local stakeholders to assess and benchmark their performance, identify opportunities for improvement, and drive changes to strengthen the chain of survival.

Ethical and legal considerations

CARES was approved by the Emory University Institutional Review Board (IRB) and considered exempt from further review. The Center for Disease Control and Prevention (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. Participation in CARES by a covered entity is thus considered "healthcare operations". Healthcare operations are activities that are performed on a regular basis that include certain legal, financial and quality improvement activities that are necessary to perform its business and support patient care and payment. Data that is collected for quality improvement purposes would be considered part of hospital operations and does not need the same permissions that a research activity would involve.

CARES is not subject to Privacy Rule requirements for research activities or patient authorization and Emory University is not a covered entity. In operating the CARES registry, the CDC considers Emory to be 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.

Discussion

Point 1: Surveillance

The CARES registry functions as a repository database of OHCA. Data from CARES are frequently utilized to observe trends in OHCA survival.[4] During the COVID-19 pandemic, CARES facilitated tracking of OHCA by utilizing outcomes data linked to COVID-19 mortality data. This approach provided insights into whether communities with high mortality from COVID-19 would experience decreases in sustained ROSC, rates of termination of resuscitation, and overall survival to discharge. The effect of COVID-19 on the likelihood of sustained ROSC was profoundly decreased during the first weeks of the pandemic. The study successfully used CARES data to better understand the impact of OHCA outcomes, even in counties with a low COVID-19 mortality rate.[5]

CARES monitors data variation and collects aggregate metrics by state to enhance understanding of OHCA incidence, resuscitation outcomes, and bystander intervention rates throughout the country. Currently, there are 19 states that voluntarily participate in the public reporting of these metrics (Table 2).

Table 2 – Public Reporting of State Aggregate Metrics, 2022.

OHCA Incidence					Bystander Intervention Rates		Non-Traumatic Etiology Survival Rates	
	CARES Cases Reported	CARES Population Catchment	% Population Covered	Incidence Rate (per 100,000)	CPR (%)	Public AED Use (%)	Utstein Survival (%)	Overall Survival to Hospital Discharge (%)
National	**147,736**	**166,391,259**	**50.1%**	**88.8**	**40.0**	**11.3**	**30.7**	**9.3**
State								
Alaska	542	608,301	83.0%	89.1	73.2	18.8	42.5	12.7
California	26,403	32,866,592	83.8%	80.3	41.0	9.6	28.6	7.8
Colorado	3,711	4,581,690	78.8%	81.0	38.8	13.9	35.2	11.6
Connecticut	2,480	2,656,834	73.7%	93.3	22.8	6.0	34.0	9.5
Delaware	1,317	1,003,384	100.0%	131.3	37.0	9.0	41.5	10.6
Hawaii	1,693	1,441,553	100.0%	117.4	37.4	10.4	38.2	10.9
Maine	1,363	1,372,247	100.0%	99.3	52.2	14.6	20.1	7.6
Michigan	9,275	8,775,764	87.3%	105.7	35.6	9.1	25.2	8.1
Minnesota	3,293	4,701,076	82.4%	70.1	37.9	11.4	33.3	10.1
Mississippi	1,695	1,884,391	63.9%	89.9	38.7	9.9	23.8	6.3
Missouri	3,134	3,228,811	52.3%	97.1	40.0	15.4	35.9	10.0
Montana	660	977,094	88.5%	67.5	50.0	6.1	26.0	11.2
Nebraska	701	1,101,328	56.1%	63.7	50.1	12.0	37.4	15.4
North Carolina	9,117	9,224,576	87.4%	98.8	38.8	11.1	29.3	10.8
Oregon	2,940	3,569,007	84.1%	82.3	56.9	12.9	40.6	14.6
Utah	1,666	3,337,975	100.0%	49.9	37.2	9.2	32.5	10.2
Vermont	547	645,570	100.0%	84.7	48.7	14.6	20.0	5.5
Washington	5,342	7,581,064	98.0%	70.5	51.7	11.3	35.8	12.6
Wisconsin	3,482	3,861,611	65.5%	90.1	38.8	11.8	36.5	10.5
District of Columbia	917	670,050	100.0%	137.0	28.9	12.7	37.7	7.1

Footnotes:

Criteria for reporting: at least 50% population catchment in state; voluntarily reporting data.

Utstein: Witnessed by bystander and found in shockable rhythm.

Bystander CPR rate excludes 911 Responder Witnessed, Nursing Home, and Healthcare Facility arrests.

Public AED Use rate excludes 911 Responder Witnessed, Home/Residence, Nursing Home, and Healthcare Facility arrests.

Annual Estimates of the Resident Population for the United States, Regions, States, District of Columbia: April 1, 2020 to July 1, 2021.

Source: U.S. Census Bureau, Population Division

Point 2: Quality improvement

CARES serves a crucial role in improving the quality of cardiac arrest care by collaborating with local EMS agencies and hospitals. The program facilitates quality improvement (QI) analysis across the entire chain of survival, encompassing bystander, dispatcher, first responder, EMS, and hospital actions. As a feedback tool, CARES aids in identifying improvement opportunities and establishing best practices within communities, contributing to enhanced survival outcomes. The dispatcher-assisted CPR (DA-CPR) module allows local systems to collect data on cardiac arrest recognition by telecommunicators-CPR instructions, and initiation of bystander CPR before the arrival of 911 responders. Integrated into CPR Life-Links, the DA-CPR module supports the implementation of and education curriculum and quality improvement efforts, contributing to the establishment of a high-performance EMS T-CPR system. This comprehensive approach enables the measurement of care quality from 911 communication centers to EMS agencies, emergency departments (EDs), and in-hospital outcomes.

In North Carolina, CARES was utilized statewide between 2010 and 2013 to measure and enhance statewide initiatives aimed at improving bystander-initiated CPR and defibrillation by First Respon-

ders.[6] The Chicago Fire Department published on their successful temporal association between survival outcomes of OHCA and evidence-based interventions implemented across the entire system. Another notable initiative is the T-CPR module, highlighted in narratives from Dane County, Wisconsin where improvements led to a significant increase in bystander CPR intervention rates from 40.2% in 2021 to 62.8% in 2022. Further examples of QI initiatives are detailed in the "CARES in Action" section of the CARES Annual Reports (Supplemental Appendix A1). These initiatives collectively showcase CARES as a valuable tool in driving continuous improvement in cardiac arrest care at various stages of the response process.

Point 3: Observational research

Each year, researchers with an interest in analyzing state-level or national-level aggregate data use CARES data to conduct observational research, which helps communities better understand cardiac arrest exposures and outcomes, including social determinants of health. A CARES research publication in 2022 played a crucial role in addressing public health disparities in racial and ethnic differences in bystander CPR. The study utilized the dataset that was geocoded internally, and a de-identified dataset linked with neighborhood-level

variables was shared with the researcher to further investigate neighborhood-level socioeconomic status.[7] There are numerous other studies leveraging CARES data at both national and state levels to uncover ethnic minorities, geographic locations, sex differences, and socioeconomic influences on cardiac arrest survival. This information guides us to plan for implementing public health interventions to reduce outcome disparities in OHCA.[8–11] Data is owned locally by EMS agencies and hospitals that participate in the program. Data is aggregated for confidential benchmarking purposes. Access to state or national aggregate data requires a research proposal to the CARES Data Sharing Committee for approval. These committees evaluate the proposal for scientific merit and makes recommendations prior to releasing the dataset. The Data Sharing Proposal form and the list of CARES publications to date can be found on the CARES website.

The CARES dataset has resulted in 136 publications to date. Noteworthy recent studies include the comparison of cardiac arrest outcomes among Asian and White individuals, analysis of cardiac arrests due to drowning, assessments of bystander CPR's impact on long-term survival in older adults using Medicare data linked to CARES data, and the association between delays in bystander CPR and survival for witnessed cardiac arrests.[8,12–14] Another valuable application of using CARES location data involves constructing a GIS model mapping to assess ECMO eligibility based on clinical characteristics variables within the CARES registry. This study could form the basis for a future strategic implementation plan for prehospital ECPR program.[15]
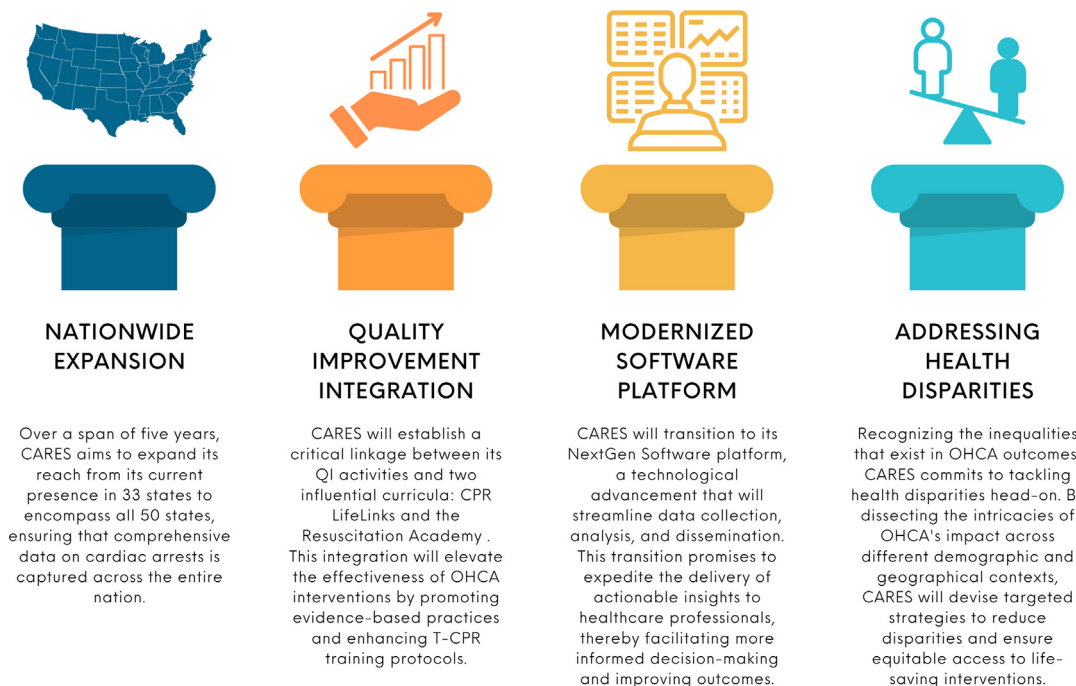
Point 4: CARES next generation software platform

The current CARES software application was modeled off an existing EMS data collection platform in 2005. Despite the expansion of the program since inception, it has incurred significant technical debt over the years due to being limited to the overall design, functionality, and programming code of the template application. CARES recognizes the essential need to modernize its software architecture, technology integrations, and platform design with the greater goal of supporting national expansion. This will require scaling the infrastructure and software capabilities of the platform as well as increasing the IT budget to accommodate growth. This CARES Next Generation (NextGen) application will be built during a 24-month period that began October 1st, 2023. The goal is to deploy a new CARES platform that strategically plans for scalability and includes improved data management tools and enhanced solutions for data visualization that will be ongoing beyond the official go-live date. CARES NextGen will be internationalized and made available globally to be hosted locally as a Software as a Service (SaaS) platform.

The NextGen Development Plan will consist of five phases. Phase One will focus on project planning and establishing the required internal and external development teams, while Phase Two will shift to the design and development of the NextGen platform. In Phase Three, the technical team will test and refine user interfaces while creating user documentation and training materials. The fourth phase will focus on deployment of the NextGen product and onboarding users to the new platform. The final phase, beyond initial release of NextGen CARES, will delve further into user evaluation and data analysis of the platform to establish a feedback process on the new system's performance that allows for continuous software development and optimization.

The software upgrade aims to enhance functionality and streamline workflow by providing a more efficient means of managing, auditing, and supporting the registry's participants. Agencies will be introduced to flexibility by being offered the ability to add optional

NATIONWIDE EXPANSION

Over a span of five years, CARES aims to expand its reach from its current presence in 33 states to encompass all 50 states, ensuring that comprehensive data on cardiac arrests is captured across the entire nation.

QUALITY IMPROVEMENT INTEGRATION

CARES will establish a critical linkage between its QI activities and two influential curricula: CPR LifeLinks and the Resuscitation Academy . This integration will elevate the effectiveness of OHCA interventions by promoting evidence-based practices and enhancing T-CPR training protocols.

MODERNIZED SOFTWARE PLATFORM

CARES will transition to its NextGen Software platform, a technological advancement that will streamline data collection, analysis, and dissemination. This transition promises to expedite the delivery of actionable insights to healthcare professionals, thereby facilitating more informed decision-making and improving outcomes.

ADDRESSING HEALTH DISPARITIES

Recognizing the inequalities that exist in OHCA outcomes, CARES commits to tackling health disparities head-on. By dissecting the intricacies of OHCA's impact across different demographic and geographical contexts, CARES will devise targeted strategies to reduce disparities and ensure equitable access to life-saving interventions.

Fig. 3 – CARES Expansion and Modernization.

fields to data collection that are commonly requested but not yet universal. The introduction of data visualization, interfacing with a third-party application to enable dynamic and customized reporting with minimal development, will be incorporated in CARES NextGen. An application programming interface (API) subscription, with the goal of reducing human workload, will facilitate improved data import and access.

Point 5: CDC CARES expansion and modernization grant

The CDC awarded the CDC CARES Expansion and Modernization Grant to Emory University in October 2023. CARES will receive $23.85 million in grant funding over the next five years which will advance the registry's impact and empower CARES to fulfill its mission. As depicted in Fig. 3, the grant will first provide more resources toward CARES' longstanding goal of expanding its coverage to include all 50 states, ensuring that comprehensive data on OHCA is captured across the entire nation. Second, CARES will invest in quality improvement efforts and technological updates and advancements to ensure more streamlined data collection, analysis, and dissemination. Using state-of-the-art software, CARES will be able to expedite the delivery of actionable insights to healthcare professionals, thereby facilitating more informed decision-making and improving patient outcomes. CARES will also establish a critical linkage between its quality improvement activities and two influential curricula: CPR LifeLinks and the Resuscitation Academy. This integration will elevate the effectiveness of OHCA interventions by promoting evidence-based practices and enhancing T-CPR and HP-CPR (high performance CPR) training protocols. Finally, this funding will bolster CARES' ongoing commitment to addressing health disparities through robust research and targeted interventions in the communities it serves. Data collection plays a key role in identifying where disparities exist, helping to determine how and why they happen, and helping local partners create improvement plans. Intervention strategies can include CPR training, improving access to AEDs, reducing risk factors, conducting bias training, or helping communities determine where they need to allocate more resources toward EMS in underserved areas.

Conclusion

Since its inception in 2004, CARES has provided insights to help communities better understand key indicators of OHCA and has assisted in identifying opportunities to improve prehospital care for cardiac arrest patients. In the next decade, CARES NextGen will be introduced to modernize its software platform, along with its plan to expand the coverage to capture the entire population of the U.S. and beyond.

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CRediT authorship contribution statement

Phudit Buaprasert: Writing – original draft, Methodology, Conceptualization. **Rabab Al-Araji:** Writing – original draft, Formal analysis, Conceptualization. **Monica Rajdev:** Writing – original draft, Methodology. **Kimberly Vellano:** Writing – original draft, Methodology. **Michael Carr:** Writing – review & editing, Supervision. **Bryan McNally:** Writing – review & editing, Supervision, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.resplu.2024.100624.

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