National Emergency Medical Services Advisory Council

INTERIM

Advisory and Recommendations

Title: Reducing Social Inequities in EMS through a National Out-of-Hospital Cardiac Arrest Registry

As prepared by the Subcommittee on Equitable Patient Care.

A. Executive Summary

Inequities in health outcomes exist for populations treated by EMS as they do for other populations who require health care. Inequities become apparent when one segment of the population experiences a different health outcome from another segment. Survival from out of hospital sudden cardiac arrest (OHCA) demonstrates disparities across the key domains of inequality: socioeconomic, political, health and culture, as well as the unequal distribution of both outcomes and opportunities that currently exist in the United States. (Carter et al, 2014) While some conditions such as cancer or traumatic injury benefit from near universal reporting to inform strategies for reducing mortality, OHCA reporting is sparse and incomplete due in part to the difficulties in collecting and reporting the data. This could be remedied by implementation of a national out of hospital cardiac arrest registry in which all US states participate.

In 2015, the Institute of Medicine (IOM) published a comprehensive report describing Cardiac Arrest in the United States. It was entitled "Strategies to Improve Cardiac Arrest Survival: A Time to Act." (Institute of Medicine, 2015) In this document, the IOM described wide variability in cardiac arrest survival rates between communities and hospitals and emphasized that these variations in outcome are disproportional and identified by individual demographics.

This committee believes that the establishment of a national cardiac arrest registry which collects comprehensive information about OHCA will offer the opportunity to understand the characteristics, causes and consequences of inequities in this realm. This registry would represent a rich source of information to inform our understanding of inequities and assist us to develop strategies for their management.

B. Recommendations

National EMS Advisory Council

N/A

National Highway Traffic Safety Administration

Recommendation 1:

The NEMSAC recommends that NHTSA continue to support the efforts to collect OHCA registry data in the National EMS Information System (NEMSIS) database.

Recommendation 2:

The NEMSAC recommends that NHTSA continue to seek strategies for developing a process to incorporate appropriate outcome measures in this registry.

Recommendation 3

The NEMSAC recommends that NHTSA should support efforts by states and territories to participate in a national OHCA registry.

Recommendation 4

The NEMSAC recommends that NHTSA should report to the NEMSAC on an annual basis, regarding the progress on collecting OHCA data from states as well as the success of integrating the acquisition and linkage of outcome data from hospitals into the NEMSIS database.

Recommendation 5

The NEMSAC recommends that NHTSA should make annual OHCA registry data easily accessible to researchers to encourage research and development of strategies to reduce disparities in survival from OHCA.

Other Department of Transportation

N/A

Federal Interagency Committee on Emergency Medical Services

Recommendation 6:

The NEMSAC recommends that FICEMS enlists the assistance of the National Committee on Vital and Health Statistics (NCVHS), the advisory body to the Secretary of Health and Human Services, to assist EMS to break through the barriers in obtaining outcome information relevant to OHCA from hospitals to which EMS transports these patients.

C. Scope and Definition

Out of Hospital Sudden Cardiac Arrest (OHCA) affects more than 356,000 individuals annually in the U.S., nearly 90% of them fatal. The incidence of OHCA in the U.S. remains high and survival remains low. Bystander intervention in the U.S. also remains low. (Viani et al, 2020) In 2017, laypersons initiated CPR in 39% of cases, used AEDs in just 6% of cases, and delivered a shock in approximately 2% of cases. (Cardiac Arrest Registry to Enhance Survival)

According to the 2020 report from the American Heart Association's (AHA) Annual Heart and Stroke Statistics update, the incidence of EMS-assessed non-traumatic OHCA in people of any age is estimated to be 356,461, or nearly 1,000 people each day. Survival to hospital discharge after EMS-treated cardiac arrest is about 10%. (Viani et al, 2020)

Despite being a leading cause of death in the U.S, there are currently no nationwide standards for surveillance to monitor the incidence and outcomes of cardiac arrest. Thus, registries and clinical trials are used to provide best estimates, including the Cardiac Arrest Registry to Enhance Survival (CARES).

The bulleted statistics below are excerpts from the American Heart Association's publication on heart and stroke statistics- update 2020. (Viani et al, 2020)

Cardiac Arrest in Adults

- Estimates suggest the incidence of EMS attended OHCA among adults is 347,322.
- The location of OHCA in adults is most often a home or residence (69.8%), a public setting (18.8%), or a nursing home (11.5%).
- OHCA in adults is witnessed by a layperson in 37% of cases or by an EMS provider in 12% of cases. For 51% of cases, OHCA is not witnessed.
- Survival to hospital discharge after EMS-treated cardiac arrest was 10.4% and survival with good functional status was 8.4%, based on CARES data for 2017. (Viani et al, 2020)
- Large regional variations in survival to hospital discharge (range, 3.4%-22%) and survival with functional recovery (range, 0.8%-20.1%) are observed in 132 counties in the U.S. Variations in the rates of layperson CPR and AED use explained much of this variation.
- Among adults treated by EMS, 25% had no symptoms before the onset of arrest.
- The initial recorded cardiac rhythm was VF (ventricular fibrillation) or VT (ventricular tachycardia), i.e., shockable by an AED in 18.7% of EMS-treated OHCAs in 2017.

Cardiac Arrest in Children

- Estimates suggest the incidence of EMS-assessed OHCA among children (<18 years of age) is 7,037.

- The location of EMS-treated OHCA was at home for 90.6% of children <1 year old, 81.2% of children 1-12 years old, and 75.7% for children 13-18 years old in the CARES 2017 data. The location was a public place for7.8% of children < 1 year old, 19.6% of children 1 to 12 years old, and 23% of children 13-18 years old.

- Survival to hospital discharge was 13.2% among children (8.2% with good neurological function).

- The incidence of non-traumatic OHCA was 1 per 43,770 athlete participant-years among students 17-24 years old participating in NCAA sports from 2004-2008. The incidence of cardiac arrest was higher among blacks than among whites and among males than among females.

D. Analysis

In 2018, registry data matched with outcomes are available for approximately 24% of the U.S. population via the CARES registry. There are significant barriers to collecting and entering OHCA data for individual EMS agencies. These barriers are currently being addressed by NHTSA with strategies in place for collection of the EMS portion of these data into the National EMS Information System (NEMSIS). Remaining barriers include participation from hospitals who may in some cases be reluctant to share the necessary outcome data, due to misconceptions around HIPAA, or to issues pertaining to ownership of data. There have been attempts by the EMS research community to explore mandatory reporting of Cardiac Arrest, however, the perceived barriers lie in the inability to convince local, state and territorial public health departments (jurisdictions) of the importance to use resources to participate in an endeavor such as the National Notifiable Disease Surveillance System (NNDSS) which is supported by the CDC Division of Health Informatics and Surveillance (DHIS).

The National Committee on Vital and Health Statistics (NCVHS) was established by Congress to serve as the statutory [42 U.S.C. 242k(k)] advisory body to the Secretary of Health and Human Services for health data, statistics, privacy and national health information policy and the Health Insurance Portability and Accountability Act (HIPAA). In that capacity, the Committee provides NCVHS is the advisory committee to HHS on health data, statistics, privacy, and national health information policy.

Investigation into this topic has revealed how alarmingly the U.S. lags behind other countries in addressing this public health crisis. Comprehensive registries currently exist and are used to improve care in multiple countries and consortiums including but not limited to the following:

- The Swedish CPR Registry
- The PAROS Clinical Research Network (Pan-Asian Resuscitation Outcomes Study)
    - Including 15 countries across the Asia-Pacific. Thailand, Pakistan, India, Vietnam, Philippines, Malaysia, Japan, Korea, UAE Dubai, Taiwan, China, Indonesia, Qatar, Abu Dhabi and Singapore
- The Canadian Resuscitation Outcomes Consortium Registry (Both Cardiac Arrest and Trauma)
- The International Cardiac Arrest Registry (INTCAR) a worldwide registry of post-resuscitation cardiac arrest care includes 83 participating hospitals; of which 73 are located in Europe/Asia and 10 in the Americas.
- European Registry of Cardiac Arrest. A centralized tool for quality management in resuscitation for those countries and regions not participating in other registries.
- The All Japan Utstein Registry
- The Out-Of-Hospital Cardiac Arrest Outcomes Registry in the UK for England, Scotland, Wales and Northern Ireland
- European Resuscitation Council
- Australian Resuscitation Consortium
- Out of Hospital Cardiac Attack Register, Ireland
- Austrian Resuscitation Council
- Fondazione Ticino Cuore, Switzerland
- Italian Resuscitation Council
- Registre electronique des Arrets Cardiaques, France
- Hart Voor Limburg, Netherlands
- German Resuscitation Registry, Reanimationregister
- Belgian Resuscitation Council
- Luxembourg Resuscitation Council
- Icelandic Resuscitation Council

- Romanian Resuscitation Council
- Serbian Resuscitation Council
- Danish Resuscitation Council
- Croatian Resuscitation Council
- Cyprus Resuscitation Council

The current understanding of the scope, cause and consequences of disparities in OHCA care is hampered by the lack of data- including the first order data showing patterns and trends in OHCA. More complete data and increased effort are needed to begin to demonstrate the consequences and of strategies for reducing disparities in the care of OHCA.

E. Strategic Vision

Our strategic vision is to have a nationwide OHCA registry that will allow us to (1) detect inequities in care and outcomes, (2) plan interventions that will address these disparities, (3) and evaluate the impact of those interventions.

F. Strategic Goals

1. NHTSA should continue to support the efforts to collect OHCA registry data in the National EMS Information System (NEMSIS) database. This should include support of strategies for collecting and linking outcome data. A report on the progress in establishing a national OHCA registry should be made available on an annual basis.

2. NHTSA should ensure that annual out-of-hospital cardiac arrest data be easily accessible to researchers so that they may contribute to the development of a robust OHCA registry. This registry would allow interested parties to develop and test strategies for reducing disparities in survival from OHCA.

3. FICEMS enlists the assistance of the National Committee on Vital and Health Statistics (NCVHS), the advisory body to the Secretary of Health and Human Services, to assist EMS to break through the barriers in obtaining outcome information relevant to OHCA from hospitals to which EMS transports these patients. Guidance would be welcome on this topic by July 2023 and should be disseminated via the NHTSA website

G. References

1. Carter, P. L., & Reardon, S. F. (2014, September). *Inequity matters*. Stanford University William T. Grant Foundation. https://ed.stanford.edu/sites/default/files/inequalitymatters.pdf

2. Institute of Medicine. (2015). *Strategies to improve cardiac arrest survival: A time to act*. The National Academies Press.

3. Viani, S. S., Alonso, A., Benjamin, E. J., Bittencourt, M.S., Callaway, C. W., Carson, A. P., Chamberlain, A. M., Chang, A. R., Cheng, S., Delling, F. N., Djousse, L., Elkind, M. S. V., Ferguson, J. F., Fornage, M., Khan, S. S., Kissela, B. M., Knutson, K. L., Kwan, T. W., Lackland, D. T., … Tsao, C. W.; on behalf of the American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee. *Heart disease and stroke statistics - 2020 update: a report from the American Heart Association*. Circulation. (2020). 141, e139–e596. https://doi.org/10.1161/CIR.0000000000000757

4. Cardiac Arrest Registry To Enhance Survival. *2017 annual report*. (n.d.) https://www.mycares.net