

Opportunities to Increase Stability and Usefulness of the Vital Statistics System for Health Research



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Timeliness of Obtaining Death Data

- The time from study completion to publication is two years or longer.
- Although there are many factors that contribute to this publication lag, the lag time to get death certificate data is one contributor
- When a participant is unreachable, being able to check death status on a case-by-case basis would allow for a more rapid resolution of follow-up status, and any signs from these deaths that would suggest a yet undetected serious adverse event.
- Opportunity:
 - Electronic Data Registration System (EDRS) utilized by all states and localities to facilitate data entry
 - A common and shared EDRS
 - Note that births are reported almost entirely via electronic system

Revising Cost Structure and Support

- NDI currently charges per death certificate obtained
 - States rely on these revenues to support their vital statistics role, some of them entirely
 - Given current computerized systems, costs to provide these certificates are more fixed (upfront) than variable (per service)
 - Fees per death certificate can be expensive for large epidemiologic studies that make thousands of data requests to NDI
- Opportunity
 - Vital statistics are a critical national health research need, and greater cost sharing between federal and state support should be considered
 - Note that in the current cost structure, the fees per certificate are paid predominately by the federal government anyway, just through research grants to investigators who use these funds to pay the fees to NDI to access the data
 - Consider a volume discount fee structure with higher rates for smaller studies and lower rates for larger studies

Streamlined process for linking NDI and health research data

- Current Process:
 - Researchers send a list with personal identifiers
 - NDI sends back candidate matches (one to many) based on probabilistic matching (but not the full dataset for each potential match)
 - Research team reviews and determines best match
- Many, including AHA, have recommended improved linkages
- Opportunity to Improve Linkages
 - Provide a protected API or data enclave that would let researchers enter personally identifiable information and retrieve immediately from NDI a full dataset of probabilistic matches to view
 - Researchers select the best fit to their participant and retrieve only the selected dataset to link to their database

AHA Scientific Statement

Essential Features of a Surveillance System to Support the Prevention and Management of Heart Disease and Stroke A Scientific Statement From the American Heart Association Councils on Epidemiology and Prevention, Stroke, and Cardiovascular Nursing and the Interdisciplinary Working Groups on Quality of Care and Outcomes Research and Atherosclerotic Peripheral Vascular Disease

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Executive Summary

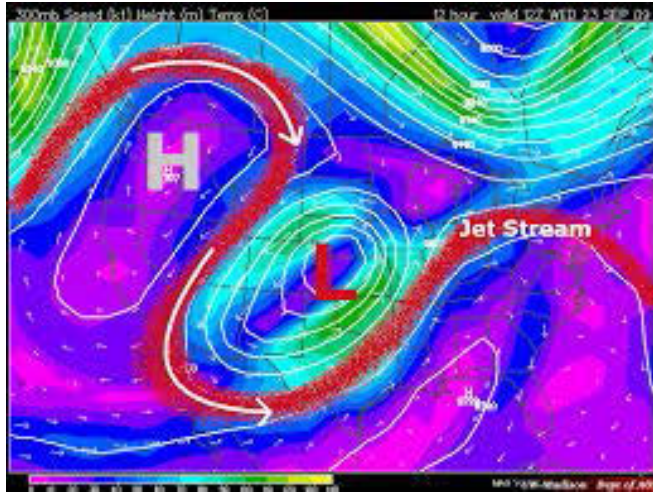
A strategic goal of the American Heart Association (AHA) is to reduce heart disease, stroke, and risk for both by 25%,¹ and Healthy People 2030 (HP2030) established 4 national goals for heart disease and stroke prevention and management.² However, the current health tracking systems (surveillance) in the United States cannot track progress toward these goals in a comprehensive and systematic manner. This article provides a brief overview of these goals, prevention and management strategies, and the role of surveillance in monitoring the impact of prevention and treatment efforts. It also provides a review of the existing surveillance system for monitoring progress toward preventing heart disease and stroke in the United States and recommendations for filling important gaps in that system. This information will serve as an important basis for advocacy to guide the development of a comprehensive surveillance system to support the current HP2030 and AHA goals and the likely future goal of eliminating the epidemic burden of heart disease and stroke. Recommendations are categorized as overarching (fundamental recommendations that cut across goal areas) or as goal-specific. They are further classified according to priority (P) (I for high priority and II for intermediate priority. No low-priority recommendations were made), staging (S) (I for early staging [1–2

years), II for intermediate staging [2–4 years), and III for later staging), and cost (C) (\$ for items estimated to cost less than \$10 million per year, \$\$ for estimates of \$10 to \$100 million, and \$\$\$ for estimates exceeding \$100 million). In addition, potential barriers to action are addressed.

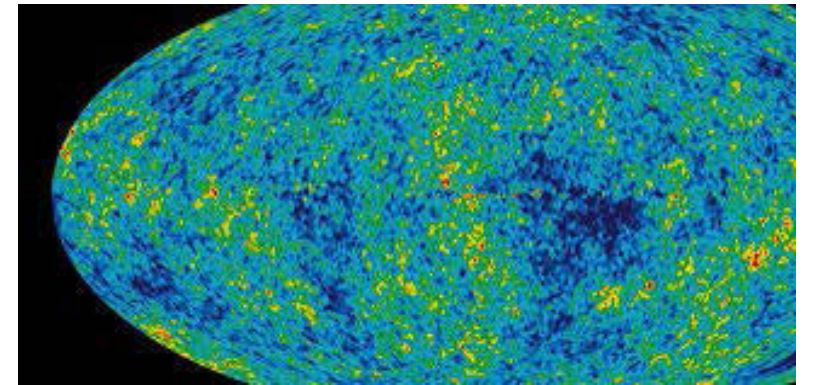
Overarching Recommendations

1. A National Heart Disease and Stroke Surveillance unit should be established to produce annual reports on key indicators of progress in the prevention and management of heart disease and stroke. P I, S I, C \$.
2. Cardiovascular disease (CVD), including cardiac arrest, acute coronary syndromes (heart attack and unstable angina), stroke, chronic heart failure (CHF), and related interventional procedures, should be classified as reportable conditions. P I, S III (although developmental work should begin earlier), C \$\$\$.
3. Data collection about patients' encounters with the healthcare system should be revised to include collection of data on lipoprotein cholesterol concentrations, blood sugar, and glycohemoglobin values. P I, S I, C \$.
4. Data elements should be standardized across surveys, and unnecessary duplication in data sources should be avoided. P I, S I, C \$ (potentially cost saving).

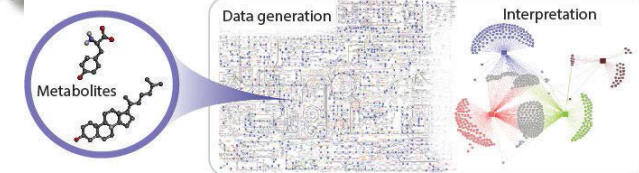
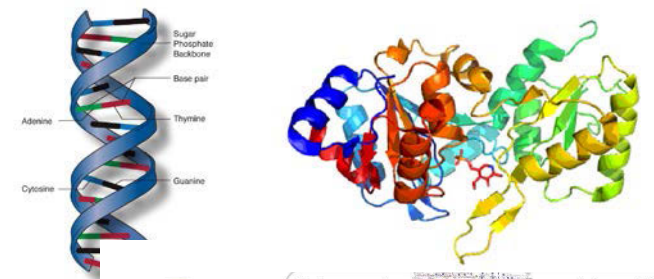
. . But Let's Think Big - *A National Health Surveillance System* Others Have It; Why Not Us?



Integrated, comprehensive national (international) surveillance systems that generate temporally dense data and provide easy data access, not only to researchers but to consumers as well



Our Fragmented, Disconnected Health Surveillance System



Brief Vision for a National Health Surveillance System

- Monitor the health of the U.S. population from birth to death
- Unique health ID for every individual
- Electronic Health Records that link to each other and to related data sets
- Increasing integration of protected genetic data with EHRs
- Core basic survey data obtained on all, more in depth or time intensive data from representative subsets
- Ability of participants to donate data, especially non-traditional data (e.g., activity trackers, heart rate monitors, location data from phone)
- Invitations to engage in clinical studies and trials
- All integrated and accessible from a data enclave that allows researchers, public health officials, and the public to track the health of the nation in real time