National Heart Disease and Stroke Surveillance Program Proposal for a Unit

In November of 2008, The National Forum for Heart Disease and Stroke Prevention issued a policy statement calling for the establishment of a national cardiovascular disease surveillance unit as a first step toward the development of a coordinated, comprehensive surveillance system designed to support the prevention and management of heart disease and stroke. The framework set out below provides the National Forum’s guidance for how such a unit should be designed and implemented.

I. Mission

A National Heart Disease and Stroke Surveillance Program would improve the health of the nation through the collection, interpretation, and dissemination of national and state level data on heart disease and stroke including their causes, prevention, detection, treatment, outcomes and disparities. Accurate, timely information with interpretation and policy recommendations is essential for progress toward national and state level goals to control and reduce these common, costly, debilitating and often fatal diseases. A national surveillance unit is key to meeting these goals.

II. Objectives

A. Review current event and risk factor surveillance programs for quality and adequacy of the data.
B. Support ongoing programs providing critical national and state level data.
C. Develop and support new mechanisms for quality data collection and calibration studies.
D. Develop systems to characterize national and states’ trends as well as those of more narrow socio-demographic sub-populations and geographic units (e.g. counties, metropolitan statistical areas (MSAs), designated rural areas).
E. Provide data in a timely manner with annual reports within six months of the end of the calendar year.
F. Provide annual surveillance reports with analysis and policy recommendations to the Secretary of the Department of Health and Human Services and Congress regarding the status of
heart disease and stroke event rates and risk factor prevalence.

G. Explore new surveillance methods including the linkage of clinic, hospital and mortality records.

H. Produce a strategic plan and annual progress report to address gaps revealed by existing data.

III. Data Scope

A. Population: United States population, no lower or upper age limit (surveillance for overweight/obesity can begin very early in life).

B. Demographic data
   1. Age
   2. Sex
   3. Geographic area/geocoding
   4. Insurance Status
   5. Linkage data
   6. Race/ethnicity
   7. Socioeconomic status (e.g., education, income)

C. Target diagnoses
   1. Coronary heart disease
   2. Stroke and transient ischemic attacks
   3. Heart failure
   4. Sudden out-of-hospital cardiac death
   5. Peripheral artery disease
   6. Congenital heart disease
   7. Co-morbidity (e.g., diabetes)

D. Risk factors
   1. Hypertension detection, prevalence and treatment
   2. Lipids including triglycerides and cholesterol, sub-fractions, diagnosis and treatment
   3. Food including information on food supply, composition, intake, supplement and nutraceuticals
   4. Tobacco use
   5. Physical activity and sedentary behavior
   6. Diabetes including incidence, prevalence and treatment
   7. Body size including weight, height, body mass index and other measures
   8. Psychosocial factors (e.g., depression)

E. Environmental, Policy, and Systems factors
   1. Health policies and laws (legislative and regulatory) affecting the prevention and treatment of heart disease and stroke and promotion of cardiovascular health
   2. Air pollution
   3. Built environment (e.g., access to fresh food, physical activity environment, access to transportation, access to medical care [e.g., distance to near hospital, nearest stroke care center, nearest hospital for heart surgery/angioplasty])
   4. Health care systems factors (e.g., EMS coverage, hospital facilities)
   5. Time to treatment.

F. Emergency Medical System (EMS)
   1. Common national form for EMS providers providing data on setting, symptoms, diagnosis, treatment and disposition.
   2. Common form for emergency department visits including diagnosis, treatment and disposition.
G. Hospital admissions
   1. Admission and discharge diagnoses, including incidence
   2. Discharge disposition
   3. Major treatments including procedures and medications
   4. Discharge medications
   5. Performance measures

H. Outpatient visits
   1. Screening for cardiovascular risk factors
   2. Diagnosis and treatment of risk factors, heart disease and stroke
   3. Number of visits/year
   4. Performance measures
   5. Rehabilitation utilization

I. Outcomes
   1. Readmissions to the hospital
   2. Revascularization
   3. Mortality
   4. Health status

IV. Functions

A. Design and implement data collection for key indicators
B. Oversee ongoing data collection programs
C. Convene expert panel working groups to address data issues and develop synthesis reports
D. Assure quality of data
E. Protect privacy of personal health information
F. Report annually to appropriate officials and congressional committees
G. Provide analyses and recommendations for policy development
H. Make information available, accessible and usable to other responsible agencies and parties for research and policy development

V. Structure

A. A diagram of the proposed structure is attached.
B. This organization could be part of the new bureau proposed at HHS for national surveillance needs. It could also be part of another agency such as the National Institutes of Health (NIH) or the Centers for Disease Control and Prevention (CDC).
C. Other agencies would need to be actively involved in an advisory capacity including DOA, NHLBI, NCHS, NHTSA, NINDS, CMS, DVA, DOD, AHA, ASA, Bureau of Census, ACC, CSTE, NACDD, EPA, and IHS (listing of abbreviations attached).
D. It is anticipated that the core unit would require approximately $4 million/year to achieve its tasks. However, approximately $100 million/year would be necessary for data collection.

ABOUT THE NATIONAL FORUM

The National Forum for Heart Disease and Stroke Prevention (National Forum) is made up of more than 80 organizations committed to building a heart-healthy and stroke-free society. The national Forum provides leadership in implementing the recommendations contained in A Public Health Action Plan to Prevent Heart Disease and Stroke.
Definitions for the Organization Chart for the National Surveillance Program Unit

**Director:** The director will lead the program working with or within the appropriate HHS agencies.

**Executive Committee:** The Executive Committee consists of the director, financial officer, technical support leader, content expert and communications leader.

**Financial Officer:** The financial officer is responsible for financial and personnel issues and the management of contracts for data collection.

**Legal Counsel:** The legal counsel is responsible for privacy protection procedures and other legal issues associated with data gathering.

**Advisory Committee:** The advisory committee consists of representatives of major government and nongovernment agencies and organizations relevant to this topic.

**Scientific Advisory Committee:** The Scientific Advisory Committee consists of external experts in cardiovascular epidemiology and biostatistics.

**Communication Group:** Communication is responsible for the preparation of reports and responses to inquiries.

**Technical Support:** Technical support is responsible for the organization and analysis of data from multiple sources.

**Content Experts:** Content experts are epidemiologists and biostatisticians with expertise in heart disease and stroke surveillance.

**Web Staff:** Web design is responsible for maintenance of a website which will allow access to reports and data collected by the unit.

**Liaison Service:** Liaison service is responsible for facilitating the use of these data by scientific and health policy organizations.

### Abbreviations

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACC</td>
<td>American College of Cardiology</td>
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<tr>
<td>AHA</td>
<td>American Heart Association</td>
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<tr>
<td>ASA</td>
<td>American Stroke Association</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
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<tr>
<td>CSTE</td>
<td>Council of State and Territorial Epidemiologists</td>
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<td>DOA</td>
<td>Department of Agriculture</td>
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<td>DOD</td>
<td>Department of Defense</td>
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<td>DVA</td>
<td>Department of Veterans Affairs</td>
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<td>EPA</td>
<td>Environmental Protection Agency</td>
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<td>IHS</td>
<td>Indian Health Service</td>
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<td>MSA</td>
<td>Metropolitan Statistical Area</td>
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<td>NACDD</td>
<td>National Association of Chronic Disease Directors</td>
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<td>NHCS</td>
<td>National Center for Health Statistics</td>
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<td>NHTSA</td>
<td>National Highway Traffic Safety Administration</td>
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<td>NHLBI</td>
<td>National Heart Lung and Blood Institute</td>
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<td>NIH</td>
<td>National Institutes of Health</td>
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<td>NINDS</td>
<td>National Institute of Neurological Diseases and Stroke</td>
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