CVD Surveillance: Challenges and Opportunities

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Have worked in CVD surveillance for 20 years and believe in necessity of an effective surveillance system.

Chaired the AHA writing group for the surveillance statement provided to the Panel.

Statement provides a detailed assessment of needs, recommended actions, with priorities and order-of-magnitude projections of possible costs.
Two Questions Posed by IOM Panel

1. What are the challenges in conducting surveillance of CVD?
2. What are the critical aspects or dimensions or norms that need to be taken into consideration in developing and integrating a framework for surveillance of CVD?
Public health surveillance is the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health.

Centers for Disease Control and Prevention. Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. MMWR 2001;50(No. RR-13).
Without Adequate Surveillance Data

- We don’t know what the most important risk factors, conditions, or populations are for designing our interventions.
- We have no way of evaluating whether our interventions are making a health impact.
- We cannot adequately communicate our priority needs to decision-makers.
- We cannot demonstrate effectiveness to funding agencies, policy-makers, and decision-makers, including at the state and local level.
Because many prevention programs and policies are implemented at the state (including tribal organizations and territories) and local level, it is a basic premise that state and local agencies need the capacity to generate and use relevant surveillance information.

Many national surveillance systems provide only national or at best regional estimates, e.g., NHANES.

State decision makers and policy makers demand state-level and local-level data.

Without adequate state-based CVD surveillance, we will not be able to demonstrate the effectiveness of the State-based Heart Disease & Stroke Prevention Program.

State and local agencies should also inform ongoing development and implementation of the surveillance system.
1. What are the challenges in conducting surveillance of CVD?

CVD is a complex disease landscape with numerous multiplicities:

- Causes, some operating over decades, some triggering acute events, some influencing long-term prognosis;
- Avenues for prevention (primordial, primary, secondary, tertiary);
- Approaches to detection, treatment and control; and
- Disease entities.

A sound surveillance system should be based on a reasonably comprehensive working model of disease development and prevention.
Logic Model: Stroke-Related Surveillance

<table>
<thead>
<tr>
<th>Pre-event Surveillance</th>
<th>Post-event Surveillance</th>
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<td>Environmental and Social Factors</td>
<td>Individual Factors</td>
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<td>National Policies &amp; Environments Transportation Recreation Housing Medical Care Etc</td>
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<td>Health Plan Policies &amp; Environments Counseling Preventive treatment Access to Care Provider Training Etc</td>
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<td>Family Influences Nutrition Physical Activity Tobacco Social support Etc</td>
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<tr>
<td>Behaviors Smoking Inactivity Unhealthy diet Salt Alcohol abuse Hormones/Oral contraceptives</td>
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<tr>
<td>Physiology Atrial fibr High BP High chol Diabetes Obesity Homocysteinemia Hx Stroke Hx TIA</td>
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<td>Stroke Event</td>
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Ken Powell

2005 Tri-State Stroke Summit
1. What are the challenges in conducting surveillance of CVD?

- There are multiple diseases of interest for which we need reliable data.
  - Cardiovascular deaths, including sudden (out-of-hospital) deaths, acute myocardial infarction, unstable angina, stable angina, stroke, TIA, heart failure, atrial fibrillation, PAD, congenital heart disease, DVT/PE.

- Numerous procedures & devices are used that affect the evolution of these diseases, influencing cost and outcomes.
  - CABG, CEA, stents, defibrillators, pacemakers, assist devices, endovascular aneurysm repair.

- Approaches include developing a priority list, valid definitions, and automated reporting and capture.
1. What are the challenges in conducting surveillance of CVD?

- Care occurs in multiple settings, increasing the complexity of data collection, management, linkage, and interpretation.
- In-patient, ED, EMS, urgent care, ambulatory care (primary & specialty care), long-term care, home care.
- When monitoring outcomes, settings could also include rehabilitation facilities, home, job.
- Need prioritization, procedures for reporting and capture, and data linkage capacity (e.g., unique health identifier).
1. What are the challenges in conducting surveillance of CVD?

- Multiple metrics are important.
  - Incidence, recurrence, and attack rates
  - Prevalence
  - Survival (short-term and long-term)
  - Quality of care, e.g., performance measures
  - Access and utilization
  - Patient centered outcomes, e.g., quality of life, functional status
  - Risk factors (biological, behavioral, social and environmental)
  - Policies
  - Cost

- Measurement standards are critical, including diagnostic data to validate events and trends over long time periods.
1. What are the challenges in conducting surveillance of CVD?

A fragmented surveillance system with redundancy and poor coordination has developed over time.

- NCHS, e.g., NHANES, NHIS, National Health Care Surveys (NHDS, NAMCS)
- CDC, e.g., BRFSS, YRBS, YTS, ATS, Coverdell
- AHRQ, e.g., Healthcare Cost and Utilization Project – Nationwide Inpatient Sample (NIS); The Medical Expenditure Panel Survey (MEPS)
- State based hospitalization registries
- NHLBI and NINDS funded surveillance projects
- IHS data
- CMS data
- VA data
- HMO or health care system data
- ACC/AHA – e.g., Action GWTG, NCDR, NRCPR
1. What are the challenges in conducting surveillance of CVD?

- Having lots of data does not necessarily equate with having important useful information.
- Despite all these data, there are gaps.
- Better oversight/management/coordination/integration could lead to streamlining, reducing undesirable duplication, & filling gaps.
1. What are the challenges in conducting surveillance of CVD?

"Easily" obtainable data have important limitations.
- Administrative data lack important clinical information.
- Clinical data systems lack data standards, accessibility and interoperability.
- Both have challenges related to case validation and repeatability over time as diagnostic criteria evolve, e.g., introduction of CK-MB then troponins, CT scans then MRIs for stroke.
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- International harmonization.
- WHO STEPwise approach to surveillance program focused on major chronic diseases and their risk factors.
  - Heart disease
  - Stroke
  - Cancer
  - Chronic respiratory diseases
  - Diabetes

http://www.who.int/chp/steps/Part1_Section1.pdf
### WHO STEPwise approach to surveillance

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<th>Step</th>
<th>Description</th>
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| 1    | Gathering demographic and behavioural information by questionnaire in a household setting. | To obtain core data on:  
• socio-demographic information  
• tobacco and alcohol use  
• nutritional status  
• physical activity. | All countries/sites should undertake the core items of Step 1. |
| 2    | Physical measurements in a household setting.                                | To build on the core data in Step 1 and determine the proportion of adults that:  
• are overweight and obese  
• have raised blood pressure. | Most countries/sites should undertake Step 2. |
| 3    | Taking blood samples in a clinic.                                            | To measure prevalence of diabetes or raised blood glucose and abnormal blood lipids. | Only recommended for well-resourced settings. |

[http://www.who.int/chp/steps/Part1_Section1.pdf](http://www.who.int/chp/steps/Part1_Section1.pdf)
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Link to the goals and strategies for CVD prevention and control – translates into need for a broadly based surveillance system with resources allocated with a focus on monitoring issues that have substantial potential for prevention.

- Risk factor prevention
  - Policies and environmental (social and physical) conditions that promote healthy behaviors
  - Population distributions of health behaviors and biological risk factors

- Risk factor detection and control – additional surveillance of
  - Population distributions of health behaviors and biological risk factors
  - Health care system performance in risk factor detection and control
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Link to the goals and strategies for CVD prevention and control.
- Early identification and treatment of acute events
  - Knowledge of signs and symptoms of acute events and of appropriate health care seeking behavior
  - Incidence of acute events
  - Quality of care prior to, during, and after acute events (including pre-hospital and rehabilitation)
  - Policies and environmental conditions related to function of pre-hospital, hospital, and post-discharge care system, e.g., availability of enhanced 911, EMS protocols, system of care.
  - Patient outcomes following events, including health status
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Link to the goals and strategies for CVD prevention and control.
- Prevention of recurrent events
  - Prevalence of CVD conditions
  - Recurrence of acute events
  - Quality of care prior to, during, and after recurrent events (including pre-hospital and rehabilitation)
  - Policies and environmental conditions related to function of pre-hospital, hospital, and post-discharge care system, e.g., availability of enhanced 911, EMS protocols, system of care.
  - Patient outcomes following events, including health status
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Link to the goals and strategies for CVD prevention and control.

- Without such data, we will be limited in comparative effectiveness research to evaluate the wide range of factors that contribute to health outcomes, including non-clinical programs and population level interventions, public policies and governmental regulations.
Accountability must be established for synthesizing data into information and integrating information into efforts to evaluate prevention programs and policies.

The accountability for development, implementation, and oversight of the surveillance system should be closely linked to accountability for CVD prevention and CVH promotion activities.

The unit charged with this accountability should address the fragmentation that has led to redundancies, inconsistencies, and gaps in the current system.

Efforts to address these opportunities are ongoing at CDC in the DHDSP.
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Many prevention programs and policies are implemented at local or state (including tribal organizations and territories) levels.
- More useful experimentation and learning can occur if the results of different local and state efforts are evaluated using standard approaches.
- Hence, surveillance systems, including those designed to provide nationally applicable information, should be designed and implemented in a manner capable of supporting evaluation of local and state prevention efforts.
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Local and state agencies should have capacity to use surveillance data and information, and ideally to contribute to the development of the surveillance system.
- There are chronic disease and cardiovascular disease epidemiologists in nearly every state health department, many of whom are experts in applied public health surveillance for chronic diseases, including CVD and COPD. This is a valuable knowledge base.
- Some states are implementing cutting edge methods - NHANES-like surveys at the state or city level; using EHR for surveillance; data linkages between EMS, ED, hospitals. These efforts could be inventoried through CSTE and/or the CDC DHDSP Epidemiology listserv.
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Data standards and system interoperability are critical to enhance the value of the clinical data in EHRs.
- Wider adoption of appropriate EHRs will be helpful.
- A process for linking information for individuals across care settings and surveillance tools is needed, for example, a unique health identifier.
2. What are the critical aspects or dimensions or norms that need to be taken into consideration?

- Sentinel centers of surveillance R&D should be established to support long-term evaluation and evolution of the surveillance system. A network of communities, diverse in geography and demography that collectively represents the US, in which intensive surveillance activities are implemented. This system provides the basis for ongoing surveillance research and development, for validation of the more broadly-based surveillance components, and for training of the next generation of surveillance experts. This component is important for calibration of the system over time and for generating a return from the surveillance effort beyond that which can be generated at the state and local health department level.
What might we do better in the coming decade with an improved CVD surveillance system?

Be more effective in identifying and disseminating successful strategies for achieving the HP2020 goals, objectives, and targets at the national, state, and local levels.

Saving lives, investing resources more efficiently, and focusing our public health agenda more effectively on this major chronic disease (thereby serving as a model system for other chronic diseases).