

## 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%,<sup>1</sup> and *Healthy People 2010* (HP2010) established 4 national goals for heart disease and stroke prevention and management.<sup>2</sup> 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 HP2010 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 arrests, 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).

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5. The design and conduct of nationally representative surveillance programs should be revised to facilitate oversampling by states, territories, and tribal organizations and to provide meaningful estimates on ethnic subgroups in the populations. Sampling within states, territories, and tribal organizations should be designed to facilitate oversampling by counties. P I, S II, C \$\$ to \$\$\$ (depending on extent of oversampling achieved).
6. Mechanisms should be developed to enable linkage between healthcare data systems, including the national surveillance programs (eg, National Ambulatory Medical Care Survey [NAMCS], National Hospital Discharge Survey [NHDS], and National Death Index), and electronic health records. P I, S II, C \$\$\$ (startup) and \$\$ (maintenance).
7. Studies are needed to establish the validity of multiple measures collected by self-report and provider report in national databases. P II, S II, C \$\$.

### **Recommendations for HP2010 Goals 1 (Risk Factor Prevention) and 2 (Risk Factor Detection, Treatment, and Control)**

Data collection in national surveys should be expanded to include important measures that are currently missing from the data collection process, such as information on awareness, detection, treatment, and control of physical inactivity, unhealthy diet, cigarette smoking, and obesity. P I, S I, C \$.

1. The states, territories, and tribal organizations should develop surveillance capacity to support program planning, implementation, and evaluation. Such capacity should include the ability to conduct standardized surveys that would include direct assessments of residents to enable collection of information about prevention, awareness, detection, treatment, and control of obesity, hypertension, dyslipidemia, and diabetes. P I, S I, C \$\$\$.
2. Indicators and systems for surveillance of policies and environmental conditions related to physical inactivity and unhealthy diet should be developed, tested, and implemented at the national, state, and local levels. P I, S II, C \$.

### **Recommendations for HP2010 Goals 3 (Early Identification and Treatment of Acute Events) and 4 (Prevention of Recurrent Events)**

1. Indicators and systems for surveillance of policies and environmental conditions (eg, proportion of the population covered by enhanced 9-1-1) related to symptom knowledge and recognition, acute healthcare-seeking behavior, availability of automated external defibrillators, and capabilities of the prehospital care system (including first responders and emergency medical services) should be developed, tested, and implemented at the national, state, and local levels. P I, S II, C \$.
2. Effective surveillance methods should be developed, tested, and implemented to support the collection of data on patients with newly diagnosed heart disease, stroke, CHF, and peripheral arterial disease (PAD) in

the outpatient setting, including data on treatment and outcomes. P II, S III, C \$\$\$.

We have identified specific barriers to obtaining the new data elements that would be required to support the development of a comprehensive surveillance system. These include various methodological challenges, privacy concerns, and the costs associated with supporting new data systems and a comprehensive surveillance system.

The success of efforts to prevent and manage heart disease and stroke is dependent on the availability of surveillance data at the national, state, and local levels to assist federal agencies, state and local health departments, and their partners in assessing prevention and treatment priorities and guiding program planning, implementation, and evaluation. This statement summarizes the information that is needed at the national, state, and local levels to address the HP2010 and AHA goals for 2010; furthermore, this document was designed with a longer-term perspective in mind. When possible, existing data collection efforts have been identified for the addition of new items. Significant gaps (eg, the complete lack of a data source for incidence and recurrence of heart attacks and strokes) and other deficiencies have been identified, and recommendations have been made for enhancement of the surveillance system in the United States. The most far-reaching recommendation may be the proposed designation of heart disease and stroke as reportable conditions across the continuum of care. This approach served to help focus attention on infectious diseases when infection control was the major public health imperative. A similar approach to heart disease and stroke is needed urgently. The other recommendations, although more narrowly focused in many instances, should result in the availability of better information for enhancing heart disease and stroke prevention and management programs. Implementation of all of the recommendations contained in this report would require commitment of substantial additional resources in addition to those already devoted to surveillance; however, some opportunities for greater efficiency were identified that could lead to cost savings, and a staged rollout of these recommendations could mitigate the financial impact. Finally, the return on investment could be substantial in terms of better population health and fewer acute episodes of heart disease and stroke, resulting in fewer inflation-adjusted healthcare dollars being devoted to acute care. Consequently, this statement should serve as a guide to policy makers as they work with public health agencies to develop and implement a surveillance system that can contribute importantly to efforts to prevent heart disease and stroke.

### **Introduction**

A strategic goal of the AHA is to reduce heart disease, stroke, and risk for both by 25%,<sup>1</sup> and HP2010 established 4 national goals for heart disease and stroke prevention and management.<sup>2</sup> However, the current health tracking systems (surveillance) in the United States cannot track progress toward these goals in a systematic manner. This report 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 HP2010 and AHA goals and the likely future goal of eliminating the epidemic burden of heart disease and stroke.

The primary objectives of this report are to (1) define the key data needed to track progress toward the prevention and optimal management of heart disease and stroke; (2) identify existing data sources and gaps relevant to these data needs; and (3) recommend and prioritize data needs. This effort was motivated by the belief that improvements in knowledge can lead to more effective action. Hence, the goal is to document the potential benefits of having more timely access to important data about heart disease and stroke in the United States by addressing 2 questions: What data are available? What additional data do we need to make better policy and programmatic decisions?

### Public Health Burden of Heart Disease and Stroke

The major sources of readily available published statistics on heart disease and stroke in the United States include the annual report from the AHA, *Heart Disease and Stroke Statistics*,<sup>3</sup> and the biennial report from the National Heart, Lung, and Blood Institute, *Chart Book on Cardiovascular, Lung, and Blood Diseases*.<sup>4</sup> It is estimated that 71 300 000 Americans have CVD, although many have high blood pressure as their only manifestation of CVD.<sup>3</sup> Heart disease and stroke are the most common of the major forms of CVD, affecting women and men of all racial/ethnic groups and ages. In 2003, 13.2 million Americans had prevalent coronary heart disease, 5.5 million had prevalent stroke, and 5 million had heart failure.<sup>3</sup> With the aging population, the prevalence of heart failure is expected to reach 10 million cases by 2007.<sup>5</sup> More than 8 million adults in the United States are affected by PAD, a condition that increases in prevalence with age and is more prevalent in blacks.<sup>3,6,7</sup> Although no surveillance system exists to monitor incidence of heart disease and stroke, estimates have been computed and published by the AHA and the National Heart, Lung, and Blood Institute.<sup>3,4</sup> The estimated annual incidence of acute myocardial infarction is 565 000, and another 300 000 recurrent attacks occur annually. The estimated incidence of stroke is 500 000 per year, and another 200 000 recurrent strokes occur annually.<sup>3</sup> Among stroke survivors, 15% to 30% are permanently disabled.<sup>3</sup>

Heart disease and stroke have been first and third, respectively, among the causes of death in the United States for several decades. In 2002, CVD accounted for  $\approx 37\%$  of all deaths among US residents and was listed as a primary or contributing cause of death on approximately 1 400 000 death certificates.<sup>3</sup> Although age-adjusted CVD death rates declined considerably from 1979 to 2002, there was only a slight decline in the absolute number of CVD deaths.<sup>4</sup> Additionally, the decline in mortality from heart disease and

stroke has not been equal across all racial/ethnic groups; non-Hispanic whites have experienced the greatest declines.<sup>8,9</sup>

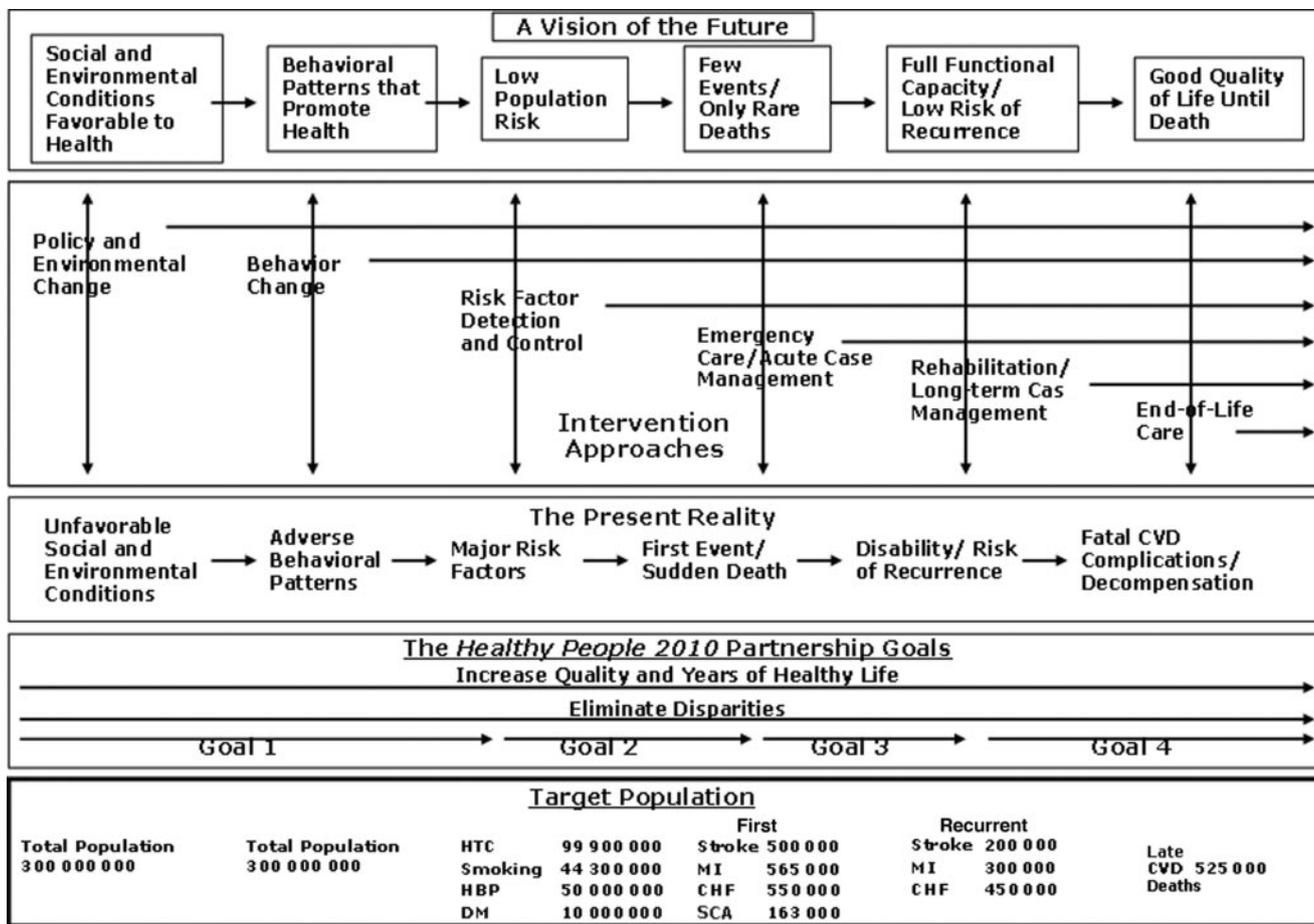
Heart disease and stroke share many of the same modifiable risk factors, such as hypertension, cigarette smoking, diabetes mellitus, obesity, physical inactivity, and, at least for ischemic stroke, dyslipidemia. The percentage of US adults free of these major risk factors decreased from 42% in 1991 to 36% in 2001 based on self-reported data from the Behavioral Risk Factor Surveillance System (BRFSS).<sup>10</sup> It is likely that these data overestimate the proportion of the population free of these major risk factors for CVD, because these data are based on self-report and, in some instances, on access to health care for diagnosis. This trend is yet another indication of the substantial public health burden of heart disease and stroke and the need to implement a coordinated and comprehensive national effort to prevent heart disease and stroke.

Efforts to reduce the burden of heart disease and stroke have been hampered by a lack of knowledge in key areas. Although the emerging obesity epidemic has been developing for several decades, widely spaced episodic surveillance programs contributed to the delay in identification and response.<sup>11</sup> Similar challenges contributed to a delay in recognizing a reversal in the downward trend in prevalence of high blood pressure and an inability to monitor hypertension control.<sup>12</sup> The lack of data on prehospital delay times in patients with symptoms of acute coronary syndromes has hindered evaluation of progress toward the "60 minutes to treatment" goal of the National Heart Attack Alert Program.<sup>13,14</sup> Current efforts to redesign systems of care for patients with ST-segment elevation myocardial infarction are constrained by a lack of knowledge of the processes of care delivery in various systems.<sup>15</sup> The lack of data has hindered efforts to increase the use of evidence-based therapies (eg, aspirin,  $\beta$ -blockers, and thrombolysis) for patients with myocardial infarction<sup>16</sup> and stroke<sup>17</sup> despite major efforts to disseminate knowledge of the effectiveness of these therapies.<sup>18,19</sup>

The annual cost associated with CVD in the United States was estimated to be \$403.1 billion for 2006.<sup>3</sup> This figure includes health expenditures such as costs of physician, hospital, and nursing home services, as well as lost productivity, but it is likely to be an underestimate because, especially for stroke, the informal care costs and costs of comorbidities may not be included.<sup>20</sup> The cost of CVD is likely to increase dramatically over the next several decades as the "baby boom" population enters the peak heart disease years, putting additional strain on the public health and healthcare delivery systems.<sup>21</sup> It will be increasingly important to conduct surveillance of healthcare costs in addition to outcomes to inform policy makers about the most rapid increases in expenditure lines, whether the return on investment is justifiable, and whether current or new policies are likely to bankrupt the system while trying to help people live longer, healthier lives.

### HP2010 and AHA Goals for Prevention and Management of Heart Disease and Stroke

HP2010 is a comprehensive set of disease prevention and health promotion objectives for the United States to achieve during the first decade of the 21st century.<sup>2</sup> The overall goals



**Figure.** Action framework for a comprehensive public health strategy to prevent heart disease and stroke. HTC indicates high total cholesterol; HBP, high blood pressure; DM, diabetes mellitus; SCA, sudden cardiac arrest; and MI, myocardial infarction.

of HP2010 are to increase the quality and years of a healthy life and to eliminate health disparities. The leading health indicators identified in HP2010 include physical activity, overweight and obesity, and tobacco use. The relevant national health objectives are to increase physical activity, reduce overweight and obesity, and decrease cigarette smoking among adolescents and adults. The 4 goals of HP2010 specific to CVD are shown in Table 1. The Centers for Disease Control and Prevention (CDC) and the National Institutes of Health have been charged with leadership responsibility for achieving these goals. The HP2010 Partnership, in which the AHA is a partner, has been established to stimulate progress toward achieving these and other HP2010 goals. The 10-year impact goal of the AHA, to reduce coronary heart disease, stroke, and risk for both by 25% by the year 2010, is aligned with these national health objectives.<sup>1</sup> Specific indicators established by the AHA are shown

**TABLE 1. HP2010 Goals Specific to Heart Disease and Stroke**

Prevention of cardiovascular risk factors
Detection and treatment of risk factors
Early identification and treatment of heart attacks and strokes
Prevention of recurrent cardiovascular events

in Table 2. Efforts are ongoing to develop goals for 2020 and beyond; hence, the recommendations provided in this document are intended to be flexible.

### Opportunities and Approaches to Prevent and Manage Heart Disease and Stroke

Meeting the HP2010 and AHA goals for preventing and managing heart disease and stroke is a challenging but achievable task. Heart disease and stroke are disorders with complex origins and multiple risk factors, so a multifaceted approach to their prevention is crucial to success. With this perspective in mind, the CDC and its key partners and stakeholders, including the AHA, the Association of State and Territorial Health Officials, and the National Institutes of Health (specifically, the National Heart, Lung, and Blood

**TABLE 2. Specific Indicators Established by AHA to Track Progress Toward Heart Disease and Stroke Prevention by 2010**

Reduction in death rate due to coronary heart disease and stroke by 25%
Reduction in prevalence of smoking, high blood cholesterol, and physical inactivity by 25%
Reduction in rate of uncontrolled high blood pressure by 25%
Elimination of the growth of obesity and diabetes mellitus

Institute and the National Institute of Neurological Disorders and Stroke) developed *A Public Health Action Plan to Prevent Heart Disease and Stroke*.<sup>22</sup> This plan directly addresses the 4 national goals for heart disease and stroke prevention described in HP2010. The action plan includes an “action framework” (Figure) that serves as both a guide for heart disease and stroke prevention efforts and a useful framework for designing a surveillance system.<sup>22</sup>

Framework development first required an understanding of the present CVD environment, in which unfavorable social and environmental conditions give rise to the adoption of adverse behavioral patterns that may lead to the development of the major risk factors for heart disease and stroke. Next, first events, many of which are fatal, occur in the population. Survivors are at risk for recurrent events, disability, decompensation, and death. In theory, prevention of heart disease and stroke could be advanced by intervening at any point in this process; however, meeting the 4 goals of HP2010 will require efforts across the full spectrum of cardiovascular health promotion and disease prevention. Prevention of the major risk factors for heart disease and stroke (goal 1) can be achieved only by addressing social and environmental conditions and behaviors. Detection and treatment of the risk factors (goal 2) can be achieved only through efforts that focus on these specific activities, although efforts to prevent the risk factors could, if successful, reduce the magnitude of the challenge inherent in this task. Early identification and treatment of acute events (goal 3) requires population-wide knowledge of symptoms and appropriate (timely) health-care-seeking behavior, as well as uniform access to high-quality emergency care and acute case management. Prevention of recurrent events (goal 4) requires uniform access to high-quality health care, including rehabilitation services, for all survivors of an acute event. Understanding the strategies required to prevent heart disease and stroke also provides an important basis for considering the requisite scope of a comprehensive surveillance system designed to track progress toward the attainment of the prevention goals set by HP2010.

### Role of Surveillance in Efforts to Prevent and Manage Heart Disease and Stroke

Public health surveillance is defined as “the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding health-related events for use in public health action to reduce morbidity and mortality and to improve health.”<sup>23</sup> Comprehensive and accurate disease surveillance systems are critical to the success of efforts to reduce the burden of CVD and stroke. Such systems are particularly important in identifying emerging trends, such as the rise in prevalence of obesity, diabetes mellitus, and chronic (congestive) heart failure<sup>3,24</sup>; the plateauing of the decline in stroke mortality<sup>25</sup>; regional and subgroup differences in the decline in myocardial infarction incidence<sup>26</sup>; or the rise in hospitalizations for atrial fibrillation.<sup>27</sup> Comparison of trends across subgroups also helps to identify groups at particularly increased risk<sup>28</sup> or that fail to benefit from overall improvements in prevention and treatment.<sup>29,30</sup> Reliable surveillance data are essential for identifying public health priorities,

tracking the progress of preventive efforts, and intensifying efforts in areas of special need. Guidelines published by the CDC have suggested several criteria for evaluating public health surveillance systems, including simplicity, data quality, acceptability, sensitivity, positive predictive value, representativeness, timeliness, stability, usefulness, flexibility, and cost.<sup>23</sup> Although a full review of this information is beyond the scope of this statement, key characteristics of reliable surveillance systems can be grouped into 3 areas: the validity of the data produced, the utility of the resulting information, and the feasibility of implementing the system itself.<sup>23,31</sup> It is particularly important for the surveillance system to have sufficient flexibility and nimbleness to enable the incorporation of important new measures in a timely manner.

Surveillance needs at various levels may serve different purposes, but all components of the system should be designed to best inform the strategies for preventing heart disease and stroke that are best implemented at that level. On the national level, surveillance systems should inform policies likely to be set nationwide, such as agricultural subsidies, federal tobacco taxes and other tobacco control policies, Medicare reimbursement for screening and treatment, practice guidelines promulgated by scientific and governmental organizations, and drug or device safety issues addressed by federal agencies. Nationally available data should also permit comparisons between countries, particularly because such comparisons can inform national health policy.

Surveillance data are also critically important at both the state and local level. State and local public health agencies require relevant surveillance data, specific to their state or local area, to use in developing and seeking funding for targeted intervention programs, informing policy makers and guiding policy decisions, and planning and evaluating programs. For example, data are needed to inform state and local decision makers about the impact of current and future policies pertaining to school nutrition and physical education programs, tobacco taxes and other control policies, and Medicaid coverage policies, as well as other prevention programs. Because funding for heart disease and stroke prevention programs is low relative to the public health burden of these diseases in most states and local areas, public health agencies must carefully prioritize their preventive efforts and continually evaluate ongoing programs to assess and improve their impact. State or local populations at particularly high risk for CVD can be identified and targeted for intensive interventions that may not be feasible or efficient on a broader scale.<sup>28</sup> State and local public health agencies cannot design, implement, and evaluate such programs without relevant, reliable, accurate, and timely surveillance data.

Several trends are occurring that will influence surveillance capacity in the years to come. Modifications to the surveillance system should be designed to benefit from, or at least accommodate, the likely effects of these influences. The development of geographic information systems technology (eg, geocoding) has enhanced the utility of surveillance data for research, program planning, and evaluation purposes. The development of health information technology, especially the electronic health record, might contribute importantly to the

development of improved insight into the processes and outcomes of healthcare delivery; however, standardization, interoperability, confidentiality safeguards, and the lack of mechanisms to link across data repositories are but a few of the barriers that must be overcome. The implementation of pay-for-performance healthcare reimbursement policies may also influence the availability of data on key performance measures that could be used to track progress toward the prevention and management of CVD. Finally, it is important to recognize that although the present report focuses on heart disease and stroke, enhanced surveillance of other chronic diseases could contribute further to our ability to make better decisions on resource allocation, thereby leading to improvements in the health of our population.

### **HP2010 Goals 1 and 2: Risk Factor Prevention, Detection, Treatment, and Control**

Risk factor prevention, detection, and control are addressed in the first and second of the 4 HP2010 goals relevant to heart disease and stroke. Because many components of a surveillance system to monitor risk factor prevention could also provide useful information about risk factor detection and control, surveillance efforts needed to monitor progress toward achieving these goals will be discussed together. Physical inactivity, unhealthy diet, tobacco use, obesity, hypertension, dyslipidemia, and diabetes mellitus are well known as the major modifiable risk factors for heart disease and stroke, and atrial fibrillation is a major risk factor for stroke.<sup>3,22</sup> Programs that seek to reduce heart disease and stroke incidence, prevalence, and mortality through risk factor prevention, detection, and control must address some or all of these risk factors. Although success in changing current trends in heart disease and stroke incidence, prevalence, or mortality may not be seen for several years after efforts to prevent or control risk factors, program impact on the risk factors themselves may be seen in a shorter time frame, provided that good measures of program progress exist. For these reasons, surveillance systems to track the prevalence, treatment, and control of risk factors over time are needed at the national and state level, and ideally at the local level, as well. In addition, state-based heart disease and stroke prevention programs are working to create policy and environmental changes that will support behavior change and risk factor prevention and control.<sup>32,33</sup> Therefore, surveillance systems are needed to monitor changes in relevant policies and environmental factors over time. The following sections address the availability of surveillance data relevant to policies and environmental conditions, the major lifestyle risk factors, and the major biological risk factors.

### **Environmental and Policy Factors**

To support behavior change, risk factor control, and uniform access to high-quality health care, heart disease and stroke prevention programs must address policy, environmental, and systems-level changes in multiple settings (eg, communities, schools, work sites, and healthcare settings).<sup>22,33</sup> This ap-

proach is illustrated by the Figure, which shows policy and environmental change at the far left of the model, with the recognition that policy change is both a way to promote improvements in the built environment that will encourage greater physical activity and a way to improve other behaviors. Although infectious disease interventions have historically focused on policy and environmental changes as effective methods of disease prevention and control, chronic disease prevention and control programs have adopted this approach much more recently. Tobacco prevention and control programs have successfully used policy and environmental strategies to reduce smoking rates (eg, laws and enforcement that limit youth access to tobacco products, cigarette taxes, and insurance coverage of evidence-based nicotine dependency treatment).<sup>32</sup> Unfortunately, aside from policies that address tobacco use and tobacco smoke exposure, there are few surveillance programs pertinent to policy and environmental factors. HP2010 includes several environmental and policy change objectives related to heart disease, stroke, and their risk factors, although many of these objectives were labeled as developmental because surveillance systems were not available to monitor progress. To assist state heart disease and stroke prevention programs in tracking progress, the CDC drafted a list of 31 policy and environmental indicators related to physical activity, nutrition, and tobacco use (Tables 3 through 6).<sup>34–40</sup>

### **Available National Data**

The School Health Policy and Programs Study is conducted at the state, district, school, and classroom level nationwide and includes data on physical activity, nutrition, and tobacco-related policies and environmental factors in schools.<sup>41</sup> The School Health Policy and Programs Study was conducted in 1994 and 2000 and will be conducted again in 2006.<sup>42</sup> Measures include the proportion of schools that require daily physical education for all students, provide access to their physical activity spaces and facilities for all persons outside of normal school hours, provide tobacco-free environments, and make healthy, as opposed to “junk,” foods available. The School Health Policy and Programs Study also provides data on state-level policies related to schools. The National Work-site Health Promotion Survey, listed as the data source for several HP2010 objectives, includes the proportion of work sites that offer nutrition or weight-management classes or counseling, offer employer-sponsored physical activity and fitness programs, have formal smoking policies prohibiting smoking or limiting it to separately ventilated areas, and provide blood pressure screening.<sup>43</sup> This survey was last conducted in 1999. A national survey of airport smoking policies was conducted in 2002, but no ongoing surveillance system of such policies exists.<sup>44</sup>

### **Available State Data**

Data from all states on smoking-related policy and environmental factors at the state level are provided by the CDC Office on Smoking and Health’s State Tobacco Activities Tracking and Evaluation System.<sup>45</sup> This system provides current and historical information on indicators such as laws about clean indoor air, preemption laws, and cigarette excise

**TABLE 3. Pilot Indicators and Data Sources for Heart Disease and Stroke Prevention, Community Setting, South Carolina and Alabama, 2001**

Indicators	Data Sources and Comments
Percent of highway funds devoted to transportation alternatives (eg, bicycle lanes linked to public transportation, mass transit systems, facilities and roadway changes; supports such as parking hubs and bicycle racks).*	National Transportation Enhancements Clearinghouse ( <a href="http://www.enhancements.org">http://www.enhancements.org</a> ). Includes only data on funding spent under the federal Transportation Enhancements Program.‡
Percent of counties or municipalities with policies requiring sidewalks in all new and redeveloped residential and mixed-use communities.	No data source found.
Percent of counties or municipalities with policies that promote recreation facilities (eg, bikeways, parks, fields, gyms, pools, tennis courts, and playgrounds) in new and redeveloped residential and mixed-use communities.	No data source found.
State policies and percent of counties or municipalities with policies and strategic plans to promote bicycle use for transportation purposes.	No data source found.
Percent of low-fat milk sales in the state (1% or less).	No data source found. Regional milk production data are available but do not reflect state sales.
No. of farmers' markets per capita in the state.*	US Department of Agriculture Farmers' Market database ( <a href="http://www.ams.usda.gov/farmersmarkets/">http://www.ams.usda.gov/farmersmarkets/</a> ). Incomplete due to inconsistent reporting and definition of farmers' markets across states.‡
State with laws on smoke-free indoor air that prohibit smoking or limit it to separately ventilated areas in restaurants, day care centers, and other public places.†	State Tobacco Activities Tracking and Evaluation system ( <a href="http://www2a.cdc.gov/nccdphp/osh/state/">http://www2a.cdc.gov/nccdphp/osh/state/</a> ).§
Proportion of smokers who report that smoking is not allowed anywhere inside their homes.	BRFSS, optional Tobacco Indicators module ( <a href="http://www.cdc.gov/brfss/">http://www.cdc.gov/brfss/</a> ).§

\*Two indicators (25%) lack specificity (ambiguous, lack precision).

†One indicator (12%) lacks sensitivity (unable to measure incremental change, measured at inappropriate level).

‡Two indicators (25%) have data sources that partially measure the indicator.

§Two indicators (25%) have adequate data sources.

taxes.<sup>46,47</sup> The Behavioral Risk Factor Surveillance System provides information on smoking policies at respondents' work sites and homes.<sup>48</sup> The School Health Profiles surveys provide state-level data on school policies and environment related to physical activity, unhealthy diet, and tobacco. The School Health Profiles are designed and coordinated by the CDC and implemented biennially by some states, territories, and cities (43 states, 1 territory, and 13 cities in 2002).<sup>49</sup> Profiles data come from 2 surveys, a school principal survey and a survey of the lead health education teacher, which are both conducted in each sampled school. At least 1 state (North Carolina) has supplemented the Profiles surveys with state-added questions, including questions related to automated external defibrillator presence and policies. Many state heart disease and stroke prevention programs have also implemented state-level surveys, and even surveillance systems, to measure relevant policies and environmental factors. For example, South Carolina and Georgia have implemented work site surveys.<sup>50,51</sup> Georgia has conducted a survey of managed care organization policies and practices.<sup>52</sup> North Carolina recently conducted a survey of healthcare practices in the state, examining use of evidence-based guidelines and protocols for treating patients with or at risk for heart disease and stroke. North Carolina also conducted the Stroke Prevention and Treatment Facilities Survey, which measured hospital policies and environments related to treatment and prevention of stroke in 1998 and 2003.<sup>53</sup> This survey is currently being conducted in South Carolina and Georgia, as well. The state-level efforts described here have not developed into true surveillance systems, but the potential exists to develop

coordinated state-level surveys that could provide comparable data across states.

### National Gaps

Although the links between tobacco-related policies and environmental factors and tobacco use and its impact on health have been relatively well established, the research into the influence of policy and environmental factors on a population's physical activity level and diet is less well developed. In some cases, it is not yet clear which policies or environmental factors most strongly influence physical activity or diet and which show the most promise for public health intervention. These unanswered questions have made it difficult to design surveillance systems at the national and state level. National surveillance systems for school and work settings have been developed; however, the National Worksite Health Promotion Survey is not scheduled to be conducted again. No national surveillance efforts have been developed to monitor risk factor prevention policies and environmental conditions in healthcare or community settings.

### State Gaps

Few coordinated state-level surveillance systems exist for monitoring policies and environments related to risk factors. The School Health Profiles surveys provide state-level data similar to the national School Health Policy and Programs Study, but some inconsistencies exist between the questionnaires. Although many individual states have conducted surveys in various settings (school, work site, healthcare site, and community), most are not surveillance systems. Coordination of these efforts across states would be required to develop comparable state-

**TABLE 4. Pilot Indicators and Data Sources for Heart Disease and Stroke Prevention, School Setting, South Carolina and Alabama, 2001**

Indicators	Data Sources and Comments
State policies that require daily physical education or its equivalent in minutes per week, for all students in K–12, with no substitution of other courses or activities for physical education.*	SHPPS ( <a href="http://www.cdc.gov/nccdphp/dash/shpps">www.cdc.gov/nccdphp/dash/shpps</a> )‡
State policies that require schools to assess students on the knowledge and skills specified by the state's physical education standards, frameworks, or guidelines.*	SHPPS‡
State policies requiring that the foods and beverages available at schools outside of school meal programs reinforce the principles of the <i>Dietary Guidelines for Americans</i> . <sup>36</sup>	SHPPS‡
State policies that require newly hired school food service managers to have a nutrition-related baccalaureate or graduate degree and certification/credentialing in food service from either the state or the American School Food Service Association.*	SHPPS‡
State policies that require all newly hired staff who teach physical education to be certified, licensed, or endorsed by the state to teach physical education.*	SHPPS‡
State policies that require all newly hired staff who teach health education to be certified, licensed, or endorsed by the state to teach health education.*	SHPPS‡
State policies that require schools to assess students on the knowledge and skills specified by the state's health education standards, frameworks, or guidelines.*	SHPPS‡
Percent of schools that provide health education instruction that includes the physical education, nutrition, and tobacco use prevention topics listed in <i>School Health Index</i> . <sup>37</sup>	No data source found. Questions from <i>School Health Index</i> could be useful for surveillance if survey mechanism is developed.
Proportion of schools with School Health Councils.†	SHEP ( <a href="http://www.cdc.gov/nccdphp/dash/profiles">http://www.cdc.gov/nccdphp/dash/profiles</a> ). SHEP is completed by a sample of principals and lead health educators in schools having at least 1 of the grades 6–12. No data source available for elementary schools.§
Proportion of schools that have adopted tobacco-free school policies that meet CDC recommendations.†	SHEP. See above. SHEP does not include questions to thoroughly assess whether tobacco policies meet recommendations.§

K–12 indicates kindergarten through 12th grade of school; SHPPS, School Health Policy and Programs Study; and SHEP, School Health Education Profile.

\*Seven indicators (70%) lack sensitivity (unable to measure incremental change, measured at inappropriate level).

†Two indicators (20%) lack specificity (ambiguous, lack precision).

‡Seven indicators (70%) have adequate data sources.

§Two indicators (20%) have a data source that could partially measure the indicator.

level surveillance systems. Such an effort might also result in the development of better instruments and methods.

### Lifestyle Risk Factors (Physical Inactivity, Unhealthy Diet, and Tobacco Use)

#### Available National Data

The National Health and Nutrition Examination Survey (NHANES) provides self-reported data on physical activity, such as the frequency and duration of moderate-intensity activity, vigorous activity, and walking or biking to work or school, as well as objective measures of fitness from a submaximal treadmill exercise test.<sup>54,55</sup> The NHANES provides data on current physical activity behavior (within the past 30 days) and changes in activity compared with the previous 12 months and a time point 10 years prior. No information is collected on whether inactive respondents are aware that physical inactivity is a health risk or whether they have been counseled to increase their level of activity. The National Health Interview Survey (NHIS) also provides self-reported data on leisure-time physical activity, such as the frequency and duration of vigorous, moderate, and light activities and strengthening activities.<sup>54,56</sup>

These national surveys also collect information on tobacco use. NHANES provides data on the self-reported prevalence of smoking and the presence of other smokers in the household.<sup>55,57</sup> The NHIS provides self-reported data on smoking

prevalence.<sup>48,56</sup> Both NHANES and NHIS provide information on current or former tobacco use and cessation attempts but not about whether respondents received healthcare provider counseling. The National Survey on Drug Use and Health conducted by the Substance Abuse and Mental Health Services Administration also collects information on current and former tobacco use among people  $\geq 12$  years of age.<sup>58</sup> Because they provide data on current as well as past cigarette smoking status, NHANES, NHIS, and the National Survey on Drug Use and Health enable estimation of the proportion of ever-smokers who have quit smoking as a measure of the effectiveness of control efforts at the national level.

Since 2002, national dietary information has been collected through the “What We Eat in America” survey. This survey integrated 2 earlier nationwide dietary surveys, the Continuing Survey of Food Intakes by Individuals, which was conducted by the US Department of Agriculture, and the dietary survey component of NHANES, conducted by the US Department of Health and Human Services.<sup>59,60</sup> Before this integration, the US Department of Health and Human Services had collected dietary information through NHANES I, II, III, and the yearly NHANES beginning in 1999.<sup>55</sup> The US Department of Agriculture had conducted other surveys of dietary patterns among Americans, such as the Continuing Survey of Food Intakes by Individuals, the Diet and Health Knowledge Survey, and the Nationwide Food Consumption Surveys, but these are no longer conducted.<sup>61</sup>

**TABLE 5. Pilot Indicators and Data Sources for Heart Disease and Stroke Prevention, Work-Site Setting, South Carolina and Alabama, 2001**

Indicators	Data Sources and Comments
Percent of work sites that have policies supporting the engagement of all employees in physical activity during work time (eg, flexible scheduling, relaxed dress codes).	No data source found.
Percent of work sites that provide showers and changing facilities to support physically active employees.	No data source found.
Percent of work sites that provide and promote ongoing on-site employee physical activity programs (eg, walking, stretching, aerobics) during the previous 24 months.	No data source found. National Worksite Health Promotion Survey measures this indicator at the national level, but the sample is too small for state analysis.
Percent of work sites with vending machines and/or snack bars that offer heart-healthy food and beverage choices, including water or flavored water, 1% or less milk products, 100% juice products, fruits, vegetables, and products labeled low or reduced calorie, low or reduced sodium, or ≤3 g of fat per serving.	No data source found.
Percent of work sites with cafeterias that offer heart-healthy food and beverage choices, including water or flavored water, 1% or less milk products, 100% juice products, fruits, vegetables, and products labeled low or reduced calorie, low or reduced sodium, or ≤3 g of fat per serving.	No data source found.
Percent of work sites that offer nutrition or weight management classes or counseling.*	No data source found. National Worksite Health Promotion Survey measures this indicator at the national level, but the sample is too small for state analysis.
States with laws on smoke-free indoor air that prohibit smoking or limit it to separately ventilated areas in government and private work sites.†	State Tobacco Activities Tracking and Evaluation System ( <a href="http://www2a.cdc.gov/nccdphp/osh/state/">http://www2a.cdc.gov/nccdphp/osh/state/</a> ).‡
Proportion of work sites (segmented by No. of employees) that cover smoking-cessation programs.*	No data source found.

\*Two indicators (25%) lack specificity (ambiguous, lack precision).

†One indicator (12%) lacks sensitivity (unable to measure incremental change, measured at inappropriate level).

‡One indicator (12%) has an adequate data source.

The US Department of Agriculture and the Department of Health and Human Services now collaboratively conduct the “What We Eat in America” survey on a continuous yearly basis as part of NHANES. Two 24-hour dietary recalls, for nonconsecutive days, are collected for all respondents with the US Department of Agriculture’s automated multiple-pass method.<sup>62</sup> This survey provides comprehensive data on all

foods eaten both at home and away from home and on dietary supplement use. It provides data for estimating energy intake and intake of 60 nutrients and food components, including fat, cholesterol, fiber, carbohydrate, alcohol, and sodium.<sup>63</sup> The “What We Eat in America” survey collects information about current dietary behavior but not about whether respondents are aware of the health effects of their dietary choices,

**TABLE 6. Pilot Indicators and Data Sources for Heart Disease and Stroke Prevention, Healthcare Setting, South Carolina and Alabama, 2001**

Indicators	Data Sources and Comments
Percent of managed care organizations that adopt a policy to incorporate nationally accredited guidelines (eg, the <i>AHA Guide to Primary Prevention of Cardiovascular Diseases</i> <sup>38</sup> ) as part of their standard-care package.*	No data source found.
Percent of managed care organizations that adopt a policy to incorporate nationally accredited guidelines (eg, the <i>AHA Guide to Comprehensive Risk Reduction for Patients With Coronary and Other Vascular Disease</i> <sup>39</sup> ) as part of their standard-care package.*	No data source found.
Percent of managed care organizations (eg, health maintenance organizations, independent provider organizations, and preferred provider organizations) that have policies or guidelines to routinely provide or reimburse for assessments and counseling for physical activity, medical nutrition therapy, and tobacco cessation to plan members as part of their standard-care package, according to the <i>Guide to Clinical Preventive Services</i> . <sup>40</sup>	No data source found.
Percent of health insurance plans that have policies or guidelines to routinely provide or reimburse for assessments and counseling for physical activity, medical nutrition therapy, and tobacco cessation to plan members as a covered benefit, according to the <i>Guide to Clinical Preventive Services</i> . <sup>40</sup>	No data source found.
Proportion of current and recent smokers who received advice to quit smoking from a health professional.	BRFSS, optional Tobacco Indicators module ( <a href="http://www.cdc.gov/brfss">http://www.cdc.gov/brfss</a> ).†

\*Four indicators (80%) lack specificity (ambiguous, lack precision).

†One indicator (10%) has an adequate data source.

have been counseled to change their diets, or have made recent changes in what they eat.

The NAMCS<sup>64</sup> and the National Hospital Ambulatory Care Survey (NHAMCS)<sup>65</sup> Outpatient Department Form provide information from healthcare settings about the provision of counseling on physical activity, diet, and tobacco use, as well as data on current smoking status, but these sources do not include measures of physical activity, dietary habits, or the effectiveness of efforts to increase physical inactivity, improve diet, or reduce tobacco use. Furthermore, these data apply only to persons who have access to the healthcare system.<sup>64,65</sup>

### Available State and Local Data

Self-reported data on physical activity behaviors among adults is monitored by the BRFSS. The core BRFSS survey annually collects information by telephone on whether or not individuals have participated in any type of leisure-time physical activity during the past month.<sup>54</sup> During some years (typically biennially), the BRFSS also collects information on the amount of moderate and vigorous physical activity that respondents engage in during a usual week and on their typical occupational activity.<sup>54</sup> In the optional CVD module, the BRFSS collects information on recent increases in physical activity levels to reduce risk for CVD and receipt of healthcare provider advice to increase physical activity to reduce risk for CVD. This information can be used to examine rates of provider counseling (as reported by participants) and self-reported behavior change.

The Youth Risk Behavior Surveillance System (YRBSS) collects information on physical activity among high school students, including the percentage engaging in moderate physical activity, vigorous physical activity, and daily physical education, as well as information on whether respondents have increased their physical activity level in an attempt to lose weight; however, no information is collected on healthcare provider counseling on physical activity.<sup>54,66</sup> Data on the prevalence of smoking among adults and youth are monitored by BRFSS and YRBSS, respectively. Both of these surveys also provide information on the proportion of smokers who have attempted to quit smoking in the past year, and both surveys enable estimation of the proportion of ever-smokers who have quit smoking as a measure of the success of state-level tobacco control programs. In the optional tobacco module, the BRFSS also collects information about receipt of healthcare provider advice to quit smoking; however, the YRBSS provides no information about healthcare provider counseling on tobacco use. The Youth Tobacco Survey and the Adult Tobacco Survey are conducted in some states; these surveys provide more in-depth information on behaviors and attitudes related to tobacco use, including information on healthcare provider counseling about tobacco use.<sup>48</sup>

Dietary information is quite limited at the state level. Data on daily fruit and vegetable consumption is captured by the BRFSS for adults and by the YRBSS for high school students.<sup>67,68</sup> The optional CVD module of the BRFSS also includes questions designed to provide information from adults on (1) self-reported changes in diet to eat fewer high-fat or high-cholesterol foods and more fruits and vege-

tables and (2) receipt of counseling from a health professional to make either of these changes. The YRBSS also captures information on milk consumption among high school students; however, it does not collect information about awareness of or counseling on dietary recommendations.

### Gaps at National Level

Before NHANES was redesigned to collect data on a continuous basis beginning in 1999, national estimates relevant to biological risk factors for CVD were based on episodic data collection with widely spaced and variable intervals. The current design of NHANES, if continued, will enable better monitoring of trends in these measures of CVD risk. There are no national sources of data on incidence of behavioral risk factors. The NHANES and NHIS data are limited by biases that affect self-reported data, although the NHANES also collects serum cotinine and objective measures of fitness. No single national database provides fully adequate information on detection, treatment, and control of physical inactivity, unhealthy diet, or cigarette smoking.

### Gaps at State and Local Levels

Data on the prevalence of physical inactivity, unhealthy diet, and tobacco use among adults are limited to self-report. To the best of our knowledge, no reports have been published on the validity of the current BRFSS physical activity questionnaire that is used to estimate moderate and vigorous activity. In addition, BRFSS does not currently collect information on cigar smoking. Likewise, physical inactivity, unhealthy diet, and tobacco use data on young people are self-reported. Validity data for the physical activity questionnaire have not been published. Dietary data at the state and local levels are limited to fruit and vegetable intake and milk consumption; the vegetable consumption questions on both BRFSS and YRBSS do not allow measurement of consumption of dark-green or orange vegetables. Not all states participate in the YRBSS, and not all participating states collect data on physical activity, fruit and vegetable consumption, or tobacco use, so data from young people are available for only some states. YRBSS is limited to high school students primarily, although a middle school survey is conducted in some states. No systems exist to routinely collect biological measures of smoking at the state level. Reliable data are available for selected substate-level areas only. The BRFSS optional modules, Adult Tobacco Survey, YRBSS, and Youth Tobacco Survey are not conducted in all states in all years.

## Biological Risk Factors (Obesity, Hypertension, Dyslipidemia, and Diabetes Mellitus)

### Available National Data

The NHANES collects directly measured and self-reported data relevant to biological risk factors.<sup>55</sup> Obesity-related measures include height and weight (used to calculate body mass index), body circumference, body composition by bioelectrical impedance analysis, skinfold measures, and self-reported height and weight history, weight loss attempts and strategies, and weight change. No information is provided about healthcare provider counseling on weight man-

agement. Hypertension-related measures include self-reported data on length of time since last blood pressure measurement, directly measured systolic and diastolic blood pressure, and self-reported history of diagnosed hypertension, hypertension awareness, and treatment. From these data, hypertension control measures can be estimated. Dyslipidemia-related measures include self-reported data on length of time since last cholesterol measurement; directly measured fasting total cholesterol, low-density lipoprotein cholesterol (LDL-C), high-density lipoprotein cholesterol (HDL-C), and triglycerides; and self-reported history of diagnosed high cholesterol, high blood cholesterol awareness, and treatment. From these data, cholesterol control measures can be estimated. Diabetes-related measures include fasting blood glucose and self-reported history of diagnosed diabetes, diabetes awareness, and treatment. Diabetes control is estimated on the basis of direct measurement of glycohemoglobin. The NHIS provides data on self-reported height and weight (used to calculate body mass index for estimates of self-reported prevalence of overweight and obesity). The NHIS also provides self-reported data on screening, prevalence, treatment, and control of hypertension and diabetes and screening and prevalence of high blood cholesterol.<sup>56</sup>

The CDC National Diabetes Surveillance System brings together data on diabetes prevalence, incidence, hospitalization, preventive care, and complications from many different sources, including NHIS, NHANES, BRFSS, NAMCS, and the NHDS.<sup>69</sup> This ongoing surveillance system collects, analyzes, and disseminates national data on diabetes mellitus and its complications through a series of publications, including the National Diabetes Fact Sheet,<sup>70</sup> more detailed periodic surveillance reports,<sup>71</sup> and other special reports (eg, *The Economics of Diabetes Mellitus: An Annotated Bibliography*<sup>72</sup>). The creation of this surveillance system has helped draw attention to the emerging epidemic of diabetes and mobilize resources to fund prevention and management programs.

The NAMCS and NHAMCS Outpatient Department Forms provide practice-reported information on provision of weight loss counseling that can be used in combination with data on height and weight to examine provision of counseling by overweight and obesity categories. These surveys also provide information on blood pressure measurements and medication use that can be used to estimate rates of hypertension diagnosis, treatment, and control; however, these estimates would be based on data from a single clinical encounter. Information on practice-reported diagnosis and treatment of high blood cholesterol and diabetes is also provided; however, no data on cholesterol, blood sugar, or glycohemoglobin concentrations are provided to enable validation of diagnosis or assessment of control. Furthermore, these data apply only to persons who have access to the healthcare system and tend to overrepresent persons who use the healthcare system frequently.<sup>64,65</sup>

### Available State and Local Data

The BRFSS collects self-reported data relevant to these biological risk factors.<sup>73</sup> Height and weight (used to calculate body mass index) data are collected in all states in all years to

provide estimates of self-reported overweight and obesity. The prevalence of self-reported diagnosed hypertension among adults has been collected at least biennially since 1984. Since 2005, an optional BRFSS module has provided information on the proportion of adults with high blood pressure who are taking action to control their blood pressure. The prevalence of self-reported diagnosed high blood cholesterol among adults and the proportion of adults who have had their blood cholesterol checked within the preceding 5 years have been estimated from data collected at least biennially since 1987. The prevalence of self-reported diagnosed diabetes among adults has been collected annually since 1988. The optional diabetes module provides information on diabetes treatment and glycohemoglobin testing. The BRFSS provides no information about control of hypertension, dyslipidemia, or diabetes.

Self-reports of height and weight also have been collected through the national and state/local YRBSS since 1999 and are used to calculate body mass index and the prevalence of overweight and those at risk for overweight.<sup>66</sup> Some states also participate in the Pediatric Nutrition Surveillance System, which is coordinated by the CDC and collects physical measures of height and weight of low-income children who attend federally funded maternal and child health and nutrition programs. The Pediatric Nutrition Surveillance System provides data on body mass index and the prevalence of overweight and those at risk for overweight among those <5 years of age.<sup>74</sup>

### Gaps at National Level

Before the redesign of NHANES, national estimates relevant to these biological risk factors have been based on episodic data collection with widely spaced and variable intervals. The current design of NHANES, if continued, will enable better monitoring of trends in these measures. There are no national sources of data on incidence of biological risk factors. The NHIS data are limited by biases that affect self-reported data, that is, misclassification due to lack of knowledge and incorrect recall. No national database exists to provide comprehensive information about obesity prevalence, awareness, treatment, and control.

### Gaps at State and Local Levels

At the state level, only self-reported data on biological risk factors are routinely available for adults. No coordinated state surveillance efforts have been made to collect direct measures of biological risk factors for data on obesity, hypertension, dyslipidemia, or diabetes prevalence, treatment, and control rates. The New York City Health and Nutrition Examination Survey and the CDC state-based examination survey initiative may lead to greater data availability in the future. In addition, the BRFSS no longer collects data on screening for high blood pressure, so this information is no longer routinely available at the state level. Among youth, the YRBSS relies on self-report of height and weight, which likely leads to an underestimate of the prevalence of overweight.<sup>66</sup> Not all states participate in the YRBSS, and not all states that do participate collect these data, so data on youth are only available for some states. Although the Pediatric Nutrition

Surveillance System provides physical measures, this survey is limited to a select population in 13 states, the District of Columbia, Puerto Rico, and several American Indian tribes. Data on weight are available for selected substate-level areas. Data on the incidence of biological risk factors are not available at the state level. Data related to hypertension, high cholesterol, and diabetes are not available for all states for all years and are only available for some substate level areas. There are no coordinated efforts between states to collect information on biological risk factors among youth.

### **HP2010 Goals 3 and 4: Early Identification and Treatment of Heart Attacks and Strokes and Prevention of Recurrent Cardiovascular Events**

Accomplishing the early identification and treatment of heart attacks and strokes invokes the vision of an efficient, effective, and coordinated emergency and acute care delivery system, and the need for such a system is obvious. However, it is important to recognize that many silent heart attacks<sup>75,76</sup> and strokes occur,<sup>77</sup> as well as nonhospitalized events that go unrecognized by acute care delivery systems. Consequently, improved identification and treatment of heart disease and stroke in the outpatient setting is increasingly important to prevent first symptomatic events and recurrent events.

#### **Surveillance of Acute Events**

The ultimate goal of risk factor prevention, detection, and control is to prevent acute events. Consequently, surveillance of cardiac arrests, heart attacks, and strokes is needed to fully assess the impact of risk factor prevention, detection, and control efforts; furthermore, such surveillance would also provide a population in which to assess the impact of efforts to rapidly identify and treat these events (goal 3). Optimal surveillance of acute events requires an understanding of the distinction between incident and recurrent events. Incident events, or first occurrences of heart disease or stroke in persons without known prior heart disease or stroke, differ in important ways from recurrent events, or later attacks in persons with known prior disease. Persons experiencing incident events are less likely to be influenced by preexisting CVD (at other vascular sites) and previous clinical care (other than, potentially, risk factor management). The success of acute treatment influences the size of the population at risk for recurrent events, and subsequent medical care, in addition to other factors, influences that risk. Surveillance systems that enable discrimination between incident and recurrent events provide a much clearer indication of the changing natural history of heart disease and stroke occurrence in the community. Surveillance of incident events is important for evaluating public health measures aimed at maintaining health and function in currently asymptomatic persons. Surveillance of recurrent events also enables the evaluation of efforts aimed at preventing recurrent events (goal 4). Surveillance systems that are limited to the estimation of attack rates, in which incident and recurrent events are not distinguishable, provide data relevant to the early identification and treatment of acute events (goal 3), including the quality and outcomes of acute care, but do not provide sufficient data to evaluate the specific

impact of separate efforts targeting prevention of incident and recurrent acute events.

Incident heart disease events can be especially difficult to monitor, however, because cardiac arrest (also known as sudden cardiac death) is often the first manifestation of ischemic heart disease.<sup>78,79</sup> Surveillance of sudden cardiac death is complicated by the poor level of agreement between sudden cardiac death rates based on vital statistics data and based on adjudicated data.<sup>80</sup> Despite this limitation, roughly half of sudden cardiac deaths are believed to occur in persons without known heart disease, and sudden deaths in persons without heart disease may comprise more than one fifth of all coronary heart disease deaths.<sup>81</sup> Sudden deaths and out-of-hospital deaths, whether due to heart disease or stroke, are often missed by hospital-based surveillance systems. Identification, validation, and classification of out-of-hospital deaths require additional surveillance efforts, including access to death certificate data and contact with next of kin, physicians, coroners, and other informants. In addition, classification of sudden death as an indicator of disease incidence requires exclusion of preexisting, or prevalent, disease, which can be difficult without detailed diagnostic evaluation and/or medical history; nevertheless, surveillance of cardiac death as the initial manifestation of heart disease would provide important insight into the effectiveness of prevention efforts targeting risk factor prevention, detection, and control.

Assessment of incidence is crucial for assessing the population burden of disease and the effectiveness of preventive efforts. Although incidence is typically expressed as a rate per specific population size and time period (such as cases/100 000 population per year), total or absolute numbers of cases are also valuable in assessing total disease burden. Population-based rates, which require reliable data on population size (denominator), are most useful for comparing risk of disease between subgroups, such as those defined by sex, ethnicity, and presence or absence of risk factors. Absolute numbers of cases are useful for evaluating disease burden and planning for distribution and use of healthcare resources.

#### **Surveillance of Community Indicators**

The early identification and treatment of heart disease and stroke starts in the prehospital phase. Improved in-hospital care and the advent of time-dependent treatments have increased the value of reducing delays from the onset of symptoms to receipt of effective acute care. Delay to treatment can be generically divided into several components: (1) prehospital patient delay (the time from symptom onset to contact with the healthcare system), (2) transport time (time from initial contact with the healthcare system to hospital arrival), and (3) in-hospital delays in diagnosis and treatment. For both heart attack and stroke, the longest of these components is usually prehospital patient delay, which is  $\approx 2$  hours for heart attack<sup>82</sup> and ranges from a median of 3 to 6 hours for stroke.<sup>83</sup> To evaluate progress in reducing all of these time elements, surveillance systems must address both community indicators and hospital indicators related to early identification of events.

The first link in the chain of recovery starts with the recognition of and response to symptoms by patients and

those in their environment. Understanding the level of knowledge about cardiac and stroke symptoms and the appropriate initial response to those symptoms is important for tailoring and improving public health campaigns and programs.<sup>84,85</sup>

Another community indicator critical for the early and rapid identification of events is the state of emergency medical services systems, including capabilities of 9-1-1 systems and other telecommunications. Emergency medical services and 9-1-1 capabilities vary widely from state to state and within states. Availability of enhanced 9-1-1, with access to technology that facilitates identification of the location of the caller, varies widely. The time a 9-1-1 call is received, dispatch determination, when the emergency medical services personnel are dispatched, arrival time, scene time, transport time, and treatments given at the scene and during transport are just some examples of the key data points that need to be evaluated in the prehospital care phase of acute coronary and stroke events. Other prehospital community-level indicators relevant to early identification and treatment of acute events include public access to and use of automated external defibrillators. Obtaining the information needed to evaluate programs aimed at improving public recognition of and response to symptoms of acute events and access to high-quality prehospital care will require the development of appropriate methods of surveillance.

### Surveillance of Healthcare Quality

The Institute of Medicine defines quality of care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”<sup>86</sup> Without quality-of-care measurement, it is not possible to know whether current treatment strategies for improving patient survival and well-being are being maximally utilized. Thus, it will be critical to embed quality-of-care measures into any national surveillance efforts that have the goal of reducing the burden of heart disease and stroke. Groups such as the AHA, the Agency for Healthcare Research and Quality, the American College of Cardiology (ACC), the Institute of Medicine, the National Heart, Lung, and Blood Institute, and the Veterans Health Administration have identified cardiovascular quality of care as a “top-tier” priority for national measurement and action to improve care delivery and thereby improve patient outcomes.<sup>87,88</sup>

Unfortunately, numerous studies have documented significant gaps in the quality of care provided in the United States, to the degree that the Institute of Medicine has identified a “quality chasm” that must be crossed.<sup>86</sup> For example, with regard to heart disease and stroke, a significant proportion of eligible patients do not receive guideline-indicated medications such as aspirin or  $\beta$ -blockers after a heart attack or warfarin for atrial fibrillation.<sup>3</sup> Although much of the focus has been on the underuse of therapies that can help patients, variation in quality of care can also be due to the overuse of therapies that are not necessary or errors in the delivery of therapies that can cause harm to patients.<sup>89</sup> Quality-of-care measurement should therefore include assessment of the delivery of necessary care (eg, guideline-indicated treatments), appropriate care, and safe care. Moreover, quality-

of-care measurement should include processes, structures, and outcomes of care.<sup>90</sup> To date, there has been little standardization of quality-of-care measures and limited regional and national quality-of-care surveillance efforts.

Several interventions have been shown to reduce the risk for death and recurrent events in patients with heart disease and stroke; these interventions are included in guidelines from the ACC and AHA.<sup>91–96</sup> Any quality performance measures to be incorporated into national surveillance of quality of care for heart disease and stroke should meet the methodological criteria for performance measures outlined by the ACC/AHA Task Force on Performance Measurement.<sup>97</sup> In brief, measures should be evidence-based (eg, stemming from class I [beneficial] or class III [not beneficial, or harmful] ACC/AHA guideline indications), have clear definitions of which patients are eligible for a given measure, be feasible to measure nationally with reasonable effort, and be actionable, or under the control of hospitals or practitioners so that steps can be taken to improve performance and thereby quality of care. This latter point highlights that national surveillance for quality of care should not be for descriptive purposes only but should be part of a broader national effort to improve quality of care (eg, through feedback of performance with benchmarking). In this way, surveillance becomes an active process in efforts to meet the AHA and HP2010 goals of reducing rates of heart disease and stroke.

To date, groups such as the Centers for Medicare and Medicaid Services, the Joint Commission on Accreditation of Healthcare Organizations, and the Veterans Administration have used some cardiovascular quality performance measures (eg, aspirin and  $\beta$ -blockers on admission and discharge, reperfusion therapy, and lipid-lowering therapy on discharge for eligible heart attack patients), but these measures are defined somewhat differently and are not currently used for national surveillance (eg, the Centers for Medicare and Medicaid Services measures are used only for patients with Medicare coverage). Furthermore, there has been an emphasis on hospital care and little on performance measurement related to longitudinal care and long-term outcomes of heart disease and stroke patients. The ACC/AHA Performance Measurement Task Force has recently developed quality-of-care performance measures for heart failure and acute myocardial infarction.<sup>97,98</sup> These efforts to measure quality of care should be coordinated to allow the identification of a set of standardized performance measures that can be part of a national surveillance system that will directly promote quality improvement, as do the CDC-funded Paul Coverdell National Acute Stroke Registry programs, currently funded in only 4 states.<sup>99</sup>

Of note, the National Quality Forum ([www.qualityforum.org](http://www.qualityforum.org)) attempts to bring together consumers, providers, health plans, purchasers, professional societies (including the AHA and ACC), and researchers with regard to national quality performance measures, and it may serve as a source for quality-of-care measures that can be used in national surveillance related to the care of heart disease and stroke patients. To date, the National Quality Forum has released a limited set of performance measures for hospital care, including some relevant to heart attack and heart failure, and has plans to

develop other performance measures for the care of patients with heart attack and heart failure, as well as measures of care coordination. Although efforts like those of the National Quality Forum may lead to identification of standardized national measures of quality of cardiovascular care, additional challenges will be how best to gather the data nationally and how to leverage it toward meeting national quality-improvement goals.

One example of a nongovernmental program with potential for use in national quality-of-care measurement and improvement is the ACC's National Cardiovascular Data Registry (ACC-NCDR; [www.accncdr.com](http://www.accncdr.com)). The ACC-NCDR collects data (based on ACC data standards) on procedures performed in cardiac catheterization laboratories, with feedback on quality measures (eg, complication rates) including comparisons with similar hospitals and national benchmarks. To date, the ACC-NCDR is not nationally representative and lacks data on longitudinal outcomes, but it represents one potential way to promote the collection and use of national surveillance data for improving quality of care, at least for cardiac catheterization laboratory procedures. The AHA National Registry for Cardiopulmonary Resuscitation program ([www.americanheart.org](http://www.americanheart.org)) is a potential contributor to safety programs that monitor and reduce in-hospital cardiovascular emergencies. The AHA's "Get With the Guidelines" (GWTG) programs for coronary heart disease, stroke, and heart failure ([www.americanheart.org](http://www.americanheart.org)) are also potential contributors to national surveillance of quality of care and quality improvement for CVDs, but these programs are not currently nationally representative and lack data on longitudinal care and outcomes.

In summary, quality-of-care measures to be included in national cardiovascular surveillance efforts should be methodologically rigorous and standardized under such efforts as the ACC/AHA Performance Measures and the National Quality Forum. Where possible, measurement of quality should be linked to quality-improvement efforts, as is done in the ACC-NCDR and the AHA's GWTG program. It will be critical to include quality-of-care measures in any national surveillance efforts to reduce the burden of heart disease and stroke and enhance patient outcomes.

### Surveillance of Case Fatality

Case fatality refers to the mortality rate among persons who experience acute events. Recent trends in coronary heart disease case fatality show steady declines that are attributed to better acute care and reduced severity of the events.<sup>100,101</sup> Adjustment for standardized measures of severity could improve the utility of case fatality as an indicator of the impact of acute care. Estimation of case fatality is often limited to deaths that occur during the course of the initial hospital stay; however, variations in the duration of hospital stay complicate interpretation of in-hospital case fatality rates. Consequently, inclusion of all deaths that occur within 30 days of an acute event has become the standard for surveillance efforts. Variations in the proportion of people with acute events who survive to reach hospital care further complicate the interpretation of case fatality; hence, the inclusion of prehospital cardiac deaths may provide a more

accurate reflection of the short-term mortality rates related to heart disease. In addition, because trends in case fatality rates may differ across communities in relation to the proportion of events that are incident versus recurrent in that community, the ability to distinguish between incident and recurrent events is also crucial for the interpretation of case fatality trends. Similar considerations apply to stroke.

### Surveillance of Event Severity

Isolated community-based surveillance studies among people hospitalized with acute myocardial infarction have provided important information on trends in the severity of such events over time. However, reports from the Atherosclerosis Risk In Communities community surveillance,<sup>101</sup> the Worcester Heart Study,<sup>102</sup> and Olmsted County, Minnesota,<sup>103</sup> have reported mixed findings on whether or not the severity of acute myocardial infarctions is decreasing. A clear picture of changes in disease severity is an important component of understanding the relative contributions of medical care and prevention to national trends in CVD mortality. Primary prevention efforts can exert an influence on disease in the face of unchanging incidence by helping to lessen the severity of clinical events, thereby also reducing case fatality rates. However, surveillance systems that only count the number of incident events fall short of providing in-depth information on the nature of the event (ie, severity indicators). The changing definitions of acute events such as those proposed for acute myocardial infarction by the ACC/European Society of Cardiology joint criteria<sup>104</sup> provide further evidence that the collection of clinical details of the events sufficient to determine severity is important to any complete surveillance system. These new definitions result in the classification of some events as acute myocardial infarctions that previously did not meet standard criteria (based on electrocardiogram and creatine kinase-MB fraction). The resulting "troponin-only" infarcts have been shown to have a higher case fatality rate in some studies<sup>105</sup> and a lower case fatality rate in others.<sup>106,107</sup> Without additional information about severity indicators, incidence rates will be difficult to interpret. Collecting information on severity will improve our ability to track progress toward reaching national goals for reducing heart disease and stroke.

### Impact of Changes in Diagnostic and Therapeutic Technology

Changes in diagnostic and therapeutic technologies may have important implications for interpretation of incidence and mortality trends. The advent of highly sensitive biomarkers for detection of heart attacks, for example, has resulted in substantial increases in heart attack hospitalization rates.<sup>108</sup> The introduction of cranial computed tomographic scanning had a similar impact on stroke trends.<sup>109</sup> The trends toward higher attack rates due to these changes may be accompanied by lower rates of complications and mortality if cases detected by newer biomarkers or imaging studies include milder events that would previously have gone undetected. The concomitant greater use of effective preventive and acute care may also reduce morbidity and mortality. Reliable data on incidence, severity, treatment, and outcomes of acute

events are needed to provide insight into the effectiveness of prevention and treatment strategies. Surveillance systems must be robust enough and detailed enough to adapt to new clinical definitions of events.

### Surveillance of Cardiovascular Procedures

Registries of invasive procedures such as thrombolysis, percutaneous coronary intervention, carotid endarterectomy, angioplasty and stenting, and coronary bypass grafting have also been used as indicators of disease burden, but the biases involved in application of these procedures render them of questionable value for purposes of disease surveillance.<sup>110–112</sup> Data about procedures do provide useful insights, however, into costs of care, as do data on trends in drug usage.<sup>113–115</sup> Procedures and drug treatment also play a role in modifying rates of case fatality and recurrence, so the collection of accurate data on their use is an important component of a comprehensive heart disease and stroke surveillance system. Surveillance systems must be easy to modify to include data capture of new therapies as they emerge.

### Limitations of Hospitalization Data

Despite the common use of hospitalization data for monitoring burden and trends in heart attacks and stroke, hospitalization data have biases related to access that limit their utility. Some people who experience an acute event may not reach the hospital owing to failure to recognize and respond to the event, being in a long-term care facility, or early death, for example. In addition, monitoring trends in acute events is complicated by the recent trend toward observing suspected cases of heart attack and stroke in an acute care setting for <24 hours, without hospitalization, as a cost-containment strategy. This approach allows ample time for a definitive diagnosis to be made through biomarker evaluation or brain imaging. Persons for whom a heart attack is ruled out may be sent home before the time at which a hospitalization becomes official for billing and surveillance purposes (24 hours). This practice may have contributed to the recent decline in hospitalizations for unstable angina, a phenomenon that complicates efforts to monitor trends in acute coronary syndromes.<sup>116</sup> The issue of outpatient care without admission is especially important as it relates to capturing incidence data and treatment patterns for heart failure. Traditional hospital-based surveillance is not adequate to fully evaluate the impact and burden of heart failure in the community, although the majority (74%) of heart failure patients are hospitalized eventually.<sup>117</sup>

### Surveillance of Patient Health Status

Patient health status includes symptom burden, functional status (eg, physical, emotional, and social function), and health-related quality of life, which is the discrepancy between actual and desired function for a given patient.<sup>118</sup> With the significant therapeutic advances in treating CVD over the last 20 years and concomitant improvements in survival, there has been increasing emphasis on patient health status as a primary outcome of care. Assessment of health status directly accounts for the patient's perspective on how the disease is affecting his or her life, and many patients express a desire for

quality of life that is equal to or greater than their desire for quantity of life.<sup>119</sup> Assessment of patient health status is consistent with the Institute of Medicine's call for more patient-centered care in order to provide the highest quality of care.<sup>86</sup> Thus, health status measurement should be considered for inclusion in any national surveillance of heart disease and stroke to ensure that the surveillance accounts for how well people are living, not just how long they are living.

Health status surveys have been developed that are valid, reliable, sensitive to clinical change, and, in many cases, predictive of subsequent cardiovascular morbidity and mortality.<sup>120–122</sup> These include both generic surveys that measure overall patient health status and disease-specific surveys that measure how one condition (eg, heart failure) influences a given patient's symptom burden, functional status, and health-related quality of life. Examples of generic instruments include the Short-Form (SF) 36 health status survey and its even shorter versions (eg, SF-12) and the EQ-5D, which is a utilities measure that allows derivation of quality-adjusted life-years when combined with economic assessment. Examples of disease-specific instruments include the Seattle Angina Questionnaire and the Mac-New questionnaire for patients with ischemic heart disease, the Kansas City Cardiomyopathy Questionnaire and the Minnesota Living with Heart Failure Questionnaire for heart failure patients, and the Stroke-Specific Quality of Life Scale (SS-QOL) and National Institutes of Health Stroke Scale for stroke patients.<sup>123–128</sup>

Although health status surveys have been used extensively in research studies (eg, to assess the impact of new therapies or interventions on quality-of-life outcomes), they have generally not been used as part of cardiovascular surveillance. Surveys by the CDC and the Agency for Healthcare Research and Quality have addressed health behaviors and risk factors but have not explicitly measured patient health status, nor have they focused on clinical conditions.<sup>88</sup> The Veterans Administration has undertaken large-scale patient health status surveys using generic instruments like the SF-36 but has not used ongoing health status surveillance or tied the health status data to clinical conditions or events.

In summary, patient health status is an essential measurement for adequately assessing the impact of heart disease and stroke, as well as of the therapies and interventions for these conditions, on patients' lives. Validated health status surveys (including disease-specific surveys for ischemic heart disease, heart failure, and stroke) are available and can provide clinically relevant and prognostic information that cannot be obtained in other ways.<sup>118</sup> To date, patient health status has, for the most part, not been part of the cardiovascular surveillance system. Future efforts toward establishing national surveillance for heart disease and stroke should incorporate patient health status assessment and thereby directly promote patient-centered care of the highest quality.

### Available National Data

National data are available on attack rates of acute events (NHDS, Nationwide Inpatient Sample [NIS])<sup>129,130</sup>; however, it is not possible to distinguish between incident and recurrent events. In-hospital case fatality rates can be determined from

**TABLE 7. 2005 Acute Myocardial Infarction National Quality Measures: Centers for Medicare and Medicaid Services and the Joint Commission on Accreditation of Healthcare Organizations**

Measure
Aspirin at arrival
Aspirin prescribed at discharge
ACE inhibitor or angiotensin receptor blocker for left ventricular systolic dysfunction
Adult smoking-cessation advice/counseling
$\beta$ -Blocker prescribed at discharge
$\beta$ -Blocker at arrival
Mean time to thrombolysis
Thrombolytic agent received within 30 minutes of hospital arrival
Mean time to PCI
PCI received within 120 minutes of hospital arrival
Inpatient mortality†
LDL Cholesterol assessment (optional test measure)*
LDL Cholesterol testing within 24 hours after hospital arrival (optional test measure)*
Lipid-lowering therapy at discharge (optional test measure)*

ACE indicates angiotensin-converting enzyme; PCI, percutaneous coronary intervention.

\*Centers for Medicare and Medicaid Services only.

†Joint Commission only.

these sources; however, linkage to other data sources such as the National Death Index is not possible. Consequently, assessment of 30-day case fatality rates is not possible, except through administrative data sources such as the Centers for Medicare and Medicaid Services. Data on use of cardiovascular procedures are available, but linkage of these data to outcomes beyond the hospital stay is difficult.

Although representative data are not available to monitor the quality of secondary prevention at the national level, several data sources provide insight pertinent to selected measures in selected populations. The Centers for Medicare and Medicaid Services and the Joint Commission on Accreditation of Healthcare Organizations have adopted a uniform set of quality measures and publish data on several secondary prevention measures among hospitalized patients (Tables 7 and 8). For appropriate stroke patients, the Centers for Medicare and Medicaid Services also provide data on warfarin use for atrial fibrillation. The Veterans Administration reports similar information. The National Committee for Quality Assurance reports data from participating managed care organizations. These data are reported by the participat-

**TABLE 8. 2005 Heart Failure National Quality Measures: Centers for Medicare and Medicaid Services and the Joint Commission on Accreditation of Healthcare Organizations**

Measure
Discharge instructions
Left ventricular function assessment
ACE inhibitor or angiotensin receptor blocker for left ventricular systolic dysfunction
Adult smoking-cessation advice/counseling

ing organizations on a voluntary basis and are collected to inform quality-improvement efforts. Measures include use of  $\beta$ -blockers at discharge after a myocardial infarction, cholesterol screening and control in patients hospitalized for coronary heart disease, control of hypertension and diabetes, and smoking cessation counseling.<sup>131</sup>

The AHA National Registry for Cardiopulmonary Resuscitation program is a hospital-based program that provides information from participating hospitals on the quality of care and outcomes of patients who experience cardiac arrest.<sup>130–135</sup> Measures include monitored status, performance of cardiopulmonary resuscitation, timely defibrillation, and hospital outcome. Recent extensions of the National Registry for Cardiopulmonary Resuscitation program include measures of patients who have risk factors for in-hospital cardiac arrest and receive interventions to reduce this risk. The AHA GWTG Coronary Artery Disease program is a hospital-based quality-improvement effort that provides information from participating hospitals on patients hospitalized for coronary heart disease.<sup>136</sup> Measures include use of aspirin,  $\beta$ -blockers, angiotensin-converting enzyme inhibitors, lipid-lowering therapy and blood pressure-lowering therapy at discharge, smoking-cessation counseling, and referral to cardiac rehabilitation. In addition, GWTG programs for stroke and heart failure have been initiated. GWTG for Stroke provides information on smoking-cessation counseling, cholesterol-lowering therapy, use of antiplatelet agents, weight and exercise management, use of anticoagulants for atrial fibrillation, and diabetes management among appropriate patients hospitalized for stroke. GWTG for Heart Failure provides information on discharge instructions, measurement of left ventricular function, and angiotensin-converting enzyme inhibitor or angiotensin receptor blocker and  $\beta$ -blocker use among appropriate patients at discharge.

Professional society-run registries also exist, such as the ACC-NCDR for cardiac catheterization/percutaneous coronary intervention, implantable cardioverter defibrillators, and carotid stenting and the Society of Thoracic Surgery's registry for cardiothoracic surgery. Finally, industry-sponsored registries exist for cardiovascular conditions such as acute coronary syndromes (CRUSADE [Can Rapid Stratification of Unstable Angina Patients Suppress Adverse Outcomes with Early Implementation of the ACC/AHA Guidelines?]<sup>137</sup>) and NRMI [National Registry of Myocardial Infarction] and heart failure (ADHERE [Acute Decompensated HEart Failure National Registry]<sup>138</sup>). CRUSADE is a quality-improvement program that involves >440 hospitals across the United States.<sup>137</sup> It provides information on use of aspirin,  $\beta$ -blockers, angiotensin-converting enzyme inhibitors, and lipid-lowering therapy at discharge. ADHERE is a registry of patients hospitalized with acutely decompensated heart failure at 260 participating US hospitals that provides information on the use of angiotensin-converting enzyme inhibitors and  $\beta$ -blockers at discharge, as well as smoking-cessation counseling.<sup>138</sup> At this time, none of these programs or registries are truly nationally representative; however, each has unique strengths and limitations, and they all have the potential for use in national surveillance.

### Available State and Local Data

State-based data on attack rates and procedure use are available from the 37 states that participate in the NIS.<sup>139</sup> A handful of population-based research studies of the incidence of acute coronary disease and stroke are currently active in selected communities: the Minnesota Heart Survey and Minnesota Stroke Survey in Minneapolis and St. Paul, Minn; the Rochester (Minnesota) Epidemiology Project; the Atherosclerosis Risk in Communities study (Washington County, Md; Minneapolis, Minn; Jackson, Miss; and Forsyth County, NC); the Worcester (Massachusetts) Heart Attack Study; the Northern Manhattan Stroke Study; and the Greater Cincinnati/Northern Kentucky Stroke Study. Some of these studies also feature out-of-hospital death investigation that allows for an estimate of incidence of fatal out-of-hospital events. Most of these hospital-based surveillance programs also collect data on use of procedures and other treatments and severity of acute events; however, all of these programs are research projects rather than public health surveillance programs. Four states (North Carolina, Massachusetts, Georgia, and Illinois) have established Paul Coverdell National Acute Stroke Registries that monitor acute care and preventive care at discharge for stroke patients hospitalized across the state.<sup>99</sup> Even fewer local and regional research studies capture data on prehospital community indicators of early identification and treatment of acute events.

### Gaps at National Level

No nationally representative data are available on incidence, severity, 30-day case fatality, or recurrence of acute coronary or stroke events in either the inpatient or outpatient settings. Available data on the quality of acute care and preventive care provided to these patients apply to selected subgroups of patients or are reported on a voluntary basis. Performance measures are not consistent across databases. No data are available on patient health status. No data are available on community indicators relevant to early identification and response to symptoms or access to high-quality care in the prehospital setting.

### Gaps at State and Local Levels

State and local regions also lack representative data on acute event incidence, severity, 30-day case fatality, recurrence, quality of acute care (in the prehospital and hospital settings), and community indicators of early identification of and response to symptoms. No systematic data are available on secondary prevention efforts at the state or local level. The Paul Coverdell National Acute Stroke Registries will provide data on stroke severity and quality of acute stroke care and preventive care at discharge for 4 states, but these registries are not designed to provide information about stroke incidence or 30-day case fatality.<sup>99</sup> No data are available on patient health status.

### Surveillance of CVD Prevalence

Prevalence data provide an indicator of the overall disease burden in the population. Potentially, prevalence data could be based on the combination of overt disease diagnosed in the healthcare setting and disease that has not yet come to the

attention of the medical system, although prevalence based on the former is more often assessed. Prevalence data could include information on persons who are living in the community as well as those who are institutionalized and bear a disproportionate share of the burden of heart disease and stroke. Although many data sources provide estimates of prevalent disease, no systematic methods have been developed for combining individual and unique data sets to provide an estimate of the overall disease burden. In addition, privacy issues make such information difficult to obtain, because linkage between different data sources, although feasible, is often proscribed. Persons who are institutionalized, particularly in nursing homes, constitute a large portion of the disease burden but are rarely included in population surveys. Finally, much prevalent disease is subclinical and undiscovered by the healthcare system and can only be detected in population surveys.

### Available National, State, and Local Data

Many data sets that touch on elements of prevalence are available. The NHANES and NHIS provide prevalence data representative of the noninstitutionalized national population.<sup>55,56</sup> The National Nursing Home Survey, last conducted in 1999, collects information on up to 7 medical diagnoses at admission and at the time of the survey; however, the National Nursing Home Survey does not collect standardized data elements specific to CVD diagnoses.<sup>140</sup> The BRFSS provides prevalence data representative of the noninstitutionalized populations of the states<sup>141</sup>; however, many data elements are lacking, especially for various institutionalized populations, and no common system is in place for merging the existing data to provide an overall picture.

### Gaps at National, State, and Local Levels

Population surveillance of prevalent disease should include institutionalized individuals and methods of detecting subclinical disease. To be useful at the state and local levels, such a system would require a large sample size, because even common CVDs are not widely prevalent in the general population.

### Surveillance of Other CVD Conditions

Although not addressed specifically in the goals set forth in HP2010, CHF (historically labeled congestive heart failure) and PAD contribute substantially to national morbidity, mortality, and healthcare costs.<sup>3-7</sup> Consequently, our ability to make good decisions about allocation of public health and healthcare resources will be improved by having access to better data on the changing burdens of these diseases.

### Chronic Heart Failure

CHF is epidemic in the United States and other industrialized countries.<sup>4,5,138,139</sup> It is estimated that 5 million Americans currently have CHF (2003), with 550 000 new cases added each year.<sup>3</sup> From 1993 to 2003, deaths due to heart failure increased 20%.<sup>3</sup> Five-year survival of CHF patients is <50%. In addition, many hospital discharges list CHF as an associated condition.<sup>4</sup> In 2003, there were 1 093 000 hospitalizations with CHF as a primary diagnosis, a 174% increase over

1979, and approximately twice as many listed CHF as a secondary diagnosis.<sup>3</sup> More than 20% of acute hospitalizations of all individuals >65 years of age list CHF as a primary or secondary diagnosis.<sup>142</sup> Outpatient visits for CHF are in the millions.<sup>4</sup> An estimated total of \$29.6 billion will be spent for CHF care in 2006.<sup>3</sup>

Several reasons are suggested for the increasing burden of CHF in the US population. The first, improved survival after acute myocardial infarction, results in more patients with damaged myocardium who are prone to developing CHF.<sup>143,144</sup> Second, the number of untreated or inadequately treated patients with high blood pressure remains high. Third, the proportion of elderly adults, the principal sufferers of this condition, has steadily increased in the population owing to increasing lifespan. Finally, improvements in medical and surgical care for patients with CHF have probably changed the natural history of disease, prolonging the lives of many.<sup>3</sup>

Although general agreement exists that the burden of CHF has increased, precise estimates are not available. Mild manifestations of a failing heart are not easily diagnosed, and debate exists over standard criteria for population studies. In addition, it has been suggested that diagnostic-related groups for Medicare reimbursement (which increase compensation for listing CHF as a primary or complicating condition) have led to diagnostic upgrading of discharge reports to augment hospital reimbursement.<sup>145</sup> Finally, although many CHF patients are hospitalized, a growing proportion of those patients first diagnosed receive treatment in the outpatient setting.<sup>146</sup> Few data exist on outpatient care for CHF, yet some have suggested that the prognosis is equally poor as for those admitted to the hospital.<sup>147</sup>

The need for ongoing and systematic surveillance of CHF is clear. Prevalence is increasing, as is the consumption of medical resources in the diagnosis and treatment of the condition, and the prognosis is poor.

#### **Available National, State, and Local Data**

In the United States, the currently available national data sets that contain information on CHF include the NHDS and NIS, which include discharge diagnoses and surgical procedures; NAMCS and NHAMCS, which include outpatient diagnoses; and NHANES, which is based on self-reported data. As mentioned above, ADHERE and GWTG for Heart Failure are registries that provide information about quality of care for patients hospitalized with CHF; however, these registries are not representative of the US population. No data are collected on CHF at the state level in the BRFSS.

#### **Gaps at the National, State, and Local Levels**

The validity of data on discharges and visits for CHF in NHDS, NIS, NAMCS, and NHAMCS is not well established. Population surveillance of CHF is difficult because the diagnosis frequently depends on clinical signs and symptoms that are poorly measured and recorded in medical charts, and tests such as chest radiographs have limitations and are frequently unavailable.<sup>148</sup> Having valid data would permit surveillance of time trends, with the understanding that any method of tracking patients in the health system does not necessarily reflect true population prevalence. Inclusion in NHANES of additional information on signs, symptoms, and

treatment of heart failure would improve the comprehensiveness of CHF surveillance. For future surveillance of CHF, agreement on a standard method of defining CHF is required. The addition of items related to CHF to the BRFSS would improve the ability to conduct surveillance of CHF at the state level; however, this information would be limited to self-reported data.

#### **Peripheral Arterial Disease**

PAD in the legs is due to atherosclerosis causing narrowing or obstruction in the major arteries serving the lower limbs. PAD sufferers may (1) remain asymptomatic, (2) develop intermittent claudication, or (3) develop the severe complication of critical limb ischemia.

Asymptomatic disease that causes a significant disruption to blood flow is usually detected by a low ratio of ankle-to-arm systolic pressure (ankle-brachial index [ABI]), a measurement that requires use of a Doppler flow probe in addition to a sphygmomanometer. This procedure is easily conducted in appropriately equipped primary care settings. An ABI <0.9 is deemed conventionally to be indicative of disease, although the precise validity in asymptomatic subjects is unknown. Other noninvasive means of detecting asymptomatic PAD, such as duplex scanning and magnetic resonance angiography, are too complex for routine surveillance.

The symptom of intermittent claudication is characterized by pain on exercise, normally in the calf and relieved within a few minutes of stopping the exercise. Standardized questionnaires are available to detect claudication. The World Health Organization/Rose questionnaire has been used traditionally,<sup>149</sup> but sensitivity is poor (60%), and more recently, questionnaires with improved sensitivity, such as the Edinburgh or San Diego claudication questionnaires, have been used.<sup>150,151</sup> In symptomatic subjects, an ABI <0.9 is accurate confirmation of the presence of PAD.

Chronic critical limb ischemia is characterized by persistent leg pain at rest, gangrene, or ulceration. This severe manifestation of PAD occurs uncommonly, with an annual incidence of  $\approx$ 5 to 10 per 10 000 adults.<sup>152</sup> The diagnosis is made on the basis of clinical symptoms and signs, with most, but not all, patients having a very low ankle pressure of <50 mm Hg.

The routine surveillance of PAD in the population is not straightforward:

1. Mortality data are unhelpful, because patients do not die of PAD per se but are at high risk for death due to coronary heart disease or stroke.
2. Hospital discharge data are not a useful indicator of prevalence because of considerable variation in admission policies; furthermore, discharge diagnostic codes, such as those from the International Classification of Diseases,<sup>153</sup> are too imprecise to capture true discharge rates for PAD.
3. Surgical interventions for PAD, including angioplasty, bypass surgery, and amputation, can be classified more precisely than diagnoses and tend to be recorded more accurately. These can give a good indication of surgical and radiological workload, but because of considerable

variation in clinical practice, they do not necessarily reflect the population prevalence of PAD.

4. In primary care settings, recording visits for intermittent claudication can provide an indication of physician workload, but differences in patient self-referral and physician diagnoses mean that rates may not be a good proxy for population prevalence. Time trends may be useful if data are collected consistently. Critical limb ischemia occurs too infrequently to be measured in primary care settings.
5. Surveys of intermittent claudication in the population by use of standardized questionnaires are the best method of assessing population prevalence of symptomatic disease.
6. Surveys of ABI in the population may give an indication of the frequency of asymptomatic PAD. Although the ABI is simple to perform and the variability is similar to that for routine blood pressure measurements, no standard method has been agreed on for measuring the ABI, nor which ankle and arm pressures should constitute a subject's result.

#### **Available National, State, and Local Data**

In the United States, the currently available national data sets that contain information on PAD include the NHDS, NIS, and National Survey of Ambulatory Surgery, which include discharge diagnoses and surgical procedures; NAMCS and NHAMCS, which include outpatient diagnoses; and NHANES, which since 1999 to 2000 has measured ABI in subjects  $\geq 40$  years of age.<sup>6</sup> No information is collected about PAD at the state level.

#### **Gaps at the National, State, and Local Levels**

The validity of data on discharges, procedures, and visits for PAD in the NHDS, NIS, National Survey of Ambulatory Surgery, NAMCS, and NHAMCS is not well established. Having valid data might permit surveillance of time trends, with the recognition that any method of tracking patients in the health system does not necessarily reflect true population prevalence. Inclusion in NHANES of a questionnaire on claudication, as well as continuing measurement of the ABI, would improve the comprehensiveness of PAD surveillance. For future surveillance of asymptomatic PAD, agreement on a standard method of measuring ABI is required. Addition of items related to PAD to the BRFSS would improve the ability to conduct surveillance of PAD at the state level; however, this information would be limited to self-reported data.

#### **Surveillance of CVD Mortality**

Although surveillance of CVD mortality, including heart disease and stroke, does not correspond directly to any of the HP2010 goals for heart disease and stroke, monitoring total and cause-specific mortality rates is core to our understanding of the health of populations. Furthermore, surveillance of CVD mortality is necessary for monitoring progress toward reaching the AHA goal of reducing coronary heart disease, stroke, and risk for both by 25% by 2010.<sup>1</sup> Information on the occurrence of a death is collected nationally with a standardized death certificate, a process that has existed for decades. Cause of death is recorded by trained nosologists using the standardized international classification published by the World Health Organization.<sup>153</sup> Death certificate data are

collected initially at the local level and forwarded to county and state health departments. From there, they are transferred to the National Center for Health Statistics, which manages the National Death Index.<sup>154</sup>

Although the fact of death is undeniable and comprehensively collected, the cause of death is frequently misclassified. This is particularly true for CVDs in the instances of out-of-hospital death, death among the elderly with multiple comorbidities, and deaths in some racial/ethnic groups. Although the system for classification of deaths is clear and systematic, data required to make appropriate classifications are frequently absent at the time of certification. In addition, data are not available in a timely fashion. State and national data are not available for  $\geq 1$  year after the end of any calendar year.

#### **Available National, State, and Local Data**

Actual death certificates are collected by the state and are computerized in many instances. They contain multiple identifiers, as well as the circumstances and classified cause of death, and these data are available at the national, state, and local levels.

#### **Gaps at the National, State, and Local Levels**

The death certification system is a comprehensive national resource; however, improvements in several areas could increase its utility. These improvements include the following:

1. *Validation of cause of death.* The accuracy of cardiovascular causes of death is frequently suspect, and misclassification is a problem. A systematic sampling with validation of cause of death that uses medical records, family interviews, and other data would enhance our ability to provide valid estimates based on the available data.
2. *Timeliness.* Death certificates are sent to the appropriate health department shortly after the fatal event; however, comprehensive data sets may not be available until years later. Improving the timeliness of classification and computerization could make the death certificate system a more useful tool in understanding disease trends.
3. *Linkage.* The inability to link death certificate data to outpatient and inpatient medical records limits our ability to understand the effect of medical care on the final outcome. Privacy regulations have placed further barriers on an already difficult situation. Common identifiers, such as a health identifier, could enable the linkage of death information with medical care information.

Death certification, including information surrounding the event and its likely causes, is central to disease surveillance. In the United States, we are fortunate to have a common system for collecting and classifying these data; however, improved validation of cause of death, more timely availability of data, and linkage of mortality data to healthcare data would considerably enhance the utility of the valuable death certification data.

## Surveillance of Healthcare Costs

Surveillance of healthcare costs related to various approaches to heart disease and stroke prevention and management is crucial to understanding where costs are increasing and whether the resources were well spent. The Medical Expenditure Panel Survey, a survey cosponsored by the Agency for Healthcare Research and Quality and the CDC's National Center for Health Statistics, provides nationally representative estimates of healthcare use, expenses, sources of payment, and insurance coverage for the US population living in communities.<sup>155</sup> These data are not available at the state or local level. State-specific information on Medicare reimbursement for traditional fee-for-service hospital care can be obtained from the Medicare claims files submitted to the Centers for Medicare and Medicaid Services; however, no public-use data set exists for this information. Information on Medicaid reimbursement for health care for the low-income population is also available at the state level in most states; however, no standardized method or policy for reimbursement exists that would allow national pooling of these state data.

## Recommendations

Recommendations are categorized as overarching (fundamental recommendations that cut across goal areas) or as goal-specific. They are further classified according to priority, staging, and cost. Priority was classified as high or moderate (no low-priority recommendations were made); staging was classified as early (1 to 2 years), intermediate (2 to 4 years), or later; and cost was classified as low (<\$10 million/y), intermediate (\$10 million to \$100 million), or high (>\$100 million).

### 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.

The establishment of a National Heart Disease and Stroke Surveillance Unit, perhaps modeled after the CDC's National Diabetes Surveillance System, is a top priority. This entity should be charged, on a continuing basis, with assembling the most currently available and relevant data, identifying critical gaps in knowledge and data systems, and proposing modifications to existing surveillance components or development of new ones to fill these gaps. This recommendation was judged to be a high priority for early staging and only moderately costly, requiring a staff of perhaps 3 or 4 appropriately trained individuals. This need is currently being addressed in part by the efforts of volunteers and staff of the AHA, as well as by professional staff in various parts of the Department of Health and Human Services (Agency for Healthcare Research and Quality; CDC [including the National Center for Health Statistics and the Division for Heart Disease and Stroke Prevention, among others]; National Heart, Lung, and Blood Institute; and the National Institute of Neurological Disorders and Stroke).

2. CVD, including cardiac arrests, acute coronary syndromes (heart attack and unstable angina), stroke, CHF, and

related interventional procedures, should be classified as reportable conditions. The reporting system should

- a. incorporate
  - i. distinction between incident and recurrent events;
  - ii. validation of diagnosis, at least in a subsample, to enable the estimation of valid rates over time;
  - iii. adjustment for changes in diagnostic technology over time; and
  - iv. collection of information on severity of the event and quality of prehospital care, acute care, procedure use, and preventive care at discharge; and
- b. enable
  - i. surveillance of 30-day case fatality through linkage with the National Death Index;
  - ii. monitoring of healthcare quality as part of efforts to prevent recurrent events after discharge; and
  - iii. monitoring of patient health status after discharge.

Classification of CVD as a reportable condition would remove many of the barriers to timely surveillance. Standard definitions exist for these diseases and for most of the relevant data elements related to quality of care and outcomes; hence, an efficient surveillance system could be developed and implemented based on a reportable event model. This recommendation was judged to be a high priority and highly costly; however, additional developmental work is required. Consequently, this recommendation was considered for later staging. It is recognized that efforts to promote healthcare quality, including pay-for-performance and accreditation programs, are creating an environment that is increasingly primed for classification of cardiovascular conditions as reportable events. Given the reality that hospitals will be reporting data on many of these conditions as part of pay-for-performance and accreditation programs, hospital reporting of CVD events may be a more feasible approach than physician reporting. Reporting of cardiac arrests will require development and integration of additional reporting mechanisms that involve emergency medical systems and other sources of data for events that occur outside of hospitals.

3. Data collection on patients' encounters with the healthcare system should be revised to include collection of data on lipoprotein cholesterol concentrations, blood sugar, and glycohemoglobin values.

Data collection on these elements is critical to our understanding of risk factor identification and control before and after the diagnosis of CVD; hence, this recommendation addresses goals 1, 2, and 4. Because surveillance programs currently exist to monitor patient encounters with the healthcare system (eg, NAMCS and NHAMCS), early staging of implementation of this high-priority recommendation could be accomplished at low cost.

4. Data elements should be standardized across surveys, and unnecessary duplication in data sources should be avoided.

We identified multiple examples of duplication in data collection activities. Improved coordination of effort, with greater standardization and less redundancy, could result in significant cost savings, thereby freeing up resources to support enhanced surveillance in critical areas. This recom-

mendation was judged to be a high priority for early staging and potentially cost saving, although some cost would be incurred in the short term to evaluate and develop a coordination plan for the existing surveillance programs. The proposed National Heart Disease and Stroke Surveillance Unit should be charged with this task.

5. The design and conduct of nationally representative surveillance programs should be revised to facilitate oversampling by states, territories, and tribal organizations and to provide meaningful estimates on ethnic subgroups in the populations. Sampling within states, territories, and tribal organizations should be designed to facilitate oversampling by counties.

Modification of national surveys to facilitate the ability of the states, territories, and tribal organizations to leverage resources through funding of supplemental samples is critical to their ability to plan and evaluate their heart disease and stroke prevention and management programs. Likewise, the states, territories, and tribal organizations should implement their surveillance programs in a manner that facilitates the ability of localities to leverage resources to attain supplemental samples to support local efforts to prevent and manage heart disease and stroke. Several ethnic subgroups in the population are disproportionately affected by heart disease and stroke; hence, it is especially important to collect sufficient data to produce meaningful estimates for these populations. This recommendation was judged to be a high priority but will require developmental work; hence, intermediate staging may be more appropriate. This effort was estimated to be moderately costly in the near term, with long-term costs potentially much greater depending on the extent of oversampling implemented. The cost implications relate to the need to modify current sampling strategies to ensure that all states, territories, and tribal organizations are represented in all nationally representative surveys. This change would result in a modest reduction in data collection efficiency at the national level.

6. Mechanisms should be developed to enable linkage between healthcare data systems, including the national surveillance programs (eg, NAMCS, NHDS, and National Death Index), and electronic health records.

To facilitate surveillance, it is critical that federal and state efforts ensure that health information systems, including the national surveillance programs (eg, NAMCS, NHDS) and electronic health records are interoperable, utilize harmonized data standards, and have appropriate safeguards in place. Discussions between public and private stakeholders are currently taking place to determine how best to achieve these goals, including within the American Health Information Community. At present, health records and surveillance systems lack linkable unique health identifiers for individuals. This shortcoming has limited our ability to gain insights about the health of the public from these records and systems. Creative strategies will be necessary for linking information between systems in a manner that safeguards confidentiality. One such model worth noting is the eHealth Initiative record locator service, which facilitates the secure linkage of patient health records.<sup>156</sup> The record locator service stores enough data to allow a person's health records to be tied back to a master index. The record locator service is

currently being tested by several communities. This model and others should be evaluated for their utility in supporting surveillance efforts. This high-priority recommendation could be highly expensive to implement, especially in the early stages; however, in the long term, the system would likely be of intermediate cost to maintain. Given the developmental work required, this recommendation was considered for intermediate staging.

7. Studies are needed to establish the validity of multiple measures collected by self-report and provider report in national databases.

Many of the data elements collected in current surveillance activities are based on self-report or provider report, and little information is available on the validity of these data. Given the complexity of the current surveillance system, validation efforts will be more expensive than necessary. Implementation of this recommendation might be more efficient after redundancies in the system have been minimized. This recommendation was judged to be a moderate priority for intermediate staging and to incur intermediate cost.

### Recommendations for HP2010 Goals 1 and 2

8. Data collection in national surveys should be expanded to include important measures that are currently missing from the data collection process, including information on awareness, detection, treatment, and control of physical inactivity, unhealthy diet, cigarette smoking, and obesity.

Efforts to prevent and control lifestyle risk factors and obesity are impeded by lack of information on public knowledge of health risks and the progress of risk factor detection and control programs. If we were tracking awareness of unhealthy lifestyle habits, we could focus our awareness efforts more effectively. Similarly, if we were tracking detection, treatment, and control efforts based, for example, on self-reported or provider-reported data, we could focus our quality-improvement efforts more effectively. This recommendation was judged to be a high priority for early staging because of the importance of lifestyle factors in the origin of heart disease and stroke, as well as many other chronic diseases. Implementation of this recommendation would be relatively low cost, because the data systems already exist through which these elements could be collected (eg, NHANES and NAMCS).

9. The states, territories, and tribal organizations should develop surveillance capacity to support program planning, implementation, and evaluation, including the ability to conduct standardized surveys that include direct assessments of residents to enable collection of information on prevention, awareness, detection, treatment, and control of obesity, hypertension, dyslipidemia, and diabetes.

The data currently available at the state level on risk factor prevalence, detection, treatment, and control are based on self-report. Consequently, only persons who are aware of their risk factor status can provide information about their control status. Given that the states have been charged with developing programs to prevent and manage heart disease and stroke, directly measured data on risk factor prevalence, detection, treatment, and control are critical to program planning, imple-

mentation, and evaluation. This high-priority recommendation is judged to be high cost, owing to the cost of covering all states, territories, and tribal organizations. Strong efforts should be made to implement this recommendation at the earliest possible stage, because progress in reducing the burden of heart disease and stroke is highly dependent on effective action at the state and local level.

10. Indicators and systems for surveillance of policies and environmental conditions related to physical inactivity and unhealthy diet should be developed, tested, and implemented at the national, state, and local levels.

As an example, the State Tobacco Activities Tracking and Evaluation system is an electronic data warehouse that contains up-to-date and historical state-level data on prevention and control of tobacco use. The main topic areas presently being offered are behaviors, demographics, economics, funding, health consequences and costs, and legislation.<sup>45</sup> The State Tobacco Activities Tracking and Evaluation system has provided the basis for generating important reports about state laws on tobacco control,<sup>46,47</sup> thereby providing information to support tobacco-control efforts. Similar systems should be developed to provide data on physical inactivity and diet. This high-priority recommendation is judged to be appropriate for intermediate staging. It is likely to be low cost, potentially requiring only several staff members to collate information, maintain World Wide Web–based databases, and generate reports.

#### Recommendations for HP2010 Goals 3 and 4

11. Indicators and systems for surveillance of policies and environmental conditions (eg, proportion of the population covered by enhanced 9-1-1 systems) related to symptom knowledge and recognition, acute healthcare-seeking behavior, availability of automated external defibrillators, and capabilities of the prehospital care system (including first responders and emergency medical services) should be developed, tested, and implemented at the national, state, and local levels.

Early identification and treatment of acute episodes of heart disease and stroke are limited by patient recognition and response to symptoms and by the capacity of the prehospital care system to respond rapidly and appropriately to patients' conditions. Information on the implementation and effectiveness of public education campaigns about symptom recognition and response, state and local policies pertinent to liability issues with the use of automated external defibrillators, the implementation and effectiveness of automated external defibrillator programs, and the capabilities of the prehospital care system (eg, enhanced 9-1-1 system, 12-lead ECGs in the field, dispatch and transport policies for suspected acute episodes of heart disease and stroke) are essential for the success of efforts to enhance early identification and treatment. This high-priority recommendation is judged to be appropriate for intermediate staging because it may be more easily accomplished after the establishment of the surveillance unit described in recommendation 1. This task is likely to be low cost, potentially requiring only several staff members to collate information, maintain World Wide Web–based databases, and generate reports. Additional pertinent information could be collected at low cost through the inclusion of additional questions (eg, about symptom knowledge) in existing surveys.

12. Effective surveillance methods should be developed, tested, and implemented to support the collection of data on patients with newly diagnosed heart disease, stroke, CHF, and PAD in the outpatient setting, including data on treatment and outcomes.

Increasingly, patients with heart disease and stroke (including CHF and PAD) are being diagnosed and treated in the outpatient setting. Reliance on hospital surveillance hinders efforts to monitor the burden of disease, including human suffering and other costs. Decreasing hospitalization rates may mislead policy makers into thinking that heart disease rates are decreasing when care may be simply shifting to the outpatient setting. Information on the broader spectrum of heart disease and stroke will enable policy makers to make better decisions on the need for outpatient care facilities and sustained prevention programs. This moderate-priority recommendation was judged to be moderately costly in the near term owing to the need for developmental work. Developmental work should begin as early as possible to support implementation at a later stage. Long-term costs will be difficult to estimate until surveillance models have been developed and tested but are likely to be high. If it proves possible to collect this information through the reportable disease system described above (recommendation 2) or through existing surveys (NAMCS), the long-term cost implications might represent only a moderate increase over the costs otherwise committed to the surveillance program.

#### Barriers

We have identified specific barriers to obtaining the new data elements that would be required to support the development of a comprehensive surveillance system. These include various methodological challenges, privacy concerns that have surfaced since the implementation of the Health Insurance Portability and Accountability Act (HIPAA),<sup>156</sup> and the costs associated with supporting new data systems and a comprehensive surveillance system.

#### Methodological Challenges

Methodological challenges to establishing and supporting a comprehensive national surveillance system can be grouped into the following categories: limited data availability in the current surveillance systems, lack of standardized surveillance indicators, limitation of some current surveillance systems to persons living in households (exclusion of nursing home residents and other institutionalized persons), inability to link across data sources, and other limitations of current data elements related to validity, reliability, or specificity.

#### Interagency Coordination

Cultural barriers exist between governmental and nongovernmental agencies that can pose barriers to the processes of sharing data and functioning cooperatively. In some instances, competition might exist for future funding or even future existence. Models of cooperation, such as the HP2010 Partnership and others, should be examined, and the lessons learned should be applied to this effort to avoid these potential barriers.

#### Health Insurance Portability and Accounting Act

The implementation of HIPAA on April 14, 2003, created new barriers to the development of a comprehensive surveil-

lance system. Under HIPAA, the privacy rule establishes minimum federal standards for protecting the privacy of individually identifiable health information, and some states have more restrictive rules. The privacy rule applies to covered entities, which are health plans, healthcare clearinghouses, and healthcare providers who electronically transmit any health information in connection with transactions for which the Department of Health and Human Services has adopted standards. The privacy rule defines protected health information as individually identifiable health information, held or maintained by a covered entity or its business associates acting for the covered entity, that is transmitted or maintained in any form or medium (including the individually identifiable health information of non-US citizens). The rule confers certain rights on individuals, including rights to access and amend their health information and to obtain a record of when and why their protected health information has been shared with others for certain purposes.

The rule defines a set of 18 variables that could be used to identify an individual or the individual's relatives, employers, or household members, including age, address, dates (eg, birth date, hospital admission and discharge dates, and date of death), telephone numbers, Social Security numbers, and medical record numbers. Protected health information may be shared by a covered entity under the following circumstances: (1) an individually signed privacy authorization form is obtained; or (2) data are deidentified by removing all 18 variables; or (3) a limited data set is created by removing all 18 variables except for dates and address, limited to town or city, state, and zip codes, in association with a data use agreement, that is, an agreement between the covered entity and the intended recipient that establishes the way in which the information in the limited data set may be used and how it will be protected; or (4) sharing is mandated by law (eg, cancer data for registries in some states).

The privacy rule adds time and costs to the development of a comprehensive CVD surveillance system. Privacy authorization forms are generally not available, so data management resources must be available at the covered entity to create deidentified or limited data sets. Limited data sets are preferable to deidentified data sets because they can contain event dates; only the year of the event is allowed in a deidentified data set, which makes it impossible, for example, to determine the sequence of events, including recurrences, within a year. Limited data sets require the development of data use agreements, which add complexity to the data acquisition and, in some instances, may require significant negotiation processes. Both deidentified and limited data sets exclude Social Security numbers so that it would be impossible to link provided data, such as hospitalizations, with other databases that contain the Social Security number, such as the National Death Index.

Some concern exists that hospitals and other health systems will be reluctant to provide data because HIPAA is perceived by them as a barrier to the use of any patient data. However, the act also states that "without individual authorization, a covered entity may disclose protected health information to a public health authority [or to an entity working under a grant of authority from a public health authority] that is legally authorized to collect or receive the information for the purposes of

preventing or controlling disease, injury, or disability including but not limited to reporting of disease, injury, and vital events (eg, birth or death) and conducting public health surveillance, investigations, and interventions."<sup>156</sup> Thus, state health departments, the federal government, and entities working under their authorization for the purpose of public health surveillance should be able to convince health systems that reporting patient data for surveillance purposes may not require patient authorization under the privacy rule. It would be to the benefit of state health departments to request assistance from the state's legal services to develop a written document that highlights interpretation of HIPAA, as well as the additional and separate issue of informed consent, to share with potential sources of hospital and medical systems data.

### Costs

Cost represents a significant barrier to the establishment of a comprehensive surveillance system for heart disease and stroke. We have not provided a detailed estimate of cost in this publication because development of a surveillance system to support prevention of heart disease and stroke could be based on enhancements of current efforts; however, we have provided comments on the relative magnitude of costs associated with the major recommendations. Although the incremental cost is difficult to estimate, it is unlikely to represent >0.1% of the societal costs of CVD, estimated at \$403.1 billion in 2006.<sup>3</sup> If surveillance data were used to inform the planning, ongoing implementation, and evaluation of strategies to prevent heart disease and stroke, it is likely that the return on investment would be substantial in terms of both human health and healthcare costs.

### Conclusions

The success of efforts to prevent and manage heart disease and stroke is dependent on the availability of surveillance data at the national, state, and local levels to assist federal agencies, state and local health departments, and their partners in assessing prevention and treatment priorities and guiding program planning, implementation, and evaluation. This statement summarizes the information that is needed at the national, state, and local levels to address the HP2010 and AHA goals for 2010; furthermore, this document was designed with a longer-term perspective in mind. When possible, existing data collection efforts have been identified for addition of new items. Significant gaps (eg, the complete lack of a data source for incidence and recurrence of heart attacks and strokes) and other deficiencies have been identified, and recommendations have been made for enhancement of the surveillance system in the United States. The most far-reaching recommendation may be the proposed designation of heart disease and stroke as reportable conditions across the continuum of care. This approach served to help focus attention on infectious diseases when infection control was the major public health imperative. A similar approach to heart disease and stroke is needed urgently. The other recommendations, although more narrowly focused in many instances, should result in the availability of better information for enhancing heart disease and stroke prevention and management programs. Implementation of all of the recommendations contained in this report would require commitment of substantial additional resources in addition to those already devoted to surveil-

lance. However, some opportunities for greater efficiency were identified that could lead to cost savings, and a staged rollout of these recommendations could mitigate the financial impact. Finally, the return on investment could be substantial in terms of better population health and fewer acute episodes of heart disease and stroke, resulting in

fewer inflation-adjusted healthcare dollars being devoted to acute care. Consequently, this statement should serve as a guide to policy makers as they work with public health agencies to develop and implement a surveillance system that can contribute importantly to efforts to prevent heart disease and stroke.

## Disclosures

### Writing Group Disclosures

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\*Significant.

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