Circulation

AHA POLICY STATEMENT

Recommendations for Cardiovascular Health and Disease Surveillance for 2030 and Beyond
A Policy Statement From the American Heart Association

ABSTRACT: The release of the American Heart Association's 2030 Impact Goal and associated metrics for success underscores the importance of cardiovascular health and cardiovascular disease surveillance systems for the acquisition of information sufficient to support implementation and evaluation. The aim of this policy statement is to review and comment on existing recommendations for and current approaches to cardiovascular surveillance, identify gaps, and formulate policy implications and pragmatic recommendations for transforming surveillance of cardiovascular disease and cardiovascular health in the United States. The development of community platforms coupled with widespread use of digital technologies, electronic health records, and mobile health has created new opportunities that could greatly modernize surveillance if coordinated in a pragmatic matter. However, technology and public health and scientific mandates must be merged into action. We describe the action and components necessary to create the cardiovascular health and cardiovascular disease surveillance system of the future, steps in development, and challenges that federal, state, and local governments will need to address. Development of robust policies and commitment to collaboration among professional organizations, community partners, and policy makers are critical to ultimately reduce the burden of cardiovascular disease and improve cardiovascular health and to evaluate whether national health goals are achieved.

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The American Heart Association's (AHA) Impact Goal for 2030 detailed in this issue of *Circulation* sets a bold course for cardiovascular health (CVH) promotion and cardiovascular disease (CVD) prevention, with a focus on increasing healthy life expectancy.[1] Metrics used to measure progress toward this goal require timely access to valid data sources on a spectrum of health and disease characteristics from the population. The goals of this policy statement are to comment on current and emerging challenges to feasible acquisition of information sufficient to fully evaluate and support these types of goals. It also aims to summarize opportunities to transform data systems, formulate policy implications, and propose recommendations for future surveillance that the AHA's vision for 2030 brings so prominently to the forefront. Although stimulated by the articulation of the AHA's 2030 Impact Goal, this policy statement takes a broad view of cardiovascular surveillance and addresses several critical features needed to advance its effectiveness in the United States over the next decade and beyond.

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Defining Surveillance

The World Health Organization (WHO) defines public health surveillance as "the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice."[2] Public health surveillance systems are complex quantitative enterprises with intricate analytical capabilities that require timely access to and input from numerous data sources.[3] The scope of public health surveillance is broad yet pragmatic and is aimed to facilitate intervention. Surveillance data are collected, analyzed, and communicated to stakeholders (eg, policymakers, scientific communities, program planners, public health authorities, medical institutions, and funding agencies) with the intent of enabling public health action. For CVH and CVD, surveillance is the act of measuring the occurrence of all manifestations of CVH and CVD—including incidence, survival, risk factors, and recurrence rates—according to person, time, and place. Surveillance provides the evidence base to quantify how indicators of CVH and CVD change over time. This is critical to monitoring progress toward improving population health through clinical interventions, public health campaigns, economic factors, health policies, evolving healthcare systems, and other behavioral and environmental changes.

Strategic Goals and Surveillance Data

Executing the AHA's strategic mission of "being a relentless force for a world of longer, healthier lives" requires reliable surveillance data to measure progress. The AHA's 2020 Impact Goal targeted a 20% improvement in CVH and a 20% reduction of coronary heart disease (HD) and stroke mortality by 2020.[4] This goal required surveillance systems to monitor not only the ongoing US death rates for CVD and stroke but also, in principle for "all Americans," trends in prevalence of each of the 7 ideal CVH metrics (tobacco use, diet, physical activity, body mass index, blood pressure, cholesterol, and glucose).[4] The AHA's 2030 Impact Goal, together with the Strategic Value Proposition, will require not only continuation of this current surveillance but also incorporation of new dimensions: health-adjusted life expectancy and indicators of overall health and well-being. Health-adjusted life expectancy is the core metric selected for goal monitoring as calculated at state and national levels. Health-adjusted life expectancy estimates are based on mortality data and disease burden estimates for nonfatal health outcomes. Although mortality data in the United States are considered robust and accessible, there are significant gaps in surveillance data for nonfatal outcomes, especially at the local level

and among certain population subgroups, several of which are identified and discussed below.

The Rising Burden of CVD

Approximately 120 million people in the United States currently have ≥1 forms of CVD, which makes it a leading cause of death, morbidity, and disability for both men and women.[3] Common types of CVD include coronary HD, stroke, hypertension, and heart failure. In 2016 alone, CVD accounted for ≈840 000 deaths in the United States.[5] Between 1968 and 2016, age-adjusted total CVD mortality declined substantially (by 71%) and HD and stroke mortality declined by 68% and 77%, respectively. Since the turn of the century, the burden of obesity and diabetes mellitus continued to increase,[5] which raised the concern that reductions in CVD mortality would eventually stop.

Recent trends substantiate this concern. In 2011, the rate of decline in CVD mortality began decelerating, and the downward trends in deaths attributable to HD reversed course in middle-aged Americans. From 2011 to 2017, the decline in average annual rates diminished to <1% per year, with a total CVD 5-year mortality decline of 4.0% and declines in HD and stroke mortality of 5.0% and 0.8%, respectively.[6,7] The number of CVD deaths increased from 2011 to 2017 by 9.7%, with the number of HD and stroke deaths increasing by 8.5% and 13.5%, respectively.[6,7] The deceleration of the decline in CVD mortality rates is evident in men, in women, and in all major racial and ethnic groups. These slowing rates of decline in age-adjusted mortality contribute to a rise in the annual number of deaths attributable to total CVD, HD, and stroke, primarily because the US population ≥65 years of age, in whom ≈80% of all CVD deaths occur, has been growing at an accelerated rate.[8]

Taken collectively, these recent reports underscore that ground is being lost in the fight against CVD,[5–7] and these new trends in CVD mortality present a major challenge to the goal of increasing healthy life expectancy over the next 10 years.

CVH in the United States Is Far From Ideal

The AHA introduced a definition of CVH in 2010 describing ideal CVH as the absence of clinically manifest CVD together with smoking abstention and optimal levels of blood pressure, blood sugar, blood cholesterol, body weight, diet, and physical activity.[4] Individuals with ideal CVH exhibit lower rates of subclinical CVD and have a lower risk of incident CVD.[5,9,10] Unfortunately, ideal CVH is rare: Fewer than 1% of US adults have ideal levels of all 7 metrics, only 5% have 6 metrics in the ideal range, and only 13% have 5 metrics in the

ideal range.[5] Younger adults are more likely to meet greater numbers of ideal metrics than older adults. Approximately half of US youth 12 to 19 years of age (48%) meet 3 or 4 criteria for ideal CVH, and ≈47% meet 5 or 6 criteria; national data are limited or lacking altogether for younger ages.[5]

Disparities in CVD Mortality Persist

Ideal CVD mortality varies by age, sex, race, ethnicity, income, education level, geography, and even zip code.[5] CVD mortality is higher at older ages[11]; however, after adjustment for age, CVD mortality is >40% higher in men than women and has been declining faster in women.[5]

CVD mortality is substantially higher among non-Hispanic (NH) blacks compared with all other major race and ethnic groups, followed by NH whites, NH American Indian/Alaska Natives, Hispanics, and NH Asian/Pacific Islanders.[5] These disparities are present for HD and stroke. The decline in mortality rate from 2000 to 2014 was greatest in NH Asian/Pacific Islanders (40.9%), followed by Hispanics, NH blacks, and NH whites, and was lowest in NH American Indian/Alaska Natives (24.5%).[5]

CVD mortality varies geographically, with the highest rates in the South, followed by the Midwest, Northeast, and West, such that the rate in the South is 15% higher than the rate in the West.[5] The South and the Midwest have the highest stroke mortality rates, followed by the West, with the lowest rate in the Northeast. Mortality rates are also heterogeneous across states, with an ≈2-fold difference in mortality rates between the highest and lowest rates for total CVD, HD, and stroke.[12] Total CVD, HD, and stroke mortality are higher in nonmetropolitan areas than in metropolitan areas by 18%, 21%, and 12%, respectively.[12] Even in smaller geographic units (ie, zip codes),[13] large disparities in CVD mortality and CVH have been noted, which underscores the importance of local surveillance. The persistence of marked disparities in CVH and CVD morbidity and mortality indicates insufficient economic and social investment and justifies robust surveillance that can allow identification of disproportionately affected subgroups to inform intervention plans.

Forging Positive Change: The Role of Robust Surveillance

The formulation of policies to reignite reductions in CVH mortality and improve CVH requires forecasting the impact of an intervention on the burden of disease. The AHA developed methods to forecast the prevalence and cost of care for CVD[14,15] using prevalence rates, average costs, and the census-projected population. Medical costs, indirect costs attributable to morbidity, and premature mortality attributable to CVD

were estimated using several major databases. Similar data were used to project the trend in deaths attributable to coronary HD and the cost of informal caregiving through 2030 and 2035, respectively.[16]

Agent-based modeling is an emerging approach based on systems science that can model complex processes involved in chronic diseases.[17–19] Unlike standard statistical models, systems science methods can dynamically integrate complex data from diverse sources.[17] Agent-based modeling is attractive because it can accommodate the growing breadth, complexity, and dynamicity of the metrics and determinants of CVD and CVH. However, it requires a large amount of individual-level data for parameterization, calibration, and validation, and naturally, the reliability of the data will impact the reliability of the models. The proof of concept of the feasibility of applying agent-based modeling to study CVD has been reported, and limitations related to data structure[20] have been underscored. Importantly, the implications of these data-driven models must be disseminated and action plans designed and implemented.

Section Summary

- Achieving the AHA's 2030 Impact Goal will require overcoming recent unfavorable trends and disparities in CVD and CVH.
- Interventions should be planned while relying on valid data, deployed with keen attention to prioritization, and monitored for effectiveness.
- Novel modeling methods can predict the burden of CVD, inform effective interventions, and guide resources allocation provided that valid and reliable data are available at state and local levels. Ultimately, risk prediction derived from these models must translate to action to improve CVH.

EXISTING RECOMMENDATIONS AND RESOURCES FOR CVD SURVEILLANCE

Previous Surveillance Recommendations

Over the past 50 years, CVD surveillance has been the topic of conferences and position papers. In 1978, the National Heart, Lung, and Blood Institute convened a conference to examine the decline in coronary disease deaths and delineate an approach to determining putative causes.[21] The establishment of a national surveillance system was one of the recommendations from this conference. Several studies were initiated thereafter, including in particular the ARIC study (Atherosclerosis Risk in Communities) in the United States and the WHO MONICA Project (Monitoring Trends and Determinants in Cardiovascular Disease) in 21 countries.[22,23] These studies have made invaluable contributions to

our understanding of the burden of CVD and relevant causative factors; however, they were not designed as national surveillance systems and only pertain to select communities. Furthermore, their activity is vulnerable given the temporary nature of their federal funding.[24]

In 2007, a scientific statement from the AHA formulated 12 recommendations for surveillance.[25] Four years later, in 2011, the Institute of Medicine (now the National Academies of Sciences, Engineering, and Medicine) proposed a framework for national chronic disease surveillance and concluded that a coordinated surveillance system was needed to integrate and expand existing information on chronic diseases across the multiple levels of decision making to generate actionable, timely knowledge at the national, state, and local levels.[26] Remarkable consistencies were evident across recommendations (Table 1), which called for the establishment of a national surveillance system of CVD, underscored the importance of doing so while focusing on eliminating disparities, and emphasized the importance of standardization, linkage, and avoidance of duplication.

In keeping with these recommendations, in 2013, the National Heart, Lung, and Blood Institute convened a workshop to evaluate the feasibility of establishing a national CVD surveillance system.[27] This led to the formulation of deliberately pragmatic recommendations that included pilot studies to evaluate feasibility and cost, development of core data elements, and standardized data collection. The recommendations also promoted efforts to evaluate technologies to directly capture and store structured electronic health record (EHR) data for clinical and public health research and engagement with the Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services, and other National Institutes of Health institutes.

Despite these recommendations formulated >40 years ago, a national system for CVD and CVH surveillance is still lacking.

Current Surveillance Resources

In 2014, the CDC engaged in a strategic and operational initiative to improve disease surveillance data sources. The surveillance strategy deployed by the CDC between 2014 and 2018 has been shared publicly.[28,29] In 2016, Congress authorized the CDC to initiate the development of a National Neurological Conditions Surveillance System. Ongoing demonstration projects will assess the feasibility and scalability of this initiative.[30] The neurological diseases initiative constitutes a potential model for the surveillance of CVD and CVH. In 2016, the CDC, in collaboration with the AHA, assembled a compendium of resources for HD and stroke surveillance, available online.[31] Table 2 makes use of

this resource guide to summarize government-funded and -managed CVD data sources, their key characteristics, and their limitations. It is apparent from this summary that current surveillance activities depend on fragmented and heterogeneous sources. Death certificate data from the National Vital Statistics System are commonly used to monitor CVD deaths. Despite coding limitations, these data provide the most comprehensive demographic, geographic, and cause-of-death information in the United States.[45–48] However, for nonfatal CVD incidence and survival, as well as recurrence rates, there are no national surveillance data sources.

Estimates of CVD prevalence and CVH factors can be obtained from the BRFSS (Behavioral Risk Factor Surveillance System), the NHIS (National Health Interview Survey), and the NHANES (National Health and Nutrition Examination Survey). Data from NHANES are nationally representative (with sampling weights applied as necessary) and contain direct objective measures of health, whereas other sources such as the BRFSS are representative at the state level but rely heavily on self-report and are subject to misclassification and incorrect recall.[49] The American Community Survey of the US Census Bureau provides demographic, social, and economic characteristics of US counties, which can be used with individual- and population-level surveillance data to gain insights into how individuals and the environment interact to impact CVH.[50,51]

Longitudinal cohort studies with large population samples have provided region-specific surveillance data. Examples include the aforementioned ARIC study,[22] the Minnesota Heart Survey,[52] the Olmsted County Study,[53,54] the Worcester Heart Attack Study, the Framingham Heart Study, the GCNKSS (Greater Cincinnati/Northern Kentucky Stroke Study), and BASIC (Brain Attack Surveillance in Corpus Christi).[55–59] Although these studies and others, such as the REGARDS study (Reasons for Geographic and Racial Differences in Stroke),[60] used methodology and definitions standardized via expert-developed protocols, none provide national surveillance estimates, and data availability is inherently precarious because they are funded through contracts or peer-reviewed grants.

Clinical registries are voluntary observational data repositories focused on a clinical condition or procedure[61] supported by diverse entities (researchers, research consortiums, nonprofit organizations, government agencies, and industry). They capture data that reflect real-world clinical practice, including patient characteristics, comorbid conditions, and patterns of care, quality of care, safety, and clinical outcomes. Examples include the AHA's Get With The Guidelines registries, the American College of Cardiology's National Cardiovascular Data Registry, the Interagency Registry for Mechanically Assisted Circulatory Support, the CDC's Paul Coverdell National Acute Stroke Registry, and the

Table 1. Summary Recommendations From AHA and IOM in 2007 and 2011

2007 AHA Scientific Statement[25]	2011 IOM Report[26]
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.	1. The Secretary of HHS should establish and resource a standing national working group to oversee and coordinate cardiovascular and chronic pulmonary disease surveillance activity. This working group should include representatives from HHS (CDC, NIH, AHRQ, CMS, IHS, ONCHIT, FDA); other relevant federal agencies (eg, VA and DOD); tribal, state, and local public health agencies; and nongovernmental organizations with relevant roles in surveillance.

2. CVD, including cardiac arrests, ACS, stroke, HF, and 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
  iv. collection of data on severity of the event and quality of prehospital care, acute care, procedure use, and preventive care at discharge
b. enable
  i. surveillance of 30-day case fatality through linkage with NDI
  ii. monitoring of healthcare quality as part of efforts to prevent recurrent events after discharge
  iii. monitoring of patient health status after discharge
	2. HHS should prioritize surveillance on systems that can:
	• Track progress on nationally recognized goals and indicators regarding cardiovascular and chronic pulmonary disease incidence, prevalence, and prevention (eg, Healthy People).
	• Evaluate and inform national, state, and local efforts to control, reduce, and prevent these chronic diseases.
	• Enable effective public health actions and policies.
	• Improve treatment outcomes.
	• Monitor and enhance quality of life.
	• Reduce disparities in risk burden of these diseases.

3. Collect data on lipoprotein cholesterol concentrations, blood sugar, and glycohemoglobin values.	3. HHS should adopt a framework that facilitates understanding of the effects of race and ethnicity on health and health outcomes and makes more effective linkages of conventional surveillance data to contextually relevant information, such as socioeconomic status, birthplace, acculturation, geography, language, and health insurance, for national surveillance of cardiovascular and chronic lung diseases.
4. Data elements should be standardized across surveys, and duplication in data sources should be avoided.	4. The working group should: • Select surveillance indicators and periodically review the surveillance system to incorporate necessary modifications. • Improve collaboration and coordination among federal, tribal, state, and local agencies and nongovernmental organizations around the collection, compilation, and dissemination of surveillance information. • Collect and make available surveillance data (survey, registry, EHR) at the most granular level consistent with protection of data privacy and confidentiality and, when feasible, link these with other data sources (ie, clinical databases, public health data). • Form public-private partnerships with the nongovernmental health sector. • Develop data sets for surveillance sources broadly accessible to support and guide action to improve health at the national, state, and local levels.
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.	5. The Secretary of HHS should designate a federal office to: • Produce and disseminate regular surveillance reports and key indicators of progress that support and stimulate action to improve health and reduce disparities at the national, state, and local level. • Ensure that surveillance data are widely accessible to users (eg, public health agencies, health systems, researchers, policy makers, and advocacy groups) at all levels while protecting privacy and documenting the extent of that use. • Implement the recommendations of the national working group.
6. Mechanisms should be developed to link healthcare data systems, including the national surveillance programs (eg, NAMCS, NHDS, and NDI), and EHRs.	6. HHS should coordinate with voluntary disease registries to promote collection and harmonization of data.
7. Studies are needed to establish the validity of multiple measures collected by self-report and provider reports in national databases.	7. Governmental and nongovernmental organizations should enhance existing national data sources in the following manner: • Information on elements of the recommended framework should be collected on the US population across the life span, with special focus on collecting data on diverse and changing populations, including information on disparities. • A minimum subset of actionable indicators, as identified by the working group, should be collected using comparable measures at the national, state, and local levels. • Data should be linked across health domains and data sources.
Recommendations for HP2010 Goals 1 and 2	
8. Data collection in national surveys should be expanded to include important measures currently missing from data collection processes, including information on awareness, detection, treatment, and control of physical inactivity, unhealthy diet, cigarette smoking, and obesity.	8. HHS should develop a cardiovascular and chronic pulmonary disease survey question bank and support its use by tribal, state, and local agencies; nongovernmental organizations; and individual researchers for the purpose of enhancing the quality and comparability of population health surveys to identify trends in risk factors, diseases, treatments, and outcomes.

(Continued)

Table 1. Continued

2007 AHA Scientific Statement[25]	2011 IOM Report[26]
9. The state, 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 mellitus.	9. The Office of the National Coordinator for Health Information Technology should expand the minimum data for EHR to include behavioral, social, and environmental risk factors for cardiovascular and chronic lung diseases in validated, interoperable ways to enhance the quality of surveillance data.
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.	
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 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.	
12. Effective surveillance methods should be developed, tested, and implemented to collect data on patients with newly diagnosed heart disease, stroke, CHF, and PAD in the outpatient setting, including data on treatment and outcomes.	

ACS indicates acute coronary syndrome; AHA, American Heart Association; AHRQ, Agency for Healthcare Research and Quality; CDC, Centers for Disease Control and Prevention; CHF, congestive heart failure; CMS, Centers for Medicare and Medicaid Services; CVD, cardiovascular disease; DOD, Department of Defense; EHR, electronic health record; FDA, Food and Drug Administration; HF, heart failure; HHS, Health and Human Services; HP2010, Healthy People 2010; IHS, Indian Health Service; IOM, Institute of Medicine; NAMCS, National Ambulatory Medical Care Survey; NDI, National Death Index; NHDS, National Hospital Discharge Survey; NIH, National Institutes of Health; ONCHIT, Office of the National Coordinator for Health Information Technology; PAD, peripheral artery disease; and VA, Veterans Affairs.

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Society of Thoracic Surgeons National Database. Because participation is voluntary, they do not constitute a nationally representative sample and cannot be used for surveillance.[61] Similarly, some data are available from large health maintenance organizations, hospital claims data, and the Agency for Healthcare Research and Quality but are not collected for the purpose of surveillance and are fragmented, incomplete, and not consistently standardized.[11,50,51,62,63]

Medicare is the federal health insurance program for individuals in the United States who are ≥65 years old, selected individuals with disabilities who are <65 years old, and individuals with end-stage renal disease. Medicare data have been used to characterize morbidity and mortality and to evaluate the effectiveness of therapies, the cost of care, and clinical outcomes. Because the vast majority of US citizens ≥65 years of age have Medicare insurance, Medicare data provide insights into health care among older individuals to guide policies.[64,65]

Attributes of Cardiovascular Surveillance to Meet Future Needs

The ideal surveillance system should accurately measure CVD mortality, incidence, and outcomes and CVH in representative samples of the whole population and of local areas, in a manner designed to provide coverage for all major population subgroups and all ages from early childhood throughout the life course. Data domains critical for monitoring progress toward health impact goals include characteristics of environment, behavior, clinical events, and disease management. The systems of the future should capture valid data on all of these domains. Social and physical environmental factors capture the context in which CVH promotion and CVD prevention operate. Examples include policy, systems, economic, and environmental factors related to housing, transportation, air quality, and access to healthy food and health care.[25] Data on behavioral factors including physical activity, diet/nutrition, and tobacco use are collected in some representative samples (Table 2), but state- and community-level data are sparse and mostly rely on self-report. Factors such as physical and cognitive function, emotional stress, sleep patterns, well-being, and patient-centered outcomes (eg, quality of life, self-rated health, pain and stress relief, caregiver burden) are not currently the subject of surveillance and should be considered in future systems. Some data sources capture clinical risk factors through self-report (eg, obesity, hypertension, high cholesterol, diabetes mellitus).[4] These are seldom measured in children.[25] Direct measurements are preferable and should be included in surveillance, as

Table 2. Metrics and Available Data Sources to Measure CVD and CVH

Type of Data	Source(s)	Examples of Information	Representation	Availability	Limitations/Gaps
Mortality	National Vital Statistics System[32]	Underlying and contributing causes of death	All deaths required to be reported	1–2 y	Coding not standardized
	HCUP[33]	Cost and quality of healthcare services Medical practice patterns Access to healthcare programs Treatment outcomes at national, state, and local levels	Series of databases that collect longitudinal billing data from all hospitals in participating states	1988–2015 (current)	Does not include details on causes of death in-hospital No details on patients outside of hospital systems
Disease prevalence	BRFSS[34]	Chronic disease prevalence (obesity) Health risk behaviors (tobacco use, nutrition, physical activity) Preventive health practices Healthcare access	Telephone-based survey of 400 000 adults ≥18 y old Conducted in all 50 states and 3 territories	1993–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and households without a phone
	YRBSS[35]	Chronic disease prevalence (obesity) Health risk behaviors (tobacco use, nutrition, physical activity) Preventive health practices Healthcare access	Biennial school-based national, state, tribal, and large urban school district surveys of representative samples of high school students	1990–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and households without a phone
	NHANES[36]	Chronic disease prevalence Current health status Physiological measurements (blood pressure, glucose levels, cholesterol, BMI) Individual and family medical history	Longitudinal survey of 5000 respondents of all ages in 15 counties Includes standardized physical examination	1999–2016 (current)	Excludes the institutionalized, nursing home residents, and active-duty military Lack of geographic generalizability Respondents not randomly selected
	National Health Interview Survey[37]	Current health status Health risk behaviors (eg, smoking, physical activity) Chronic disease prevalence Healthcare access and use Health disparities	Cross-sectional survey of 35 000 households	1962–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and active-duty military
	Medicare Current Beneficiary Survey[38]	Healthcare cost and utilization Health status Insurance coverage Cardiovascular disease prevalence Preventive health behaviors	Continuous, nationally representative survey of Medicare beneficiaries	1991–2016 (current)	Data limited to Medicare beneficiaries
Hospitalizations	National Hospital Care Survey[39]	Use of healthcare resources Quality of health care Inpatient discharges ED visits Disparities in healthcare services	Establishment survey of ≈500 hospitals Electronic data are collected for all inpatient and ED visits Integrates data formerly collected by the National Hospital Discharge Survey, National Hospital Ambulatory Medical Care Survey, and the Drug Abuse Warning Network	2010–present	Recruitment of hospitals has been difficult Hospitals have numerous competing reporting requirements EHR systems not fully interoperable
	HCUP[33]	Cost and quality of healthcare services Medical practice patterns Access to healthcare programs Treatment outcomes at national, state, and local levels	Series of databases that collect longitudinal billing data from all hospitals in participating states	1988–2015 (current)	Does not include details on causes of death in-hospital No data on patients outside of hospital systems

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Table 2. Continued

Type of Data	Source(s)	Examples of Information	Representation	Availability	Limitations/Gaps
Behavioral	BRFSS[34]	Chronic disease prevalence (obesity) Health risk behaviors (tobacco use, nutrition, physical activity) Preventive health practices Healthcare access	Telephone-based survey of 400 000 adults ≥18 y old; conducted in all 50 states and 3 territories	1993–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and households without a phone
	YRBSS[35]	Chronic disease prevalence (obesity) Health risk behaviors (tobacco use, nutrition, physical activity) Preventive health practices Healthcare access	Biennial school-based national, state, tribal, and large urban school district surveys of representative samples of high school students	1990–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and households without a phone
	National Adult Tobacco Survey[40]	Health risk behaviors (tobacco use) Preventive health practices (tobacco cessation)	Biennial, national survey of noninstitutionalized adults	2009–2014 (current)	Self-report
	National Youth Tobacco Survey[41]	Health risk behaviors (tobacco use) Preventive health practices (tobacco cessation)	Biennial, national survey of noninstitutionalized youth		Self-report
	NHANES[36]	Chronic disease prevalence Current health status Physiological measurements (blood pressure, glucose levels, cholesterol, BMI) Individual and family medical history	Longitudinal survey of 5000 respondents of all ages in 15 counties Includes standardized physical examination	1999–2016 (current)	Excludes the institutionalized, nursing home residents, and active-duty military Lack of geographic generalizability Respondents not randomly selected
	National Health Interview Survey[37]	Current health status Health risk behaviors (eg, smoking, physical activity) Chronic disease prevalence Healthcare access and use Health disparities	Cross-sectional survey of 35 000 households	1962–2016 (current)	Self-report Excludes the institutionalized, nursing home residents, and active-duty military
	SHPPS[42]	Physical education and physical activity Health services Nutrition environment and services Healthy and safe school environment Physical environment Employee wellness	Nationally representative sample of public and private elementary schools, middle schools, and high schools	Since 1994 on a periodic basis (most recently: 2016)	
Biological	NHANES[36]	Chronic disease prevalence Current health status Physiological measurements (blood pressure, glucose levels, cholesterol, BMI) Individual and family medical history	Longitudinal survey of 5000 respondents of all ages in 15 counties Includes standardized physical examination	1999–2016 (current)	Excludes the institutionalized, nursing home residents, and active-duty military Lack of geographic generalizability Respondents not randomly selected
Environmental	AQI[43]	Air quality Levels of health concern Ground-level ozone Carbon monoxide Particulate matter Sulfur dioxide Nitrogen dioxide	Index of daily air quality Major pollutants recorded at >1000 locations and converted into AQI values Cities with >350 000 people required to report	1980–present	Data may only be available on a small geographic area rather than individual level

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Table 2. Continued

Type of Data	Source(s)	Examples of Information	Representation	Availability	Limitations/Gaps
Social determinants of health	American Community Survey (Census Bureau)[44]	Household income Population demographics Ancestry Language proficiency Education level Employment/ occupation Migration Disability Health insurance Government assistance Housing characteristics	Nationwide, continuous survey of ≈3.5 million households (≈2.5 million completed interviews/year) Provides yearly data for planning Aggregates data into 1-, 3-, and 5-y estimates down to an assortment of geographic areas	2005–2016 (2017 data released in September 2018)	Frequent format changes makes inferences difficult Estimates less reliable than long-form census estimates Estimates more reliable in larger geographic areas

AQI indicates Air Quality Index; BMI, body mass index; BRFSS, Behavioral Risk Factor Surveillance Survey; CVD, cardiovascular disease; CVH, cardiovascular health; ED, emergency department; EHR, electronic health record; HCUP, Healthcare Cost and Utilization Program; NHANES, National Health and Nutrition Examination Survey; SHPPS, School Health Policies and Practices Study; and YRBSS, Youth Risk Behavior Surveillance System.

should clinical events occurring in and out of the hospital and the delivery of care.

Section Summary

- Although consistencies across recommendations intended to improve surveillance posited over the past several decades are evident, many have gone unfulfilled.
- Despite an extensive list of available data sources, most do not provide a cohesive approach to national or local cardiovascular surveillance and are limited to self-report.
- Monitoring of disease incidence, survival, recurrence rates, other nonfatal outcomes, overall health, and factors such as well-being and quality of life is essential to understanding changes in mortality and developing strategies for improvement; however, this information is not currently captured for the US population.
- Furthermore, surveillance of CVH in individuals <12 years of age is limited or altogether lacking.
- CVH metrics are crucially important for primordial prevention in the earliest years of life, from birth throughout the life course, and in population subgroups, but are not captured or are insufficiently captured by current surveillance systems.
- Current surveillance must be modernized to incorporate new dimensions and domains and must be capable of evolving as new risk factors and novel technologies emerge.

EMERGING OPPORTUNITIES TO TRANSFORM SURVEILLANCE OF CVH AND CVD

Emerging Community Programs

Most current systems (Table 2) are designed to operate at the national or state level; however, disease prevention and health promotion programs are increasingly deployed at the county or city level. Examples of current initiatives to provide local (at the county or city level) data on the health of communities are provided below.

- The County Health Rankings & Roadmaps program is a collaboration between the Robert Wood Johnson Foundation[66] and the University of Wisconsin Population Health Institute.[67] It measures health outcomes and risk factors, including high school graduation rates, obesity, smoking, unemployment, access to healthy foods, the quality of air and water, income inequality, and teen births, in nearly every county in America. A number of the metrics captured by this program are relevant to CVD and CVH and could be integrated into a large-scale digital surveillance program, although much of these data are aggregated within the rankings.
- In 2015, the Robert Wood Johnson Foundation and the CDC Foundation launched the 500 Cities Project.[68] It provides city- and census tract–level estimates for chronic disease risk factors, health outcomes, and clinical preventive service use for the largest 500 cities in the United States. Its objective is to allow cities and local health departments to ascertain chronic disease burden and thus design and implement public health interventions.
- Community health needs assessments have been federally mandated for tax-exempt hospitals since the Affordable Care Act was passed in 2010. A community health needs assessment must be conducted every 3 years, and a strategy must be defined and adopted to address those needs. Community health needs assessments are required every 5 years by the Public Health Accreditation Board for local health departments that seek accreditation.[69]

The opportunities for synergies among these examples are intuitive and in some cases have been examined

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proactively.[70] These programs currently have limited access to local data on disease burden and outcomes, which impedes their ability to adequately assess policy impact. This gap creates an opportunity to coordinate surveillance activities and local disease prevention and health promotion programs to assist stakeholders in assessing prevention and treatment priorities and guiding program planning, implementation, and evaluation.[25]

The "Public Health Data Superhighway"

A major new initiative to strengthen public health surveillance across the nation was announced in 2019 by the Council of State and Territorial Epidemiologists in *Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway*.[71] This initiative calls for transformation of the nation's public health surveillance system in accordance with 5 key principles and their consequent recommendations: (1) enterprise approach to data systems modernization; (2) interoperable data systems; (3) security to protect data; (4) workforce prepared for the information age; and (5) partnership and innovation with the public and private sectors. Such a transformation could be strongly supportive of the surveillance requirements of CVH promotion and CVD prevention, if its scope is broadened to include cardiovascular and other noncommunicable diseases and their determinants. This initiative merits vigorous support as it becomes implemented, if inclusive of the attributes required for 2030 and beyond, discussed previously.

Mobile Platforms and EHRs

Patient- and person-generated data are now widely available via mobile health (mHealth) applications.[72,73] Opportunities and challenges relevant to their application to surveillance have been delineated.[74] Several of the CVH metrics are examples of patient-generated data and thus lend themselves to the surveillance capability of mHealth.[4] However, the potential value of mHealth is challenged by the *digital divide*, a term used to describe disparities in access to technology related to age, race, and ethnicity and social determinants of health.[75] Privacy concerns could also impact the surveillance potential of mHealth. The role of mHealth in the CVD and CVH surveillance remains to be defined, and pilot studies are needed.

The growth of EHRs opens the door to new approaches to surveillance. EHRs enable increased access to dense longitudinal clinical data sets that, when combined with innovations such as machine learning, can greatly expand the reach of surveillance while generating new challenges. Phenotypes must be standardized to optimize validity and reliability, and data generated

from heterogeneous sources must be integrated with EHRs. Examples of the use of EHRs for CVD surveillance have been published.[76,77]

Within the EHR environment, methodological rigor, attention to new sources of bias (eg, digital divide, differential internet access by geography, socioeconomic status), and attention to issues regarding use of medical records (eg, missing data, variations in care-seeking behaviors) are critically important. Unlike primary data collection for research, medical record data are collected for the clinical episode and are influenced by the patient's health status and care-seeking behavior, as well as by the clinician's documentation practices. Hence, patients and providers, not researchers, determine the time of observation, which impacts inferences that can be drawn from the results. Large-scale collection of data, as enabled by digital technology and EHRs, shares the limitations and biases inherent to all data generated in the course of care, no matter the sample size. Far from reducing uncertainty, reliance on EHRs can amplify it, because large numbers will yield tighter confidence intervals without lessening bias or minimizing confounding. Many large-scale EHR networks, such as the Patient-Centered Outcomes Research Institute–funded PCORnet,[78] have developed methods to consolidate EHR data from various healthcare networks and patient populations into a standardized data format. PCORnet contains consolidated EHR data from >150 million patients with medical encounters in the past 5 years. Investigators from these EHR "networks of networks" are currently developing methodology related to these extensive EHR data sources for public health surveillance purposes.

Section Summary

- Local programs are emerging as resources that could contribute to a multidimensional approach to population surveillance and could provide timely assessment of disparities in CVD burden across geographic regions, as well as foster health promotion and surveillance work anchored in communities.
- The national initiative proposed by the Council of State and Territorial Epidemiologists offers a vision of public health surveillance that could potentially be of immense value to policy development in CVH promotion and CVD prevention, if its scope includes CVD, other noncommunicable diseases, and their determinants, as it develops and becomes implemented.
- Despite coverage limitations, rapid deployment of digital technology and EHRs offers opportunities to conduct surveillance. A plan to manage these complex data and transform them into actionable knowledge is needed.

POLICY IMPLICATIONS

Ethics of Surveillance

The WHO's ethical guidelines on public health surveillance articulate an affirmative duty to undertake, maintain, and utilize the results of surveillance for the common good.[79] If there is a compelling public health rationale, surveillance does not require individual informed consent. A comprehensive approach is needed and should encourage drawing on data collected for other purposes. The WHO guidelines underscore an obligation to share data with appropriate safeguards and justification.[79] Recent high-profile data breaches in the private sector have created a sense of vulnerability and present a challenge to advocating for extensive data sharing for the purpose of public health surveillance. These can evoke a history in which public health surveillance has stirred deep fears about privacy, stigmatization, and discrimination.[80] Health equity and a "right to be counted" better capture the history of surveillance since the 1980s. For chronic disease, communities have often emerged as strong advocates for surveillance, arguing that without understanding the patterns and causes of disease, population-level intervention can be difficult, if not impossible.[80] Given trends in income inequities and health disparities, the extent to which the digital divide limits participation in digital health ecosystems might loom larger than the protection of privacy as an ethical concern.[81,82] Often a failure to share data for purposes of surveillance is not attributable to community fears but to poor planning and technical and legal difficulties.[83,84]

The WHO's ethical guidelines make the case that when valid, complete data sets are required and relevant privacy protections are in place, informed consent is not ethically required.[79] Furthermore, the seeking of informed consent with large populations lacks feasibility, may be prohibitively costly, and may be unwarranted when the risks are low.[79] However, if individuals can opt out of surveillance or assert a "right to object" to data, the population benefits of surveillance may not be realized.

Although informed consent may not be required, community engagement and partnership remain key. Entities overseeing surveillance systems should embrace and integrate communities in planning, implementing, and using data. Doing so ensures transparency, contributes to the identification of community priorities, and fosters the trust necessary to build and sustain surveillance.[79]

Whether or not consent is sought, information about the nature and purpose of surveillance and any risk for harm should be publicly accessible. This is particularly important in cases in which government-private or government-industry partnerships may be involved.

There is an ethical obligation to share results with the communities. Communities may lack resources to implement the programs that surveillance may demonstrate as effective, but without access to the insights of surveillance, communities cannot, in turn, advocate for resources they may be lacking.

Sustainability and Funding

National public health authorities typically bear responsibility for public health surveillance systems. In

Table 3. Summary Policy Priorities

Unfavorable trends in CVD and CVH require urgent interventions by federal, state, and local governments, NGOs, and state and territorial health officials supported by committed policy making and sustainable funding.
These interventions require CVD and CVH surveillance that uses robust existing data and novel methods to predict the clinical, public health, societal, and economic burden of poor CVH and to monitor effectiveness. Surveillance should be based on samples that represent all ages from early childhood throughout the life course and should be relevant both nationally and locally. Sampling frames should provide meaningful estimates for historically underrepresented or misrepresented racial, sex, religious, and sexual identity subgroups within the population.
Federal, state, and local governments should conduct purposeful interagency and intergovernmental coordination to link surveillance to public health practice, resource prioritization, strategic planning, and policy development.
Funding considerations should recognize the cost-effectiveness of surveillance as a means to reduce the burden of disease. Private-public collaboration should be explored to provide sustainability for optimal surveillance.
Government agencies conducting surveillance should leverage novel digital platforms, including EHRs and mobile health, for behavioral and environmental risk factors and social determinants of health, as well as healthcare data systems, and should include quality of care indicators. Pilot studies should establish the feasibility of any proposed approach and the validity of measures collected. Robust local surveillance should be enhanced to supplement state and national systems to contribute to a multidimensional approach to population surveillance.
Federal, state, and local CVD and CVH surveillance systems should be HIPAA compliant. Personally identifiable information (ie, name, address) should be protected according to the strictest standards of legal and research ethics. All systems should include clear protections of economic, social, and civil rights.
Federal, state, and local CVD and CVH surveillance systems should identify, evaluate, minimize, and disclose risks for harm before surveillance is conducted.
When conducting CVD and CVH surveillance, federal, state, and local governments should consider the values, priorities, and concerns of the population. Communities should be given ample opportunities to be engaged on how the surveillance can benefit them, as well as on how it can accurately reflect their ethos.
Data gathered from federal, state, and local CVD and CVH surveillance systems should be effectively communicated to target audiences.

CVD indicates cardiovascular disease; CVH, cardiovascular health; EHR, electronic health record; HIPAA, Health Insurance Portability and Accountability Act; and NGO, nongovernmental organization.

the United States, growing financial constraints gravely threaten and disproportionately impact organizations that conduct surveillance. Thus, sustainability is a key consideration in any realistic consideration of building the surveillance systems of the future. The relative cost of surveillance of a cardiovascular condition is small compared with the medical cost of care and management of patients. For example, in 2012 the annual cost of the North Carolina Coverdell Acute Stroke Registry was approximately one-fifth of the amount spent on stroke hospitalizations across the state every day.[85] This perspective on the cost of surveillance might resonate with lawmakers, policy makers, and other stakeholders. Partnerships, including private-public collaboration, could also provide sustainability and must be actively explored.

Section Summary

- New policy initiatives to support cardiovascular surveillance will require sensitivity to ethical issues around data privacy, consent, and the common good.
- Financial sustainability is a key consideration in transforming surveillance systems capable of monitoring health goals for the next decade and beyond.

RECOMMENDATIONS

The recommendations formulated as part of this policy statement are summarized in Table 3. They build on principles and approaches formulated >4 decades ago and include and support recent recommendations of the Council of State and Territorial Epidemiologists regarding transformation of public health surveillance for the United States.

CONCLUSIONS

Aspirations such as those articulated by the AHA's 2030 Impact Goal require metrics that rely on a framework of agile and imaginative population surveillance. This policy statement summarizes the strategic principles and operational domains of a contemporary surveillance system for CVD and CVH for the next decade and beyond. Although prior recommendations calling for a national comprehensive surveillance system have yet to be fully implemented, valuable tools and platforms have emerged that could be used if coordinated in a pragmatic matter. We must marshal the convergence of technology and the scientific mandate into action to improve health and reduce disease in all sectors of the population. Existing resources and emerging data platforms and novel information systems and

technologies should be formally evaluated to determine their potential to inform the creation of the cardiovascular surveillance systems of the future. Such systems should generate the data required to evaluate the nation's investment in health promotion and disease treatments, to disseminate interventions that are effective, and to reengineer those that are not. They should be person and patient centric, provide comprehensive data, respond with agility to local and national needs, and synergize with community programs, thereby expanding the scope of public health practice within communities. Data management approaches must commit to interoperability and data sharing, privacy, and security. Attention to the need for realistic approaches, the development of robust policies, and an unwavering commitment to collaboration among professional organizations and policy makers are critical to ultimately reduce the burden of CVD and improve CVH. Where we go from here, and how fast, depends on the level of urgency among stakeholders. The AHA has set a bold new target for extending healthy life by 2030; the response among professional organizations and policy makers should be equally courageous.

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*Modest.

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*Significant.

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