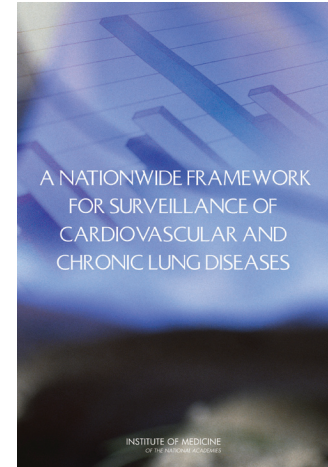


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A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases



Chronic diseases, such as cardiovascular disease and chronic lung disease, are common and costly, yet they also are among the most preventable health problems. Surveillance systems focused on chronic diseases have a potentially key role in reducing this health toll. Currently, surveillance data are collected from a variety of sources, often with beneficial results. But a critical link is missing: there is no surveillance system that operates on a national basis and in a coordinated manner to integrate current and emerging data on chronic diseases and generate timely guidance for stakeholders at the local, state, regional, and national levels.

To help close this gap, two federal health agencies—the National Heart, Lung, and Blood Institute of the National Institutes of Health, and the Division for Heart Disease and Stroke Prevention of the Centers for Disease Control and Prevention—turned to the Institute of Medicine (IOM) for advice. Specifically, the agencies asked the IOM to appoint a study committee to develop a framework for building a national chronic disease surveillance system focused primarily on cardiovascular and chronic lung diseases. The agencies specified that the system should be capable of providing data on disparities in incidence and prevalence of the diseases by race, ethnicity, socioeconomic status, and geographic region, along with data on disease risk factors, clinical care delivery, and functional health outcomes. *A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases* presents the committee's findings and recommendations.

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Survey of Common Surveillance Tools

Surveillance systems are meant to inform public health and clinical practitioners, policy makers, and the general public of the scope, magnitude, and cost of a health problem in order to influence priority setting, program development, and evaluation of services or policies. The ultimate aim is to catalyze actions to reduce morbidity and mortality and improve health, within a framework of finite resources used in an efficient and cost-effective way.

To underpin its deliberations, the IOM committee conducted a detailed assessment of the various data sources and tools that could be useful in a national surveillance system. Among current efforts, surveys are particularly valuable for learning about the prevalence and distribution of chronic diseases, as well as about associated risk factors that may contribute to the diseases and their consequences. Examples include the Behavioral Risk Factor Surveillance System and the National Health and Nutrition Examination Survey. Disease-specific registries, such as the National Cardiovascular Data Registry, are used for capturing data on individual patients. Cohort studies are valuable in following—prospectively or retrospectively—large groups of people who share a common characteristic or experience. Through the Framingham Heart Study, for example, the heart health of residents in this Massachusetts community has been monitored since 1948.

Data also are obtained from medical records and from claims filed with insurance companies. Both of these sources may include sufficient details to provide information on the incidence rate of a chronic condition, the types of services that patients receive, and the social characteristics of people who receive services. Also, death records, which include underlying and contributing causes of death and are compiled at the local and state level in nearly all states, provide information on mortality trends and patterns. The

records are sent to the National Center for Health Statistics.

New Surveillance Tools Emerging

Notably, the committee points to new surveillance tools that are emerging with the growing use of health information technologies, such as electronic health records (EHRs), which can economically and completely capture care events and processes. Expanding the use of EHRs in surveillance will have challenges, including the relatively low numbers of hospitals and practices now using the technology. But use of EHRs is expected to expand as health care reforms advance, necessitating their inclusion when planning for a national surveillance system.

In parallel, patients are recording a wealth of health data on their own, with or without initiation or direct support from health providers or organized care systems. This trend has its roots in the emergence of the internet and new online social relationships. Increasingly, this information is being comingled with other health data within large electronic data stores and used for population surveillance, performance assessment, predictive modeling, and care management. Although these sources have yet to be fully assessed, the potential is great that some, if not all, of them may complement and extend chronic disease surveillance efforts, although privacy issues must be addressed.

Steps Toward a National Surveillance System

The committee concludes that a coordinated surveillance system is needed and that existing surveillance data collection efforts can and should be strengthened and integrated to provide the basis of the system. The Department of Health and Human Services (HHS) should take the lead, as it already is responsible for the funding and con-

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duct of numerous surveillance efforts and can bring together stakeholders from both the public and private sectors, as well as from multiple geographic levels. HHS should establish and support a national working group to oversee and coordinate development and implementation efforts. This group should include representatives from HHS and other relevant federal agencies, such as the Veterans Administration and the Department of Defense, as well as representatives from tribal, state, and local public health agencies and non-governmental organizations involved in surveillance.

In its design, HHS should work to develop a system that can provide various types of data that individually and collectively can be used to understand the continuum of disease prevention, progression, treatment, and outcomes. It also must be flexible enough to respond to new challenges and opportunities. Among other things, the system HHS should develop needs to include data in the following areas:

- incidence and prevalence of cardiovascular and chronic lung disease over time, which will enable tracking of progress in reaching established national health goals, such as those detailed in the government's Healthy People reports;
- primary prevention, including the reduction of behavioral, clinical, and other risk factors associated with cardiovascular and chronic lung diseases and conditions; on

secondary prevention, such as early detection and intervention; and on tertiary prevention to manage symptomatic disease;

- health outcomes following surveillance, including changes in quality of life, and on costs, including direct medical costs and the indirect costs of lost productivity, earnings, and social burden;
- representative samples and data (e.g., at the substate or county level) to support local public health action to prevent and control chronic diseases; and
- disparities in these factors by race or ethnicity, geographic region, and socioeconomic status.

Among other recommendations, the committee presented a conceptual framework for national surveillance of cardiovascular and chronic lung diseases and called on HHS to adopt it. The framework organizes data from traditional, evolving, and novel surveillance sources to reflect the development and progression of chronic conditions over the life course, and also captures the importance of disease prevention. Information collected throughout this framework can be assembled into both specific and general metrics to inform practices at all levels of the health care system as well as the deliberations of policy makers in multiple roles.



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Conclusion

Without a national surveillance system, the gaps in current monitoring approaches will continue to exist, making it more difficult to track the nation's health status despite advances in technology and data collection. A robust surveillance system will serve as a benchmark for clinicians treating patients with cardiovascular and chronic lung diseases. It will help in monitoring, evaluating, and improving policies, programs and services and in directing the placement of resources, and it will provide a stronger basis for advocacy and education. The framework put forth by the IOM committee not only could help with tracking and monitoring cardiovascular and chronic lung disease but might well become a building block for an integrated surveillance system for the broad spectrum of chronic diseases. 

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