Surveillance of Disparities in Vision and Eye Health in the United States: An Expert Panel's Opinions

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• PURPOSE: To define surveillance approaches and metrics to capture the burden of vision health disparities and to identify properties of a surveillance system to guide public health interventions.

• DESIGN: Expert panel.

• METHODS: Analysis of relevant literature and deliberations of expert panel.

• RESULTS: The panel identified that the purpose of vision surveillance was to link data to public health interventions. Panel members noted the importance of assessing vision through self-reported and performance-based measures. Defined populations should be included in a surveillance system to assess disparities in utilization of eye care and vision loss. The panel suggested that ophthalmic/vision measures should be sustained in national surveys and suggested that a vision surveillance system should be forged among federal agencies.

• CONCLUSIONS: Employing the 6 outlined strategies would improve vision surveillance and help reach the vision-related objectives of *Healthy People 2020.*   (Am J Ophthalmol 2012;154:S3–S7. © 2012 by Elsevier Inc. All rights reserved.)

INTRODUCTION: UNDERSTANDING THE GOALS OF REDUCING DISPARITIES IN VISION AND EYE HEALTH

VISION LOSS IS A SERIOUS PUBLIC HEALTH PROBLEM in the United States and will worsen in the next 30 years without effective programs to detect, correct, or prevent vision loss. In 2004, it was estimated that 3.3 million people aged 40 years and older in the United States were visually impaired or blind.[1] The most common eye diseases that may cause irreversible vision loss include age-related macular degeneration,[2] diabetic retinopathy,[3,4] and glaucoma.[5] Other treatable forms of visual impairment, such as cataract and refractive error, affect millions more Americans.[6,7]

Vision loss is not uniform across various adult populations. For example, vision loss is higher in female subjects, those of lower socioeconomic status, and older adults.[8] Given equal care and equal biologic responses to treatment, one might expect vision loss to be proportional to the prevalence of eye disease in each population. Significant variations in vision outcomes among demographic groups suggest differences in biologic response or access to or effectiveness of care delivery. While biologic differences are possible, differences in access to/effectiveness of care are likely to be an important independent factor. For example, those with vision loss often report poorer access to eye care[9–11] and general health care.[12] The reduction in these disparities in access is a goal for both healthcare organizations and public health.

We believe that, for those who have visual loss that affects function from cataracts or refractive error or other conditions that can be effectively "cured," there should be NO severe visual loss, eliminating any disparity in the outcomes of visual loss and blindness. Some conditions are blinding, even with care. For those with these conditions, early and appropriate preventive measures would eventually reduce rates of vision loss.

The United States government, in conjunction with the vision sciences and eye care communities, has identified the reduction of population disparities in visual loss and in access to eye care services as top public health priorities in *Healthy People*
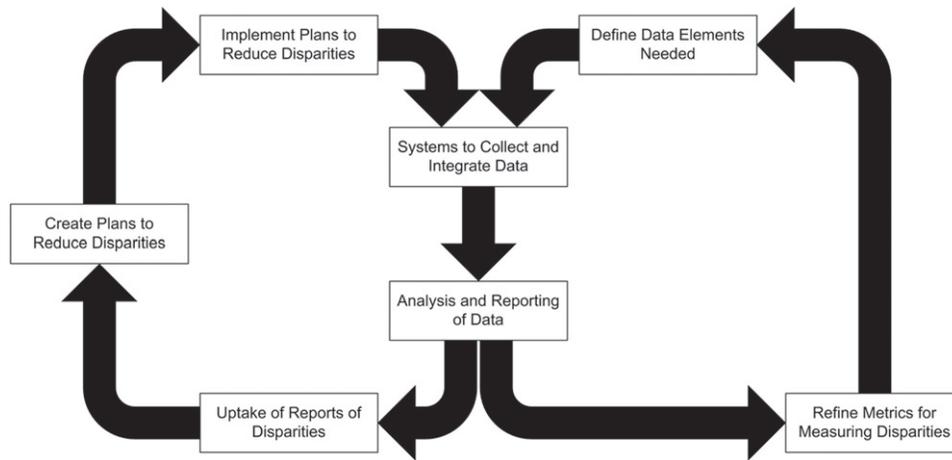
FIGURE. Conceptual diagram of vision surveillance system.

2020 (HP2020), a series of health-related goals set for the nation.[13] Others have called attention to the public health dimensions of vision loss and need for vision surveillance.[14–16] Because of these concerns, the Centers for Disease Control and Prevention (CDC) convened an expert panel in July 2010. This panel's charges were to: (1) explore possible surveillance approaches and metrics to capture the burden of vision health disparities; and (2) suggest what properties a surveillance system should have to provide meaningful guidance to improve public health interventions and support disparity reduction programs. This report summarizes the discussion of the members of the expert panel.

PUBLIC HEALTH SURVEILLANCE IN PRINCIPLE

SURVEILLANCE SERVES AS THE FOUNDATION OF PUBLIC health prevention programs. It is defined as the ongoing systematic collection, analyses, and interpretation of health related data essential to planning, implementation, and evaluation of health practices . . . . The final link in the surveillance chain is to apply the data toward prevention and control.[17] Surveillance has 3 main functions: monitoring, prioritizing, and evaluating. *Monitoring* detects new health problems and assesses and tracks the magnitude and risk factors of a population. Findings from surveillance activities can be employed to *prioritize* key problems or target groups for interventions, set national objectives for management and prevention, identify research needs, and plan, facilitate, and justify use of resources. Finally, surveillance data can be used to *evaluate* and track the public health response to a problem, and to track progress on national health objectives. A variety of data sources—state and national surveys, administrative data, and electronic medical records—may be assembled to establish a surveillance system.[18]

PANEL MEMBER OBSERVATIONS

THE PANEL MEMBERS SOUGHT TO MINIMIZE THE DATA collection burden by identifying a limited number of key metrics capturing the essential disparity-related attributes associated with vision loss. As such, the key metric of vision loss represents a "common end pathway" for many eye diseases. In addition, indices of access and utilization of care were identified as important factors to be monitored. The panel members generally agreed on how such a surveillance system would work and what the minimal content of such a system might entail for meaningful use. The panel observed that employing the 6 strategies outlined herein would improve vision surveillance and help reach the vision-related objectives of *Healthy People 2020*.

(1) A vision surveillance system needs to link data collection and analyses with ongoing public health interventions to improve eye health disparities.

The Figure illustrates this model and shows how a feedback loop contributes to a systematic approach to link public health surveillance data collection with public health initiatives to reduce disparities in vision loss, so that problems are identified and interventions are developed, implemented, and evaluated using the same metrics. Evaluation of interventions will identify new data needs to improve both the surveillance system and the likelihood of program success, thus assuring the improvement of the surveillance system and the public health interventions. Therefore, a surveillance system must be regarded as an action tool, generating data that are used by implementers of change.

(2) A vision surveillance system needs to effectively assess vision loss.

Based on the available scientific literature, the panel agreed that vision loss should be measured using both performance-based and self-reported methods:

• PERFORMANCE-BASED MEASURES: To optimize the measurement of vision in the general population, panel members supported a threshold approach to capture central visual acuity and contrast sensitivity. Contrast sensitivity loss is generally regarded as a predictor of functional status that is independent of central visual acuity. New performance-based approaches to accurately measure visual acuity, such as simpler approaches to visual acuity testing using handheld devices, could be explored to more easily assess acuity within surveys and across a variety of settings.

• SELF-REPORTED MEASURES: Multiple self-reported measures are employed to assess visual function (for example, reading newspaper print, recognizing a friend across the street) in surveys, but there is great variability in these self-report questions. There are currently no standard, universally accepted questions. Steps to harmonize questions across surveys and validate them should be considered.

Standardized measures of acuity, contrast sensitivity, and self-reported function would allow for comparability across surveys and allow for integration of data from multiple surveys into a system, strengthening the ability to measure disparities in the population as well as identify barriers to and enablers of care.

(3) A vision surveillance system needs to effectively assess utilization of eye care.

Although panel members acknowledged that multiple methods to measure vision care access and utilization are available through self-report and analysis of claims databases, access to eye care is measured in fewer than half the states. Surveys regarding access to rehabilitation services lack sufficient sample size to guide practice or policy. Surveys might routinely ask about the interval from the most recent use of eye care services, such as a dilated eye examination, if respondents do not achieve threshold visual performance or if they report impaired visual functioning. Moreover, if the respondent did not access eye care, questions might be asked about barriers including cost, insurance, inadequate time, transportation, language barrier, continuity of care, trust in the provider or system, and/or lack of knowledge or understanding of access points. Questions might also be asked about access to vision rehabilitation services for those below the threshold. Linked electronic health records could soon provide greater granularity and timeliness to assess utilization of eye care.

(4) A vision surveillance system needs to include defined populations to assess the disparities in vision loss and in utilization of eye care services.

Population-based vision and eye health studies confirm disparities based on age, gender, race/ethnicity, and socioeconomic status indicators. Disparities are often poorly characterized because they are not adequately surveyed or sample sizes are insufficient to make state or national inferences. The limitations of current surveillance activities result in incomplete knowledge to measure change or to inform policy and practice. Given the known disparities in prevalence of vision loss and eye disease among various groups, and given the known differences in access to vision and eye care, the panel members agreed that surveillance systems should capture racial/ethnic, gender, and socioeconomic (income/education) and geographic location differences (both region and urban-rural) in vision status and access to and use of eye health care services.

(5) A vision surveillance system needs to include and sustain ophthalmic/vision measurement and question components within national surveys.

A vision surveillance system should make best use of existing and emerging data sources. Several national and state surveys exist and could be used to establish the surveillance system, such as the National Health and Nutrition Examination Surveys (NHANES), the National Health Interview Survey (NHIS), and the Behavioral Risk Factor Surveillance System (BRFSS). NHANES has been the only nationally representative survey to include measures of visual acuity, screening tests, and a comprehensive visual functioning assessment in addition to self-reported questions. However, this survey was discontinued in 2009. It was suggested by the panel to support the eye health and vision components in NHANES to continue to obtain national estimates and trends on visual acuity, refractive errors, and age-related eye diseases such as diabetic retinopathy and age-related macular degeneration. The survey represents a unique resource for obtaining data for improving eye and vision health. The NHIS vision supplement, essential to track HP2020 vision objectives, was implemented in 2002 and 2008. Continuing the supplement would provide national ongoing, comparable data. The BRFSS Vision Module, a 9-question survey addressing visual function, access, and eye conditions, was the only survey to provide data on vision and access to eye care at the state level. The module was implemented in 23 states since 2005; however, it was discontinued in 2011.

Innovative strategies to make the best use of electronic medical records that may provide immediate access to vision and eye care data should be explored in the coming years.

(6) A vision surveillance system needs to be forged among federal agencies and other stakeholders to monitor the nation's eye health and eye care utilization for trends in disparity.

It was suggested that federal agencies and others work together to establish a national surveillance system. Such a system would harmonize the questions regarding self-reported vision and vision functioning asked of participants in national and state-level surveys; promote the implementation of the surveillance system, preferably in conjunction with other public health entities at the state

and local levels; and offer input to providers and other end users for implementation of policies and programs that help mitigate/reduce/eliminate disparities.

DISCUSSION

A VISION SURVEILLANCE SYSTEM WOULD HELP US KNOW where we are meeting or failing to meet the *Healthy People 2020* vision health goals. Such a system would further national efforts to focus on vision loss prevention and, when possible, restoration. Periodic review of the entire surveillance system would help ensure that the system operates efficiently and is responsive to changing conditions and the development of new measures of vision and visual functioning. The suggested goal of a "learning" surveillance system would, for example, enable newer methods of measurement such as observed task performance to be assessed and included as they are validated and made reliable.

Members of the panel supported the idea that the surveillance system would serve as an infrastructure resource to improve use of eye care services. This way, the surveillance system could help create a routine performance improvement cycle, linking measurement of key metrics to programs aimed at reducing visual loss. The surveillance system would develop core information to guide future public health efforts to reduce visual loss, with particular focus on minimizing disparities in access or in care.

Upon reviewing the available scientific literature, panel members generally agreed that visual acuity and contrast sensitivity were independent measures of visual performance, and both should be included in an initial surveillance system. The panelists also concluded that subjective, self-reported vision measures would provide complementary information.

The use of eye care services remains a key variable in the surveillance system, but details of this assessment are limited to those services related to vision loss to create maximum efficiency and usability of the proposed surveillance system.

CONCLUSION

A VISION SURVEILLANCE SYSTEM COULD PROVIDE IMPORTANT data to monitor the progress of public and private efforts to reduce visual loss. When integrated with the delivery system in a feedback loop, a vision surveillance system could be a key component of national efforts to accomplish the vision-related goals of *Healthy People 2020*.

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