

EDITORIAL

Vision Surveillance in the United States: Has the Time Come?

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A CLUSTER OF MEASLES CASES OCCURS IN A KINDERGARTEN, reported by local pediatricians to the state health department. Investigators find that measles vaccination in families who use the kindergarten is less than 50% and undertake remedial action to increase vaccination in the families and their contacts. Such a scenario illustrates well the elements of a working surveillance system: (1) collection of data on cases of a disease with public health significance; (2) reporting of data to a body that can monitor the data for trends; (3) identification of a “trigger” from the trend analyses that requires public health intervention; (4) public health investigation and resulting action to rectify any threat; and (5) continued monitoring to ensure the return to a “normal” state. All elements are necessary, as the collection of data alone without an action plan for data use once a problem is identified is not a good use of scarce resources, and an action plan without quality data to indicate when it should be used is equally unreasonable. A functioning surveillance system is based on these principles of a positive feedback cycle.

Surveillance systems are classically used for infectious diseases, to detect unexpected bursts of new cases, as the example illustrated. In this case, the cluster of measles cases was the “trigger” that initiated the intervention. Surveillance for disease outbreaks, or unexpected trends, is a well-respected tool in public health, and is used routinely in the United States to monitor, for example, vaccination rates or trends in obesity.^{1–5} However, the principles could apply to chronic diseases as well. Given the less acute nature and longer duration of chronic conditions, such as the major eye diseases causing vision loss in the United States, periodic national surveys as well as classic surveillance systems could be considered for surveillance purposes. Can a reasonable case be made for vision surveillance, what would be a “trigger,” and to what purpose?

As summarized in the accompanying articles and panel report in this Supplement, we believe that disparities in rates of vision loss justify using resources invested in national surveys for surveillance purposes to detect and reduce disparities in vision loss. First, there are effective interventions for

the major eye diseases—surgery for cataract, correction for refractive error, surgical and medical treatment for diabetic retinopathy, injections for choroidal neovascularization, and medications/surgery for glaucoma. Second, a priori there should be no differential vision loss by race, ethnicity, sex, or socioeconomic status from these diseases. Whereas rates of underlying diseases DO vary by these factors, the presence of effective treatments without evidence of differential benefit by race, ethnicity, or sex strongly suggests that the proportion of visual loss among those with eye diseases should not vary, provided that timely treatment is provided to those in need. Third, the evidence is clear that visual loss is associated with significant decrements in quality of life, functioning, employment, and life satisfaction. Disparities in vision loss indicate inequalities in health outcomes and inequitable use of health dollars.

If we agree that surveillance for variations in rates of vision loss is a worthwhile public health activity, then to efficiently accomplish this goal we need to answer a series of questions.

First, what is the “trigger” or health outcome that we are monitoring? The panel felt that vision loss and blindness, rather than specific diseases, should be the core measure.

Second, what methodology would be used to define such loss? The panel recommended, as a minimum, a standard test of acuity as well as complementary self-reported perceptions of visual status. Use of perceptions must be carefully considered at this stage, for at least 2 reasons. The first reason is that there is little information on biases in reporting perception of vision by different racial/ethnic/socioeconomic groups and their relationship to performance-based assessments, but recent research suggests such biases can exist. The second reason is that many of the major national surveys rely on self-report of vision loss using a variety of questions that differ in the question stem or the response sets. Thus, results are not directly comparable, and the relationship of responses to seemingly similar questions and to acuity testing is not well understood. Therefore, the panel further suggested that work be done to harmonize self-report items used in national surveys, to determine how differences in culture may manifest in responses, and to understand the relationship to performance-based tests. Until we are certain that all groups have similar expectations for their visual function, it is likely that objective tests will be more revealing of disparities in vision loss.

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Third, are there any existing national surveys that could combine both patient-reported outcomes and performance-based measures of visual function? The National Health and Nutrition Examination Survey (NHANES) captures a snapshot of the nation's health. It is conducted by the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC) and is supported by the various National Institutes of Health (NIH) institutes. While NHANES has a medical examination component, a vision examination is only done sporadically. The panel suggested that the vision component, including acuity testing, should be supported on a regular basis to enhance the national vision surveillance system. This is a critical piece, and the larger vision and eye health community should promote this suggestion within NIH. We also support the suggestion that sufficient sampling of high-risk groups be included so as to generate stable rates for detection of differences in order to make it useful for measuring disparities.

The impact of new technology and the potential effect of changes in health care financing and delivery models, together with the rapidly growing use of electronic health records, also suggest alternative surveillance methods for the future. Linking to medical records from around the country would provide more in-depth information about visual loss, albeit skewed towards those actually using the care delivery system. Indeed, other transformative options may become apparent soon for survey work, such as the Apple iPad visual acuity tester "app."

A true surveillance system is an active, dynamic process that feeds data to end users who can effect change in policy and programs. The panel recognized this essential component by adopting the 2-part figure, which shows the data on eye health disparities feeding into state and federal authorities. Herein lies one of the major challenges to an effective surveillance system: who will synthesize these data, prepare reports, and feed them to the relevant change agents? We believe that the Centers for Disease Control and Prevention, as its name suggests, may be one federal agency to take responsibility for monitoring, report generation, and advocacy. This charge would need to be added to the mandate of the CDC section on vision, as it was added to the diabetes division of the CDC. Moreover, the creation of a vision surveillance system will need partnerships among many stakeholders in order to monitor the nation's eye health and eye care utilization for trends in disparity and commit to acting on the findings. The CDC already has links with federal health agencies and state health departments, enabling the dissemination of information and advocacy. The partnership could be the focus for the involvement of the vision community, as change agents and supporters of modest efforts to collect information sufficient to detect, and ultimately conquer, disparities in eye and vision health.

To take full advantage of the panel's report and burgeoning opportunities in the future, we need to develop a useful surveillance system within a structure that creates the feedback systems essential to achieving improved vision for all.

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REFERENCES

1. Thacker SB. Historical development. In: Teutsch SM, Churchill RE, St. Louis ME, editors. Principles and practice of public health surveillance. 3rd ed. New York: Oxford University Press, 2010:1–17.
2. Buehler JW. Surveillance. In: Rothman KJ, Greenland S, Lash TL, editors. Modern epidemiology, 3rd ed. Philadelphia: Lippincott-Williams and Wilkins, 2008:459–480.
3. Thacker SB, Stroup DF. Future directions for comprehensive public health surveillance and health information systems in the United States. *Am J Epidemiol* 1994;140(5):383–397.
4. Updated Guidelines for Evaluating Public Health Surveillance Systems. Available at www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm. Accessed September 6, 2012.
5. WHO | Public health surveillance. Available at www.who.int/immunization_monitoring/burden/routine_surveillance/en/index.html. Accessed September 6, 2012.

Biosketch

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