

# Building a Basis for Action: Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States

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- **PURPOSE:** To examine the ability of current surveillance systems to assess and monitor disparities in: (1) vision impairment, (2) eye disease, (3) vision-related functioning, (4) access to vision and eye care, and (5) access to supports and services for those needing vision rehabilitation.
- **DESIGN:** Review of surveillance systems and instruments.
- **METHODS:** We defined surveys and surveillance systems as data collection systems that used an active survey or data abstraction instrument, regardless of the sampling unit, and excluded strictly administrative data sources. We assessed 8 surveys against key surveillance attributes of representativeness, flexibility, and timeliness, as well as their contribution to establishing a national vision surveillance system.
- **RESULTS:** The key challenges facing a national vision surveillance system are: (1) the lack of consistent outcome data with adequate sample size and coverage to enable identification and tracking of vision health disparities, (2) lack of standardized data elements, and (3) a paucity of data that influence disability such as behavioral and environmental data.
- **CONCLUSIONS:** Current systems for assessing and monitoring vision health in the United States are limited and do not provide adequate information to guide interventions and policy decisions. Vision surveillance can help to document the burden of the condition, to identify high-risk populations, to develop strategies to reduce the individual and societal burden, and to guide public health programs and policies. Existing surveillance systems could be enhanced by integrating data and by periodically including patient-reported outcomes measurements including, but not limited to, specific barriers for people with vision impairment and related disabilities. (Am J Ophthalmol 2012;154:S8–S22. © 2012 by Elsevier Inc. All rights reserved.)

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**V**ISION IMPAIRMENT INCREASINGLY IS RECOGNIZED as a public health problem because it affects a large number of people—3.3 million people 40 years of age and older in the United States<sup>1</sup>; is associated with smoking<sup>2</sup>, diabetes,<sup>3,4</sup> and cardiovascular health<sup>5</sup>; is associated with higher prevalence of chronic comorbid conditions such as falls,<sup>6</sup> injuries,<sup>7</sup> and premature mortality<sup>8</sup>; and most could be prevented by early detection and timely treatment. Moreover, people who are older, are female, are black, are Hispanic, are poorer, and live in rural areas are more likely to experience or to be at risk of vision impairment.<sup>9</sup> People with vision loss often report poorer access to eye health care<sup>10,11</sup> and general health care.<sup>12</sup> The importance of vision and eye health was recognized with the introduction of 10 vision objectives in Healthy People 2010 that continued with Healthy People 2020.<sup>13</sup>

Despite our knowledge about the socioeconomic burden of vision loss and eye diseases and existing disparities, as well as the broadly recognized gravity of vision impairment, there is no public health surveillance system in the United States systematically to estimate the population of people experiencing vision problems, to monitor trends in vision impairment, or to gauge changes in access to eye care, health and health behaviors, and access to and effectiveness of services that potentially improve health and quality of life of those who experience impaired vision.

Public health surveillance is defined as “the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health.”<sup>14</sup> Public health surveillance has developed into a rigorous science characterized by deliberate steps to gather, disseminate, and apply health information.<sup>14</sup> Public health surveillance is further characterized by “defined outputs and a specific public health purpose” and a “consistent case definition.”<sup>15</sup> 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 used to prioritize key problems or target groups for interventions, to set national objectives for management and prevention, to identify research needs, and to plan, facilitate, and justify use of resources. Finally, surveillance data can be used to evaluate and track the public health response to a problem

**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
National Health Interview Survey (NHIS)	Administered by the NCHS in the CDC; contains core questions administered annually (household, family, sample adult, and sample child components); vision supplement administered 2002 and 2008 only	National; estimated 35 000 households and 87 000 individuals surveyed annually (for core questions); participants are adults and children of all ages	Cross-sectional	Personal household interview; core question data collected on an ongoing basis; proxy respondents are allowed	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>● National, population-based survey</li> <li>● Provides information on functioning, social participation restriction, access to care, and access to supports and services</li> <li>● Capacity for monitoring disparities (gender, age, SES, race)</li> <li>● Considered reliable and valid</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>● Does not validate with clinical examination (self-reported data)</li> <li>● Several key vision questions are asked on the supplement component, which is not administered on a regular basis</li> <li>● Does not include institutionalized population (e.g., nursing home residents) or military personnel</li> <li>● Time between collection of data and release may be a minimum of 6 mos</li> <li>● Vision component contains 2 years of data; may not be able to perform small, subpopulation group analyses</li> </ul>	<a href="http://www.cdc.gov/nchs/nhis.htm">http://www.cdc.gov/nchs/nhis.htm</a>

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**TABLE.** Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (*Continued*)

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
Behavioral Risk Factor Surveillance System (BRFSS)	Administered by the CDC; contains core component (fixed core, rotating core, and emerging core); optional modules (including the vision impairment and access to eye care module), and state-added questions; vision module available to states beginning in 2006	State-level; more than 350 000 adults interviewed annually (for core component); participants are 18 years of age or older	Cross-sectional	Annual telephone survey; all data are self-reported	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Measures functioning health risk behaviors, preventative health practices, and health care access</li> <li>A source of timely, accurate, state-level data on health-related behaviors, specifically as they related to chronic diseases and injury</li> <li>Data is collected by December and available by April the following year</li> <li>State data can be combined to produce national estimates for certain variables</li> <li>Core questions considered moderately to highly reliable and valid</li> </ul>	<a href="http://www.cdc.gov/brfss/">http://www.cdc.gov/brfss/</a>

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**TABLE.** Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (*Continued*)

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
					<p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Does not validate data with clinical examination (self-reported data)</li> <li>• Several key vision questions are asked on the vision component, which has been administered in 19 states between 2006 and 2008</li> <li>• Telephone survey may introduce bias due to nonresponse and noncoverage</li> <li>• Does not include institutionalized population (e.g., nursing home residents or military personnel)</li> <li>• Vision module available only for recent years and in limited states</li> </ul>	

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**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (Continued)**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
National Health and Nutrition Examination Survey (NHANES)	Administered by NCHS; interview administered annually (with vision component); vision examination administered annually; ophthalmology examination administered in 2007 to 2008, 2005 to 2006	National; NHANES (1999 to present) surveys approximately 5000 persons annually; participants are adults and children of all ages	Cross sectional	Personal household interview; Vision and Ophthalmology examination	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• National, population-based survey</li> <li>• Data from clinical examination and self-report are collected</li> <li>• Vision component administered annually</li> <li>• Vision examination and questionnaire performed from 1999 through 2008 will allow for analyses of subpopulations</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Survey data are released on public use data files every 2 years</li> <li>• Does not include the institutionalized population (e.g., nursing homes)</li> <li>• Vision component not included in 2009 to 2010 survey</li> <li>• Ophthalmology examination only performed in 2005 to 2006 and 2007 to 2008, may not be able to perform small, subpopulation group analyses</li> </ul>	<a href="http://www.cdc.gov/nchs/nhanes.htm">http://www.cdc.gov/nchs/nhanes.htm</a>

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**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (Continued)**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
Medical Expenditure Panel Survey (MEPS)	Administered by the Agency for Healthcare Research and Quality (AHRQ); continuous, nationally representative survey of United States noninstitutionalized population (subsample of NHIS participants); survey (including vision component and diabetes care module) administered annually	National; approximately 12 000 to 13 000 persons are surveyed biannually; participants are adults and children of all ages	Longitudinal panel (2.5-yr follow-up)	Personal household interview; repeated interviews conducted every 5 to 6 mos	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>● National, population-based survey</li> <li>● Vision component administered annually</li> <li>● Provides information on access to care</li> <li>● Panel participants rotate every 2.5 years, allowing researchers to monitor changes over time</li> <li>● Vision impairment questions are repeated each year (data can be pooled over multiple years)</li> <li>● Repeated measurements of individuals over time enables analysis of changes in health care access and use and health status</li> <li>● Data allow for an examination of associations between access and use of health care services with vision impairment</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>● Does not validate data with clinical examination (self-reported data)</li> <li>● Does not include institutionalized population (e.g., nursing home residents) or military personnel</li> </ul>	<a href="http://www.meeps.ahrq.gov/meepsweb/">http://www.meeps.ahrq.gov/meepsweb/</a>

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**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (Continued)**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
Medicare Current Beneficiary Survey (MCBS)	Administered by Centers for Medicare and Medicaid Services (CMS); continuous, nationally representative sample of aged, disabled, and institutionalized Medicare beneficiaries; collects information on health status, health care use and expenditures, health insurance coverage, and socioeconomic/ demographic; participants remain in the MCBS for 4 yrs	National; estimated 12 000 persons surveyed 3 times yearly (beginning in 1991); participants are adults $\geq$ 65 y of age	Longitudinal panel design (4-y follow-up)	Face-to-face interviews in households and institutions	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Data can be merged easily with Medicare claims to enhance analytic power</li> <li>Institutionalized beneficiaries included in the survey</li> <li>Participants remain in cohort for 4 y; follow-up of the same subjects over several years allows for the monitoring of changes in health care use and health outcomes over time</li> <li>Data can be used to determine expenditures related to vision</li> <li>Data for nonrespondents to the interview can be obtained from Medicare files, so that characteristics of persons who declined to be interviewed or could not be located can be compared with those who completed the interview and used to adjust weighting</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>Only includes Medicare beneficiaries</li> <li>Does not validate data with clinical examination (self-reported data)</li> </ul>	<a href="http://www.cms.gov/MCBS/">http://www.cms.gov/MCBS/</a>

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**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (Continued)**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
National Hospital Discharge Survey (NHDS)	Administered by NCHS; collects information on patient characteristics (demographics, payment source, diagnoses, and procedures) of inpatients in short-stay hospitals in the United States; Conducted annually since 1965	National; between 1988 and 2007, the NHDS collected data from approximately 270 000 inpatient records from a national sample of approximately 500 hospitals	Cross-sectional	Abstractions of hospital records	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• National, population-based data</li> <li>• Provides information on access and use of vision and eye care (via ICD-9 codes)</li> <li>• Data are available annually</li> <li>• Population statistics from the NHDS are derived by a multistage estimation</li> <li>• Probability design of the NHDS permits the calculation of sampling errors in procedure that produce unbiased national estimates</li> </ul> <p><u>Limitations</u></p> <ul style="list-style-type: none"> <li>• Includes only hospitals with an average length of stay &lt; 30 days</li> <li>• Federal, military, and Department of Veterans Affairs hospitals, prison hospitals, and hospitals with &lt;6 beds also are excluded</li> </ul>	<a href="http://www.cdc.gov/nchs/nhds.htm">http://www.cdc.gov/nchs/nhds.htm</a>

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**TABLE. Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (Continued)**

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
The National Ambulatory Medical Care Survey (NAMCS)	Administered by NCHS; designed to collect data on medical care rendered in physicians' offices (symptoms, diagnoses, smoking habits, medications, demographics, services provided, payment source); survey was conducted annually from 1973 through 1981, in 1985, and annually since 1989	National; each year, 3000 physicians are selected randomly to provide data on approximately 30 patient-visits each	Cross-sectional	Data are collected by the physician, randomly assigned to a 1-week reporting period; data are recorded on a standard encounter forms provided to physician	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>● Provides national and continuous data on access to and use of medical care</li> <li>● Population statistics from the NAMCS are derived by a multistage estimation procedure that produces unbiased national estimates</li> <li>● Probability design of the NAMCS permits the calculation of sampling errors</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>● Relatively small sample size</li> <li>● Restricted to visits to physicians (excludes visits to optometrists, nurse practitioners, etc.)</li> </ul>	<a href="http://www.cdc.gov/nchs/ahcd.htm">http://www.cdc.gov/nchs/ahcd.htm</a>

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**TABLE.** Enhancing Public Health Surveillance of Vision Impairment and Eye Health in the United States: General Characteristics of Surveys Meeting Inclusion Criteria for Evaluation (*Continued*)

Survey	Description	Population Level/ Population Size	Survey Type	Method of Data Collection	Study Design and Data Elements	URL for Additional Information
The National Hospital Ambulatory Medical Care Survey (NHAMCS)	Administered by NCHS; designed to collect data on ambulatory care rendered in hospital emergency and outpatient departments; survey was conducted annually from 1973 through 1981, in 1985, and annually since 1989	National; 500 nationally representative hospitals	Cross-sectional	Clinic staff complete a patient record form for a random sample of patient visits during a 4-wk reporting period	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>● Provides national and continuous data on access to and use of medical care</li> <li>● Population statistics from the NHAMCS are derived by a multistage estimation procedure that produces unbiased national estimates</li> <li>● Probability design of the NHAMCS permits the calculation of sampling errors</li> </ul> <p><u>Limitations</u></p> <ul style="list-style-type: none"> <li>● Includes only short-stay hospitals (average length of stay 30 days)</li> <li>● Federal, military, and Department of Veterans Affairs hospitals, prison hospitals, and hospitals with 6 beds are also excluded</li> </ul>	<a href="http://www.cdc.gov/nchs/ahod.htm">http://www.cdc.gov/nchs/ahod.htm</a>

CDC = Centers for Disease Control and Prevention; ICD-9 = International Classification of Diseases, ninth edition; MCBS = Medicare Current Beneficiary Survey; NAMCS = National Ambulatory Medical Care Survey; NCHS = National Center for Health Statistics; NHAMCS = National Hospital Ambulatory Medical Care Survey; NHDS = National Hospital Discharge Survey; NHIS = National Health Interview Survey; SES = socioeconomic status.

and to track progress on national health objectives. More broadly, surveillance systems may assemble data from a variety of sources to create a comprehensive, dimensional, and dynamic representation of a public health concern.<sup>15</sup>

This study evaluated key United States surveys and surveillance systems in terms of how well they contribute to establishing a national vision surveillance system and examined the vision questions in these surveys and their ability to establish a standard case definition to capture eye disease, vision impairment, vision-related disability, and access to care and services. Finally, strategies to establish an effective vision surveillance system are proposed.

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## METHODS

FOR THE PURPOSES OF THIS REVIEW, SURVEYS AND SURVEILLANCE systems were defined as data collection systems that used an active survey or data abstraction instrument, regardless of the sampling unit, and excluded strictly administrative data sources. In addition, surveys had to meet the following 4 minimum inclusion criteria to be included for further analysis: (1) nationally representative, population-based sampling design; (2) component related to vision health, eye disease, vision-related disability, or use of vision-related treatment or rehabilitation services; (3) ongoing and continuous (administered at least every 5 years); and (4) included adults 40 years of age and older because these are the individuals at greatest risk for vision impairment.

Existing United States surveys with a vision component were evaluated for general strengths and limitations related to overall design and data elements and access to vision health data, as well as 3 of the key attributes for any surveillance system<sup>14</sup>: (1) representativeness, (2) standardized data elements (flexibility), and (3) timeliness. Although other key attributes exist, our evaluation was focused in accordance with Centers for Disease Control and Prevention guidance on the evaluation of surveillance systems, such that emphasis was put on those attributes that are most important to the objective of assessing and monitoring disparities in vision health.<sup>14</sup>

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## RESULTS

EIGHT DATA SOURCES MET THE 4 MINIMUM INCLUSION criteria (see Table) and were evaluated against the key attributes of representativeness, standardized data elements, and timeliness. These 8 data sources were evaluated against the 3 attributes identified as key evaluation criteria as well as for their ability to contribute to a national vision surveillance system.

- **REPRESENTATIVENESS:** Most of the national health surveys follow similar multistage area probability designs allowing representative sampling of households. Such a design involves

the designation of primary sampling units that are geographically based on units such as a county, a small group of contiguous counties, or a metropolitan statistical area. A sample is drawn from the primary sampling units, and then a second-stage design is implemented that further delineates and samples smaller units within the primary sampling unit. These surveys have the capacity to oversample racial minority and older adult populations to improve data on important population subgroups. A limitation of these surveys is that they often exclude institutionalized populations, which, in the case of diseases of aging, may exclude more severely affected individuals, particularly those in nursing homes. The National Health and Nutrition Examination Survey uses a complex sample survey involving primary sampling units generally made up of United States counties and evaluates approximately 5000 persons annually. The National Health Interview Survey uses a first-stage sampling of 428 primary sampling units drawn from almost 1900 primary sampling units that cover the entire United States, followed by a second-stage sampling of 77 primary sampling units, resulting in an estimated 35 000 households containing 87 000 persons surveyed annually (for core questions). The Behavioral Risk Factor Surveillance System has a large representative sample and provides a good platform for the generation of state-specific estimates of population parameters, with more than 350 000 adults interviewed annually for the core survey component.

The Medicare Current Beneficiary Survey comprises a representative sample of persons receiving Medicare benefits. A new panel is selected each year using a stratified multistage probability sample design similar to that described for the National Health Interview Survey and National Health and Nutrition Examination Survey. Briefly, the primary sampling units include metropolitan statistical areas and groups of rural counties (nonmetropolitan statistical areas) selected according to metropolitan and socioeconomic characteristics. The second stage involves selection of zip codes contained within each primary sampling unit, and then beneficiaries within the sampled zip codes are stratified and subsampled by age for an equal probability of selection among 7 different age groups. Approximately 16 000 sample persons are interviewed in each round. However, because of the rotating panel design, only 12 000 sample persons receive all 3 interviews in a given calendar year.

The hospital and ambulatory surveys (the National Hospital Discharge Survey, National Ambulatory Medical Care Survey, and National Hospital Ambulatory Medical Care Survey) use similar multistage sampling schemes to include a nationally representative sample of visits to nonfederal hospitals and outpatient physician offices. For example, the National Hospital Ambulatory Medical Care Survey is based on a 4-stage probability sample design: the primary sampling units include a geographically defined area in which hospitals are selected (second stage), the third stage includes clinics within the selected outpatient departments, and patient visits make up the fourth and final stage. Because the patient

visit is used in hospital and outpatient survey data and is not the individual patient, repeated entries by a single patient cannot be accounted for, representing a major limitation of this sampling design. Use of the patient visit as the unit of analysis may lead to overrepresentation of certain diagnoses in the database, particularly for chronic conditions for which repeated visits during a small window of time are more common.

- **STANDARDIZED DATA ELEMENTS:** Collecting data in a standardized and uniform fashion can enhance comparisons across studies. To address disparities in vision health, data collected on race should be uniform across various data sources. Currently, there is no standardized method for assessing and categorizing race among surveillance data sources. For example, in the National Health Interview Survey and the National Health and Nutrition Examination Survey, respondents are asked to identify which Hispanic subgroups they belong to through a positive response to “Are any of the following groups your national origin or ancestry?” (National Health Interview Survey) and “Do you consider yourself to be Latino or Hispanic?” (National Health and Nutrition Examination Survey). If respondents say yes to these questions, a list of Hispanic ethnicities are provided from which the respondent chooses 1 or more. The 2 lists, however, are not synchronized. The National Health Interview Survey lists Puerto Rican, Mexican, Chicano, other Latin American, and other Spanish, whereas the National Health and Nutrition Examination Survey lists Puerto Rican, Cuban, Dominican, Mexican, Central or South American, other Latin American, or other Hispanic or Latino. The Behavioral Risk Factor Surveillance System, however, simply asks “Are you Hispanic or Latino?” without providing any choices indicative of ethnicity. Respondents are likely to answer differently to the race questions based on the answer choices provided (e.g., the same respondent may identify as Chicano in one survey and Mexican in another).

The National Health and Nutrition Examination Survey and the National Health Interview Survey are quite similar in the way they attempt to address the impact of vision impairment on daily activities and participation in social roles. However, to our knowledge, incorporation of information related to these factors is limited in other surveys. Information on comorbid conditions has been assessed in various ways. For example, the National Health Interview Survey asks respondents directly whether they have any one of a list of conditions; the Behavioral Risk Factor Surveillance System asks whether a doctor has ever told them that they have a specific condition; and the National Health and Nutrition Examination Survey asks about symptoms related to specific conditions (e.g., Have you ever had any pain or discomfort in your chest?). Finally, there is limited standardization for the way low-vision or blindness is measured.

Standardization is of central importance to data linkage efforts and for maximizing information across survey in-

struments. Several population-based health surveys with vision health data have been linked successfully with other databases, resulting in an increased knowledge of related risk factors and health outcomes. The National Health Interview Survey and the National Health and Nutrition Examination Survey also have been linked to the National Death Index. A study by Christ and associates provides an example of the usefulness of such data linkage in vision research, where authors examined the impact of self-reported vision impairment on health, disability, and mortality and demonstrated a direct association between vision impairment and mortality.<sup>8</sup>

- **TIMELINESS:** Data on vision health are collected intermittently in several national surveys including the National Health and Nutrition Examination Survey, the Behavioral Risk Factor Surveillance System, and the National Health Interview Survey. Hospital and ambulatory surveys are administered annually, such as the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey; however, none of these provides continuously collected data on vision. Administrative datasets, such as the Medical Expenditure Panel Survey and the Medicare Current Beneficiary Survey, have a rotating panel design and provide continuous access to health related data. However, these datasets were not designed with a public health agenda in mind, so they are limited. For example, these surveys provide a rich source of information on health care expenditure and use rates, but they provide limited information pertaining to vision impairment, functional loss, or perceived disability related to vision impairment.

Timely access to data not only includes timely collection of data, but timely dissemination to users. Although the continuous (meaning administered annually) iteration of the National Health and Nutrition Examination Survey was released in 1999 to improve coverage and timeliness, survey data by design currently are released on public use data files every 2 years. The National Health Interview Survey can have more than a 6-month lag between data collection and release. The Behavioral Risk Factor Surveillance System has the timeliest access, with data collected by December and available by April the following year. The health encounter data are available for users 2 years after data are collected and processed. For example, the National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical Care Survey data collected in 2007 were released in 2009, and 2008 data were available in 2010. Although vision and eye health are not likely to exhibit rapid change, the ability to inform policy and practice is restricted by a lack of timely access.

- **CAPACITY OF SURVEYS TO CONTRIBUTE TO VISION SURVEILLANCE SYSTEM:** Vision impairment represents a multifactorial, multidimensional, dynamic condition that

affects multiple aspects of a person's lived experience. Vision impairment can be measured in terms of the underlying eye disease, visual function (e.g., acuity), its effect on the individual (e.g., ability to perform daily activities like reading the newspaper), and the impact on societal roles (e.g., ability of a person with vision impairment to work). Also important to the assessment of vision impairment is identifying barriers to treatment and rehabilitation services. This section represents a summary evaluation of available surveillance tools and their current capacity to capture each of these aspects of vision impairment.

*Eye Disease.* Many major national health surveys do not measure the major eye diseases. Comprehensive eye examinations in such surveys are expensive, time consuming, and burdensome for the participants and those administering the survey. Therefore, some surveys have core questions that assess self-reported eye disorders of aging: cataracts, glaucoma, age-related macular degeneration, diabetic retinopathy, and refractive error. In addition, the questions are not standard components of the surveys in that they are not assessed each year. For example, in the National Health Interview Survey, the disease-specific questions are part of the supplement, which was administered only in 2002 and 2008. Vision questions in the Behavioral Risk Factor Surveillance System are asked only as part of the vision module, which has been administered in only 22 states from 2005 through 2009 and has not necessarily been repeated in most of those states. Eye examinations were administered in National Health and Nutrition Examination Survey from 1999 through 2008 for visual acuity, but not eye disease, and no ophthalmologic examinations were administered to detect eye diseases such as glaucoma and retinal conditions until 2005 through 2008. The health encounter databases (Medical Expenditure Panel Survey, Medicare Current Beneficiary Survey) are limited in the information on specific eye disease, although the Medical Expenditure Panel Survey does include a question related to diabetic retinopathy. The hospital and ambulatory datasets are limited to International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis and procedure codes related to eye diseases or disorders.

*Vision Impairment.* Most public health survey and health encounter datasets have core questions that assess self-reported vision impairment. However, the questions and responses differ by surveys; therefore, comparisons cannot be made across surveys. Furthermore, there is no single standard against which to compare one's own vision when answering the question about low vision, and current questions have not been validated. The hospital and ambulatory datasets are

limited to International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis and procedure codes related to eye diseases or disorders.

As with eye disease, the National Health and Nutrition Examination Survey is the only health survey that measures visual function via objective measurement and includes only visual acuity. Other aspects of vision such as visual field, contrast sensitivity, glare sensitivity, color vision, and stereoacuity are not measured routinely.

*Vision-Related Disability.* Both the National Health Interview Survey and National Health and Nutrition Examination Survey provide a meaningful set of questions that reflect limitation and participation restriction. Many of the questions on limitation achieve further granularity around the nature of vision impairment (i.e., difficulty with distance vision, difficulty with night vision). A concern related to many of these questions is the inherent contingency on individuals having ability or access to participate in the activities identified; for example, if a respondent does not own a car or is illiterate, many of these questions do not apply. Unfortunately, the National Health Interview Survey vision supplement questions were asked only in 2002 and 2008. The National Health and Nutrition Examination Survey is hampered in its usefulness by study design limitations, including small sample size, delayed public release of data, and exclusion of the vision component in the most recent survey.

There are 2 vision-related functioning questions asked in the Behavioral Risk Factor Surveillance System. The questions that are asked are subjective and are prone to confounding. For example, the answer to the question "How much difficulty, if any, do you have in recognizing a friend across the street?" can be reflective of the characteristics of streets in a particular area (width, traffic, etc.) or the distinguishing characteristics of individuals or populations. The Medical Expenditure Panel Survey and the Medicare Current Beneficiary Survey added questions on difficulty reading prescription labels, and the Medical Expenditure Panel Survey refined the recognition question to "people 2 to 3 feet away." The hospital and ambulatory datasets do not include data on vision-related functioning or disability.

*Participation Restriction.* Vision impairment not only impacts one's ability to perform daily activities, such as bathing, dressing, and eating, but it can also impair one's ability to take part in social roles. Participation restriction carries the greatest societal burden, and it is the outcome that should be the focus of public policy and interventions. The National Health Interview Survey and the National Health and Nutrition Examination Survey are the only surveys with questions directly assessing the impact of vision on one's ability to participate in social activities such as work, child care,

and community activities. The Medicare Current Beneficiary Survey (MCBS) assesses the impact of vision impairment on accessing health care.

*Access to Care and Services.* Access to health care, and specifically vision care, are important pieces of information to measure in vision and eye health surveillance. Although preventive care is important for vision health, access to treatment and rehabilitation services are of greatest importance to prevent vision impairment, increase use of residual visual function, decrease disability, and increase social participation. Most of the health surveys contain questions to assess whether the participant has visited an eye care professional or whether the respondent experiences barriers accessing vision care. The National Health Interview Survey is the only survey to ask about use of rehabilitation and adaptive services for those affected by vision impairment. The hospital and ambulatory data are useful tools for measuring use rates of treatment services, such as cataract removal. Finally, the Medicare Current Beneficiary Survey and the Medical Expenditure Panel Survey are valuable resources for measuring expenditures related to vision impairment, because these statistics will be very useful in evaluating the economic benefits of future interventions.

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## DISCUSSION

CURRENT SURVEYS FOR MONITORING VISION AND EYE health in the United States are limited and do not provide adequate information to guide interventions and policy decisions. That said, vision impairment is a complex and serious public health problem, and no single survey would be able to capture all elements needed to assess the burden of vision impairment, visual function and disability, and access to eye care. As a first step to strengthen vision surveillance, there are a variety of national surveys meeting key requirements of a chronic disease surveillance system—representative sample, standardized data elements, and timely access to data—that may be assembled to improve inquiry regarding access to vision health, eye disease, vision impairment, vision-related disability, and restricted participation. Some surveys may provide data on vision impairment and eye diseases; others may provide data on barriers and facilitators to eye care services, and others may provide data on rehabilitative

services. By assembling surveys and data sources into a vision surveillance system, we could better identify at-risk populations and disparities in care and outcomes leading to poor vision. Moreover, this surveillance system could isolate barriers to eye and vision care, availability and effects of vision rehabilitation, and trends regarding populations and changing care. Additional steps then could be taken to refine measurement strategies in face-to-face and telephone surveys.

Because no single surveillance instrument can be all things to all stakeholders, it is important that each instrument has standardized data elements enabling linkage with other datasets. Linking data from multiple data sources increases surveillance effectiveness. For example, linkage provides a mechanism for validating self-reported survey data. By linking health surveys with administrative claims data, it becomes possible to evaluate the accuracy of self-reported data on factors such as medical expenditures and health conditions that are subject to response error. Data quality also can be enhanced by imputing missing data from one data source to the other. Finally, researchers and policy makers can use information provided by 2 linked databases to investigate questions beyond the scope of either. Linkage in current surveys is hampered by a lack of standardization of data elements. For example, the fact that race is categorized differently across the surveys impedes the ability to compare trends in race disparities, particularly for smaller racial and ethnic groups such as Hispanics, Asian Americans, and American Indians. Efforts should be made to standardize common data elements and to evaluate the validity of responses to each question type to inform standardization of these questions. Finally, increased attention to standardizing the way low vision or blindness is measured should be the focus of vision health surveillance efforts. A consensus definition of vision impairment that encompasses more than acuity and includes all meaningful aspects of visual function that significantly impact daily life would strengthen vision surveillance substantially.

Finally, to establish a vision surveillance system that is sufficiently robust to portray this population, self-reported and clinical data need to be collected consistently and continuously. This information would help policy makers, planners, and practitioners serve the growing population of people at risk of vision impairment more effectively.

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## **Biosketch**

April Zambelli-Weiner received her PhD in Epidemiology/Human Genetics from Johns Hopkins University and went on to found Translational Technologies International after serving as senior epidemiologist and Chief Operating Officer for Epidemiology International Inc. Dr Zambelli-Weiner is a seasoned Epidemiologist with over 15 years of experience in clinical research, epidemiology, biostatistics, strategic health program planning, implementation, and evaluation, and health communications. She has extensive experience in chronic disease epidemiology and health outcomes across the lifespan.