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## Establishing a Vision and Eye Health Surveillance System for the Nation: A Status Update on the Vision and Eye Health Surveillance System

David B. Rein, PhD, MPA<sup>1</sup>, John S. Wittenborn, BS<sup>1</sup>, Emily A. Phillips, MPH<sup>1</sup>, Jinan B. Saaddine, MD, MPH<sup>2</sup> Vision and Eye Health Surveillance System Study Group

<sup>1</sup>NORC\* at the University of Chicago, Chicago, Illinois

<sup>2</sup>Centers for Disease Control and Prevention, Vision Health Initiative, Atlanta, Georgia

Vision loss and eye disorders cost the US health care system \$65.1 billion in 2013, the fifth leading cause of medical expenditures.<sup>1</sup> Americans fear losing vision as much as or more than memory, hearing, or speech, and consider blindness among the top 4 worst things that could happen to them.<sup>2</sup> It is estimated that as much as 98% of visual impairment and blindness, much of it consisting of uncorrected refractive error and untreated cataracts, in the United States can be prevented through timely diagnosis and early treatment.<sup>3</sup>

Currently, no national visual health surveillance system provides information on prevalence, health disparities, or changes over time. Visual health (inclusively defined as vision status, loss, disease, disorders, and injuries) prevalence estimates are usually drawn from meta-analyses of population-based study data, which are not contemporary and lack national representativeness. Estimates are also taken from self-reported responses to visual health questions contained in national surveys, which are generally broad, vary in measure definition, and may suffer from unreliability. In both cases, existing estimates are limited to a small number of common eye conditions, and the resulting visual health estimates may vary widely and inconsistently between various data sources. For example, reported estimates of the number of blind Americans vary from 1.3 to 7.0 million persons.<sup>4,5</sup>

In 2016, the National Academies of Science, Engineering, and Medicine issued a call to “develop a coordinated surveillance system for eye and vision health in the United States.”<sup>3</sup> Previously, several national institutions have recommended additional surveillance activities or concluded that additional evidence is needed to inform visual health decisions at the population level. A 2012 Centers for Disease Control and Prevention (CDC) panel of visual health experts recommended the establishment of a US visual health surveillance system. In 2016, the US Preventive Services Task Force concluded that visual health information was insufficient to support screening to detect impaired visual acuity in older adults.<sup>6</sup>

Correspondence: David B. Rein, PhD, MPA, NORC at the University of Chicago, Atlanta Office, 1447 Peachtree Street, NE Suite 700, Atlanta, GA 30309. rein-david@norc.org.

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## Establishing a Vision and Eye Health Surveillance System for the Nation

In 2015, the CDC awarded a cooperative agreement to the non-partisan and objective research organization (NORC) at the University of Chicago to begin to develop a Vision and Eye Health Surveillance System (VEHSS), a comprehensive data and dissemination system intended to collect and centralize prevalence and use estimates from traditional and novel visual health data sources, and conduct analyses to summarize these different data sources into a set of national prevalence and service use estimates. Under this agreement, NORC has partnered with members of leading visual and public health organizations, including the American Academy of Ophthalmology, KPMG, Prevent Blindness, Uniformed Services University of the Health Sciences, the University of Wisconsin-Madison School of Medicine and Public Health, VSP Vision Care, The University of Washington's Institute for Health Metrics and Evaluation, and others to lead this effort. The project's design and development are reviewed on an ongoing basis by an advisory committee composed of leading scientific experts in ophthalmology, optometry, surveillance, data science, epidemiology, and public health research to provide critical review and guidance.

The VEHSS has several related aims: (1) estimate the national and local-level prevalence of vision loss and eye disorders; (2) identify disparities in visual health and access to care; (3) provide periodic updates to monitor trends in prevalence, use, and practice patterns, and evaluate the impact of interventions; and (4) broadly disseminate information to the public, researchers, and decision makers at the federal, state, and local levels. To achieve these aims, the VEHSS staff are conducting a number of activities, including to identify, describe, and prioritize secondary data sources to be analyzed and included in VEHSS; develop initial case definitions that can be applied in a uniform fashion across data sets; estimate diagnosed or self-reported prevalence from each data source using consistent case definitions, age, and race categories; perform meta-regression analyses of all data sources to create national prevalence estimates; and effectively communicate both the process and the outcomes of VEHSS-related activities. Details of these activities are discussed next.

### Identifying and Selecting Data Sources

During the design phase, and under the guidance of the expert advisory committee, the VEHSS team identified, evaluated, and selected data sources from among 4 categories of data: previously published population-based studies, national surveys, administrative claims databases, and electronic health record (EHR) registry systems. As an initial step, the team conducted a systematic review of published prevalence estimates. This review identified potential data sources and information to develop case definitions, and collected prior prevalence estimates from population-based studies. The team also reviewed national surveys, identifying 16 surveys containing vision and eye health-related questions, and summarized and compiled information from these surveys about key methodological features and condition indicators. Administrative claims databases and EHR-based registries were evaluated on the basis of their level of representation of the national population, and the demographic, geographic, and patient characteristic variables available. On the basis of this review, VEHSS intends to include information from multiple national surveys, population-based studies, and administrative claims data from Medicare, Medicaid, Truven

Health Analytics MarketScan, and VSP Vision Care, as well as EHR data from the American Academy of Ophthalmology's Intelligent Research in Sight (IRIS) Registry.

## Creating Case Definitions

Concurrent to the identification and selection of data sources, the VEHS team began developing case definitions intended to organize previously recorded diagnoses, functional measures, or survey self-reports into conceptually similar categories. For survey data, the VEHS team organized vision and eye health-related questions from 16 surveys into a 2-level categorization system of 9 categories and 24 subcategories to facilitate comparison of conceptually similar measures across surveys, a commonly identified research need.<sup>3</sup>

For administrative and registry data, the VEHS team worked with clinical experts to identify and categorize approximately 5000 unique vision and eye health International Classification of Diseases 9th and 10th Revision diagnosis codes into a 2-level categorization system intended to define clinically meaningful condition groups while ensuring reliable measurement across datasets. The categorization structure is similar to a previously developed diagnosis classification system.<sup>7</sup> Currently, the team is working to test the reliability of 17 major categories and approximately 100 subcategory definitions to identify the treated prevalence of conditions in administrative claims and IRIS data. The VEHS team will also measure best-corrected visual acuity in IRIS data and investigate options for identifying uncorrected refractive error in available data. Future work will incorporate public comments and adjustments to the categorization systems with the goal of establishing some or all of them as the basis for clinically meaningful case definitions to be used to guide surveillance in the future.

## Analysis and Publication of Surveillance Estimates

The VEHS team is planning several steps of analysis and dissemination of VEHS data in the upcoming years. In the first set of analyses, the VEHS team plans to apply consistent case definitions, age categories, and race/ethnicity definitions to the extent possible in each data source selected for system inclusion. Standardizing the analysis of claims and EHR data is relatively straightforward; however, some surveys and population-based studies may not support every analytic categorization desired. Although vision and eye health indicators from many of these data sources have been ably analyzed before, comparisons and meta-analyses of these results have been limited by differences in categorical definitions of conditions, age groups, and race/ethnicity across studies. The VEHS system's single-source estimates will provide an opportunity to assess differences in prevalence or treated prevalence estimates when measured across widely divergent data sources using a consistent set of measurement definitions. In a second step of analysis, VEHS is working in partnership with members of the Global Burden of Disease Project to use innovative statistical methodologies to integrate prevalence estimates from across data sources into a single national estimate.

## Stakeholder Involvement, Scientific Oversight, and Public Dissemination

Open and inclusive communication with stakeholders and interested members of the public is vital to further refine and increase the acceptance and usability of the system by its intended users, including federal agencies, state and local health departments, health organizations, the medical and research communities, and the public at large. In addition to operating under the oversight of the expert advisory panel, representatives of the VEHSS team have presented system information at visual health medical conferences and national visual health organization information sessions and workshops to ensure transparency of development and to seek stakeholder input. Further dissemination of VEHSS methodology and results will be achieved through peer-reviewed publications, as well as self-published project white papers and technical reports. Finally, VEHSS is developing a CDC website to organize and disseminate project documentation material and results, and to allow for user feedback.

## Moving Forward

When completed, VEHSS will offer a concerted attempt to organize, summarize, and present many sources of visual health data into one integrated system. The new system will address some of the current difficulties in summarizing visual health measures across self-reported national surveys. It will provide consistently defined and categorized estimates of visual health diagnosed prevalence and service use from administrative claims and EHR records across a much larger number of condition categories, while creating consistent case definitions using these data. It will use advanced statistical methods to provide more comprehensive summary national estimates of the prevalence of several major categories of ophthalmic conditions and outcomes. The VEHSS represents a timely start on the goal of establishing a vision and eye health surveillance system, but like all surveillance systems, the information contained in VEHSS can only improve through additional data collection, comparison with alternative surveillance approaches, academic scrutiny, public use, and constructive feedback.

## Footnotes and Financial Disclosures

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## References

1. Wittenborn JS, Rein DB. Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States. Chicago: NORC at the University of Chicago; 2013.
2. Scott AW, Bressler NM, Ffolkes S, et al. Public attitudes about eye and vision health. *JAMA Ophthalmol.* 2016;134: 1111–1118. [PubMed: 27490785]
3. National Academies of Sciences Engineering, Medicine, Health, and Medicine, Board on Population Health, Public Health Practice, et al. Making eye health a population health imperative: vision for tomorrow. In: Welp A, Woodbury RB, McCoy MA, Teutsch SM, eds. Washington, DC: National Academies Press; 2016; Available at: Link for additional info: <https://www.nap.edu/read/23471/chapter/1>; Accessed November 20, 2017.

4. Vision Problems in the U.S. [Internet]. Prevent Blindness America. 2012 Available at: <http://www.visionproblemsus.org/> Accessed January 25, 2017.
5. 2011–2015 American Community Survey 5-Year Estimates Disability Characteristics [Internet]. U.S. Census Bureau 2017 Available at: <http://factfinder.census.gov> Accessed January 25, 2017.
6. US Preventive Services Task Force. Screening for impaired visual acuity in older adults: US preventive services task force recommendation statement. JAMA. 2016;315:908–914. [PubMed: 26934260]
7. Lee PP, Jackson CA, Relles DA. Estimating eye care workforce supply and requirements. Ophthalmology. 1995;102: 1964–1972. [PubMed: 9098304]