Published in final edited form as:

JAMA Ophthalmol. 2016 May 01; 134(5): 578–579. doi:10.1001/jamaophthalmol.2016.0334.

Public Health Surveillance—The Integral Role of Community-Based Studies

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In the United States, active surveillance exists for notifiable conditions, such as communicable diseases and foodborne out-breaks, with data routinely collected directly from the health care system and shared with local, state, and federal public health departments tasked with protecting the public from health emergencies. In contrast, there is no fixed infrastructure to continuously monitor chronic conditions.

Surveillance of vision impairment from eye disease occurs through investments in different forms of data collection, each of which has its own advantages and limitations. The National Health Interview Survey, the primary method of monitoring health in the United States, captures information from large numbers of participants through household interviews at relatively low cost for its subject-matter sponsors. Questions on vision and eye disease are periodically included; participants selected for inclusion provide self-reported responses. While National Health Interview Survey data provide useful information overall, the yield is questionable on some topics. For example, in the case of age-related macular degeneration (AMD), relying on self-report is suboptimal because older individuals without overt symptoms often do not seek a clinical diagnosis and some people with symptoms fail to access clinical care. Hence, the presence of AMD is underestimated in a survey of affected individuals who are unaware of their disease status.¹

The National Health and Nutrition Examination Survey (NHANES) is another federal survey used for surveillance purposes. The NHANES involves both home interviews and objective examinations performed in specially equipped mobile examination trailers. Examination components, selected for inclusion for 2 years at a time, are frequently abbreviated in scope owing to space and time limitations. Data from the NHANES are useful to generate prevalence estimates representative of the civilian, noninstitutionalized US population, but because of its design and sampling strategy, ethnic-specific estimates are frequently limited to highly prevalent disorders; imprecise for less common conditions, such as AMD; and unavailable for some ethnic groups.²

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Conflict of Interest Disclosures: The author has completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

Disclaimer: The opinions expressed in this commentary are those of the author and do not necessarily represent the official position of the National Institutes of Health.

The advantage of an in-depth ocular examination in a geographically circumscribed population-based sample is that, while more expensive to conduct, it permits a more complete assessment of the constellation of signs and symptoms associated with ocular disease among those enrolled, particularly when considered along with personal and health behaviors influenced by the dynamic social environment in which the study participants live, learn, work, play, and access medical care. A report from one such study, by Varma et al,³ appears in this issue of *JAMA Ophthalmology* and contributes an important new piece of information about the prevalence of AMD among US adults of Chinese ancestry. Participants in the study consisted of 5429 individuals (approximately 94% of an eligible sample of 5782) from the city of Monterey Park, California, who self-identified as Chinese American and agreed to enroll. After completing a home interview, 79% of the eligible sample reported for a comprehensive dilated ocular examination collecting data on visual acuity, lens opacities, AMD, diabetic retinopathy, open-angle glaucoma, and angle-closure glaucoma, as well as completed extensive questionnaires about vision-and health-related quality of life.⁴ After standardizing for age, an estimated 7.8% and 0.4% of Chinese Americans exhibited signs of early (drusen, but no geographic atrophy or choroidal neovascularization) and late (geographic atrophy or choroidal neovascularization) AMD, respectively, with the risk for AMD being higher for men than women and rising with increasing age.³ After extracting published results from other studies and recalculating age-adjusted prevalence against a standard population to allow for comparison across studies, the authors reported the prevalence of AMD in the Chinese American Eye Study (CHES) was lower than in all but one earlier study conducted in non-Chinese ethnic groups, but was higher than the AMD prevalence reported in studies of the mainland Chinese population.

Although not included as a comparison study in their article, the prevalence of AMD was also measured in Chinese, white, Hispanic, and black participants of the Multi-Ethnic Study of Atherosclerosis (MESA).⁵ Unlike the eye-centric CHES, MESA piggybacked a retinal and vision component on a multicenter community-based study designed originally for studying cardiovascular disease outcomes as another way to conduct surveillance by leveraging a relatively small investment of funds to build on an extensive existing study infrastructure, therein buying access to a wealth of other data on concomitant systemic conditions, genetic profiles, and behaviors that influence multiple health outcomes. Using the same standard—the 2010 US Census Asian population—the age-adjusted prevalences of early and late AMD among 699 Chinese participants in MESA were 2.6% and 1.5%, respectively. Notably, the prevalence of early AMD in CHES was 3-fold higher than among Chinese participants in MESA, whereas the converse was true for late AMD. The reason for the differences is unclear, although the number of Chinese participants in MESA was considerably smaller than in CHES. In both studies, Chinese men had higher AMD risk compared with Chinese women and China was reported as the country of origin for most of the participants. It may well be, as Varma and colleagues suggest,³ that factors associated with geography and acculturation play a role, consistent with differences in AMD prevalence observed between MESA sites in Los Angeles, California, and Chicago, Illinois.⁵

Fortunately for CHES participants, few with AMD had vision loss. Subsequent articles by these investigators could contribute information about the co-occurrence of multiple eye conditions, factors associated with increased risk for various AMD lesions, and the effect of

eye health on quality of life. Acquisition of follow-up data on this cohort will be a further asset, providing data on the incidence of early and late disease, as well as on visual loss resulting from AMD alone and in combination with other coexisting ocular conditions. Longitudinal data may also help to substantiate whether inferences gleaned from the study,³ NHANES,² and MESA⁶ are accurate, namely that while the actual number of AMD cases are increasing owing to more people living to old age, the absolute risk associated with AMD, particularly signs of advanced AMD, in later-born birth cohorts may be decreasing.

Surveillance data contributed by multiple sources thus provide a more complete picture of the nature and extent to which vision impairment from eye disease affects diverse population subgroups of various ages. Such knowledge can serve multiple purposes: tailoring of health literacy strategies to optimize knowledge of when and how to access eye care to maximize health for prospective patients; permitting health care organizations to better align eye care needs with sufficient clinical capacity while managing cost; fostering culturally relevant interactions among physicians and patients to improve the delivery and uptake of care; and providing data useful to public and private stakeholders using research and development tools for prevention, diagnosis, and therapy. Surveillance also facilitates creation of benchmarks against which to measure progress in improving eye health and ameliorating health disparities.⁷ Finally, surveillance data provide confirmation to public health officials that vision-threatening eye disorders appear among the array of health conditions important to Americans and provide evidence to decision makers who allocate resources, including the provision of funds to support future surveys, population-based studies, and basic biomedical research.

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