CENTERS FOR DISEASE CONTROL AND PREVENTION

Building a Basis for Action

ENHANCING PUBLIC HEALTH SURVEILLANCE OF VISUAL IMPAIRMENT AND EYE HEALTH IN THE UNITED STATES

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1 INTRODUCTION

Visual impairment, defined as correctable and uncorrectable blindness and low-vision, underlies some of the health outcomes most costly to human health, human capital (disability, quality of life), and to the US economy. According to the World Health Organization (WHO), approximately 314 million people worldwide are visually impaired, 45 million are blind, and nearly ***80% of the world's blindness can be prevented or treated*** (1). Disparities in vision health (eye disease, visual impairment, and related disability) exist among certain age, sex, socio-demographic, racial, and geographic subgroups. Therefore public health strategies to enhance awareness, promote education, and increase access to successful prevention, treatment, and rehabilitation services among populations at greatest risk for poor vision outcomes will be key to protecting vision health in this country and globally. Systematic and ongoing collection of relevant data to track disparities in vision health is paramount to developing and monitoring the impact of public health initiatives, programs, and policies aimed at reducing the burden of visual impairment and eliminating the existing disparities. The goal of this paper is to outline the general characteristics of public health and chronic disease surveillance, review the existing state of knowledge as it relates to disparities in vision health, and to evaluate our current capacity for collecting useable data to track disparities in vision health outcomes.

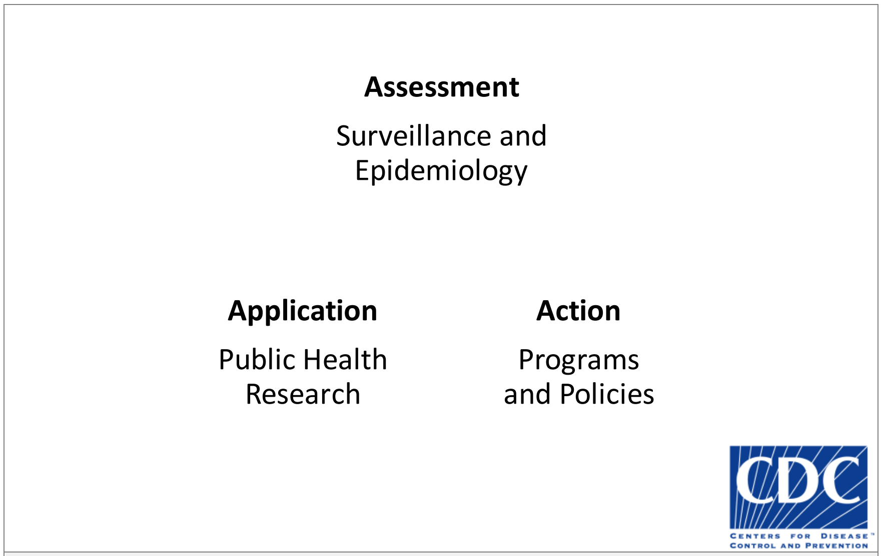
1.1 Definition of Public Health Surveillance

Public health surveillance is the **ongoing**, **systematic** collection, analysis, interpretation, and dissemination of outcome-specific data for use in public health action to reduce morbidity and mortality and to improve health (2). An inherent attribute of surveillance is the ability to monitor trends, with the goal of detection of unusual occurrence of disease. For infectious disease, the detection of "outbreaks" is an integral part of surveillance systems. Due to the rapid onset and resolution of the majority of infectious diseases, the timely collection, organization, analysis, and dissemination of these data are critical to prompt public health response. Chronic disease surveillance differs in that the outcomes are multi-factorial and of varying latency.

The term chronic disease surveillance applies to tracking and forecasting for all aspects of chronic disease: risk factors and social determinants of health, events, access to and utilization of health care, and other related outcomes (e.g. functional, disability-related). Chronic disease surveillance is derived from multiple data sources. For example, mortality data and disease registries have historically been useful for estimating the magnitude of specific disease burdens and to monitor local and national trends in disease incidence and prevalence. The Surveillance Epidemiology and End Results (SEER) sponsored by the National Cancer Institute is an example of a chronic disease surveillance system in the United States. The SEER program seeks to reduce the cancer burden in the US by collecting information on incidence, prevalence and survival from specific geographic areas representing 26 percent of the US population. Other national and state-based surveillance systems such as the National Health and Nutrition Survey (NHANES), the National Health Interview Survey (NHIS), and Behavioral Risk Factor Surveillance System (BRFSS) and have been developed and implemented to monitor risk factors and outcomes for chronic disease. The goal for these types of national and state surveillance systems is to collect data in a uniform way, with standard questions and evaluations designed to allow for comparisons across geographic regions and calendar time. In this way, NHANES, NHIS, and BRFSS can provide valuable information pertaining to trends in chronic diseases and risk factors across various subpopulations over time, which can help to shape public health policymaking, direct program planning, and inform allocation of resources.

1.2 Importance of Vision Surveillance

The CDC Vision for the 21st Century of "Health Protection…Health Equity" speaks to the importance of programmatic initiatives that drive at the prevention of disease and disability and elimination of health disparities (3). CDC's commitment to making data-driven decisions and providing both national and international leadership on issues paramount to protection of public health emphasizes the Agency's principal leadership role in public health surveillance.


Assessment

Surveillance and Epidemiology

Application

Public Health Research

Action

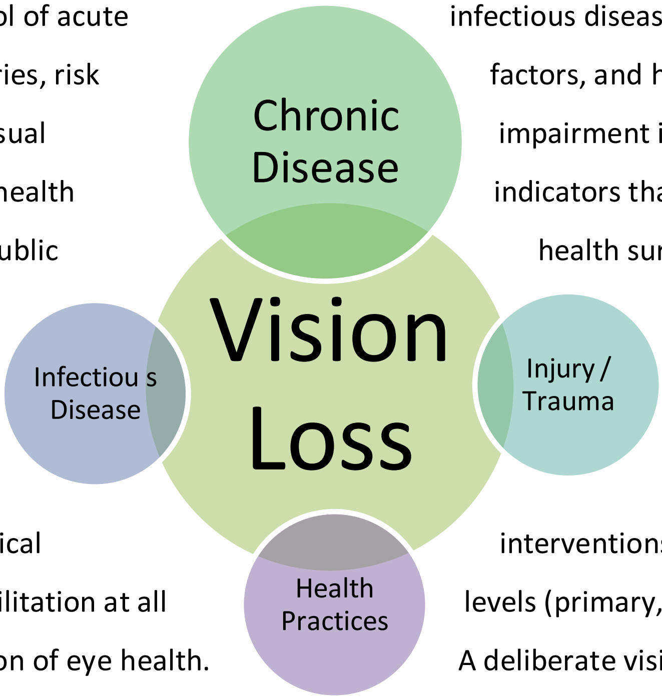
Programs and Policies

A New Integrative Public Health Approach

The Vision Health Initiative (VHI) is a dynamic team based in CDC's Center for Chronic Disease Prevention and Control that provides leadership and expertise in the promotion of vision health and prevention of eye diseases, eye injury, visual impairment and resulting disability.

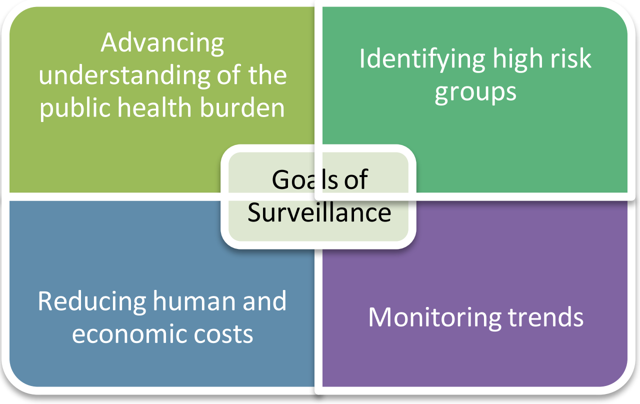
Control of visual impairment and resulting disability can be accomplished through a coordinated, population-based systems approach that seeks to place emphasis on the dynamic relationships between the different factors that shape the disability experience. By embracing a more expansive and inclusive perspective of surveillance, from that focused primarily on the prevention and control of acute infectious diseases to one that includes chronic diseases, injuries, risk factors, and health practices, it becomes clear that visual impairment is integrated with the major outcomes and health indicators that are key components of a comprehensive public health surveillance program.

The end goal of vision health surveillance (to include surveillance of eye disease, visual impairment, and related disability) is the development of practical interventions for prevention, treatment, and rehabilitation at all levels (primary, secondary, and tertiary) and promotion of eye health. A deliberate vision health surveillance



program - characterized by the systematic collection of quality and timely data, translation of that data into actionable knowledge, and dissemination of information – is essential to understanding the vision and eye health experience of populations and will serve as the foundation for effective vision health promotion and prevention activities at the state, national, and international level.

Goals of Vision Surveillance



An important function of any surveillance system is the ability to **estimate the burden of disease** and to **monitor trends** over time and across various populations. Gaps remain in our understanding of the true burden of eye disease and visual impairment (measured as disability), particularly among certain age, sex, socio-demographic, racial, and geographic subgroups. Access to quality and timely data from a vision health surveillance system would enable data-driven decision making around resource allocation at the national and local levels. For outcomes like vision, characterized by complex, multi-factorial etiology and underlying disparities in risk and associated health outcomes, widespread generalized interventions are often ineffective and impractical. Effective prevention and rehabilitation interventions that are targeted at those with the greatest risk of eye disease and visual impairment need to be community-driven and supported at the local level, for example through public-private partnerships. Therefore, a primary goal of vision health surveillance is to **<u>identify</u> and characterize the experience of those subgroups that are disproportionately affected**, particularly with regard to vision-related disability. Elucidating those factors which may contribute to the persistence of vision health disparities, such as barriers to eye and vision care, will also be informative for developing effective surveillance programs in vision health.

Widening the Lens: Advocating a Systems Approach to Visual impairment Surveillance

A systems approach to visual impairment surveillance encourages stakeholders to visualize the larger context and the dynamic interrelationships that affect those with visual impairment.

Leischow and Milstein wrote in their 2006 editorial "Systems Thinking and Modeling for Public Health Practice":

> *Conventional forms of problem framing, action planning, and evaluation often exclude or ignore precisely those features of dynamic complexity that make public health challenges so formidable and public health responses so innovative.*
>
> *Although there is no single operational method for identifying and interpreting these relationships, there is, in fact, a common conceptual orientation recognizable as a systems approach: it is a paradigm or perspective that considers connections among different components, plans for the implications of their interaction, and requires transdisciplinary thinking as well as active engagement of those who have a stake in the outcome to govern the course of change.*

Primary prevention is an important goal of public health. Population-based studies in the United States and globally have demonstrated that a significant proportion of older adults with visual impairment have treatable or preventable disorders. A visual impairment surveillance system will undoubtedly **serve as a valuable source of data for etiologic studies**. Beyond primary prevention of health conditions, secondary and tertiary prevention efforts are of significant importance for visual impairment public health initiatives. In addition, disparities exist and persist both in the prevalence of specific health conditions and at the level of communal or cultural practices and traditions (literacy, religious practices), and individual attitudes and behaviors. **Developing and integrating data that can identify these factors and their impact on eye disease and resulting disability**, as well as **evaluating and improving public health programs and policies** are critical to reducing vision health disparities in the United States.

Healthy People Objectives (HP2010 and HP2020)

The Healthy People Objectives serve as a primary tool used by local and state public health departments to guide program and policy development in their jurisdictions. Objectives related to vision were included for the first time in the Healthy People 2010, with an overall goal to improve the visual health of the nation through prevention, early detection, treatment, and rehabilitation. There were 10 vision-related objectives, 4 of which pertained to reducing impairment due to refractive error, diabetic retinopathy, glaucoma, and cataract. All 10 objectives have been retained from Healthy People 2010 and 2 new objectives added. Three of these objectives pertained explicitly to children (including protective eyewear use among children), four were occupational/injury related, one objective (reducing uncorrected visual impairment due to refractive error) was combined with "Reducing Visual Impairment", leaving the four following objectives pertinent to adult visual impairment in the US:

1. Increase the proportion of adults who have a comprehensive eye examination, including dilation, within the last 2 years and/or by age 45 (V HP2020–4)
2. Reduce visual impairment (V HP2020–6): 5 sub-objectives (refractive errors, DR, glaucoma, cataract, AMD)
3. Increase vision rehabilitation (V HP2020–8): 2 sub-objectives
4. Increase the proportion of Federally Qualified Health Centers (FQHCs) that provide comprehensive vision health services.

One important goal of a national vision health surveillance system is to evaluate and advance achievement of Healthy People Objectives. Data sources such as the NHIS can help elucidate recent trends in eye care utilization (including receipt of a comprehensive eye exam w/dilation), visual impairment due to AMD, glaucoma, DR, and cataract, and use of vision rehabilitation services and adaptive devices among those with visual impairment. Timely analysis and interpretation of these self-reported data can provide a useful tool for tracking progress towards achieving <u>3 of the 4</u> Healthy People Objectives (listed above). NHANES data can address the prevalence of *uncorrected* refractive error among US adults. Analysis and interpretation of these data will directly measure progress towards achieving the Healthy People 2020 Objectives, and should be a priority for researchers in the field of visual impairment.

1.3 Disparities in Vision Health

It is important to recognize that vision health disparities exist at all levels: disease, impairment, and disability

One of the goals of Healthy People 2010 is to eliminate health disparities that occur by race and ethnicity, gender, socioeconomics (education and income), geographic location, disability status, or sexual orientation. For the purposes of vision health surveillance, it is important to recognize that disparities exist at all levels, including but not limited to eye disease prevalence. Data are needed to characterize disparities in eye disease, visual impairment (function), and disability due to visual impairment. Our capacity to document disparities at all three levels will enable the conception of public health interventions that are reflective of and responsive to the complexity of the disease experience.

Equally important to creating focused public health interventions in vision health will be to identify the underpinning causes for disparities, which will inform strategies to overcome barriers and prevent risk factors that may play a role in poorer outcomes in certain groups. For example, vision surveillance should aim to isolate barriers and facilitators to accessing vision and eye health services, particularly in populations at greatest risk for poor vision outcomes. Finally, the capacity to monitor trends among certain high risk populations will allow stake holders to track progress towards reducing disparities in vision health outcomes. The following section represents an overview of the existing state of knowledge as it pertains to disparities in vision health at the levels of disease, function, and disability.

1.3.1 Age-Related Macular Degeneration (AMD)

Older age is the most important risk factor for AMD, and represents the greatest disparity for this condition (5). By definition, a diagnosis of AMD is restricted to people older than 50 years of age, and risk for developing AMD rises sharply with older age (6). In a review and meta-analysis by Evans and colleagues (7) authors suggest a possible gender disparity in risk of AMD, with women experiencing a slightly greater risk than men (Summary RR=1.13, 95% CI: 1.01-1.26). However, as authors of this study mention, the apparent increase may simply be due to the tendency of women to live longer than men. Although the evidence is limited, there does not appear to be a clear association between socioeconomics and AMD (7).

There is a substantial amount of evidence supporting a race disparity in AMD. AMD is more prevalent among Whites than any other racial or ethnic group, and is the leading cause of blindness among Whites (8). According to the Eye Disease Prevalence Research Group (EDPRG), Whites experience higher prevalence of AMD compared to Blacks, particularly among the very elderly group (≥ 75 years) (8). Furthermore, one study showed that AMD accounted for 54% of all cases of blindness among Whites, compared to only 4% and 14% of blindness among Blacks and Hispanics(9). Data from the National Health and Nutrition Examination Survey III (NHANES) provides evidence for a higher prevalence of age-related maculopathy in Whites (0.5%) compared to both Blacks (0.13%) and Mexican-Americans (0.06%), among persons older than 40 years (10). Self-reported data from the NHIS also supports the higher prevalence of AMD in Whites (1.3%) compared to Blacks (0.5%) or Hispanics (0.6%), based on a positive response to the question: “Have you ever been told by a doctor or other health care professional that you had macular degeneration?”(11)

1.3.2 Diabetic Retinopathy

According to the EDPRG, there does not appear to be a consistent disparity in DR by age or gender among persons with diabetes (12). There does however, appear to be some evidence for disparities in DR according to geographic location. Using data from the 2006 BRFSS, Hale and colleagues (13) identified a significant disparity in self-reported DR among persons with diabetes by rural vs. urban geographic residence. According to these recent data, persons living in rural areas of the United States experienced a higher prevalence of DR compared to persons living in urban areas (25.8% vs. 22.0%, p=.007). Authors of this study also found that lower income, but not education was associated with an increased likelihood of having DR.

Data on race disparities in DR and associated visual impairment are highly consistent across studies, specifically those demonstrating a disproportionately greater risk among Hispanics and Blacks compared to Whites. For example, according to results of a recent national survey of persons older than 20 years, 20.1% of Hispanics and 16.1% of Blacks compared with only 11.0% of Whites had either diagnosed or undiagnosed diabetes, even after adjusting for population age differences (14). Data from the NHIS also support these findings, with 1.2% of Blacks, 1.3% of Hispanics, vs. only 0.6% of Whites responding positively to the question “Have you ever been told by a doctor or other health care professional that you had diabetic retinopathy?”(11)

Studies further demonstrate that Blacks with diabetes are more likely than Whites with diabetes to develop DR. This evidence suggests that the higher prevalence of DR among racial minority groups is not entirely driven by a higher prevalence of diabetes alone. For example, results from the 1988-1994 Third NHANES data revealed that among adults (≥ 40 years) with diabetes, the prevalence of DR was 46% and 84% higher in Blacks and Hispanics compared to Whites (15). Self-reported data from the NHIS also found a greater odds of DR among Blacks (OR=1.08, 95% CI: 0.70-1.67) and Hispanics (OR=1.3, 95% CI:0.76-2.21) compared with Whites with diabetes. Furthermore, Emanuele and colleagues (16) found that higher prevalence rates of moderate to severe DR among Blacks and Hispanics with diabetes compared to their White counterparts could not be accounted for by known risk factors such as age, duration of diagnosed diabetes, or A1C levels (a measure of glucose control).

Parallel findings from the Multi-Ethnic Study of Atherosclerosis (MESA) demonstrated that among persons with diabetes aged 45 to 85, prevalence of DR was higher among Blacks (37%) and Hispanics (37%) compared to Whites (25%) and Chinese (26%) (p=0.01) (17). Data from the Atherosclerosis Risk in Communities (ARIC) study also demonstrated that among people with diabetes between the ages of 51 and 72, there was a higher prevalence of DR among Blacks (28%) compared to Whites (17%) (18). No data on Hispanics was available in this study. Two of the largest and most recent population studies of Mexican-Americans found similarly high prevalence rates in this ethnic group. In the Los Angeles Latino Eye Study (LALES), nearly one half (47%) of all participants (primarily of Mexican ancestry) with diabetes had DR (19). The Proyecto Vision Evaluation and Research (VER) study of Mexican-American adults with diabetes showed similar prevalence rates of DR (48%) (20)(West, 2001).

Prevalence rates of DR are similar among Native Americans and Hispanics with diabetes (approximately 40%), although available data on this subgroup are limited (21). According to the few studies that have included Asian-Americans, similar prevalence of DR exist among Asians and Whites with diabetes (17) (22).

In addition to having a higher prevalence of diabetes ***and*** a higher prevalence of DR among those with diabetes, Blacks may also be more likely than Whites to develop visual impairment due to DR. In the Salisbury Eye Evaluation (SEE) study, which evaluated visual impairment associated with DR, Blacks experienced a 6-fold higher prevalence of DR-related visual impairment compared to Whites (1.2 % and 0.2%, respectively)(23).

1.3.3 Glaucoma

People of older age are at greatest risk for developing glaucoma (24). Gender disparities have also been reported, although findings have been inconsistent. For example, according to results of a Bayesian meta-analysis performed by Rudnicka and colleagues (25), men experienced a greater prevalence of primary open-angle glaucoma (POAG) than women, even after adjusting for age, race, and year of publication (Summary RR=1.37, 95% CI: 1.22-1.53). The EDPRG group, on the other hand, did not find any significant gender differences in prevalence of POAG (26). The evidence for gender disparities in primary angle closure glaucoma (PACG) is more consistent, with several studies demonstrating a higher risk among women (as reviewed by Vajaranant) (27). There is limited data assessing socioeconomic disparities in presence of glaucoma in the US, and most studies in this area have focused on attitudes and knowledge of glaucoma rather than disease prevalence (28).

Published studies on the prevalence of glaucoma in the US are limited in general, particularly those directly comparing rates across racial and ethnic minority groups. The EDPRG estimated similar prevalence rates of glaucoma among Hispanics and Whites, with Blacks experiencing nearly a 3-fold prevalence compared to both groups. Interpretation of these data must be made with caution, however, as the source of data on Blacks (Baltimore Eye Study) and Hispanics (Proyecto VER study) were not derived from nationally representative samples and may not necessarily represent the national prevalence among these racial groups (26). For example, Blacks in the Baltimore Eye Study may have different levels of access to care, education, and income compared to Blacks living in other, perhaps more rural areas of the US. Similarly, prevalence data from the Proyecto VER study were collected primarily on Mexican-

Americans living in Arizona, which may not be generalizable to other Hispanic groups such as Cubans, Puerto Ricans or other South-Americans due to potentially varying cultural, geographic, and lifestyle factors among each ethnic subgroup. Highlighting this issue, results of the Los Angeles Latino Eye Study (LALES) illustrates a slightly different picture, as these data suggest that prevalence of POAG among Hispanics (4.74%) are more similar to the prevalence among Blacks (4.97%) than Whites (1.69%)(29). Authors of the LALES study offer possible explanations for the higher prevalence among Hispanics in the LALES study compared to the Proyecto VER study, stating factors such as differences in the genetic admixture of the two populations as a potential reason for the observed differences.

Self-reported data from the NHIS were comparable to findings reported by the EDPRG; the prevalence of self-reported glaucoma among Blacks was twice that of Whites, who experienced similar prevalence of glaucoma as Hispanics (11). It should be noted that self-reported data may not be a highly accurate measurement of actual disease burden, particularly among groups in which poorer access to health care has been well documented. For instance, Varma and colleagues found that only 25% of the LALES participants with POAG had been previously diagnosed and were aware of their condition (29).

1.3.4 Cataract

The presence of cataract increases with age, representing the primary risk factor for this disease (30;31). West and colleagues (32) conducted a review of studies on risk factors for cataract, including gender and education. Study authors reported some evidence, mostly from case-control studies, for an association between lower educational level and higher rates of cataract. Authors also found consistent evidence for a slightly greater risk among women, a finding that has been supported by more recently pooled data derived from 7 population studies (31). According to these data, women experience significantly higher odds of cataract than men, even after adjusting for age (OR=1.37, 95% CI: 1.26-1.50).

Data from the EDPRG pooled analysis demonstrated that the prevalence of cataracts was higher among Whites than Blacks, except in females younger than 70, among whom the prevalence was greater among younger Black females compared to younger White females (31). There are significant limitations with interpreting these results, given that it was based on two studies, the Salisbury Eye Evaluation (SEE) Project (which included only adults over 65 years) and the Barbados Eye Study. Relying on studies of Blacks living outside of the US to estimate prevalence among Blacks in the US may lead to an inaccurate portrayal of the true prevalence, as cultural, environmental, genetic, and access to health care factors are likely to vary between the two populations.

According to Sommer and colleagues (33), Black participants in the Baltimore Eye Study were 5 times as likely as Whites to have un-operated cataract. One limitation of these findings is the potential lack of generalizability, due in part to the fact these data were collected nearly 20 years ago and access to health care among Blacks may have improved in more recent years. Results of the EDPRG pooled analysis revealed that Hispanics, on the other hand, experienced a higher prevalence of cataracts compared to both Blacks and Whites, a finding that authors noted had not been previously documented (31). Again, these data must be interpreted with caution as the data on Hispanics were based solely on the Proyecto VER study, which included only Mexican-Americans living in Arizona (34). Prevalence rates in this group may not be representative of other Hispanic subgroups or Mexican-Americans living in other regions of the US. According to the self-reported NHIS data, lifetime prevalence of cataracts was highest among Whites (9.3%) compared with Blacks (7.5%) or Hispanics (6.0%)(11).

To our knowledge, there are no recently published studies on US national prevalence estimates of cataracts in other racial and ethnic subgroups.

1.3.5 Refractive Error

Studies on age disparities in refractive error have been moderately consistent, with more recent data demonstrating an overall increasing prevalence of hyperopia and decreasing prevalence of myopia associated with older age (4;35;36). For example, according to a recent analysis of NHANES 1999-2004 clinical data on refractive error, hyperopia (defined as SphEq value of ≥3 D) was greatest in older adults over 60 years of age (10.0%) compared to younger adults ages 20-39 (2.4%) and ages 40-59 (1.0%)(4). Conversely, myopia (defined as SphEq value of ≤-1.0 D) was greatest in younger adults ages 20-39 (36.2%) and ages 40-59 (37.6%) compared to older adults over 60 years of age (20.5%). This general trend in prevalence of hyperopia and myopia by age group appears to be supported in other studies (35;36); although it is unclear to what degree the age pattern holds in racial and ethnic minority groups.

Recent studies provide consistent evidence for gender disparities in hyperopia, but a similar prevalence of myopia in men and women. Using pooled data derived from 6 population-based studies, the EDPRG found a higher prevalence of hyperopia among women compared to men among adults 40 years and older, even after adjusting for age and race/ethnicity (OR: 1.28, p<0.001). Results from the 1999-2004 NHANES were similar, with a greater proportion of women (6.5%) than men (3.8%) 40 years and older experiencing hyperopia. The EDPRG found no gender disparities in prevalence of myopia among persons 40 years and older, even after adjusting for age and race/ethnicity (36). 1999-2004 NHANES data showed similar trends, with no significant gender disparities in myopia occurring among adults 40 years and older. Authors of the NHANES study did report that younger women (ages 20-39) experienced higher rates of myopia compared to their younger male counterparts (39.9% vs. 32.6%, p<0.001).

US national data on disparities in refractive error according to socioeconomic status are limited, and most of what we know is derived from local and international studies of small sample size that are not representative of the general US population. Based on these data, it appears that hyperopia prevalence declines with increasing education, while myopia increases with increasing years of education (35)---also cite ref id 3236, Morgan, 2004; Wensor, 1999).

Pooled data from the EDPRG showed that, after adjusting for age and gender, Whites have a significantly higher prevalence of both hyperopia (OR=1.22, p<0.001) and myopia (OR=1.25, p<0.001) compared with Hispanics. Hispanics, in turn, had higher prevalence rates of both hyperopia (OR=1.69, p<0.001) and myopia (OR=1.52, p=0.001) compared with Blacks. (36) As mentioned previously, these results should be interpreted cautiously when making assumptions about the national population, since data for Blacks and Hispanics relied on one single study each (the Baltimore Eye Study and the Proyecto VER study). However, self-reported data from the 1999-2004 NHANES demonstrate highly comparable trends; the prevalence of hyperopia and myopia were highest in Whites, then Hispanics, and lowest among Blacks (4).

To our knowledge, there are no published studies on US national prevalence estimates of refractive error in other racial and ethnic subgroups.

1.3.6 Visual impairment

It is well known that sensory impairment, including visual impairment, increases with older age. According to a recent data brief from the National Center for Health Statistics (NCHS), 1 in 6 Americans over 70 years old has some visual impairment (defined as not being able to read letters or number of the line 20/50 or below on the visual acuity chart in the better-seeing eye), and prevalence generally doubles with age (37). Visual impairment, according to the report, was also more common among Americans with lower income, with older Americans living below the poverty level experiencing prevalence rates 50% higher than all other older adults. Authors of this study found no gender differences in prevalence of visual impairment among older Americans (aged 70 and older). Data from the BRFSS 2005 vision module (administered in five states) suggests that women are more likely than men to report having visual impairment (21.5% vs. 16.0%), determined by responding: "a little difficulty," "moderate difficulty," "extreme difficulty," or "unable to do because of eyesight" to the question, "How much difficulty, if any, do you have in recognizing a friend across the street?" or to the question, "How much difficulty, if any, do you have watching television?"(38)

Racial and ethnic disparities in visual impairment have also been documented throughout the literature. The aforementioned NHCS report found that Blacks (21.1%) and Mexican-Americans (24.0%) experienced a greater prevalence of visual impairment compared to Whites (13.8%)(37). According to EDPRG, the prevalence of age-specific blindness (based on US definition of < 20/200 or the WHO standard of < 20/400 for visual acuity in the better-seeing eye) is highest among Blacks compared with Whites (OR=2.77; 95% CI, 1.56-4.92) or Hispanics (OR=3.13; 95% CI, 2.29-4.29), while the prevalence of low vision (< 20/40 best-corrected vision in the better-seeing eye) is highest among Hispanics (9). There are also significant racial and ethnic disparities in the prevalence of self-reported visual impairment based on responses to the questions "Do you have any trouble seeing, even when wearing glasses or contact lenses?" and "Are you blind or unable to see at all?" According to these data, Ryskulova and colleagues (11) found that among adults (aged 18 and older), Blacks were more likely than Whites to experience age-adjusted visual impairment or blindness, but that Hispanics and Whites experienced similar prevalence rates.

Lam and colleagues (39) reported on visual impairment among racial and ethnic subgroups (also based on NHIS data), allowing for a more in-depth view of the Hispanic group in particular. Impairment was defined based on positive response to two questions, "Do you have any trouble seeing, even when wearing glasses or contact lenses?" (some visual impairment), and "Are you blind or unable to see at all?" (severe visual impairment). Authors of this study found that among middle-aged adults (45-64 years), individuals who defined themselves as Native American, Puerto Rican, Dominican, and of mixed race experienced significantly higher prevalence of self-reported visual impairment, when compared with Whites. Among older adults (≥ 65 years), prevalence of any visual impairment was greatest among Native Americans, Chinese Americans, Puerto Ricans, Dominicans, and Central/South Americans, compared with all other racial and ethnic groups. Comparing the results of the Lam and Ryskulova studies highlights the fact that “Hispanic” (referring to a group of people of Spanish-speaking ancestry that actually represents several, heterogeneous ethnic groups) is too broad a category for identifying disparities in visual impairment, and using this classification scheme can often obscure the true picture.

More recently, researchers have employed definitions of visual impairment that are associated with substantial impairment of day-to-day routines and leisure time, representing a more meaningful portrayal of the total disability related to visual impairment than compromised acuity alone. For example, some scholars have recognized that visual acuity represents only a single aspect of visual functioning, (40) but that there are other aspects of vision (e.g. contrast and glare sensitivity, visual fields) that are associated with disability and should be incorporated into surveillance systems of vision health (41). Monitoring disparities at the level of disability will be essential for measuring the impact of disease and visual impairment on certain high risk groups, and represents the most important outcome for vision health surveillance.

1.3.7 Vision Related Disability and Quality of Life

Visual impairment results in disability and decreased quality of life, particularly among the elderly population. A large body of research has demonstrated an association between visual impairment among older adults and an increased dependence on others to perform daily activities, decreased participation in social activities, higher rates of depression, increased likelihood of falls and injury, and other undesirable health outcomes (42-55) (56). However, studies elucidating disparities (e.g. by race, gender, SES) in disability resulting from visual impairment are limited. Vision health surveillance should develop and strengthen the capacity to monitor disparities at the level of disability, which will help to inform public health interventions aimed at reducing disparities in vision health.

1.3.7.1 Activities of Daily Living

Recent studies have shown a clear association between visual impairment and decreased ability to perform daily activities. For example, Crews and colleagues(55) found that, compared to older adults without sensory problems, those with self-reported impaired vision were 3-4 times as likely to report difficulty walking, getting outside, getting into and out of a bed or chair, managing medication, and preparing meals(55). Similarly, using data from the Salisbury Eye Evaluation (SEE) study, authors found that visual acuity, contrast and glare sensitivity, stereoacuity, and visual fields were independent predictors of self-reported disability (measured with the Activities of Daily Vision scale)(53). According to these data, visual acuity and contrast sensitivity were associated with decreased mobility (e.g. walking up stairs, getting up from a chair) and performance of everyday tasks (e.g. inserting a key into a lock or a plug into a socket, dialing a phone)(54).

1.3.7.2 Social and Emotional Consequences

It is also common for people with impaired vision to refrain from social interaction, perhaps due to impaired mobility, or even embarrassment and/or fear. For example, Crews and colleagues reported that older people with self-reported visual impairment were less likely to report visiting friends in the past two weeks than older persons without sensory loss (55). In an extensive review by Burmedi et al (48), authors identified several studies that showed associations between visual impairment and decreased social activity, loss of social roles, and lower social engagement. Withdrawal from social participation can place heightened stress on families, spousal relationships, and other interpersonal ties, and can result in isolation and loss of support systems. Such disengagement can also have dire emotional consequences for those who are affected. For example, in a population-based study conducted in Europe, authors found that persons with self-reported low vision were more likely to lose interest and enjoyment in their activities, and were also more likely to feel fatigued, irritable, sad, and tearful (47).

A higher prevalence of depressive symptoms compared to the general population have been reported in elderly persons with visual impairment in numerous other studies (as reviewed by Burmedi et al (48). Similarly, general well-being (which incorporated measures of mood, psychological distress, morale, and life satisfaction) was also found to be significantly poorer among the visually impaired in most of the studies reviewed by Burmedi and colleagues. According to recently published data from 1997-2004 NHIS, adults with self-reported visual impairment and severe depressive symptoms were more likely to smoke, more likely to be obese, less likely to be physically active, more likely to have fair to poor health, and had more difficulties with managing self-care than adults with neither depressive symptoms nor visual impairment (42).

1.3.7.3 Health and Mortality Outcomes

Greater efforts to standardize measures of disability are imperative to enhanced vision surveillance.

Visual impairment has also been linked to poorer health outcomes and mortality in several epidemiologic studies. For example, studies have found that self-reported and measured visual impairment is associated with unemployment resulting from permanent sickness and poorer general health (44), an elevated risk of adverse health outcomes (46), and increased mortality and overall functional decline (45). Injury due to falls has also been linked to visual impairment. In a study by de Boer and colleagues, authors demonstrated that self-reported visual impairment was an independent risk factor for recurrent falling and fractures (43). In another study by Freeman and colleagues, authors demonstrate that vision field loss was the primary vision component associated with an increased risk for falls (visual acuity, contrast sensitivity, and stereoacuity were not associated with falls) and state that these individuals are most likely to benefit from mobility training to prevent injury (57).

In summary, there is a large body of literature demonstrating the functional, emotional, social, and physical disability related to visual impairment. Results of these studies illustrate unequivocally the significance of vision-related disability, and public health surveillance programs should absolutely consider these outcomes as a way to measure the magnitude of the burden and to monitor progress towards vision health objectives. There is little national US data describing disparities in vision-related disability, and further work in this area is necessary to illuminating the burden of eye disease and visual impairment in certain high risk groups.

Greater efforts to standardize measures of disability are also imperative to vision surveillance. Several classification systems have been developed including the Lawton Instrumental Activities of Daily Living Scale (IADL)(58) and Activities of Daily Living (ADL)(59) and more recently the International Classification of Functioning Disability and Health (ICF), a conceptual framework for measuring health and disability. These measurement and classification tools provide a mechanism for collecting information on the impact of disease and functional loss, and can be used to address changes in vision-related disability over time. Several recent studies have demonstrated that visual impairment is associated with lower scores on both IADLS and ADLS (49-52) and incorporation of these or other similar standardized measurement tools into vision surveillance systems may improve public health initiatives to track trends and monitor disparities in vision-related disability.

1.3.8 Access to Health Care and Utilization of Vision and Eye Health Services

As the population of visually impaired persons continues to grow, greater access to health care and increased utilization of vision health services are of the utmost importance for public health initiatives around vision health. Identifying barriers to health care access and receipt of vision-related health services are critical for informing public health interventions aimed to increase prevention, detection, treatment, and rehabilitation for those at risk for or affected by visual impairment. Research and surveillance efforts should aim to isolate characteristics of the health care delivery system (e.g. insurance coverage, availability of medical facilities) and populations at risk for or affected by visual impairment (e.g. income, transportation, trust in health care professionals) that can either facilitate or act as barriers to access to care. Improved knowledge of these factors, particularly those that are amenable to change through public policy or public health programs, could potentially lead to increased utilization of preventive and therapeutic treatments and significantly reduce the total burden as well as narrow disparities in eye disease, visual impairment, and related disability.

1.3.8.1 Defining Access to Health Care

The definition of “access to care” (or lack thereof) has posed significant challenges to researchers and policy makers alike in monitoring and comparing results across studies regarding the association of “X” and access to health care. Various indicators have been used to measure the presence or absence of “access”, such as insurance coverage, the presence of a usual source of care, or receipt of preventive services. Some have defined access to care as the number of medical facilities in a given geographic region, or the amount of time a patient has to wait before being seen by a physician. Others believe that availability of primary care physicians defines access, as these physicians are seen as the “gatekeepers” of all medical health services. Aday and Andersen, in their published paper “A Framework for the Study of Access to Medical Care”, lay out a very clear and concise way to study access, which will serve as the backdrop for the following discussion on access to vision care. These authors make clear the distinction between properties of the health care system and populations at risk (factors which affect whether or not a person enters into the health care system), and the outcome or “output”- the actual passage through the system, both of which can have a significant impact on the other. (60)

Characteristics of the health care delivery system include factors such as the gender or race of the physician, required co-pays, appointment waiting time, the number of available physicians in a given geographic area, availability of care at night and on weekends, amount of time spent during a visit, coverage for medications, travel time to the health care facility, among others. All of these factors have the potential to either facilitate or hinder an individual’s ability to obtain health care. There are aspects of the individual to consider as well, which include household income, level of education, transportation, other mobility issues, willingness and motivation to seek care, knowledge and attitude towards health care and disease, social support, health care literacy- all of which are equally as likely to affect whether or not someone receives needed health care. Aday and Andersen state that "implicit in the characterizations of access as properties of the individual and the system, then, is the assumption that the quantity and quality of an individual's passage through the medical care system are affected by these factors" (60).

But even after measuring the barriers and facilitators to access to care, we still need an "external validation" system to determine whether those who need care are actually getting it. This is the proof of access, and a way to evaluate whether public health interventions aimed to increase access are actually working. In order for health care policies and programs to be effective, we must first explicitly define the relevant health care needs, and then provide a reliable and valid method for determining whether those needs are being met (e.g. are the people who need treatment receiving it? Are patients satisfied with their care? Which treatments have proved to be successful? Has receipt of care decreased disability or improved their quality of life?) Monitoring trends in health care utilization rates that are appropriate to the existing need for care, as well as perceived benefits and success of the care received may provide very effective tools for measuring progress towards improving access to vision and eye health care.

1.3.8.2 Barriers to Accessing Vision and Eye Care

Knowing the barriers to accessing vision and eye care among people at greatest risk for visual impairment could greatly inform public health interventions aimed at decreasing the number of people with visual impairment and resulting disability.

Preventive Services

Receipts of regular eye exams are important to prevent and detect eye disease in its earliest stages when treatments are most effective. However, fewer than half (42%) of people at greatest risk for visual impairment (people with diabetes, people over 65 years, people with eye problems) had a dilated eye exam within the past 12 months, according to one study (61). Other studies have demonstrated specific individual characteristics that can act as barriers to receipt of eye exams. For example, several studies have shown that the likelihood of receiving a dilated eye exam is lower among men (61;62), individuals with no insurance or public insurance (Medicare, Medicaid) (61-63), Blacks (64), and people with no usual source of care (63). Fewer studies have looked at characteristics of the delivery system that impact receipt of vision care (65;66), and more research into these factors (e.g. number of ophthalmologists per capita, wait time to see an eye care professional) are needed to identify other potential barriers that are amenable to policy intervention.

Most studies on access to vision and eye care have focused on use of eye care professional services (67). However, general access to medical care may be just as important for prevention and early detection of eye disease, particularly since primary care providers typically serve as the gatekeepers to all other specialty care, including vision and eye care. For example, in a recent Morbidity and Mortality Weekly Report (MMWR) by the Centers for Disease Control (CDC), study authors found that among women (aged 40 and older) with eye disease, lack of insurance coverage and not having routine medical check-ups were both associated with not receiving recommended follow-up eye care (68). Interventions to increase access to general medical services will be important for improving access to preventive vision and eye care services.

Treatment Services

Treatment services for people with eye disease are necessary to delay progression and prevent low vision and blindness. Specific individual level barriers to treatment services for eye disease have been documented and include Black race (33;69), low income (70), and lack of insurance (70). Our review of the literature did not identify studies on the characteristics of the health-care delivery system that may serve as barriers to the treatment of the major causes of visual impairment in the US.

Low-Vision Rehabilitation Services

Vision rehabilitation services include aids and devices to improve use of whatever vision functioning remains, as well as training and education for patients and their families designed to increase independence and improve quality of life. There is some evidence supporting the usefulness and perceived benefits of low-vision services. For example, a recently published study evaluating an 8-week group program aimed at enhancing self-management skills among visually impaired patients showed that patients perceived this type of service as useful, having a positive effect on patients' mood and ability to manage with low vision.(71). Despite these perceived benefits, utilization rates of low vision services are low; it has been estimated that only 5-10% of people with visual impairment use some rehabilitation service (72).

Individuals with visual impairment face special challenges in obtaining rehabilitation and other clinical support services, and studies on access to care among persons with visual impairment have helped to elucidate some of these barriers. According to a study by O'Day and colleagues (73), patients with low vision reported concerns about physicians' beliefs that they cannot fully manage their own self care; communication barriers; physical access barriers (getting to and around physicians' offices); and information barriers (receiving written materials inappropriate for people with low vision or blindness). Results from a focus group of visually impaired patients and their families revealed that patients and their families lacked awareness of low vision rehabilitation services, experienced transportation issues, had difficulties communicating with eye care professionals, and lacked referrals from eye care professionals for vision rehabilitation services(72). In 2008 Zhang and colleagues reported that more than 8% of people with self-reported vision problems lacked health insurance coverage, and those lacking coverage were less likely than those with either private or public health insurance to use eye care services (74).

Finally, in a more recent study using pooled data from the 2002-2004 Medical Expenditure Panel Survey (MEPS) (67), authors found that persons with self-reported visual impairment were significantly more likely than persons with no visual impairment to "delay or be unable to obtain necessary medical care, prescription medications and dental care." According to these data, there were also significant differences in self-reported barriers to accessing health care among persons with and without visual impairment. For example, persons with visual impairment were more likely to experience problems accessing health care due to cost of care, rather than insurance coverage, when compared to persons with no visual impairment. Furthermore, individuals with self-reported blindness were three times more likely than all other respondents to cite transportation issues as a barrier to obtaining care. These and other similar findings point to the fact that vision surveillance will be greatly enhanced by incorporating questions addressing barriers to accessing important clinical care services (including general medical care and vision and eye- specific health services), particularly among populations at greatest risk for eye disease, visual impairment, and vision-related disability.

2 THE CURRENT STATUS OF VISION LOSS AND EYE DISEASE SURVEILLANCE IN THE UNITED STATES: Data Sources and Surveillance Systems

2.1 Evaluation of US Surveys or Surveillance Systems with a Vision and Eye Health Component, Focus on Disparities

Visual impairment represents a complex disability experience. Vision impairment frequently occurs with aging and is often associated with the co-occurrence of other health limitations. This combination of disabilities negatively impacts an individual's overall health on multiple levels. As an example, many older adults are affected by depression and AMD. It is well established that visual impairment is a risk factor for depression (48) but depression is also a treatable disorder that exacerbates the impact of AMD on quality of life (75). Fried and colleagues found, in a female Baltimore population, that self-reported visual impairment was one of the most frequently co-occurring chronic conditions in their study population (Table 1) (76).

> A visual impairment surveillance system must yield data actionable at all levels of prevention.

Table 1. Co-occurrence of visual impairment and other chronic conditions (adapted from Fried 1999)

Rank	Disease	Proportion with Both (%)
1	Arthritis	44
2	High Blood Pressure	40
4	Any heart disease	17
5	Hearing impairment	15
9	Diabetes	12
10	Cancer	10

Further, it was demonstrated that visual impairment, coupled with other chronic conditions such as arthritis and stroke, had a synergistic effect on measures of disability. For example, arthritis with visual impairment significantly elevated the risk of mobility impairment greater than either condition alone. Similarly, the co-occurrence of visual impairment and stroke resulted in a large increase in risk of higher function and self care impairment compared to either alone. These results highlight the importance of surveillance that is designed to collect data reflective of the multiple layers of disability associated with visual impairment, including data on co-morbid conditions that can exacerbate impairment due to low-vision or blindness.

Visual impairment is ripe for secondary prevention activities, aimed at preventing progression of disease and minimizing severity. Primary prevention strategies for eye diseases such as AMD and glaucoma are limited because these ocular diseases are degenerative and often asymptomatic in early stages. The work of Fried and colleagues suggests that, with co-occurrence of chronic conditions, minimizing the severity of one disease may minimize the resulting disability from all diseases. For example, routine screening for and management of early eye problems among diabetics might result in meaningful decreases in disability both related to eye disease and to other chronic diseases associated with diabetes. Tertiary prevention drives at reducing the negative impact of an already established disease and seeks to restore function and maximize quality of life. Changes to the environment, such as through the provision of services or the development of policies that ensures access to visually impaired persons, can serve to minimize disability resulting from visual impairment. Vision support systems are currently underutilized and evaluation of the benefit and value of currently available services from a disability perspective, as well as barriers to accessing these services will be important output from a visual impairment surveillance program.

2.2 Objectives

Our objectives for the present evaluation were to examine the ability of current surveillance systems to assess and monitor disparities in 1) visual impairment, 2) eye disease, 3) vision-related functioning, 4) social participation restriction, 5) access to vision and eye care and 6) access to supports and services for those who need vision rehabilitation. We also reviewed each data source with the following objectives:

a. Identify the general characteristics, strengths, and limitations of these surveillance systems
b. Determine the extent to which these surveillance systems allow adequate collection, analysis, and interpretation of data

c. Determine the ability of these surveillance systems to 1) estimate the magnitude of the problem, 2) determine distributions, including geographic, 3) generate and test hypotheses, 4) stimulate research, program design, implementation and evaluation, 5) detect changes in health practices

2.3 Identification of Existing US Surveys and Surveillance Systems with a Vision / Eye Health Component, Focus on Disparities

In order to identify existing US surveys and surveillance systems relevant to vision health, we carried out a two-pronged approach to our systematic review: (1) using a key word search of the major scientific databases (including Pubmed, Google Scholar, Medline, Cochrane Library, ClinicalTrials.gov, and CINAHL); and (2) canvassing of experts in visual impairment and eye disease surveillance. We carried out the initial review of the peer-reviewed literature using a combination of the following keywords for vision and eye disease (vision; visual; eye disease; eye injury; eye care; blindness; blind; low-vision; Cataracts; Glaucoma; Age-Related Macular Degeneration (ARMD); Diabetic Retinopathy; Refractive Error) and surveillance (survey; surveillance; data collection; screening; database).

Results from this initial search yielded a voluminous amount of published studies, therefore we deemed it necessary to enforce limits to restrict our search to a more focused and relevant pool of studies. We limited our search to 1) literature published between 1995 and 2010 (because we are interested in data that is collected and disseminated on a continuous basis, therefore only studies that have been published in the last 15 years were deemed appropriate; 2) articles written in English Language; and 3) Human studies. All searches were documented to include information on the date the search was performed, the specific database searched, specific search terms and limits, and the number of results yielded from each search. We reviewed all titles and abstracts, and identified any relevant articles prima facie. We performed additional hand-searches of bibliographies to generate a list of additional studies not captured in the initial search.

In addition to performing a thorough review of the peer-reviewed scientific literature, we initiated direct contact with vision experts to identify other major survey and surveillance instruments that contained a vision component. For the purpose of our evaluation of the current state of vision surveillance in the US, we included only nationally representative, population-based surveys that contained the following key components:

a. Survey contained a component related to vision health, eye disease, vision-related disability, or utilization of vision-related treatment or rehabilitation services
b. Survey was **ongoing and continuous** (administered at least every 5 years)
c. Survey included adults >40 years of age, who are at greatest risk for visual impairment

Data sources considered included:

a. National Health Interview Survey (NHIS)
b. National Health and Nutrition Examination Survey (NHANES)
c. National Vital Statistics System—Mortality (NVSS-M)
d. National Hospital Discharge Survey (NHDS)
e. National Hospital Ambulatory Medical Care Survey (NHAMCS)
f. National Ambulatory Medical Care Survey (NAMCS)
g. Behavioral Risk Factor Surveillance System (BRFSS)
h. National Profile of Local Health Departments (NPLHD)
i. Medical Expenditure Panel Survey (MEPS)
j. Medicare Claims Beneficiary Survey (MCBS)
k. Survey of Income and Program Participation (SIPP)
l. National Worksite Health Promotion Survey (NWHPS)
m. National Notifiable Disease Surveillance System (NNDSS)
n. Monitoring the Future Study (MTF)

2.3.1 General Characteristics, Strengths, and Limitations of Existing Surveillance Systems

Existing US surveillance systems with a vision component were evaluated for general strengths and limitations related to overall design and data elements (See Vision Grid, Tables 1a and 1b) as well as against the three key overarching requirements for any chronic disease surveillance system: (1) timely access to data, (2) representative sample, and (3) standardized data elements.

Timely Access to Data

Surveillance of vision health is currently conducted in several national surveys including NHANES, BRFSS, and NHIS which are all administered annually. Hospital and ambulatory surveys are also administered annually, such as NHDS, NAMCS, and NHAMCS. However, none of these surveys provide continuously collected data on vision. Therefore, there is no “true” national surveillance system for vision health. Administrative datasets such as MEPS and MCBS 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 databases provide a rich source of information on health care expenditure and utilization rates, but do not provide any information pertaining to visual impairment, functional loss, or perceived disability related to visual impairment.

From the perspective of disease surveillance, it could be argued that the latency inherent to most chronic diseases, including visual impairment, makes “true” (or continuous) surveillance unnecessary. However, if we approach chronic disease surveillance from a more holistic perspective that captures the dynamic interaction of the individual with the environment, it becomes clear that our ability to measure the health impact of changes in the environment will be limited by the frequency of data collection.

Timely access to data not only includes timely collection of data, but timely dissemination to users. NHIS can have more than a six month lag between data collection and release. While the “continuous” (meaning administered annually, no off years) iteration of NHANES was released in 1999 to improve coverage and timeliness, survey data are currently released on public use data files every two years. Data from BRFSS is collected by December and available by April the following year. Administrative and hospital discharge data are available for users 2 years after data is collected and processed. For example, NAMCS and NHAMCS data collected in 2007 is currently available for public use, and 2008 data will become available later in 2010.

Representative Sample

Most of the national health surveys (NHIS, NHANES, and BRFSS) follow similar multistage area probability designs that allow representative sampling of households. Such a design involves the designation of Primary Sampling Units (PSUs) 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 PSUs and then a second-stage design is implemented that further delineates and samples smaller units within the PSU. An important strength of these surveys is that they often oversample racial minority and elderly 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.

The current sampling scheme for NHIS involves a first stage sampling of 428 primary sampling units (PSUs) drawn from almost 1900 PSUs that cover the entire United States and a second-stage sampling design (77), resulting in an estimated 35, 000 households, containing 87,000 persons surveyed annually (for Core Questions). Participants in the MEPS are also drawn from this same sampling scheme, and are comprised of a subsample of households participating in the previous year's NHIS sample.

NHANES is also a complex sample survey, involving PSU's generally made up of single US counties, although smaller counties are sometimes combined to produce larger population sizes. Prior to 2002, the sampling design was linked to the NHIS in that NHANES PSU's were drawn from a subset of the PSUs previously selected for the NHIS. Recently, however, an independent set of PSU's were selected from all US counties. The additional stages of selection in the probability design for NHANES involve clusters of households, from which each person in the selected households is screened and one or more persons per household are selected for the sample. As a result, NHANES surveys approximately 5,000 persons annually.

BRFSS has a large representative sample and provides the best platform for generation of state-specific estimates of population parameters, with over 350,000 adults interviewed annually for the core survey component. Unlike the NHANES and NHIS surveys, the BRFSS data are collected via telephone surveys, with telephone numbers randomly selected from a probability sample of all households with telephones in the state. Use of a telephone-based sampling scheme reduces the representativeness of the sample population, as responders may differ from non-responders in a variety of ways. For example, persons without a working telephone may be more elderly and/or of lower socioeconomic status. The degree to which this influences interpretation of results varies according to the proportion of people without telephones in the state where data is being collected. For example, it was estimated that about 6% of the United States population did not have a telephone in 2008. This estimate, however, varies greatly by state, from 3% in Washington to nearly 12% in New Mexico and 26% in Puerto Rico. (78) Furthermore, response rates to phone interviews are very low (79), so that persons willing to participate in the telephone interviews may represent a selected group of individuals not representative of the general population.

The MCBS is comprised of 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 NHIS and NHANES. Briefly, the PSUs include metropolitan statistical areas (MSAs) and groups of rural counties (non-MSA) selected according to metropolitan and socioeconomic characteristics. The second stage involves selection of zip codes contained within each PSU, and then beneficiaries within the sampled zip codes are stratified and sub sampled by age for an equal probability of selection among seven different age groups.

The hospital and ambulatory surveys (NHDS, NAMCS, and NHAMCS) use similar multi-state sampling schemes to include a nationally representative sample of visits to non-federal hospitals and outpatient physician offices. For example, the NHAMCS is based on a four-stage probability sample design; the PSUs 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 makes up the record in hospital and outpatient survey data and not the individual patient, repeated entries by a single patient cannot be accounted for, thus representing one major limitation of this sampling design. Use of the patient-visit as the unit of analysis could potentially lend 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

Because no single surveillance instrument can be all things to all stakeholders, it is important that each instrument have standardized data elements that enable linkage with other datasets. There are many important benefits of linking data from multiple data sources, including enhanced data quality and an expanded capacity for generating and testing specific research questions. 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 can also be enhanced by imputing missing data from one data source to the other. Finally, researchers and policymakers can use information provided by two linked databases to ask and answer questions that are beyond the scope of either database alone.

As example, several population-based health surveys with vision health data have been successfully linked with other databases, resulting in an increased knowledge of related risk factors and health outcomes. One example is a project called “Chronic Disease and the Environment” that links health survey data (BRFSS, NHIS, NHANES) with EPA air quality data to investigate the association between environmental pollution and various health outcomes. The NHIS and NHANES have also been linked to the National Death Index, and a study by Christ and colleagues provides an example of the utility of such data linkage in vision research. These authors examined the impact of self-reported vision impairment on health, disability, and mortality (80) and demonstrated a direct association between visual impairment and mortality.

This is one example of how important data linkage is to informing public health research and policy supporting vision health. Other standard data elements include social security numbers, which can link each of these databases to one another. However, linking on personal identifiers requires consent to use both databases, so that personal information collected from a health survey cannot be linked to information collected from a medical care provider unless informed consent has been received for both sets of data.

Collecting data in a standardized and uniform fashion can also enhance comparisons across studies. For example, 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 between vision surveillance data sources. For example, in the NHIS and NHANES surveys, respondents are asked to identify with Hispanic subgroups they belong to through a positive response to “Are any of the following groups you national origin or ancestry?” (NHIS) and “Do you consider yourself to be Latino or Hispanic?” (NHANES). If respondents say yes to these questions, a list of Hispanic ethnicities are provided from which the respondent chooses one or more. The two lists, however, are not synchronized. The NHIS lists Puerto Rican, Mexican, Chicano, Other Latin American, and Other Spanish- while the NHANES lists Puerto Rican, Cuban, Dominican, Mexican, Central or South American, Other Latin American, or Other Hispanic or Latino. The BRFSS, on the other hand, 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 upon the answer choices provided (e.g. the same respondent may identify as “Chicano” in one survey and “Mexican” in another). Similarly, the NHIS lists Indian (American), Eskimo, or Aleut, while the BRFSS created the more general category of American Indian/Alaskan Native. The disparate nature of race categorization between 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.

Information on co-morbid conditions, disability, and access to health care are even more disparate between the various data sets. NHANES and NHIS are quite similar in the way they attempt to address the impact of visual impairment on daily activities and participation in social roles (see grid for questions). However, to our knowledge, surveys incorporating information related to these factors are limited. Information on co-morbid conditions has been assessed in various ways. For example, NHIS asks respondents directly whether they have any one of a list of conditions; BRFSS asks whether a doctor has ever told them that they have a specific condition; and NHANES asks about symptoms related to specific conditions (e.g. have you ever had any pain or discomfort in your chest?). Efforts should be made to evaluate the validity of responses to each question type to inform standardization of these questions. For example, it may be that people are less likely to accurately report having a condition unless they have actually been diagnosed by a medical doctor.

Finally, as discussed previously, increased focus on standardizing the way low-vision or blindness is measured should be the focus of vision health surveillance efforts. The following section includes a more detailed discussion on how visual impairment is currently measured, as well as ways that the current surveillance system can be improved.

2.3.2 Access to Vision Health Data

Visual impairment represents a multi-factorial condition that affects all aspects of a person. As such, measurements of visual impairment should reflect the various dimensions of its influence. For example, visual impairment should be measured in terms of the underlying eye disease, the actual 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 and responsibilities (e.g. ability of a person with low-vision to go to work). Also important to the assessment of visual impairment are identifying barriers to accessing 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 visual impairment.

Eye Disease

The public health surveys (NHIS/NHANES/BRFSS) all have core questions that assess the major eye disorders of aging: cataracts, glaucoma, age-related macular degeneration, diabetic retinopathy, and refractive error. Assessment is made by self report of diagnosis in each survey (e.g. “Has a doctor ever told you that you have cataracts?”). However, these questions are not standard components of the surveys in that they are not assessed each year. For example, in the NHIS the disease specific questions are part of the supplement, which has only been administered in 2002 and 2008. BRFSS includes only self-report of diagnosis questions and most of these key vision questions are asked on the vision component, which has been administered in less than 19 states from 2006 to 2008. In addition to the self-report questions, NHANES conducts physical exams. Eye exams were administered from 1999-2008 for visual acuity, but not eye disease, and no ophthalmologic exams were administered to detect eye disease until 2005-2006. Furthermore, the vision component (including visual impairment and eye disease) is not a part of the 2009-2010 NHANES.

The administrative databases (MEPS, MCBS) are very limited in the information on specific eye disease, although the MEPS does include a question related to diabetic retinopathy: “Has your diabetes caused problems with your eyes that needed to be treated by an ophthalmologist?” The hospital and ambulatory datasets are limited to ICD-9-CM diagnosis and procedure codes related to eye diseases or disorders.

Overall, health surveys are the most useful data tools to assess eye disease. NHANES is particularly valuable because ophthalmology exams were included to verify self-reported diagnoses; however it is limited by small sample size which can present significant challenges for subgroup analyses. This is especially important given the disparate prevalence estimates between self-report and clinically verified data for specific eye conditions such as glaucoma and DR. BRFSS represents an existing platform with a significant sample size and an existing vision module that could be improved upon and expanded. However, in order to be useful surveillance tools, efforts must be made to ensure that the vision component of existing surveys is administered every year so that trends in eye disease prevalence may be monitored over time.

Visual impairment

Both public health surveys (NHIS/NHANES/BRFSS) and administrative datasets (MEPS/MCBS) have core questions that assess low-vision or blindness. Each survey asks participants about current use of corrective eye wear (glasses or contacts) as well as questions designed to identify blindness. Each question is asked differently and is, therefore, subject to different potential biases that affect the validity of the question. Furthermore, there is no single standard against which to compare one's own vision when answering the question about low vision. A key addition to the existing surveys would be a way of assessing self-report of low vision in a standardized way. For example, one could ask whether or not somebody could see the face of Lincoln on a penny when held at arm's length. An internationally applicable standard would also be beneficial. The hospital and ambulatory datasets are limited to ICD-9-CM diagnosis and procedure codes related to eye diseases or disorders.

As with eye disease, NHANES is the only health survey that measures visual function via a clinical eye exam. However, NHANES measures visual acuity only, which represents only a fraction of visual functioning. For example, several studies have shown that there are other aspects of vision, such as visual field, contrast sensitivity, glare sensitivity, color vision, and stereoacuity- all of which are meaningful measures of visual impairment that are associated with disability. Limiting measurements of visual impairment to standard acuity tests severely underestimates the true functional loss for many individuals. Future surveillance tools should incorporate other measures of visual function, particularly those that have been demonstrated to impair daily activities and social participation. Furthermore, in order to harmonize and compare results over time and across disciplines, it is of utmost importance to come to a consensus definition of low-vision, one that encompasses more than acuity and includes all meaningful aspects of visual function that significantly impact daily life.

Vision-Related Disability

Both NHIS and NHANES provide a meaningful set of questions that reflect limitation and participation restriction. Many of the questions on limitation also drive at achieving further granularity around the nature of visual impairment (i.e. difficulty with distance vision, difficulty with night vision). A concern related to many of these questions is the inherent contingency upon individuals having ability or access to participate in the activities identified. As example, if a participant does not own a car or is illiterate many of these questions are inapplicable, or difficult to answer accurately at best (see Vision Grid, Table 2b). Unfortunately for NHIS, similar to the disease-specific questions, the functional questions are part of the supplement, which has only been administered in 2002 and 2008. NHANES is hampered in its utility 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 limited vision-related functioning questions asked in BRFSS. The questions that are asked are highly subjective, prone to confounding, and not amenable to comparison across populations. For example, the answer to the question "How much difficulty 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. In fact, 2008 North Carolina BRFSS data show that this question is highly non-informative, with 85% of the population reporting "no difficulty." However, among those reporting difficulty, rates varied significantly by ethnicity with African Americans having consistently higher rates than Whites (e.g. 9.3% versus 13.1% for "A little difficulty", non-overlapping confidence intervals, both genders) (81).

The MEPS and MCBS data added questions on difficulty reading prescription labels and the MEPS refined the recognition question to "people 2-3 feet away." The hospital and ambulatory datasets do not include data on vision related functioning or disability.

Participation Restriction

Visual 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 and activities. Participation restriction carries the greatest societal burden, and is the outcome that should be the focus of public policy and interventions. The NHIS and NHANES 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 MCBS assesses the impact of visual impairment on accessing health care. Greater focus on participation restriction is necessary to evaluate the impact of rehabilitation services and other social interventions.

Access to Care and Services

Access to health care, and specifically vision care, are important pieces of information to measure in vision surveillance. While preventive care is important for vision health, access to treatment and rehabilitation services are of greatest importance to prevent visual 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, as well as barriers to accessing vision care. These tools could be enhanced by including more information on specific barriers for people with visual impairment and other related disabilities (e.g. receipt of readable materials, ability to read prescription labels). Further, low vision technologies are rapidly changing. Examples of such technologies include desktop video magnifiers, talking clocks and watches, and voice labeling systems. Tracking use and benefit of these technologies would help to focus programs and policies on the most successful approaches.

Table 2	ICF Domain	Sub domains / Definition	Vision Examples	Data
Health Condition	Underlying Condition	Diseases, disorders, injuries	▪ Cataracts ▪ Glaucoma ▪ AMD ▪ Diabetic Retinopathy ▪ Refractive Error	▪ NHIS ▪ BRFSS ▪ NHANES ▪ MEPS ▪ MCBS
Body Structures and Function	Functioning	▪ Physiological functions of body systems ▪ Psychological functions ▪ Anatomical parts of the body such as organs, limbs, etc	▪ Blindness ▪ Low Vision	▪ NHIS ▪ BRFSS ▪ NHANES ▪ MEPS ▪ MCBS ▪ NHDS ▪ NAMCS ▪ NHMACS

Table 2	ICF Domain	Sub domains / Definition	Vision Examples	Data
Participation **Participation Continued**	Functioning	Involvement in life situations ▪ learning and applying knowledge ▪ general tasks/demands ▪ communication ▪ mobility ▪ self-care ▪ domestic life ▪ interpersonal interactions and relationships ▪ major life areas ▪ community ▪ social ▪ civic life	Difficulty with: ▪ Housework ▪ Childcare ▪ School ▪ Hobbies ▪ Community activities ▪ Obtaining medical care	▪ NHIS ▪ NHANES ▪ MCBS
Environmental Factors	Contextual Factors	Human-built, social, and attitudinal environment ▪ products and technology ▪ natural environment ▪ human-made changes to the environment ▪ support and relationships ▪ attitudes ▪ services ▪ systems ▪ policies	▪ Utilization of vision health care ▪ Vision insurance coverage ▪ Affordability of interventions (eye glasses) ▪ Utilization of vision services ▪ Use of adaptive devices	▪ NHIS ▪ BRFSS ▪ MCBS ▪ NAMCS ▪ NHAMCS

Table 2	ICF Domain	Sub domains / Definition	Vision Examples	Data
Personal Factors **Personal Factors Continued**	Contextual Factors	Personal factors that may influence how disablement is experienced by the individual ▪ sex ▪ age ▪ other health conditions ▪ fitness ▪ lifestyle ▪ habits ▪ upbringing ▪ coping styles ▪ social background ▪ past and current experience ▪ character style	▪ Demographic characteristics ▪ Fitness: physical activity measures ▪ Lifestyle/habits: smoking, diet, BMI, physical activity, alcohol use, sexual behavior, drug use ▪ Upbringing: country of birth, age of mother at birth, maternal smoking habits, weight at birth ▪ Coping: social support, religious worship, depression screening, emotional support; life satisfaction ▪ Social Background: education, income, language spoken at home, current employment status	▪ NHANES ▪ NHIS ▪ BRFSS

The NHIS is the only survey to ask about use of rehabilitation and adaptive services for those affected by visual impairment. The hospital and ambulatory data are useful tools for measuring utilization rates of treatment services, such as cataract removal. Finally, the MCBS and MEPS are valuable resources for measuring expenditures related to visual impairment, as these statistics will be very useful in evaluating the economic benefits of future interventions.

2.3.3 Capacity for Public Health Assessment and Action Related to Vision Health Disparities

The key challenges facing a national vision surveillance program that would effectively support program planning, implementation, and evaluation are: (1) the lack of continuous outcome data with adequate sample size and coverage to enable surveillance among minority populations and (2) a paucity of data that drives at capturing the complex disability experience such as behavioral and environmental data.

With a sample size of over 350,000 people surveyed annually, BRFSS generally has sufficient sample size to provide stable estimates. With regard to measuring outcomes in population subgroups, such as by ethnicity, the limiting factor for vision becomes the absence of outcome data. In 2008 only 8 states administered the vision module (Alabama, Connecticut, Indiana, Missouri, New Mexico, North Carolina, Tennessee, and Wyoming). Evaluation of state-level health disparities has been accomplished using BRFSS data for many outcomes. Where state-level data has been insufficient in the past due to lack of sufficient outcome data, such as with diabetes (82), efforts have been made to improve coverage and have resulted in the ability to measure health disparities (83).

That said, measuring rates of chronic diseases, like vision outcomes, while important, is not where the public health action lives because of latency issues. The opportunity for action lives in the modifiable risk factors and health behaviors. If we utilize the ICF as a conceptual framework for characterizing the types of data, or information, we would need to ask important questions about prevention of visual impairment and resulting disability, and post-harmonize with existing surveillance instruments, a foundation for effective vision surveillance exists. That said, data collection needs to be expanded to capture more of the activities, participation, environmental, and personal factors that are the targets for public health programs and policies (see Table 2).

3 INTERNATIONAL VISION SURVEILLANCE EFFORTS

More than a decade ago, the WHO and the International Agency for the Prevention of Blindness (IAPB) partnered up to launch Vision 2020: The Right to Sight, a global health initiative to prevent avoidable blindness around the world. The core objectives of this initiative include 1) increasing awareness of the causes of avoidable blindness as well as solutions to eliminate the problem; and 2) identifying and securing the appropriate resources to increase prevention, treatment, and rehabilitation programs. Improved mechanisms for monitoring and evaluating progress are necessary for achieving the goals of VISION 2020. “If progress in all the activities of VISION 2020 is to continue and accelerate, greater support will have to be provided to national coordinators in collecting and analyzing data. Increased efforts to collect and make available data at district, country and regional levels is a critical requirement for the success of VISION 2020, as good information helps ensure that blindness prevention and treatment activities are directed to areas that need them the most”(84).

In response to the VISION 2020 global health initiative, countries around the world have initiated their respective solutions, most of which have included efforts to evaluate and improve data collection methods relevant to visual impairment and eye disease. Review of these efforts and data sources can serve to inform our own effort here in the US, by providing guiding examples for how to evaluate and improve vision health surveillance at the national level. In this section we will focus on the international data sources from the United Kingdom, Australia, and Canada which meet our criteria for vision health surveillance: data that 1) contains information on vision, the major eye diseases in the US, and/or access to eye health care; 2) is collected in an ongoing and continuous fashion; 3) includes a nationally representative sample; and 4) includes adults over the age of 40.

Using the same methods as described in section 2.3, we identified several key national data sources in the UK, Australia, and Canada meeting our definition for vision health surveillance. These data sources can be classified into five basic types: 1) active disease surveillance; 2) population-based health surveys; 3) clinic-based surveys; 4) registries of eye care workforce; and 5) health administrative databases (e.g. hospital, pharmaceutical, Medicare, disability services). We have reviewed each data source for its utility in estimating the burden of visual impairment.

Similar to the US, active surveillance of visual impairment due to common eye diseases is limited. In the UK, however, there are several key national surveillance and screening systems in place, and lessons learned from such systems may provide insight as to the feasibility and utility of implementing similar programs in the US.

For example, in 2003 the UK implemented the Diabetic Retinopathy Screening Service, a national screening service that is offered to every diabetic patient seen by a general practitioner in the UK. The goal for this population-based screening effort is to decrease visual impairment due to diabetic complications through timely detection of retinopathy among people with diabetes. Although the aim for participation in this national program was 98% of all general practitioners and 98% of all diabetic patients, studies show that actual participation of diabetic patients ranged from 38% to 85%, depending on the specific region (85). To produce reliable prevalence estimates, participation rates close to 98%, and national registries of all diabetic patients should be established and maintained in order to determine the proportion of people with diabetes who actually receive a screening. Sustained efforts to promote education and awareness of this screening program and its value among providers of diabetes care, as well as patients with diabetes are also needed to ensure near 100% participation. Implementing a similar national screening system in the US would not only ensure that all persons receiving care for diabetes are screened for DR, but it would also permit the pooling of regional/state level data that can be used to derive reliable and timely population estimates of DR among people receiving diabetes care.

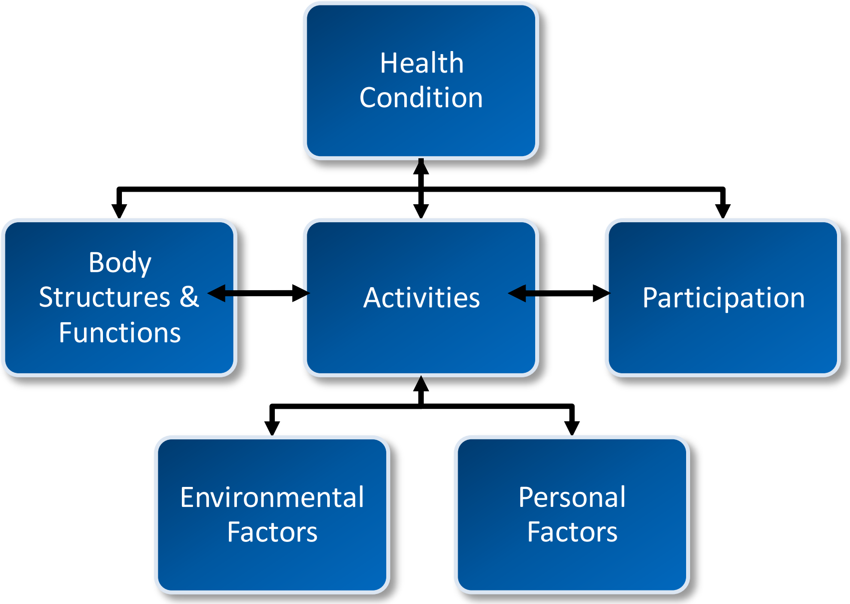
Another model of active vision surveillance in the UK is the British Ophthalmological Surveillance Unit (BOSU), a nation-wide surveillance unit established in 1997 and designed to actively ascertain cases of rare ophthalmological disorders and events in the UK(86). This system relies upon monthly reporting by participating ophthalmologists in the United Kingdom, which is recorded according to the specifications in the study protocol to ensure systematic and uniform collection of data. In a study by Foot and colleagues (86) authors reported that most ophthalmologists participating in this program perceived the program as "useful in assisting the study of rare eye conditions." Adopting such an active surveillance system in the US to monitor visual impairment and the major eye disease could be beneficial in attaining timely data on disease occurrence. Such a system would, however, require the participation of the majority of ophthalmologist in every state, and given the volume of cases for common eye disorders in the US, this type of surveillance may not be the most feasible due to the heavy burden it would place on ophthalmologists and other eye care workers. For example, in the same study by Foot and colleague, they also showed that recall of the patient's identity at the time of reporting was a major barrier to participation in the program.

Given that active surveillance of visual impairment and eye disease is sparse even in the international community, we broadened our search to determine how these countries were actually assessing prevalence of disease. Our search revealed that the majority of published prevalence estimates of visual impairment in Australia and Canada were derived from population-based studies such as the Blue Mountains Eye Study (87) and the Melbourne Visual Impairment Project (VIP) in Australia (88), the Canadian Study of Health and Aging (CSHA) in Canada (89), and the MRC trial of assessment and management of older people in the community in the UK (90). Based on our review, it appears that population-based studies are currently the standard method for obtaining national prevalence estimates for visual impairment both in the US and abroad. As stated previously throughout this report, repeated measures over time are critical to monitoring progress towards achieving the goal of decreasing the overall burden of visual impairment. Therefore, if population-based studies are the principal method for obtaining prevalence data, they need to be repeated on an ongoing basis; repeated surveys need to be conducted at intervals that are meaningful and facilitate evaluation of the effects of new policies and interventions. Population-based studies can be extremely costly and time intensive, thus the conception and validation of alternative methods to the traditional population-based study design may prove beneficial in achieving these objectives.

For example, Muller and colleagues published a report advocating for a more cost-effective alternative to the expensive population-based studies currently used to assess eye disease prevalence in Australia (91). According to this paper, the cost of one exam for one participant in the VIP study was high (approximately $400 US dollars per exam), and required one full hour for each eye exam. These authors propose using mass mailings to recruit volunteers for eye examinations instead of making house visits to cut costs in recruitment. They also propose using a non-mydriatic digital camera for fundus and lens photography and frequency doubling perimetry (instead of the Humphrey automated visual fields) to remove the need for dilation thus reducing the time required for the exam by one half. Authors of this study report that using such methods to rapidly assess changes in undetected eye disease will cut costs by nearly a third. Adopting similar recruitment and assessment methods in US population-based studies of eye disease may be a means to a more cost-effective alternative to the time intensive and expensive traditional population-based study design.

From a global health perspective, vision surveillance represents an urgent need, and as various stakeholders in the international community are brought together to collaborate harmonization will be key. That is, while systems and strategies must be reflective of differing jurisdictions, a universal framework from which to approach the complex disease/disability experience of visual impairment beyond the condition, or diagnosis, is paramount to speaking the same language on the front end, as surveillance systems are developed, to be sure we are building a basis for public health action. Measuring visual impairment and vision-related disability reliably and with consistency requires that a common framework be developed, one in which a standard set of definitions and classification systems can be established and applied across studies and discussed among the relevant professional fields (ophthalmology, gerontology, nephrology, etc).

The ICF Model (World Health Organization)



The International Classification of Functioning Disability and Health (ICF) model is a conceptual framework for measuring health and disability at both individual and population levels. Similar to the International Classification of Diseases, the World Health Organization (WHO) developed the ICF framework using a global consensus building process that involved multiple stakeholders, including persons with disabilities (92). The ICF was endorsed in May 2001 by the World Health Assembly as a member of the family of International Classifications. In 2007 an IOM committee issued a report, *The Future of Disability in America*, in which they recommended that federal agencies, among others involved in disability research, explicitly adopt the ICF framework and support efforts to improve it (93).

The ICF offers a holistic "systems thinking" paradigm for understanding health and serves as a useful tool for understanding the "buckets" of data, or information that will be required for the development of successful public health programs and policies to reduce visual impairment disparities in the US. The ICF also provides a standardized language of function and health that can facilitate communication among the health care and research communities and can help to bridge gaps between stakeholders.

Activities or interventions directed towards knowledge, understanding and integration, communication, and social life have significant potential to prevent progression of disease and further functional repercussions. Thomas Frieden, author of “A Framework for Public Health Action: The Health Impact Pyramid”, describes the impact of public health interventions using a 5-tier pyramid, postulating that interventions aimed at addressing social determinants of health (represented by the lowest tier of the pyramid) will have the greatest impact on improving the population’s health. At the level of tertiary prevention, activities aimed at removing barriers can serve to restore function and reduce disease-related complications. Ultimately, a robust national vision surveillance program will provide important risk factor and outcome information at a granularity that is meaningful for etiologic research and program and policy development, as well as the longitudinal data to support effective public health program evaluation.

4 CONCLUSIONS

The risk factors of today are the diseases of tomorrow.

Bonita et al. The WHO Stepwise Approach to Surveillance of Non-Communicable Disease Risk Factors (2003)

As discussed previously, the important attributes of a national vision loss and eye disease surveillance effort designed to improve vision health in the United States are: availability of complete, timely, and high-quality data, representativeness of samples, and development of standardized data elements. Beyond these general characteristics, which are desired attributes of any surveillance system, the following needs were identified as critical to the success of future vision surveillance efforts:

A Focus on Behavioral Risk Factor Surveillance over Disease Surveillance

Vision surveillance efforts, like all chronic diseases surveillance, should involve *behavioral risk factor surveillance.* The assessment of risk factors, health behaviors, and other modifiable environmental factors are the direct targets of interventions and public health programs. As Pekka Puska wrote in the 2003 Chapter *Why is Global Surveillance Necessary*:

> *Infectious disease surveillance primarily targets diseases and their outbreaks, because this focus provides valuable information on the outbreak source. However, for [chronic diseases] measuring disease rates does not help us take action because the length of time associated with disease development is too long. [Non-communicable disease] prevention efforts target risk factors, usually behaviors, and consequently they should be the key items for surveillance.*

Current surveillance instruments with vision components are disease-driven. That is, the majority of the questions are focused on characterizing visual impairment and eye disease. While some questions do drive at vision-related disability and can be post-harmonized to a conceptual framework like the ICF to some degree, the role of the environment and the activity impairment and participation restriction that results from underlying visual impairment can and should be better characterized and more substantively represented on future vision surveillance efforts.

Increased Focus on Access to Vision Care

Access to vision care, receipt of therapeutic medications and surgeries, and utilization of rehabilitation services for people with visual impairment is critical for preventing and treating visual impairment and related disability. Surveillance tools to assess barriers to vision care will be necessary to inform focused public health efforts to increase timely access to needed services. Furthermore, these data can be used to evaluate the perceived benefits of available treatments and services, which will become increasingly important as the population of elderly people at greatest risk for visual impairment continues to grow.

Systems-Thinking and Adoption of a Conceptual Framework

The global burden of chronic diseases and the intrinsic collaboration required for international chronic disease surveillance dictate the need for standardized data elements. For vision, in particular, the complex and dynamic disability experienced by those with visual impairment should be captured in vision surveillance tools.

> *Conventional forms of problem framing, action planning, and evaluation often exclude or ignore precisely those features of dynamic complexity that make public health challenges so formidable and public health responses so innovative.*
> *Leischow, 2006*

In order to facilitate a common language and the ability to make meaningful comparisons, a conceptual framework for capturing the complex disability experience around visual impairment should be agreed upon. In 2007 the IOM published *The Future of Disability in America* whereby the Committee on Disability in America recommended that "federal agencies involved in disability monitoring explicitly adopt the ICF conceptual framework *and* support efforts to strengthen it" (94).

A systems approach to visual impairment surveillance simply implies embracing a broader perspective of the disease experience and an understanding and focus on the complex relationship among factors that influence health. Critical considerations toward this end include: better standardization of data to allow linkage and integration, adoption of a conceptual framework that captures the dynamic disability experience, and utilization of appropriate techniques for the study of complex health-related phenomenon. If successful, the promise of such a paradigm is the ability to "understand and harness the reciprocal relationships among biology, behavior, and environment." (95)

Harmonization and Development of Data Standards

The need for standardized data elements and consensus definitions related to visual impairment has been discussed throughout this report. The adoption and modification of core vision questions to be used in national and international surveys is of central importance to successful vision surveillance. It will be important to identify which diseases will be virtually impossible to include as part of a national vision surveillance effort because of the need for very detailed eye examinations.

In conclusion, current opportunities for visual impairment surveillance in the US are limited. That said, vision surveillance can and should be improved upon by building on, harmonizing and complementing existing systems. BRFSS represents the best existing platform from which to build upon based on its large sample size, continuous administration, and flexibility of infrastructure. Data linkage will be critical to successful efforts going forward. As Cathy Backinger, Brach Chief for the Tobacco Control Research Branch at NCI, and colleagues so concisely summarized in their recent article published in the *American Journal of Preventive Medicine* on the need for enhanced tobacco cessation surveillance, “If the things that get measured are the things that get done, then we need to assure that we are measuring all the components…in a systematic way” (96).

Appendix A: Overall Prevalence Estimates of Eye Disease and Visual Impairment

Visual Impairment

Varying definitions of “blindness” and “low-vision” can complicate the ability to determine prevalence and compare results across studies. For example, the World Health Organization (WHO) defines blindness as best-corrected visual acuity of less than <20/400 in the better seeing eye, and low-vision as acuity better than 20/400 but worse than 20/60 (97). The US on the other hand defines blindness as best-corrected visual acuity of 20/200 or worse in the better seeing eye (98), and low-vision as best-corrected acuity better than 20/200 but worse than 20/40 (which coincides with restrictions on a driver’s license in most US states) (9). Other definitions of blindness and low vision have depended upon the degree of functional impairment associated with visual impairment, such as the inability to drive or work, which may represent more meaningful measures of vision impairment than other more simplified definitions. For example, in The Lighthouse National Survey (1995) on Visual impairment, visual impairment was defined based on self-reported inability to recognize a friend across the room or the inability to read regular newspaper print, even when wearing glasses/contacts. Variations in definitions of low vision and blindness (e.g. clinical vs. self-report, variation in the types of questions asked, differing cut points) in part explain some of the variability of prevalence estimates. Therefore, the development of international standards and guidelines for assessing visual impairment are imperative to the development of appropriate and reliable surveillance systems. Definitions should include aspects of vision, such as visual field, contrast sensitivity, glare sensitivity, color vision, and stereoacuity, associated with functional loss for a more robust and meaningful measure of visual impairment.

Few population-based studies have attempted to establish the prevalence of visual impairment in the US, and those that have are limited in their ability to generalize findings due to geographic and demographic variations in access to health care, co-morbid conditions, and other risk factors for visual impairment (9). For example, in 2004, The Eye Disease Prevalence Research Group (EDPRG) (sponsored by the National Eye Institute and Prevent Blindness of America) estimated cause-specific prevalence rates of visual impairment and determined their distributions across varying demographic groups (i.e. age, race, sex)(9). In order to produce such estimates, prevalence rates were derived from population-based studies conducted within and outside of the US (Western Europe, Barbados, West Indies, and Australia) and applied to the 2000 US population census data. Although inclusion of prevalence rates from countries outside of the US enhanced the robustness of the data, it simultaneously limited the interpretation of findings due to regional differences in diagnostic criteria, access to health care, and treatment services. Furthermore, these data do not include persons younger than 40 years old, since younger adults were not assessed in these population-based studies due to low disease prevalence. Therefore, prevalence estimates derived from these pooled data are likely to underestimate the total population affected by visual impairment. Nonetheless, aggregated data from these studies represents the most current and reliable US population estimates of uncorrectable visual impairment (99).

Based on pooled data from these population-based studies, **blindness is estimated to affect 0.78% (approximately 1 million) US adults over the age of 40**, with an additional **2% (approximately 2.5 million) US adults over the age of 40 impacted by low vision** (9;99). These numbers are expected to increase to 1.6 million and 3.9 million for blindness and low vision (respectively) by the year 2020, largely due to a rapidly growing elderly population (9).

Visual impairment, in itself, is not a discrete disease but is rather a consequence of other underlying conditions of the eye. Visual impairment can occur as a consequence of trauma to the eye, infectious disease, diabetic retinopathy, and/or other age-related eye conditions. The five major contributing conditions to visual impairment in the US are: 1) age-related macular degeneration (AMD), 2) glaucoma, 3) cataracts, 4) diabetic retinopathy, and 5) refractive error. The following discussion on visual impairment is limited to these 5 causes of blindness and low-vision, as they represent the most important contributors to visual impairment in this country upon which limited public health resources should be focused.

Age-related macular degeneration (AMD)

Age-related macular degeneration (AMD) is an eye disease associated with aging and is characterized by the presence of yellow deposits (drusen) in the macula, abnormalities of the retinal pigment epithelium, such as changes in pigmentation, geographic atrophy of the RPE and choriocapillaris, and or/neovascular maculopathy (100). AMD can be detected during a comprehensive eye exam that includes a visual acuity test to measure the ability to see at various distances and a dilated eye exam to examine the retina and optic nerve. (5)

Varying definitions in the epidemiologic literature have been used to determine prevalence estimates of early, intermediate, and advanced AMD. In the most recent NHANES 2007-2008, early ARM was defined by the presence or absence of drusen and/or pigmentary abnormalities; late ARM by exudative ARM signs and/or geographic atrophy (101). The EDPRG defined AMD according to the guidelines published by the International ARM Study Group (102), characterizing intermediate AMD as the presence of at least 1 large druse (≥ 125 µm in diameter) in 1 or both eyes, and advanced AMD as the presence of neovascular age-related macular degeneration or geographic atrophy in either eye. According to this definition, study authors estimated that **6.12% (7.3 million) and 1.47% (1.75 million) of US adults over the age of 40 have *intermediate and advanced* AMD**, respectively. (8). Another study by the EDPRG demonstrated that AMD is responsible for approximately 430,000 and 480,000 prevalent cases of blindness and low-vision (respectively) among US adults over the age of 40 (9).

More recently, in 2009 Rein et al (103) published US population projections for early and advanced AMD through the year 2050, given various treatment scenarios. Authors of this study utilized the Age-Related Eye Disease Study (AREDS) definition of AMD, classifying subjects with early AMD if they had large drusen (≥ 125 µm in diameter) *or* retinal pigment epithelium (RPE) abnormalities, and advanced AMD if they had evidence of choroidal neovascularization (CNV) or geographic atrophy in either eye. Authors of this study projected that there will be **9.1 million cases of *early* AMD in 2010**, and that treatments are not likely to prevent new cases of AMD. However, authors also estimated that **1.7 million people would have *advanced* AMD in 2010**, and that increased use of antioxidant vitamins in patients with early stages of AMD and anti-vascular endothelial growth factor (VEGF) therapy for subfoveal CNV could reduce the prevalence of AMD-related visual impairment by 35%. It should be noted that these estimates are merely forecasted projections based on an aging population, and as Klein and Klein point out in their 2009 JAMA editorial, “forecasting is iffy business”(104).

Using self-reported data has yielded highly similar prevalence estimates for AMD. For example, results from a nationally representative sample in the US have demonstrated that 2 million US adults over the age of 18 have macular degeneration, based on a positive response to the questions ""have you ever been told by a doctor or other health professional that you had macular degeneration, and if so, did you have the condition during the past 12 months?" (11). Because AMD affects central vision and is noticed by the patient, ***using self-reported measures of AMD may represent a cost-effective alternative to more lengthy and costly eye examinations.***

Diabetic Retinopathy

Diabetic retinopathy (DR) occurs as a complication of diabetes mellitus and results from damage to blood vessels in the retina. With delayed or no treatment, DR can lead to impaired vision and even blindness (105;106) with nearly 100% of type I diabetics and more than half of type 2 diabetics becoming blind within two decades of disease onset (107). In fact, research has shown that persons with DR are 25 times as likely as the general population to develop blindness, (108) representing the number one cause of blindness among working aged Americans (12). As the population of people with diabetes continues to grow, particularly among certain racial and ethnic groups (109), the contribution of DR to the overall burden of visual impairment will become increasingly substantial. A study by Saadine et al (110) predicted that the number of Americans 40 years and older with DR will triple between 2005 and 2050.

Varying outcome measurements of DR have produced differing prevalence estimates across epidemiologic studies. For example, the EDPRG pooled data from 8 population studies which used a color fundus photograph reading center to diagnose DR among diabetics over the age of 40. Based on these data, **prevalence of DR in the US was estimated at 3.4% (4.1 million) of US adults over the age of 40** (12). According to this study, of the 4.1 million persons with DR, nearly 900,000 individuals will develop vision-threatening DR.

In contrast, self-reported data from the National Health Interview Survey (NHIS) produced very different estimates. Based on positive answers to the question "have you ever been told by a doctor or other health professional that you had DR, and if so, did you have the condition during the past 12 months?" estimates for the prevalence of DR dropped to about 1.3

million (11). Differences in self-reported and clinically verified estimates could reflect the fact that earlier stages of DR produce no visual symptoms and are unlikely to result in patients seeking medical attention. Poorer access to health care may also explain some of the incongruence between self-reported and clinically verified prevalence estimates for DR. This is especially likely given that major risk factors for DR include poor glucose control and hypertension (111), two preventable conditions that can be managed through primary care prevention, and whose uncontrolled presence is linked to poorer access to health care(112-114). As such, surveillance systems that utilize self-reported data to determine the magnitude of DR (and perhaps other eye diseases that are linked to poorer access to health care) are unlikely to capture the true magnitude of the problem.

Glaucoma

Glaucoma is a characteristic optic neuropathy that produces loss of peripheral vision initially and only leads to central visual impairment late in the disease. Glaucoma can occur at high or low eye pressure. (115) Although there are several types of glaucoma, open-angle glaucoma is the most common form, affecting approximately **1.86% (2.2 million) of US adults over the age of 40** (26). According to a study by the EDPRG, glaucoma is responsible for more than 85,000 and 98,000 prevalent cases of blindness and low-vision (respectively) among US adults over the age of 40 years(9).

There is currently no gold standard for defining open-angle glaucoma in epidemiologic studies (26), although most definitions have included evidence of visual field abnormalities and/or optic disc cupping (116-118), determined through detailed and lengthy ophthalmological exams with or without photographic documentation of the optic nerve head status. The necessity of time-consuming and costly exams to diagnose glaucoma may not always be feasible for the purposes of surveillance, and self-reported data may provide a less costly alternative for measuring the prevalence. However, it is important to consider that several studies have demonstrated that only half of the people with glaucoma have actually been diagnosed (26;119). Furthermore, many who report a diagnosis of "glaucoma" do not have the disease and are either suspects or have no clinical evidence of glaucoma (120). This finding is supported by the significantly higher prevalence of glaucoma resulting from self-reported data (11). Based on positive responses to the question "have you ever been told by a doctor or other health professional that you had glaucoma, and if so, did you have the condition during the past 12 months?", it was estimated that 4 million people over the age of 18 had glaucoma, representing a prevalence nearly twice as large as what was reported by the EDPRG (using clinically verified data).

Cataract

Cataract is a clouding of the crystalline lens that most frequently occurs with aging and is the most common cause of low vision and blindness (other than refractive error). Cataracts can occur in one or both eyes, but does not spread from one eye to the other. (121)

Many studies rely on the Lens Opacities Classification System II (LOCS II) to measure the presence of cataracts due to its ease of administration and good reproducibility (122). However definitions of cataract used to determine prevalence have not been consistent in that some include the requirement of visual impairment and some do not. For example, using a definition for cataracts that did not require visual impairment[1], the EDPRG estimated that approximately **17.2% (20.5 million) of US adults over the age of 40 have cataracts in at least one eye (31).** Recently published national data on self-reported cataracts in the United States estimated that **8.6% (17 million)** of US adults over the age of 18 had cataracts (11). According to the EDPRG, cataracts are responsible for approximately 112,000 and 1.3 million prevalent cases of blindness and low-vision (respectively) among US adults over the age of 40 years(9).

Refractive error

A refractive error occurs when the eye cannot clearly focus images, resulting in blurred vision. The most common types of refractive errors are 1) myopia (nearsightedness); 2) hyperopia (farsightedness); 3) astigmatism (irregularly curved cornea); and 4) presbyopia (inability to focus on near objects that occurs with aging). Refractive errors are not preventable, but can easily be treated with corrective eye glasses or contact lenses, and in some cases corrective surgery. (123) According to The Eye Diseases Prevalence Research

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[1] Presence of a cataract was defined by having either 1) posterior subcapsular cataract; 2) cortical cataract occupying 25% or more of the lens visible through a dilated pupil; or 3) nuclear cataract greater than or equal to the penultimate grade in the system used (i.e. grade ≥ 3 in the Wilmer Cataract Grading System, and in the LOCS II and grade ≥4 in the Wisconsin Cataract Grading System)

Group, approximately 25.4% (30.4 million) and 9.9% (11.8 million) of US adults over the age of 40 have myopia and hyperopia (respectively) (36). Vitale and colleagues assessed the prevalence of myopia using data from the 1971-1972 National Health and Nutrition Examination Survey (NHANES) and 1999-2002 NHANES (124). Results of this study showed that prevalence of myopia increased significantly among people ages 12 to 54, from 25.0% in 1971-1972 to 41.6% in 1999-2002. In another study by Vitale and colleagues, authors estimated that of the 14 million Americans over the age of 12 with visual impairment (defined as distance visual acuity of 20/50 or worse), more than 11 million cases were due to uncorrected refractive error(125).

Appendix B: Prevention and Treatment of Eye Disease and Visual Impairment

A significant proportion of visual impairment associated with the four major eye diseases could be reduced through preventive and therapeutic treatment services. There are some key differences between the major eye diseases that should be considered to determine whether to focus public health efforts on prevention, early detection, treatment, or rehabilitation.

Currently, there is no proven way to prevent age-related macular degeneration, although several studies have attempted to identify risk factors that provide formative evidence that could inform possible prevention strategies. For example, studies have demonstrated an association between cardiovascular risk factors (smoking and high cholesterol) and AMD, which suggest that proper management of these factors may prevent the onset of AMD (126;127). Results from a meta-analysis showed that consumption of omega-3 fatty acid-rich foods may also decrease incidence of AMD (128). Although studies on ultraviolet radiation as a cause of AMD are inconsistent, there is some evidence that chronic exposure to sunlight may increase the risk (129;130).

There is currently no curative treatment for people with AMD, though several therapies (laser surgery, photodynamic therapy, antioxidants, and eye injections) can slow progression and preserve visual impairment related to the disease. There is evidence showing that the amount of time from diagnosis to treatment is a significant predictor for visual impairment associated with AMD (131), therefore, timely diagnosis and treatment is of utmost important for affected individuals.

Preventing the onset of retinopathy among persons with diabetes should be the primary goal for preventing blindness among patients with diabetes. DR can be prevented through tight glycemic and blood pressure control in persons with diabetes (132-135).

Once a patient develops proliferative retinopathy (the most advanced stage of retinopathy), there is about a 50% chance of becoming blind (136-138). With treatment, however, this risk is significantly reduced (less than 5%), especially if performed early rather than later in the disease course (139). Current treatment therapies include focal laser photocoagulation (140), vitrectomy (141;142), and intravitreal injections of steroids(143).

There are currently no known mutable risk factors for the onset of glaucoma other than intraocular pressure (24;144) which can be lowered with medication.

While nerve damage and visual impairment associated with glaucoma cannot be reversed, glaucoma can be controlled with the use of eye drops, medications, and surgery which may prevent further visual impairment. Because glaucoma is a slow-progressing disease, early treatment interventions could significantly reduce visual impairment in affected individuals. Without treatment, however, permanent loss of vision is likely to result.(115)

There is strong evidence for the causal relation of excess sunlight exposure (145;146)and use of corticosteroids (147;148) in the development of cataracts. There is more limited evidence supporting the link between smoking and incidence of cataracts (149;150). Even less conclusive is the evidence for an association between antioxidant supplementation and decreased risk for cataracts (151).

For people with cataracts, corrective lenses have proven very effective in improving vision once vision becomes impaired. Surgical treatment is recommended only in patients for whom visual impairment impedes on their ability to perform normal activities. Surgery to remove the cataract has been shown to be successful, with 90% of patients experiencing significantly improved vision after surgical removal of the cataract. Although surgical removal is the only proven available treatment for cataract, some more recent studies have also looked into non-surgical medical treatment (e.g. anti-cataract drugs, such as carnosine) that may provide a less costly alternative for those who cannot afford the high cost of surgery(152).

Appendix C: The Economic Burden Associated with Eye Disease and Visual Impairment

A 2007 report (153) of the economic burden associated with visual impairment (due to AMD, cataracts, DR, and glaucoma) estimated the annual total financial burden to the U.S. economy due to the major adult vision problems (visual impairment, blindness, AMD, DR, primary open-angle glaucoma, cataracts, and refractive error) was **$35.4 billion**, of which $16.2 billion was attributed to direct medical costs, $11.1 billion for other direct costs, and $8 billion in lost productivity. Medical costs include outpatient and inpatient physician services, facility costs, medications, multivitamins, eyeglasses, and contacts. For example, in another paper by Vitale and colleagues, these authors estimated that it would cost $3.8 billion annually just for refractive correction alone (corrective lenses and refractive examination to all Americans over 12 with poor distance vision). Other direct costs in the Rein 2007 analysis included use of guide dogs, nursing home care, and government programs for the visually impaired. Productivity loss was defined in the 2007 report as lost wages and labor among working aged individuals that was due to visual impairment. For example, only 44% and 30% of visually impaired and blind individuals (respectively) were in the work force, compared to 85% of people without any visual impairment. Similarly, the estimated average annual salary of visually impaired and blind individuals was $23,345 and $21,374 (respectively) compared to average earnings of $33,195 among persons without any visual impairment. Authors of this study further note that these costs reflect only a conservative estimate of the true burden, since they do not take into account the indirect costs of vision-related disability such as depression and injury. A similar analysis was done by Frick and colleagues (154), using self-reported data from the Medical Expenditure Panel Survey rather than claims data used by Rein et al. Use of self-reported data allowed study authors to incorporate into their analysis the cost of informal care-givers and loss of well-being due to visual impairment and blindness (authors assigned a $50,000 for loss of well-being for 1 year). Authors of this study estimated the annual economic impact associated with visual impairment and blindness to be approximately $16 billion, or about $4,000 for each affected person. Regardless of the exact dollar amount, public health interventions to improve screening and treatment of eye diseases and other underlying conditions (e.g. diabetes mellitus) are likely to result in a sizeable reduction in the economic burden currently associated with visual impairment.

Appendix D: Definition of Terms

Term	**Definitions**
AMD	Age-related macular degeneration; an eye disease associated with aging and characterized by the presence of yellow deposits (drusen) in the macula, abnormalities of the retinal pigment epithelium, such as changes in pigmentation, geographic atrophy of the RPE and choriocapillaris, and or/neovascular maculopathy
Blindness	A total lack of visual perception- various scales are used to define blindness
Cataracts	A clouding of the crystalline lens that most frequently occurs with aging
Disparities in Vision Health	Differences in rates of eye disease occurrence, visual impairment, and/or related disability according to race, gender, age, socioeconomics (income, education), and/or geographic location
DR	Diabetic retinopathy; occurs as a complication of diabetes mellitus and results from damage to blood vessels in the retina
EDPRG	The Eye Disease Prevalence Research Group; a consortium of principle investigators sponsored by the National Eye Institute and Prevent Blindness of American to conduct population-based studies of eye disease and visual impairment
Glaucoma	A characteristic optic neuropathy that produces loss of peripheral vision initially and only leads to central visual impairment late in the disease
Low-Vision	A lesser degree of vision loss- various scales have been used to define low-vision
Refractive error	Occurs when the eye cannot clearly focus images, resulting in blurred vision. The most common types of refractive errors are 1) myopia (nearsightedness); 2) hyperopia (farsightedness); 3) astigmatism (irregularly curved cornea); and 4) presbyopia (inability to focus on near objects that occurs with aging)

Rehabilitation services	Vision rehabilitation services include aids and devices to improve use of whatever vision functioning remains, as well as training and education for patients and their families designed to increase independence and improve quality of life
Surveillance	The ongoing, systematic collection, analysis, interpretation, and dissemination of outcome-specific data
Vision Health Surveillance	Includes surveillance of eye disease, visual impairment, related disability, and access to vision and eye care services
Vision-Related Disability	The compromised ability to perform routine activities of daily living (e.g. eating, bathing) and/or engage in social activities due to visual impairment. Disability due to visual impairment can also manifest as depression, anxiety, or other declines in mental health
Visual Acuity	The clarity or clearness of the vision; the ability to distinguish details and shapes of objects
Visual Impairment	Includes correctable vision loss (vision loss due to refractive error) and uncorrectable vision loss (blindness and low vision)

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