



**Paul Lee, MD, JD**  
**University of Michigan**

## Surveillance of Vision Problems

# Surveillance of Vision Problems

Paul P. Lee, MD, JD

- University of Michigan
- Duke University
- PBA (past board member)
- CDC (past consultant)

- Conflicts of Interests

- Genentech
- Pfizer
- Quorum Consulting
- Health services research funding

# Summit Agenda

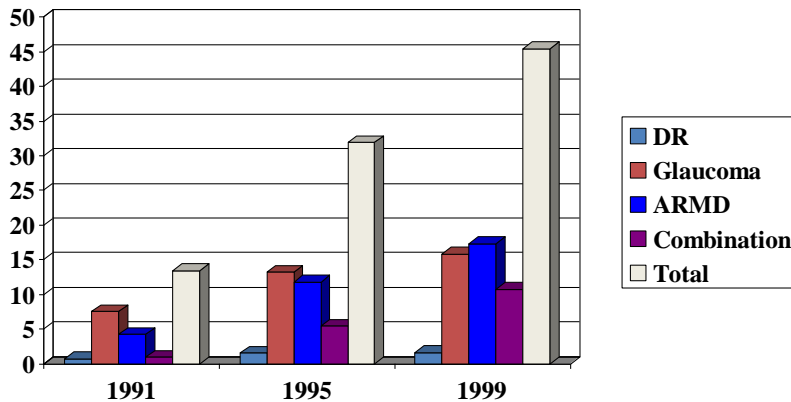
- Vision Problems in US
- Economic Impact of Vision Problems
- Co-morbidities and Vision
- National Plan for Eye and Vision Research
- **Surveillance**
- Integrating Vision into Public Health Programs
- Low Vision
- Keynote: Diabetes and the Eye

# Why Do We Care?

## Impacts Almost Everyone

Prevalence (%) of Chronic Eye Diseases in Cohort Panel in Medicare Population

Lee PP et al, Arch Ophth 2003



## Vision Care is Cost Savings to Society

LXIII Edward Jackson Memorial Lecture:  
Eye Care: Dollars and Sense

HUGH R. TAYLOR, AC, MD

• **PURPOSE:** The development of health economic data for vision loss and eye disease is described.

• **DESIGN:** Data from population-based epidemiologic studies of eye diseases, studies of the impact of vision loss on daily living, Australian national health-care costs, causes, and demographic projections were combined to develop a model of the economic impact of vision loss in Australia.

• **METHODS:** Data were considered to assess the current magnitude and costs of vision loss and to make projections as to future costs. Further analysis investigated the costs and economic benefits of various interventions to address avoidable vision loss.

• **RESULTS:** The amount of vision loss increases threefold and the number with vision loss will double in 20 years. Vision loss cost Australia a total of AU \$9.85 billion in 2004. Vision loss makes seventh in causes of loss of well-being. An intervention package to address avoidable vision loss would cost AU \$190 million or AU \$5,591/Quality Adjusted Life Year (QALY) and give lifetime savings of AU \$911 million.

• **CONCLUSIONS:** Although specific for Australia, these data can help guide health care policy debate and the priority given to eye care in other developed economies. For each dollar spent on the prevention of vision loss and eye care, there is a 5 dollar return to the community. (Am J Ophthalmol 2007;143:1-8. © 2007 by Elsevier Inc. All rights reserved.)

Previous Jackson lectures including Paul Litcher and Dan Albert have given wonderful descriptions of Edward Jackson's life and contributions.<sup>1-4</sup> For those of you who are not familiar with these may I recommend strongly these reviews as being of high interest.

### THE PRIORITY GIVEN TO VISION LOSS

LIKE ALL OPHTHALMOLOGISTS, JACKSON INSTINCTIVELY knew the importance of good vision and eye health. The treatment of eye disease and the prevention of blindness is our highest priority, it is our calling. As ophthalmologists, we all accept the importance of good vision without question.

In 1980, the World Health Organization (WHO) asked me to review eye services in Pakistan at the request of the Pakistani government. When I presented my report to the Pakistani Minister of Health, he received the report, but then he stated vision loss was just not a priority for him. As Health Minister, he was faced with many problems; infant mortality, maternal deaths, the provision of primary health care. He had expensive hospitals to run, and also the health problems of a million Afghan refugees present in Pakistan at that time.

The problem I faced was how to convince others of the importance of eye care services and to prioritize them relative to other pressing health demands. This is a challenge we all face, both as individual ophthalmologists and as a profession, whether we are working in our own hospitals, or lobbying politicians and policy makers. On every side, there is competition for health dollars.

### POPULATION-BASED EVIDENCE

EPIDEMIOLOGIC FIELD STUDIES CAN PROVIDE A WIDE range of information. In ophthalmology, they have given us great information about the prevalence and incidence of eye diseases and disease risk factors. In 1991, there were no coherent data on the magnitude or causes of vision loss in Australia. At best, only fragmented reports were available. To address this gap, the "Melbourne Visual Impairment Project" (VIP) was started. It was a large, population-based

IT IS A GREAT HONOR TO BE INVITED TO GIVE THE LXIII Edward Jackson Memorial Lecture. Since my first Academy meeting I have enjoyed and learned much from the giants of ophthalmology who have been selected to receive this recognition over the years by the American Ophthalmic Publishing Company and the Academy.<sup>1</sup> I am proud to be the ninth international Jackson Lecturer and the first from Australia.

Accepted for publication Oct 2, 2006.  
From the Centre for Eye Research Australia, University of Melbourne, East Melbourne, Victoria, Australia.  
Inquiries to Hugh R. Taylor, AC, MD, Centre for Eye Research Australia, University of Melbourne, 32 Gairdner Street, East Melbourne VIC 3002, Australia; e-mail: h.taylor@unimelb.edu.au.

# Healthy People 2020

- **GOAL:** Improve the visual health of the Nation through prevention, early detection, timely treatment, and rehabilitation.
- Objectives address screening and examinations for children and adults, early detection and timely treatment of eye diseases and conditions, injury prevention, and the use of vision rehabilitation services.

# Healthy People 2020 Objectives

- Increase the proportion of preschool children aged 5 years and under who receive vision screening.
- Reduce blindness and visual impairment in children and adolescents aged 17 years and under
- Reduce occupational eye injuries

# Healthy People 2020 Objectives

- Increase the proportion of adults who have a comprehensive eye examination, including dilation, within the past 2 years
- Increase the use of personal protective eyewear in recreational activities and hazardous situations around the home
- Increase vision rehabilitation

# Healthy People 2020 Objectives

- Reduce visual impairment in US population
  - Uncorrected refractive error (12 and older)
  - Diabetic retinopathy
  - Glaucoma (45 and older)
  - Cataract (65 and older)
  - Age-related macular degeneration (AMD) (45 and older)



# Healthy People 2020 Activities

## Utilization of Services

- Childhood vision screening from 40.1 to 44.1 %
- Adult comprehensive exam from 55 to 60.5%
- Rehabilitation
  - Services from 30.1 per 1000 with impairment to 33.1
  - Device use from 11.2 to 12.3 % with impairment

## Reduce Visual Impairment

- 17 years and under from 28.2 per 1000 to 25.4
- Adult causes by 10%
  - Uncorrected refractive from 136.1 to 122.5 per 1000
  - DR from 34.1 to 30.7 per 1000 with diabetes mellitus
  - Glaucoma from 13.7 to 12.3 per 1000 over aged 45

# Public Health Surveillance

CDC Comprehensive Plan for Epidemiologic Surveillance, 1986

- “... the ongoing systematic collection, analyses and interpretation of health related data essential to planning, implementation and evaluation of health practices...The final link in the surveillance chain is to apply the data toward prevention and control.”

# CDC Expert Panel - Surveillance of Vision Disparities Summer 2010

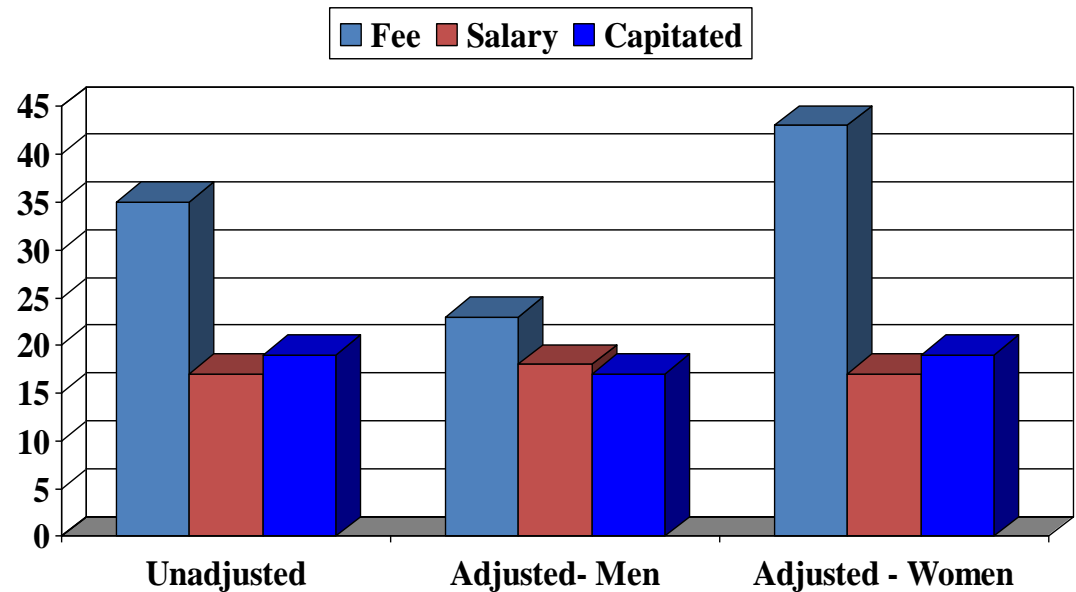
- Sheila West (Co-Chair)
- Paul Lee (Co-Chair)
- Sandra Block, OD, Med
- Janine Clayton, MD
- Mary Frances Cotch, PhD
- Colin Flynn, ScM
- Linda Geiss, MA
- Ronald Klein, MD, MPH
- Timothy Olsen, MD
- Cynthia Owsley, MSPH, PhD
- Susan Primo, OD, MPH
- Gary Rubin, PhD
- Asel Ryskulova, MD, PhD, MPH
- Sanjay Sharma, MD, MSc, MBA
- David Friedman, MD, MPH, PhD
- Xinzhi Zhang, MD, PhD
- John Crews, DPA
- Jinan Saaddine, MD, MPH

# Surveillance – 3 Main Functions

- Monitoring
  - Detect new problems; assesses and tracks magnitude of problems; risk factors of population
- Prioritization
  - Target key problems, groups; set national objectives; identify research needs; allocate resources
- Evaluation
  - Track response effectiveness; progress towards goals

# Key Target Populations – Disparities

- Age
- Ethnicity
- Race
- Gender
- SES
- Geographic



Cataract Surgery Rates in Southern CA  
Lubick, et al, JAMA, 1997

# Target Populations for Surveillance

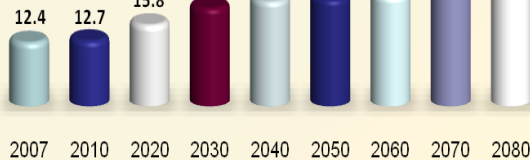
## Age / Ethnicity and Chronic Eye Disease (Glaucoma)

### The Aging U.S. Population

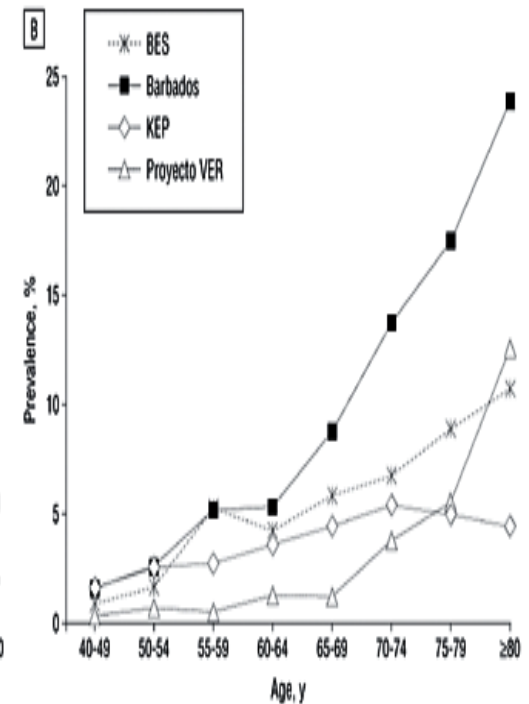
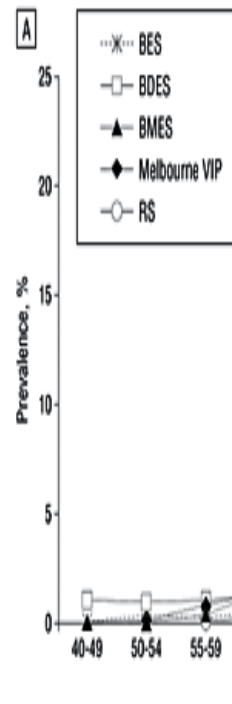
Number of individuals  
age 65 or over (in millions)



Percentage of  
Population



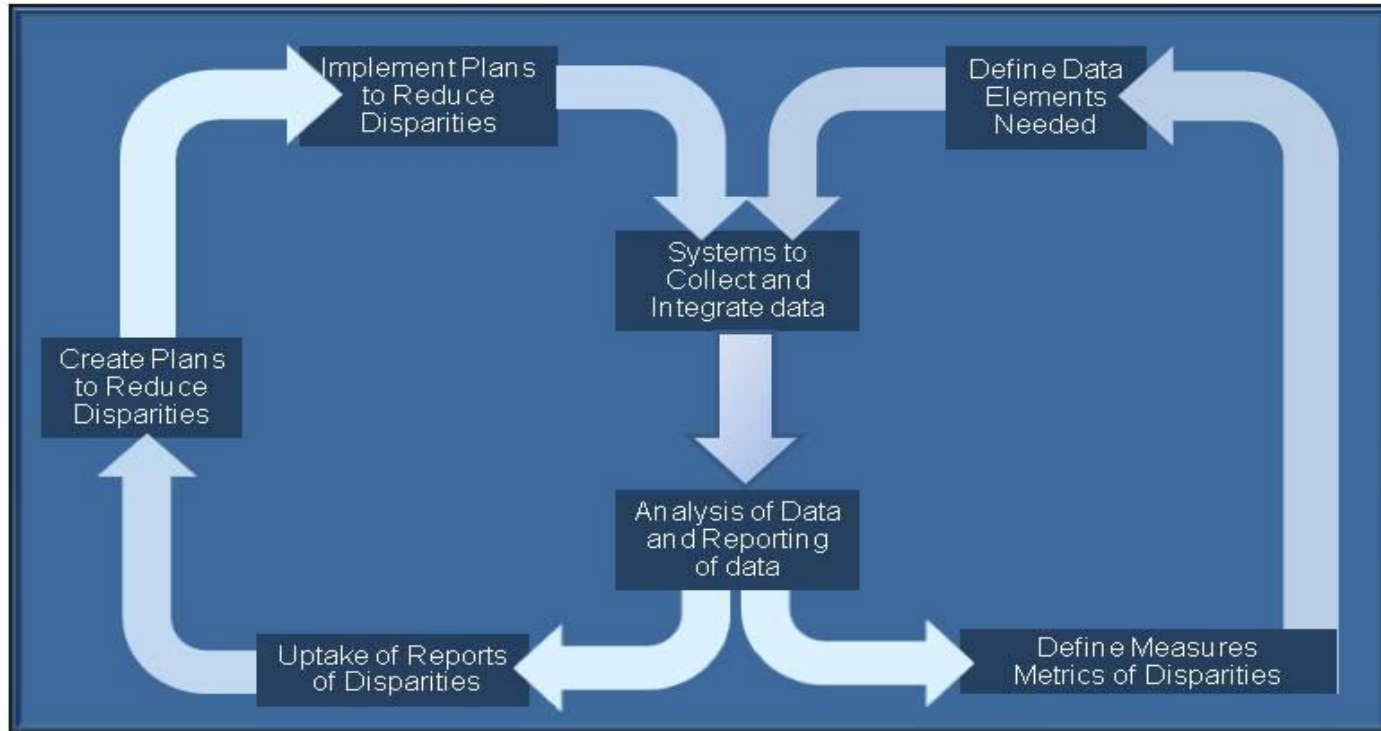
Source: U.S. Social Security Administration  
2007 OASDI Trustees Report (April 2007), Table V.A.2



The Eye Diseases Prevalence Research Group, Arch Ophthalmol 2004;122:532-538.

# Essential Surveillance Methods for Healthy People 2020

- Define valid endpoints and groups of interest
- Collect data using reliable means
- Provide usable information to those who interact directly with residents of US
- Implement efforts to reach those who would benefit
- Re-collect data after efforts



**FOCUS ON EYE HEALTH:  
A National Summit**



# Functions (Minimum) of Vision Surveillance System to Achieve Objectives

- Establish standard definitions of endpoints for Healthy People 2020 objectives
- Reliably collect data on Healthy People 2020 objectives
- Integrate with “effectors” who can implement programs to increase utilization of appropriate services and reduce visual impairment
- Feedback loop of endpoint measurement of progress towards meeting objectives

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# What are Potential Endpoints

Adapted from Lee P, J of Glauc, 1995; Vitale S, 2009

	<u>Organ</u>	<u>System</u>	<u>Person</u>
<b>Clinician</b>	<b>IOP / RNFL</b>	<b>Visual Acuity Contrast Sensitivity</b>	<b>Task Performance</b>
<b>Person</b>	<b>Symptoms</b>	<b>Vision Function</b>	<b>Health Perceptions</b>
<b>Payor</b>	<b>Costs of care</b>	<b>Cost-effective</b>	<b>Satisfaction</b>
<b>Society</b>	<b>Surveillance</b>	<b>Utilities</b>	<b>Disability</b>

# Defining Vision Loss for “Visual Impairment”

- “Final common pathway” of visual diseases
- Known performance / reliability for “performance-based” measures
  - Visual acuity (BUT standardize definition)
  - Contrast sensitivity
- Relationship to societal policies
  - Driving
  - Disability

# Additional Measures of “Vision Loss”

- **Patient reported outcomes** (PRO's) to assess visual function – **patient centered approach**
  - Multiple questions / instruments available
  - Independent but related to traditional measures
  - Potential cultural differences
- Observed test performance for mobility, driving, task performance – cost / availability

# Sources of Data for Vision Loss

## Current HP 2020 Sources

- National Health Interview Survey (NCHS/CDC)
  - Vision supplement in 2002/08
- National Health and Nutrition Examination Survey (NCHS/CDC)
  - Vision examination of 5000
  - Examination stopped 2009
- National Electronic Injury Surveillance System
- HHS Health Indicators Warehouse

## Potential Additional Sources

- Behavioral Risk Factor Surveillance System (BRFSS)
  - CDC telephone tracking survey
  - State level data (23 states)
  - Discontinued in 2011
- Health and Retirement Survey (NIA)
  - Linked claims data
- American Community Survey (Census Bureau)
- Claims data (Javitt J, et al, Ophthalmology 2007)

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# Outcomes of Eye Care – Why Regular Eye Care is Important

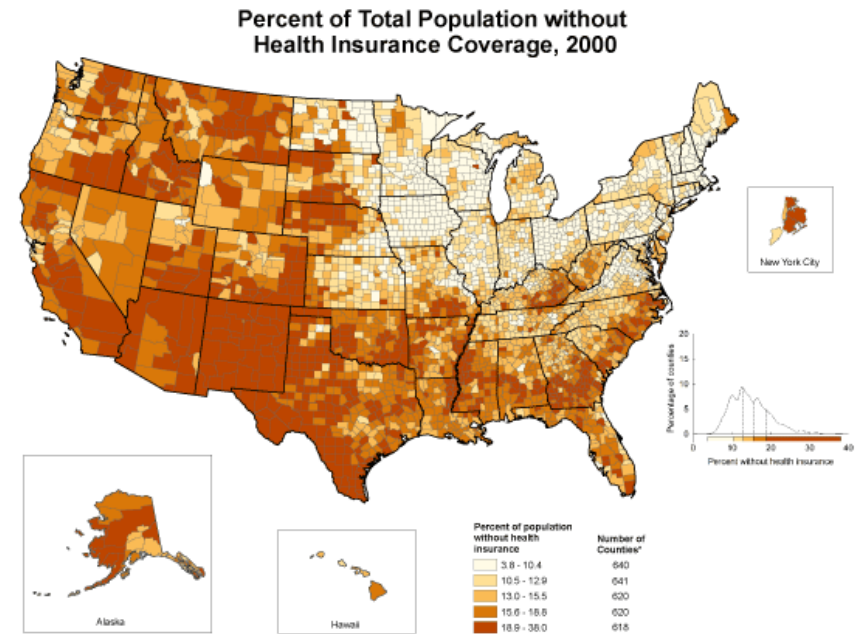
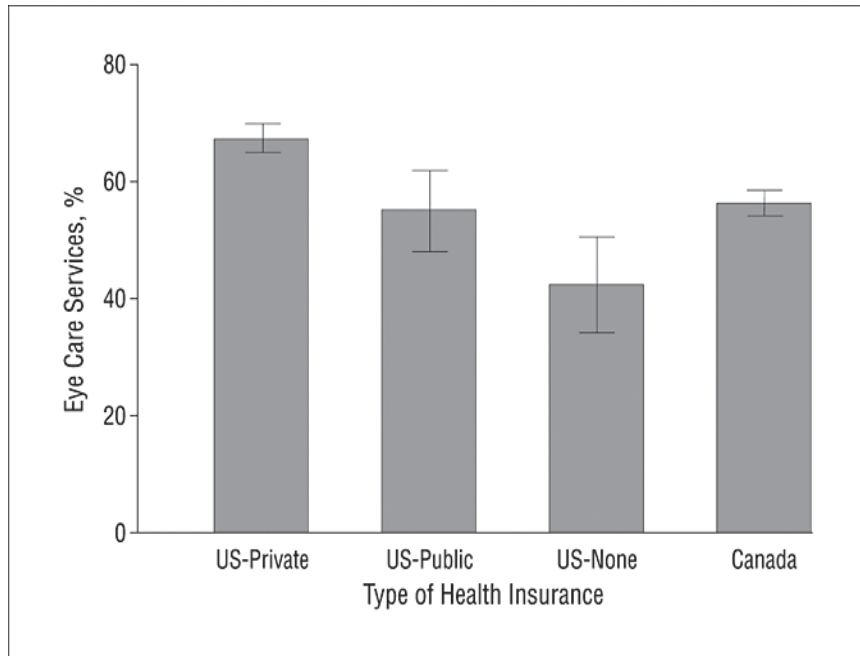
Sloan FA, et al, JAGS, 2005

- 21% of population (NLTCs) developed increase in IADL limitations between 1994 and 1999
- Effect of moving from 1.64 annual eye exams to 2.64 annual exams (mean of 2.14)
  - = decrease from 27.5% to 14.5% ( $p = 0.041$ )
- DM / Cataract / AMD / Age / Female / Yrs. of education / DxCG / Less HMO / Dementia increased risk



# Insurance and Use of Eye Care

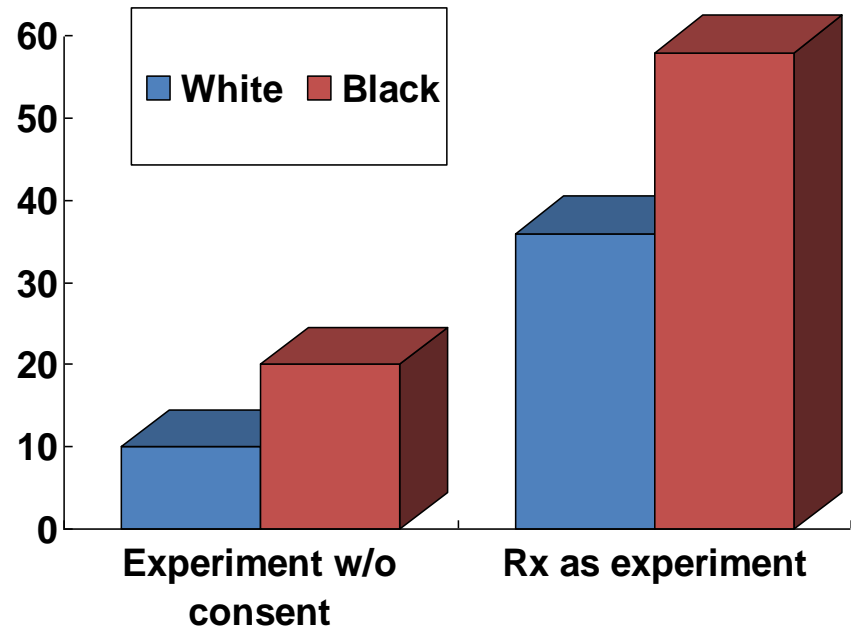
Zhang X, et al, Arch 2008



# Focus Groups: Why People Don't Use Services

Owsley et al, IOVS, 2006 // SGIM 1995

- Affordable and accessible transportation
- Cultural sensitivity
- Age-appropriate communications
- **Trust-building**
- Differing expectations



# Measuring Utilization of Eye Care

- Direct endpoint in Healthy People 2020
- Data sources noted
  - National Health Interview Survey (NHIS)
  - HHS Health Indicators Warehouse
- Additional data sources
  - Claims linked databases
    - Medicare / Medicaid
    - Current Medicare Beneficiary Survey
    - Commercial insurers
  - AHRQ datasets
    - Medical Expenditure Panel Survey (MEPS)
    - Healthcare Utilization Project (HCUP)
  - National Health Surveys

# Possible Future Data Sources

## Visual Impairment

- Electronic Health Records
- Patient Registries
- Online Systems
  - Communities
  - Search queries (e.g., flu)

## Care Utilization

- Electronic Health Records
- Patient Registries
- Robust claims data analyses with ICD-10 coding

# Engaging **Care System** to Meet Healthy People 2020 Objectives

- Essential link in continuous improvement / learning systems approach
- Enterprise approach with coordination of care system stakeholders
  - Support surveillance system
  - Coordinate implementation programs / approaches

# Additional Implementation Models

## Non- US Approaches

### Aravind (India)

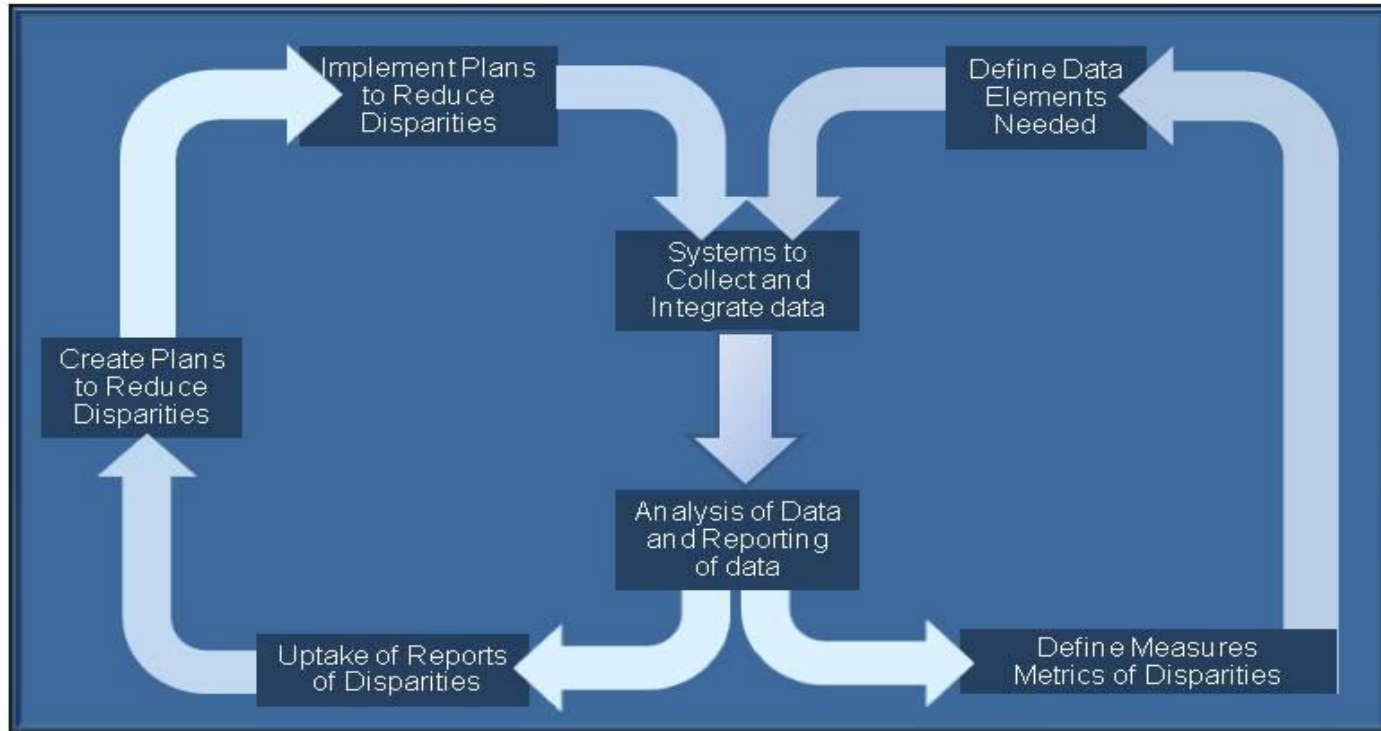
- A leading model for cataract surgery programs (“Focus Factory” approach)
- Business and Value-based as well as care model
- Numerous business cases / studies of efficiency and economic models
- ? Scalability to other eye conditions
- Tele-ophthalmology with vans with satellite connections

### LV Prasad (India)



# Research and Work Agenda

- Harmonize PRO questions and endpoints
- Better understand relationships between various endpoints for vision loss
- Assess and where appropriate integrate new methods of measuring vision performance
- Support methods of collecting nationally representative data on HP 2020 objectives

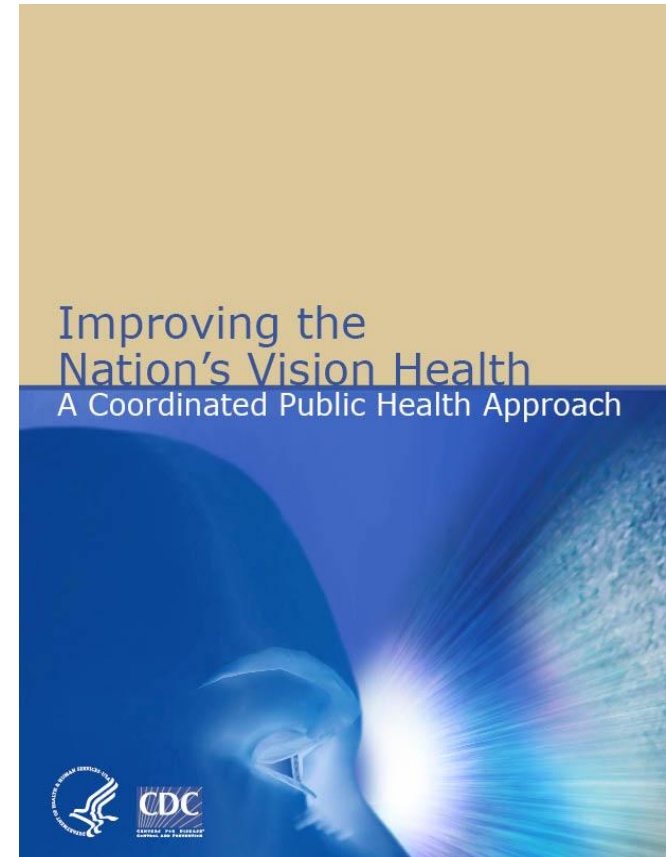


## FOCUS ON EYE HEALTH: A National Summit



# Surveillance's Role

- Monitor / Prioritize / Evaluate
  - Vision loss
  - Use of eye care
  - Eye injury and protection
- Integrate data with programs to meet Healthy People 2020
  - Reduce disparities



# Eye Care for the Future

Hugh Taylor, Wiesenfeld Lecture, IOVS, 2002

- Poor vision is bad for you
- Poor vision is much more common than we think
- Lots of simple things to be done for poor vision
  - Refractive error
  - Cataract
  - Diabetes
  - Glaucoma
  - AMD
- Vision 2020 and national action plans (e.g., Healthy People 2020)

## L E C T U R E

### Eye Care for the Future The Wiesenfeld Lecture

Hugh R. Taylor

I am particularly proud to give the Mildred Wiesenfeld Lecture because she was truly a great lady. Mrs. Wiesenfeld died in 1997 at the age of 76.<sup>1,2</sup> She had lost her vision as a teenager to retinitis pigmentosa, but when she was only 25, she established the National Council to Combat Blindness, which soon became known as Fight for Sight. Its first research grants were provided in 1947 and, over the years, many of the young researchers became the leaders in ophthalmology in the United States and overseas. In 1949, Mildred Wiesenfeld started working with others to have blindness added to the mandate of the National Institute of Neurologic Diseases and she continued pressing until the National Eye Institute was finally established. Fight for Sight is a very important supporter of eye research, particularly focusing on young researchers and fellowship applications. ARVO took over the peer review of these applications in the mid 1980s, and this has continued under the leadership of Art Silverstein. In 1988, Fight for Sight became the research division of Prevent Blindness America.

I was very proud to receive the first Fight for Sight citation for achievement in clinical research at ARVO in 1980 as a very young researcher. I take this opportunity to recognize the great contribution of my colleagues and mentees, with whom I shared this award: Art Silverstein, Chan Dawson, and Bob Prendergast. I had the distinct privilege of winning this award a second time in 1987, this time in collaboration with our President, Sheila West, Beatrice Hixson, and other colleagues. It was during this time that I also had the pleasure of meeting Mrs. Wiesenfeld.

Mrs. Wiesenfeld enlisted many famous people to support her work, ranging from Bob Hope to Liza Minnelli, and she continued to work full time until her death. Her enormous contribution was recognized by ARVO and the American Academy of Ophthalmology and also by President Harry S. Truman. Mildred Wiesenfeld was passionate about the importance of ophthalmic research and the need to make a difference in people's lives.

#### POPULATION-BASED DATA

I have chosen to talk about eye care for the future, but before you can look at the future, you have to know where you are. The work that I present here draws on the experience of many studies, but particularly on the work that we have done in Melbourne. We are based at the Royal Victorian Eye and Ear Hospital, which is as much an "ivory tower" as you will find

anywhere. However, we were concerned to find the status of eye care and eye disease in our community, and to do this we had to get out to where the people are, rather than wait and examine only those who came to see us at the clinic.

As with the other major population-based studies such as the Beaver Dam Eye Study, the Blue Mountains Eye Study, the Rotterdam Eye Study, the Salisbury Eye Study, and so forth, we first defined a particular area and then went door to door to do a private census to identify every resident older than 40 years.<sup>3</sup> We set up a local examination site with all our equipment in a suitable local house or office. We collected detailed background information and medical histories from participants. We used standardized measurements of acuity, refraction, and so forth and standardized eye examinations with photographs of the lens, retina, and discs that were all later graded. For those who could not come to our examination site, we conducted examinations at home. We wanted to make sure that nobody who was in the sample escaped our net if we could help it.

Our initial work was done over several years and involved nine randomly selected sites in the Melbourne metropolitan area that gave us an urban sample of 3271.<sup>4</sup> We then randomly sampled nursing homes in the areas around the field sites to get a sample of 403 people in aged care and nursing homes.<sup>5</sup> Finally, we examined a rural sample of 1473.<sup>6</sup> We then had a representative sample and could reconstruct the distribution of eye disease across the whole community. We had examined a total of 5147 people aged more than 40 years; the oldest participant was 103. Overall, we had a very good participation rate of 86%. Having gathered these data, it was just a "simple matter" of feeding them into the computer, turning the handle three times, and out comes all the information. Basically, there are only three things you need to know.

#### 1. Poor Vision Is Bad for You

The first thing to recognize is that poor vision is bad for you, and now data are available to quantify this. Data from the Salisbury Eye Study and the Blue Mountains Eye Study show that even a moderate level of visual impairment—that is, less than 6/12 (20/40)—has a significant impact on the ability of people to enjoy healthy aging (Table 1). Difficulties in daily living, social functioning, and religious participation, all are altered twofold by just this very modest reduction in acuity.<sup>7</sup> The use of community services increases 12% for each line of vision lost (Wang JJ, Mitchell P, Smith W, Cumming RG. ARVO Abstract 3077, 1998).

Not only is there an impact on social isolation, but this level of moderate visual impairment has a significant impact on morbidity. The Beaver Dam Eye Study and others have shown an increased risk of falls and hip fractures<sup>8,9</sup> and an increase in depression.<sup>10</sup> Probably of greatest importance is the doubling in mortality attributable to this moderate visual loss, even after adjusting for the other factors that affect morbidity that can be measured in a population-based study.<sup>11–13</sup>

From the Centre For Eye Research Australia, Department of Ophthalmology, University of Melbourne, East Melbourne, Victoria, Australia.

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Disclosure: H.R. Taylor, None.  
Corresponding author: Hugh R. Taylor, Centre For Eye Research Australia, Department of Ophthalmology, University of Melbourne, 32 Gibberne Street, East Melbourne 3002, Victoria, Australia.  
h.taylor@unimelb.edu.au

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