

Making Vision a Health Priority

Older Adults Combined Older Adults

I. Introduction

- Groups of older adults were held in five geographically and ethnically diverse cities:
 - o Chicago (Hispanic/Latino Spanish-Speaking, Caucasian).
 - o San Francisco (Hispanic/Latino English-Speaking, Hispanic/Latino Spanish-Speaking, Caucasian).
 - o Houston (African American, Hispanic/Latino English-Speaking).
 - o Miami (Hispanic/Latino English-Speaking).
 - o New York City (African American, Hispanic/Latino English-Speaking, Hispanic/Latino Spanish-Speaking).
- These groups of older adults were further divided by age—people between 40–59 years old and those more than 60—for each demographic in each city listed above.

II. Key Findings

- Dr. Oz and The Doctors TV shows were very popular among most groups. These groups reported watching these shows to get health information.
- Other sources of health information included the Internet, friends, and family.
- The general feeling about vision among participants was that it slowly deteriorates as one gets older.
- Many said that they did not like the feeling of having their eyes dilated and that it can be a hindrance to going to an eye care professional.
- Participants said they considered vision important, but admitted that they take vision for granted.
- One group (40–59) discussed the use of marijuana to treat eye conditions. In that same group, a participant talked about seeking the help of an "eyeologist" ("someone who can read your eyes and tell what's going on inside your body and organs") to help prevent vision loss from glaucoma.
- Health insurance was a major concern, and participants said they were interested in learning other options for payment of eye care.
- Participants said that the public should be more aware of eye health.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Eye problems participants cited included having plugged up eyelash ducts and dandruff in the eye lashes (40–59).
- Participants stated that when they have problems with their vision, they see an eye care professional or talk with their friends and family. However, one participant (60+) said that there is a big problem with unlicensed physicians in Hispanic/Latino communities. Another participant (60+) warned that friends and family might recommend natural medicines that "contradict" with other medicines they are taking.
- A shaman was mentioned in one group (40–59) as a person who could treat vision problems (other group members agreed).
- Participants in another group (60+) reported using natural remedies to treat vision problems, such as pinhole spectacles, eye wash, urine, and black coffee as vision aids.
- Participants stated they wanted information on natural remedies for vision improvement.
- Most participants had heard of cataract, primarily from a family member who had dealt with cataract.
- Most participants did not know about glaucoma. One participant said it was "pressure
 in the back of your eye." Another said the pain from glaucoma felt like a "punch with
 an ice pick."
- Very few participants had heard of diabetic retinopathy or low vision.
- The term "age-related vision problems" made several participants think that after age 40, people need reading glasses. One participant said, "You wear out your vision as you grow older, particularly if you read a lot."
- The degree of comfort that participants felt when speaking with their primary care physician or eye care professional ranged from "totally comfortable" to "not comfortable." One participant said she thought primary care physicians do not have enough time to spend with their patients, while eye care professionals do.
- Participants said they would like to receive information about new procedures through newsletters sent by mail or on the Internet. One participant also stated that he would like to see a website featuring an older adult explaining eye health issues.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants considered vision the most important of the senses and the mere thought
 of losing it was frightening. However, more than half of the participants did not know
 anything about eye diseases, and very few participants did anything to prevent vision
 loss.
- Most participants related having eye problems with having to wear eyeglasses.
- Cataract was very common in some groups, and most participants appeared to understand what a cataract is.
- Other than cataract, participants lacked awareness or were misinformed of eye conditions, such as age-related macular degeneration, glaucoma, diabetic retinopathy, and low vision.
- One group (40–59) opined that Hispanics/Latinos were not aware of many health issues and that they need to be instructed through different venues.
- Some participants said that diabetes affected vision and that the diet Hispanics/Latinos typically eat can contribute to diabetes.

- Family caregivers play an important role in the healthcare professional/patient relationship and in the process of looking for information.
- Participants in these groups (40–59) said that they will often treat eye conditions with over-the-counter medication or purchase over-the-counter reading glasses rather than seek medical attention from an eye care professional.
- Participants named a number of sources for getting health information, including the Internet (Univision.com, Peopleenespanol.com, Hola.com, CNN.com, Mayo Clinic, Pasteur Institute, and Johns Hopkins Websites), newspapers (*El Diario, El Nuevo Dia*), radio (WADO), television (Dr. Katz, Univision), and print materials (AARP).
- Most participants stated that healthcare professionals are their most trusted source of
 information. Healthcare professionals who speak Spanish were preferred and help
 patients feel more comfortable. For healthcare professionals who do not speak
 Spanish, familial caregivers and relatives become important and are the main link of
 information between the two.
- Participants' motivation for getting an eye exam included having enough money to pay or having insurance that covered the exam.

Caucasian (40–59 and 60+)

- Participants receive their health information from a variety of sources, but their most trusted source of information was their primary care physician.
- Participants also look to their healthcare insurers, particularly Kaiser Permanente and Blue Cross, for information about preventive information.
- Although most participants understood and could explain cataract, knowledge of other eye diseases—diabetic retinopathy, diabetic eye disease, and glaucoma—was limited.
- The term "glaucoma" was recognized by most participants, but few were able to describe what it meant.
- These participants understood age-related macular degeneration better than other eye diseases.
- Almost no participants had heard of the term "low vision."
- Most participants stated that they felt comfortable with their primary care physicians, but that if they were not satisfied with the care they received, they felt empowered to change physicians.

Comparison of 40–59 and 60+ Groups Across Demographics

• The most notable difference between the 40–59 groups and the 60+ groups was that the 60+ groups were more likely to identify barriers to receiving eye care than were the 40–59 groups (see section titled "Barriers to receiving eye care").

III. General Health

Self-assessment of general health

African American (40–59 and 60+)

• Overall, participants felt that they were in good to excellent health. Only a few rated their health as poor due to a few health issues they had encountered.

- Most participants in the older groups took their age into consideration when determining the status of their health. (60+)
- Most participants with health issues reported going to their healthcare professional as scheduled and taking their medications as prescribed.

Hispanic/Latino English-Speaking (40–59 and 60+)

• Participants had a wide range of responses when rating their overall/general health. Their responses included, "poor," "fine," "under control," "excellent," and "up and down."

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants in two groups (60+) said that they had begun to feel the repercussions of how they had treated their bodies when younger. Among the conditions mentioned were depression, hypertension, diabetes, kidney transplant, and heart surgery.
- Participants in several groups (40–59) said that Hispanics/Latinos tend to eat too many carbohydrates on a daily basis and are not aware that this kind of diet can lead to diabetes.
- Several said that "in this stage of life" (60+), keeping your body healthy becomes harder, and therefore, it is important to eat well (and not too much), exercise, drink lots of fluids, and get enough sleep.
- In one group (40–59), all participants considered themselves to be in good health, even though several of them had conditions such as diabetes, high blood pressure, and obesity. As long as they had their eyesight and were able to carry on with their daily activities, they considered themselves healthy.
- Participants in one group (40–59) said that the stress of the lifestyle they follow in the United States has affected their health because they do not eat properly.
- Among the health issues mentioned by some participants were high blood pressure, high cholesterol, migraines, arthritis, eye conditions, thyroid problems, diabetes, and stress related to the work they do in this country and the style of life they follow.
- A few mentioned feeling that their health started to decline after turning 40.

Caucasian (40–59 and 60+)

• Most participants said that their health was good to excellent. They maintained their diets and were active.

Frequency of healthcare professional visits

African American (40–59 and 60+)

- On average, most participants reported visiting the healthcare professional once to twice a year.
- Most participants stated they had had their eyes examined at least once in the past year.
- In general, participants believed that people should have their eyes examined at least once a year.

Hispanic/Latino English-Speaking (40–59 and 60+)

• Participants' self-reports of visiting their healthcare professionals ranged from "once or twice a week" to "never."

- The stated range of last having visited a healthcare professional was from every two vears to more than once a month.
- Most participants reported having had their eyes examined within the past year.
- Participants felt that children should also have their eyes examined every year.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants with chronic health conditions tended to see a healthcare professional more than twice a year, while those who felt healthy tended to see a healthcare professional either once a year or when they were sick.
- Female participants in one group said that they see a healthcare professional at least twice a year, while the male participants in that group said that they only seek medical attention when they are sick.
- One participant went to a healthcare professional every month because of numerous health problems.

Caucasian (40–59 and 60+)

• There was no pattern in how often participants in these groups visited a healthcare professional, with some seeing one as often as once every three months to those who had not seen a healthcare professional in more than two years.

Where they get information on health issues

African American (40–59 and 60+)

- TV (Dr. Oz, The Doctors).
- Internet (Google, WebMD).
- Magazines (Prevention, Men's Health, New England Journal of Medicine).
- Healthcare professionals.
- Department of Aging.
- AARP.
- Mailed brochures.
- Radio.

Hispanic/Latino English-Speaking (40–59 and 60+)

- TV (CNN, The Doctors, Dr. Oz, Oprah).
- Internet (Google, YouTube, WebMD).
- Magazines (*Prevention*, health magazines from local hospitals).
- Newspapers (New York Times, Miami Herald).
- Radio (Dr. Dean Edell, and a Saturday-morning radio show featuring a Spanish-speaking physician from Jackson Memorial Hospital in Miami).
- Health insurance company (Aetna, United Health, Kaiser Permanente)
- Shamans.
- Family members and friends.
- Healthcare professionals.
- American Heart Association.
- Centers for Disease Control and Prevention.
- Pamphlets.
- Library.

- AARP newsletter.
- Pharmacy.

<u>Hispanic/Latino Spanish-Speaking (40–59 and 60+)</u>

- TV (Dr. Oz, Dr. Phyllis, and Dr. Katz).
- Internet (Univision.com; Peopleenespanol.com; Hola.com; CNN.com; WebMD.com; Kaiser.com; Google; and the Mayo Clinic, Pasteur Institute, and Johns Hopkins websites).
- Radio (WADO).
- Newspapers (El Diario, El Nuevo Dia).
- Healthcare professionals (especially those who speak Spanish).
- Family members who act as interpreters during appointments.

Caucasian (40–59 and 60+)

- Internet (Google, WebMD, Mayo Clinic).
- TV (Dr. Oz, The Doctors, PBS).
- Magazines (*Prevention*, other health magazines).
- Newspapers.
- Commercials.
- Newsletters.
- AARP.
- Hospital.
- Friends and family.
- Johns Hopkins symptoms book.
- Medscape (WebMD phone app).
- Insurance companies (Kaiser Permanente, Blue Cross/Blue Shield).

IV. Vision

Frequency of eye exams

Hispanic/Latino English-Speaking (40–59 and 60+)

• According to most participants, people should have their eyes examined at least once per year, and more often if they are having problems.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

• There were no standard answers from this group on how often people should have their eyes examined.

Caucasian (40–59 and 60+)

Participants said that people should have their eyes examined once a year, and more
often if there were other issues.

Why vision is important to them

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants stated that vision was important to them because "if you lose your sight, you lose everything."
- Vision was characterized as being "essential for your quality of life."
- Participants also said that vision is important because "it's how you see the world."
- Some participants (40–59) said they couldn't *hear* without their glasses.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- For participants in all groups, the thought of losing their vision was traumatic and frightful; "vision is everything to me" was a common sentiment.
- Participants said that vision was important to them because they could not do anything without it, and that it allowed them to have contact with others and the world around them.
- Participants in one group (60+) expressed the sentiment that without vision, one has no control and cannot do anything.

Caucasian (40–59 and 60+)

- Participants stated they believe vision provides independence and mobility.
- They said that eye examinations allow the healthcare professional to find out about a patient's health.
- Participants also stated that vision is like hearing; they are both needed senses, so take care of them.

Topics discussed with eye care professionals during visits

African American (40–59 and 60+)

- Eye health.
- General health, including health issues such as type II diabetes.
- Family.
- Reasons for the visit/changes in vision.
- Eye surgery.
- Diet and nutrition.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Laser surgery.
- Flickering of the eyes.
- Eye sight/eye conditions.
- Symptoms.
- Prescriptions.
- Costs.
- General health.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Changes in lens prescription.
- Conditions like cataracts and glaucoma.
- Laser surgery.

Caucasian (40–59 and 60+)

- Types of lenses.
- Health of their eyes.
- Changes in their eyes.
- High blood pressure.
- Diabetes.

Views on having eyes dilated

African American (40–59 and 60+)

- Participants in several groups stated not liking to have their eyes dilated because they could not see afterward. One participant noted that after dilation, she "felt deprived of vision and it's a bad feeling."
- Most agreed that people should have their eyes dilated once a year, and if there are eye health issues, then twice a year.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants gave a wide range of responses when asked how often people should have their eyes dilated. One participant thought it should be every three months, others felt it should be once a year, and others said whenever someone went to the eye care professional.
- Some participants said they had never had their eyes dilated.

<u>Hispanic/Latino Spanish-Speaking (40–59 and 60+)</u>

- Approximately half of the participants in each group said they had had their eyes dilated at least once.
- When asked how often people should have their eyes dilated, participants responded that they should do so every time they have their eyes examined, or as often as the eye care professional recommended.

Caucasian (40–59 and 60+)

• Participants' views on how often dilation should take place ranged from every time a person sees an eye care professional to only when a person is having specific troubles with their eyes.

Motivation/disincentives to get eyes examined

- Participants named the following as incentives for having their eyes examined:
 - o Fear of going blind.
 - Eye problems, especially those affecting daily activities, such as driving at night and using a computer.

- Insurance.
- o Change in eyesight after turning 40.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants named the following as incentives for having their eyes examined:
 - o Glaucoma.
 - Headaches.
 - o Blurry vision.
 - o Routine yearly examination.
- Participants mentioned the following as barriers to having their eyes examined:
 - Cost of eye exams.
 - o Need to search for a trustworthy physician.
 - Lack of health insurance.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants named the following as incentives for having their eyes examined:
 - o Requirement for commercial driver's license. (40–59)
 - o Difficulty in seeing.
 - o Recommendation by general practitioner.
 - Headaches.
- Participants named the following disincentives to having eyes examined:
 - o Lack of insurance or money (noted in all groups).
 - o Cost of prescription eyeglasses.
 - o Fear of being deported (reported by one participant).
- Some participants stated that Hispanics/Latinos need more education regarding health issues and health care.

Caucasian (40–59 and 60+)

- Participants named the following as incentives for having their eyes examined:
 - o Poor vision.
 - o Discount for eyeglasses when receiving an eye exam.
 - o Encouragement from coworkers, friends, and primary care physicians.
 - o Change in vision or onset of eye problems.
 - o Guilt.
 - o Nagging friend.
 - o Insurance.

V. Knowledge of Eye Diseases

- In general, participants were not familiar with age-related macular degeneration or diabetic retinopathy; however, most were familiar with cataract.
- Some participants felt that certain eye issues can be treated, such as glaucoma, through dietary nutrition.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Most participants were familiar with eye health-related diseases; however, some explanations of eye diseases were inaccurate.
- The term "diabetic retinopathy" appeared to be unfamiliar to most participants, unless they or someone in their family had diabetes.
- The term "cataracts" was most familiar to participants in all groups, as several had been diagnosed with cataract or had family members with the diagnosis.
- Approximately half of the participants in these groups also appeared to be somewhat familiar with the term "age-related macular degeneration," as their eye care professionals had discussed it with them.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Most participants said they had heard the terms "cataract," "glaucoma," and "low vision"; however, many were misinformed or unaware about these eye diseases, their treatments, and what preventive steps can be taken to prevent vision loss.
- A smaller number of participants had heard of age-related macular degeneration or diabetic retinopathy.
- Participants generally interpreted the term "at risk" to mean that one is more likely to get an eye disease or that it is hereditary.

Caucasian (40–59 and 60+)

- Almost all participants knew about cataract and could explain what it was.
- A few participants in each group were aware of diabetic eye disease and diabetic retinopathy, especially if they had family members with diabetes.
- Although many participants had heard about glaucoma, only one or two in the groups could explain what it was.
- Most participants in these groups were familiar with age-related macular degeneration.
- Only one or two participants in these groups had heard the term "low vision." This term was completely new to them, and none of the participants was able to explain what it was.

Glaucoma

- Participants believed that people with diabetes or those of a certain race (with African Americans being at higher risk) and/or age are more likely to be at higher risk for glaucoma.
- Participants reported that glaucoma causes the following:
 - o Pressure behind the eye.
 - o Other health problems.
- Many participants believed that glaucoma could be treated.
- Participants stated that the following could put people at a higher risk for glaucoma:
 - o Heredity.
 - o Family history.
 - o Behavior that causes glaucoma.
- Some participants said anybody could be at higher risk.

- Participants stated that vision loss from glaucoma could be prevented by the following:
 - o Getting regular eye exams.
 - o Maintaining a healthy diet.

<u>Hispanic/Latino English-Speaking (40–59 and 60+)</u>

- Although a number of participants said they were familiar with the term "glaucoma," most did not know anything about glaucoma. One participant said it was "pressure in the back of your eye." Another said the pain from glaucoma felt like a "punch with an ice pick."
- To prevent vision loss from glaucoma, one participant suggested lowering one's blood pressure.
- Participants considered glaucoma a serious condition because people can go blind if they "don't take care of it."
- Participants were unsure about whether glaucoma could be treated; some thought it could be treated with "drops, surgery, and laser."
- Participants said that glaucoma is hereditary and can cause blindness. One participant said he had to use drops every night or else "his blood pressure goes up." The key to preventing eye disease, according to one participant, was good nutrition.
- According to participants in one group, glaucoma can be prevented by having regular eye exams and having one's eye pressure measured. To maintain eye health, participants also mentioned taking contact lenses out before going to sleep, not touching one's eyes with dirty hands, and keeping glucose levels under control.
- Participants in one group said that people who have diabetes and "hereditary conditions" are at higher risk for glaucoma. The term "at higher risk" means it is more likely to happen and that people should "just be careful." Those in another group said that people with high blood pressure were at higher risk for glaucoma.
- None of the participants in one group were familiar with how glaucoma affects vision, but one participant did say that her sister has glaucoma and can't "see your face. It's like a cloud."
- Participants were able to mention some concepts related to glaucoma, including that it affects people with diabetes and has to do with increased pressure in the eye. Most did not know the symptoms of glaucoma, but a few mentioned that it was a painful condition.
- To prevent vision loss from glaucoma, participants said people should have their eyes examined, keep their diabetes under control, use protective glasses, and protect their eyes from sunlight.
- Participants considered glaucoma a serious condition because people can lose their eyesight.
- Participants said that vision loss from glaucoma can be prevented by the following:
 - Eating healthy.
 - o Getting exercise.
 - o Getting regular eye exams.
 - o Detecting glaucoma early.
 - o Taking care of oneself.
 - o Taking control of blood pressure.
 - o Being consistent with daily routines for maintaining health.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- While most participants said they had heard the term "glaucoma," very few understood what caused the condition, how it was diagnosed, how it was treated, or what the long-term effects were.
- Participants gave various descriptions for glaucoma:
 - o "An increase in pressure in the eye."
 - o "Something in the eye that doesn't let you see well."
 - o "The same reason for which diabetics lose their vision; it's similar to cataracts, I think."
 - o "I think it's the degeneration of the iris."
 - o "It's a pressure that builds behind the eye and that's why they dilate the eyes."
 - o "Inflammation in the eye."
 - o "From what I know, it is a change in the liquid, and the capillaries cannot process the liquid because it's too thick."
- Symptoms that participants associated with glaucoma included the following:
 - o The effects they mentioned included going blind and having tunnel vision.
 - o One participant said she did not have any symptoms of glaucoma. Others said that symptoms included experiencing redness and tearing, and seeing stars.
 - Symptoms of glaucoma that were mentioned by participants included dizziness, headaches, blurry vision, and loss of vision. Eye pressure was mentioned as a cause of glaucoma. Some participants said that this pressure caused the eye to close. One participant said that if a person has glaucoma, that person has an 80 percent chance of going blind.

Direct Quotes:

- "Maybe the loss of sight."
- o "An infection."
- "It's like a cloud."
- o "Seeing blurry."
- o "A sting."
- o "Light can bother."
- o "The person starts to feel pain, the pressure, and headaches."
- o "They say that glaucoma is like high blood pressure. A person can suffer from high blood pressure and not know about it because nothing hurts, there are no symptoms, and that's why it's important to get checked."
- Participants suggested that glaucoma could be prevented by the following:
 - o Getting regular eve exams.
 - o Eating healthy and taking vitamin C and Omega.
 - Wearing polarized sunglasses.
 - o Using screen filters with the computers.
 - o Avoiding harsh temperature changes.
 - o Exercising your eyes with focus exercises.
 - Using appropriate prescription glasses.
 - o Eating carrots or drinking carrot and orange juice.
 - Avoiding eye strain.
 - Using eye drops.

Direct Quotes:

- o "Not to wait too long or you can lose your sight."
- o "It's like cancer, you need to treat it on time."

- "Us diabetics have a tendency to suffer of that when we don't pay attention to our food, exercise, and proper medicine; the pressure in the eye elevates and it causes blindness."
- o "Cleaning the eye internally."
- Participants said that those at higher risk for glaucoma are as follows:
 - o People over 40 years old.
 - o People with diabetes.
 - o Older people.
 - o Those who suffer from high blood pressure.
 - o People with low blood pressure.
 - o People with high cholesterol.
 - o Everyone.
 - o Those with a family history of glaucoma.
 - o African Americans (because of genetics).
- Most participants believed that glaucoma could be treated or prevented through the following:
 - o Surgery or medicine.
 - Eye drops or eyeglasses.
 - o Early detection.

Low vision

African American (40–59 and 60+)

- Only a few participants across all groups had heard of the term "low vision."
 - o One participant thought it meant having a problem seeing far away.
 - o Another guessed that it was the step before you go blind.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Only a few participants in the focus groups had heard the term "low vision" to describe a visual condition, and no one was able to explain it. Participants had a number of interpretations for the terms "vision loss" and "low vision":
 - o "Total blindness."
 - o "Deteriorated eyesight or completely lost."
 - o "That we are going to go blind."
 - o "That we lose sight completely."
 - o "Loss means not seeing any more."
 - o "It would be very sad and depressing to lose sight."
 - o "That we are going to be dependent on someone or something, like those who need a dog."
 - "Low vision results when your capacity to see is diminished; as you age, your vision runs out."
 - o "Needing help."
 - o "Slowly losing your vision."
 - "Less vision than normal."
 - "When you can't see well."
 - o "Seeing less."
 - o "That the sight diminishes."
 - o "That you see blurry."

- "Not being able to see well from afar."
- o "Not having 20/20 sight."
- o "Something that is not normal."
- o "That's why you need to use bifocals."
- o "There is a lot of technology and therapies that can probably avoid it."
- o "It's the inability of the nervous system to transmit light to the brain."
- o "Poor visibility."
- o "To lose it slowly."

Views on preventing vision loss

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Getting regular eye exams.
- Being conscious about vision.
- Following the eye care professional's instructions.
- Using homemade medications.
- Exercising the eyes.
- Eating healthy foods, including vegetables.
- Using glasses.
- Using prescription eye drops.
- Controlling sugar.

Caucasian (40–59 and 60+)

- Using eye drops.
- Eating nutritious foods, including mulberry and carrots.
- Getting frequent eye exams.
- Wearing sunglasses/protective eyewear.
- Wearing contacts for the appropriate amount of time and cleaning them appropriately.
- Monitoring one's glucose/sugar levels.
- Getting regular examinations.
- Not sitting in front of the computer or television all day.

VI. Vision and Aging: Perceptions and Beliefs

Concerns about their vision

- A common concern shared by participants in one group (60+) was that losing their vision would mean a loss of independence and would require a huge readjustment to relearn and cope with not being able to do things they are accustomed to doing.
- Some participants reported low vision has affected day-to-day activities such as the following:
 - o Driving at night.
 - Using a computer.
 - o Adjusting from wearing contact lenses to eyeglasses.
 - Watching TV.

o Reading.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants in every group (40–59 and 60+) expressed concern with vision deteriorating with age.
- Some participants expressed concern with the following:
 - Losing vision.
 - Receiving adverse reports from eye care professionals (such as needing to have Lasik redone or having one's vision get progressively worse).
 - o Driving at night.
 - o Getting macular degeneration.
 - o Needing cataract surgery.
 - o Having tunnel vision.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants expressed frustration at not being able to see like they could when they were younger.
- Participants expressed their concerns with cataract.
- Some participants said that sweets cause their eyesight to blur and they did not know why.
- Participants had questions about the long-term effects of Lasik.
- Several participants who have eye problems said they felt frustrated when they forgot to take their eyeglasses with them, because they felt dependent on others.
- Some participants stated they felt embarrassed that others might think they did not know how to read if they asked 'what's the price on this?' or 'what does this tag say?'; they feel lost without their glasses.

Caucasian (40–59 and 60+)

- Participants stated that they do not want to lose their vision.
- Participants said they fear that loss of vision would require them to be dependent on others.
- Participants expressed concern with the following:
 - Needing to wear glasses.
 - o Getting diabetic retinopathy.
 - o Receiving the wrong prescription.
 - Having their vision deteriorate.
 - Needing to refocus.
 - o Losing the ability to read.
 - o Losing the ability to see sites they enjoy.
 - o Having a family history of macular degeneration.

How they address their concerns

- Participants stated that when they have concerns, they do the following:
 - Watch their diet.
 - Use home remedies.
 - Educate themselves.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants in this group stated that when they have concerns, they do the following:
 - o Go to an eye care professional.
 - o Check WebMD.
 - o Consult with family and partners about their concerns.
 - o Perform an eye wash. (60+)
 - Use eye drops.
 - o Use home remedies, such as urine, black coffee, and Preparation H. (40–59)
 - o Try not to strain their eyes.
 - o Purchase reader glasses.
 - o Speak with a pharmacist.
 - o Try to eat better.
 - o Hope it gets better.
 - o Learn to compensate for the problem to avoid seeing an eye care professional:
 - One participant (60+) cautioned that there is a big problem with unlicensed physicians in Hispanic/Latino communities.
 - Another (60+) warned that friends and families might recommend natural remedies that might conflict with other medicines a person is taking.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Participants stated that when they have concerns, they do the following:
 - o Are careful not to strain their eyes too much.
 - Watch less television.
 - o Take breaks when on the computer.

Caucasian (40–59 and 60+)

- Participants in this group stated that when they have concerns, they do the following:
 - o Go to an eye care professional.
 - o Get their eyes examined.
 - o Clean their glasses.
 - o Rest their eyes.
 - o Discuss the problem with family or friends.
 - o Eat lots of fruits and vegetables.
 - o Take vitamin B complex.
 - Use hot and cold compresses.

How eye problems affect their daily life

- Participants stated that eye problems affect them when they do the following:
 - o Drive at night.
 - o Use a computer.
 - o Have to adjust from wearing contact lenses to wearing glasses.
 - Watch TV.
 - o Read a book.
 - o Read a digital clock.
 - o Are not able to read the numbers on a stove.

o Have to rely on very large print to read.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants stated that eye problems affect their daily life in the following ways:
 - o Have difficulty reading.
 - Need more light.
 - o Become frustrated and irritable because of the difficulty in seeing.
 - o Experience tired eyes.
 - Experience headaches.
 - Are unable to drive at night.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- o Participants stated that eye problems affect them when they have to ask someone to read a label for them.
- o Many also said that having eye problems made them feel dependent on others.

Caucasian (40–59 and 60+)

- Consequences that participants stated they have experienced because of eye problems:
 - o Reading less/losing interest in reading.
 - o Having to always have their glasses with them.
 - Having three pairs of glasses (reading glasses, sunglasses, and night-driving glasses).
 - o Having problems with night driving.

Comparison of 40–59 and 60+ Groups

• Although it appeared that more participants in the 60+ groups experienced specific problems with their eyes, participants in both age groups and across all ethnic groups expressed similar concerns.

Understanding of the term "vision loss"

Hispanic/Latino English-Speaking (40–59 and 60+)

- Only a few participants had heard the term "low vision."
 - o According to one participant, low vision "means you can't see everything."
 - o Another participant said that he had low vision when driving at night.
- When asked what they thought of when they heard the term "age-related vision problems," participants responded as follows:
 - o "Senior citizens."
 - o "The old saying, 'When you get to 40, everything goes downhill."
 - o "Your eyes are the first to go."
- A lot of questions were raised about what the term "age-related vision problems" meant. One participant said that glaucoma was not an age-related problem.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

• Only a few participants in the focus groups had heard the terms "vision loss" or "low vision," and none were able to explain it.

Caucasian (40–59 and 60+)

- Only a few participants had heard of the term "vision loss."
- Participants in one group (60+) said that "vision loss" sounded "scary."

How are aging and vision related?

African American (40–59 and 60+)

- Although most participants felt that vision loss in relation to aging was a natural progression, in one of the groups, a participant (40–59) stated that there are some seniors who have 20/20 vision, which shows that age isn't always associated with vision loss.
 - o "Like the deterioration of the organs in the body, I think that loss comes with age." (60+)
 - o "As you get older, your eyes just get worse." (40–59)
- A participant said that physicians should give eye health as much attention as other areas of health.
- A common concern shared by participants in one group (40–59) was that the print on labels will continue to get smaller, making it harder for them to read since their vision will continue to get worse as they age.

Hispanic/Latino English-Speaking (40–59 and 60+)

- For most participants, vision problems were viewed as being synonymous with other symptoms of aging.
- Several said that the link between vision loss and aging was not necessarily causal, as evidenced by older people without glasses and younger children with glasses.
- The term "age-related vision problems" made one participant think that after age 40, people need reading glasses. Another participant said that you "wear out your vision" as you grow older, particularly if you read a lot. (60+)
- Participants mentioned cataract and glaucoma as age-related vision problems.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- While participants in some of the focus groups thought that there was a relationship between aging and vision problems, others did not think that vision necessarily deteriorated as one got older. Some participants were convinced that the link between vision loss and aging was normal, while others believed that having eye problems was something unique to each organism.
- Participants in several groups stressed the importance of taking good care of one's eyes in order to reduce the likelihood of vision problems.

- Most participants felt that vision loss was directly related to aging.
- One participant said that there is an inevitable link between vision loss and aging, but they were not sure if that link was to "vision loss" or "vision change."

Views on preventing vision loss

African American (40–59 and 60+)

- The most notable difference between the 40–59 age groups and the 60+ age groups was that the 60+ groups were more likely to identify barriers to receiving eye care than the participants in the 40–59 age groups (see section "Barriers to receiving eye care").
- Participants felt that certain eye diseases, such as diabetic eye disease, are treatable but not preventable.
- In general, participants thought that vision loss could be prevented through the following:
 - Exercise.
 - o Diet.
 - Medication.
 - o Regular examinations.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants thought that vision loss could be prevented by the following:
 - o Avoiding using computers.
 - o Not sitting close to the TV.
 - o Taking care of one's eyes.
 - o Having regular eye exams.
 - o Using the right eyeglasses.
 - o Reading with good light.
 - o Washing one's eyes every night.
 - o Taking vitamins and supplements, such as vitamin A, beta-carotene, antioxidants, and Ocuvite.
 - o Improving nutrition and eating foods like carrots and blueberries.
 - Wearing sunglasses and protective eyewear.
 - o Not looking directly into the sun.
- One participant said that vision loss was unavoidable.

- Participants in this group thought that vision loss could be prevented by doing the following:
 - o Getting regular exams.
 - Wearing sunglasses.
 - Wearing safety glasses.
 - o Getting proper nutrition.
 - o Using dietary supplements.
 - o Getting rest.
 - o Exercising.
 - o Using eyewash.
 - o Taking care of problems immediately.
 - Avoiding diabetes.
 - Keeping eyes moistened.
 - o Performing eye exercises.
 - Wearing correct eyeglasses.

Maintaining proper hygiene.

VII. Health Information Preferences

Level of comfort in communicating with primary care physicians

African American (40–59 and 60+)

- Most participants stated they were very comfortable talking with their physicians.
- Participants said it was important to build a close relationship with physicians and have them convey information using layman terms.

Hispanic/Latino English-Speaking (40–59 and 60+)

• The degree of comfort that participants felt when speaking with their primary care physician ranged from "totally comfortable" to "not comfortable."

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Most participants reported that they felt comfortable in general with their current physician. However, many of them also said they have had experiences in the past when the physician did not take enough time to listen to them and that they changed physicians because of this problem. Participants said that they want their questions answered and to feel that their physicians are taking them seriously.
- A few participants said that they felt ashamed or scared to talk with their physicians about their symptoms, so they looked on the Internet for information instead.
- Some participants said that it is difficult to understand the technical terms physicians use.
- Many participants chose to see physicians who speak Spanish. Participants who saw physicians who don't speak Spanish had to be accompanied by a relative (daughter/son), and they reported this makes them feel uncomfortable.
- The majority of participants felt that their physicians did not share information with them.
- A few participants expressed the belief that physicians nowadays do not take the time to find out what's wrong with their patients or to explain their health situation clearly because of time constraints in the healthcare system overall.

- Most participants said they felt very comfortable with their physicians.
- Some participants felt that their physicians rushed them out of the examining room, while others felt more connected.
- Participants who were insured by Kaiser Permanente said they could e-mail their physicians and receive an answer within 24 hours.
- Two male participants in one group said they would feel more comfortable talking with their physicians if they were male.
- Participants in one group said their physicians did not share information with them about eyesight.
- Participants stated that the lines of communication could be strengthened if physicians spend more with patients, tell patients if they do not know the answers to their questions, and improve their bedside manner.

Level of comfort in communicating with eye care professionals

African American (40–59 and 60+)

• Participants said that they have often felt that their eye care professionals were trying to sell them eyeglasses rather than focus on their specific problems.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants in this group stated the following about communicating with their eye care professionals:
 - o "The specialist was rude. He gave me five minutes and I had to get the nurse to get him back to ask questions." (40–59)
 - o "The doctor has a different terminology of saying things and you can't understand exactly what they are saying." (40–59)
 - "If only they took a little bit more time and used normal, everyday language." (40–59)
 - o "My eyes were always burning and I thought I had dry eyes. I didn't need eye drops, but she said it was because of the computer." (40–59)
 - o "I don't have an eye doctor; if my regular doctor thinks that I need to see a specialist, then I go." (40–59)
 - o "A lot of charts on the wall; too many." (60+)
 - o "Conversations with the eye health professional consist of 'eye looks good' and if there are problems, put warm compress on eyes and use Johnson and Johnson baby shampoo to help with infection." (60+)

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Most participants tended to look for Spanish-speaking eye care professinals. Some participants reported having to go accompanied by a relative (daughter/son) to see eye care professionals who do not speak Spanish, and this made them feel uncomfortable.
- Two participants in one group (60+) said they had received written information from their eye care professional.

Where they get health information

African American (40–59 and 60+)

- TV (Dr. Oz, The Doctors).
- Internet (Google, WebMD).
- Magazines (Prevention, Men's Health, New England Journal of Medicine).

Hispanic/Latino English-Speaking (40–59 and 60+)

- Commercials.
- Publications on the Internet (WebMD mentioned specifically in several groups).
- People with health problems.
- Healthcare professional (eye care professional, primary care physician, etc.).
- E-mail.

Caucasian (40–59 and 60+)

- Discussion with their healthcare professionals.
- Research of additional information on the Internet (Medline Plus, Kaiser Permanente, and Google).
- Library.
- Primary care physician.
- Eye care professional.
- Insurance company.
- Merck manual (there is a manual for healthcare professionals and another manual for individuals).
- Reputable organizations.
- Older people.
- Dr. Oz (others said Dr. Oz is "a joke").

Most trusted sources of health information

• For all groups, the single most trusted source of health information was usually the primary care physician.

Information seen in the media about vision

African American (40–59 and 60+)

• Most participants reported not having heard anything in the media on eye health in the past 12 months.

Hispanic/Latino English-Speaking (40–59 and 60+)

- A local radio talk show about eye surgery.
- Information on laser treatment in the media.
- Ads or sales on eveglasses.
- An interview with someone on television about blurry vision.
- Information from the National Federation of the Blind.
- A Saturday-morning radio program that featured Spanish-speaking professors from a local university talking about dry eyes.

<u>Hispanic/Latino Spanish-Speaking (40–59 and 60+)</u>

- Lasik and optician commercials.
- Information about conjunctivitis and glaucoma on television and in newspapers.

- Advertisements for Lasik surgery.
- Commercials about dry eye.
- Information on the radio about the eye care professional for the San Francisco 49ers who performs Lasik surgery.
- Information about vision clarity.
- Information about macular degeneration on the news.
- Magazine article on cholesterol affecting vision.

• Celebrities who have vision problems (Willie Brown; Steve Wynn, the Las Vegas casino owner).

Types of information about eyesight/vision they have looked for

African American (40–59 and 60+)

• Most participants said they had not looked for information regarding vision.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Most participants stated they had not looked for information regarding their eyesight.
- Others said they had sought out the following information:
 - o Information about "blurry spots."
 - o Anything related to eye surgery.

<u>Hispanic/Latino Spanish-Speaking (40–59 and 60+)</u>

- Most participants said that they had not looked for any information about eyesight or vision.
- Others said they had looked for information about cataract and glaucoma.

Caucasian (40–59 and 60+)

• Most participants said they had not looked for information regarding their eyesight.

Need for further information about vision

African American (40–59 and 60+)

- Participants stated that their preferred formats to receive information are in the mail, by e-mails from a trusted source, from commercials on TV, and in seminars ("for those that can't read").
- A few participants thought that eye care professionals should disseminate information to their patients about vision loss.

Hispanic/Latino English-Speaking (40–59 and 60+)

- Participants stated being interested in receiving information about the following:
 - Their particular eye conditions.
 - o Information about new procedures.
 - New types of contact lenses.
 - o "Overall" and "general" information about eye health.
- Participants said they would like to receive information in the following ways:
 - o In brochures, newsletters, or pamphlets sent by mail.
 - o Through educational sessions in senior centers.
 - o On a website featuring an older adult explaining eye health issues.
- Participants felt that material in Spanish would be best.

Hispanic/Latino Spanish-Speaking (40–59 and 60+)

- Among the needs for further education about vision, participants mentioned needing information on the following:
 - o General eve health and eve diseases.
 - o Eyeglass prescriptions and explanation of their prescriptions.

- o Explanation as to why eyeglass prescriptions change over time.
- Vision and aging.
- o Care for the eyes.

Direct Quote:

- o "More publicity on vision treatments; you hear a lot about Lasik, but not much about prevention or how to take care."
- The participants said they would like to find information on vision through the following:
 - o TV, including public service announcements (PSAs) and shows such as Dr. Oz.
 - Internet
 - o Books.
 - o Work.
 - Media and communication campaigns.
 - o Discussion groups/information sessions.
 - o Professional health publications at health fairs.
 - Brochures
 - o CDs and DVDs.

Caucasian (40–59)

• Participants in one of the 40–59 groups said they would like to receive further education on whether glaucoma and cataract can be prevented.

Recommendations for access to information

<u>Hispanic/Latino Spanish-Speaking (40–59 and 60+)</u>

• Participants stated that information should be in both English and Spanish so that people can understand it "100 percent."

Caucasian (40–59 and 60+)

• There was no preferred method for getting information about vision, with some participants preferring information written in pamphlets and others preferring to get their information over the Internet or through mass media.

Barriers to receiving eye care services

African American (60+)

 Participants in several groups commented that eye care professionals appeared to be more interested in selling products than in providing the products and services needed by the patient.

Hispanic/Latino English-Speaking (60+)

- Participants stated the following as barriers to receiving eye care:
 - o Difficulty in finding eye care professionals.
 - Lack of insurance.
 - One participant mentioned that she had wanted to see a particular eye care professional, but couldn't because her insurance did not cover that eye care professional.
 - o Eye care professionals' perceived lack of time.

• Patients' own attitudes (since they do not realize they have the right to ask questions).

Hispanic/Latino Spanish-Speaking (60+)

- Among the obstacles participants mentioned to finding information about eye care
 were the technical terminology that eye care professionals use and the high cost of
 exams and eyeglasses.
- Participants said that language also is often a problem because they do not always have access to an eye care professional who speaks Spanish.
- One participant said she was embarrassed to ask for an explanation when she did not understand what her eye care professional was saying.

VIII. Summary

"One thing" that the National Eye Institute (NEI) could do for people who are aging

African American

- Provide more information about preventative care and how important it is for them to get routine exams.
 - Send more information.
 - Collaborate with health insurance companies to distribute information to their customers.
 - o Implement a mobile eye care truck for senior citizens and send it to senior citizen homes.
 - o Sponsor more advertising on TV.
 - o Make information available at churches.
- Target senior citizens to provide them with information and services relating to eye care.
 - Host health fairs for seniors.
 - Visit senior citizens at nursing homes and conduct programs that will educate them and their families.
 - Visit community board meetings.
- Help people who cannot afford eye care.
- Develop a nonprofit organization that provides services for poor people.
 - o Provide services for free or at a reasonable cost.
- Disseminate the information to all, not just in selective places.
 - o Ensure that politicians are paying attention to eye care.
 - o Incorporate eye care into an annual physical exam.
 - o Incorporate eye health education into the school system.
 - O Distribute eye health information to schools to the younger generation so that they can take it home to their parents.
- Distribute more materials in size 14 font.
 - o "It helps to see it."

Hispanic/Latino English-Speaking

- Sponsor medical care and research.
 - o Provide a cure for eye diseases and conditions.

- o Recommend better eye care professionals.
- O Develop a mobile eye van.
- o Explain the black dust (in participant's eyes).
- Have centers located closer to participants so they do not have to travel to Washington, DC, for treatment.
- See that patients are getting treated fairly.
- Provide information to the public.
 - o Distribute PSAs.
 - o Provide choices of natural methods, such as treatments without glasses or that do not make the pharmaceuticals money, for vision problems.
 - o Promote NEI more through community outreach.
 - o Provide affordable information via a newsletter and the Internet.
 - o Send a magazine in "our everyday language."
 - o Send information by e-mail to save trees.
 - o Launch an educational campaign using e-mail.
 - o Mail or e-mail information.
 - Provide information to primary care physicians, not just at eye care professional locations.
 - o Provide education on health insurance.
 - o Develop a multilingual website.

Direct Quotes:

- "Have programs, like on PBS, with panels providing information on particular vision situations that may happen."
- o "On talk shows or a reality show on vision, or how it has affected people with celebrity to catch your attention."

Hispanic/Latino Spanish-Speaking

- Information desired
 - o "Educate us about different conditions and how they affect our health."
 - Ads that instruct people to see an eye care professional if they are experiencing eye problems.

Direct Quotes:

- "Provide information so people get motivated to learn more about vision. Eye insurance shouldn't be optional."
- "More information for those who are planning on getting laser surgery."
- Format in which information should be provided
 - o Conferences.
 - o Seminars.
 - o Magazines and newsletters.

Direct Quote:

- "I would like them to tell me through e-mail how to improve my sight or keep it from deteriorating."
- Outreach
 - Sponsor health education workshops.
 - O Distribute more information about how to improve vision and how to cure eye problems through print materials and television programs.

Direct Quotes:

"[Provide] information at schools."

- "Work/partner with nonprofits who are dedicated to eye conditions."
- "Inform through the radio that their website exists."
- "Important conditions like cancer, diabetes, and AIDS capture the media, but there's nothing on the eyes."
- "Develop a campaign for organ donations. Something that says 'I'm seeing through your eyes.'"
- "Develop awareness campaigns like the ones for breast cancer and the heart."
- "Do eye health fairs."

• Free/low-cost services –

- o Offer free or low-cost eye examinations and screenings for the poor.
- o Be more accessible so patients can go for an eye exam.
- o Post information about their services and costs.
- o Accept all insurance.
- o Conduct medical screenings at venues at the park districts, the Navy pier, health fairs, and at events such as Taste of Chicago.

Direct Quotes:

- "Since it's part of the federal government, it should create a mobile unit and go to churches and low-income neighborhoods so that people can get eye exams."
- "Do clinics or health fairs at work or shopping malls and provide eye exams."

Caucasian

- Improve communication about eye health.
 - o Provide information so the public can be aware of where they can get information.
 - o Publish periodicals.
 - Provide access to the NEI Website.
 - "Since [NEI is with the] government, they should have a website with preventative care."
 - Sponsor PSAs on TV.
 - o Call people by telephone.
 - o Partner with AARP.
 - o Publish a newsletter or magazine on eye health.
 - o Sponsor ads on other health websites.
 - Sponsor a hotline for questions on eye health.
 - Use Facebook (the ads that come up on the side).
 - o Partner with VSP (vision care provider).
 - o Provide more lobbyists for healthcare.
 - o Partner with Walgreens, ophthalmologists, and optometrists.
 - o Promote NEI as a resource for information about eve health.
 - o Develop an ad campaign on TV so people become familiar with NEI
 - Provide information about NEI to be made available through healthcare professionals' offices.
- Provide specific kinds of information.
 - o Make the public aware of the importance of getting regular dilated eye exams.
 - o Describe usefulness of natural herbs for enhancing eyesight.
 - o Describe symptoms of eye diseases and conditions for better detection.
 - o Provide information about better eye care.

- o Provide simplified information.
- o Remind teenagers about telling their parents to get their eyes examined.
- o Remind people to get regular eye exams.
- Provide financial support.
 - o Send everybody a coupon that's good at every eye care professional's office.
 - o Provide more money for research.
 - o Provide free examinations.
 - o Provide cheaper glasses.
 - o Sponsor some type of insurance through NEI.
 - o Make eye care more affordable for everybody.
 - Offer eye exams in school (it was free in younger schooling levels, so also offer it in high schools).
 - o Assist with the financial aspects of eye care.
- Develop regulations on Lasik.