



Diabetes Combined People With Diabetes

I. Introduction

- Diabetes groups were held in a total of five cities:
 - Washington, DC.
 - Houston, TX.
 - Atlanta, GA.
 - Cleveland, OH.
 - Miami, FL.
- These groups were divided by the following ethnicities:
 - African American.
 - Hispanic/Latino English-speaking.
 - Hispanic/Latino Spanish-speaking.
 - Caucasian.
- Participants in these groups had all been diagnosed with diabetes and ranged in age from 17 to 70 years.

II. Key Findings

African American

- Most participants were very knowledgeable about diabetes in general but acknowledged needing more information about how this disease affects the eyes. The participants knew that if they had diabetes, they would need to have their eyes examined, but the reason for this didn't seem clear to them.
- Participants stated they believed that there is not enough information about vision care available, particularly information regarding the relationship between vision and diabetes.
- Most stated that it is important to see their eye care professional on a regular basis and understood that if they kept their sugar levels under control, then it would be easier to manage their diabetes and the impact on their eyes.
- The most trusted source for information was the primary care physician. Participants also reported that they sometimes complement information received from their physician with information found on the Internet.
- The cost of eye care was a concern for many.
- There was no consensus on the preferred formats to receive information—brochures, pamphlets, electronic newsletters, e-mails, radio, and TV public service

- announcements (PSAs) were all mentioned. Print materials in general seemed to be the most popular.
- In general, participants agreed that it was important to have a physician with whom one felt comfortable and who communicated with one's other healthcare professionals so that everyone would be on the same page.

Hispanic/Latino English-Speaking

- Participants stated that they receive much of their health-related information, including information about diabetes, from their health insurance provider.
- A healthcare professional's cultural competency was very important for participants; they stated wanting a healthcare professional who could respond to their questions and provide guidance, referrals, and additional information regarding health-related issues.
- Participants stated that more emphasis should be made on the accompanying health issues that come with diabetes.
- Participants in all groups said that they wanted to learn more about eye health.
- Participants recommended that the National Eye Institute (NEI) increase awareness about eye health to underserved communities through the following:
 - Billboards.
 - Social media (since many people get their information this way).
 - Resource materials in healthcare professionals' offices.

Hispanic/Latino Spanish-Speaking

- Few participants in these groups had heard of diabetic eye disease (DED), and few appeared to understand that diabetes could affect their eyes.
- Although participants reported regarding vision as being very important to their quality of life, they tended to see an eye care professional only when they experienced a problem.
- Participants stated that they get health information from their healthcare professionals, the Internet, Caracol (radio broadcast), family members, and magazines.
- Participants expressed concern about the high cost of eye exams and glasses, and stated that when they visit a healthcare professional, they are given only minimal information about expensive remedies.
- Participants in one group stated that they did not feel their healthcare professionals understood them and that they want their healthcare professionals to spend time with them and explain health-related issues to them in a simple way.
- Participants stated that they did not remember seeing any information about eye health or diseases in the media.
- Few participants in these groups had heard of NEI.

Caucasian

- Although the participants in these groups all had diabetes, very few of them were familiar with DED.
- Participants who had a good relationship with their primary care physician reported good levels of diabetes management, sugar monitoring, and sugar maintenance.

- Participants reported that they did not like having their eyes dilated. One participant noted that eye care professionals have a new machine that allows them to photograph the eye.
- Participants stated believing that insurance policies often dictate what can and cannot be done with respect to eye exams and that this issue affects the care people seek.
- Most participants were aware that diabetes and blood sugar levels affect vision.
- Participants in some groups stated that they believe healthcare professionals “push” pills, treatments, or eyeglasses to increase their income rather than prescribing treatments based on what is best for the patient.
- Several participants admitted that when they were first diagnosed with diabetes, they did not want to follow their physician’s recommendations, but after a while, it “sunk” in (and they began following recommendations).
- Participants acknowledged that controlling sugar intake is important in DED prevention.
- One participant, still in denial of having diabetes, stated believing that if she didn’t think about it, it would go away. This participant was aware that this was not reality, but stated that this reflected her current emotional state.
- Individuals who have had multiple health issues, such as heart bypass surgery, cancer, or chronic back problems, considered diabetes to be a minor problem in comparison.

III. General Health

Self-assessment of general health

African American

- Overall, the groups rated their general health as being between “good” and “fair.”
- Some of the older participants had been through a few surgeries, while younger participants had been diagnosed with diabetes fairly recently.
- Some participants reported feeling that their health was improving because of lifestyle changes they had made, such as eating healthier, changing their diet, and exercising.

Hispanic/Latino English-Speaking

- Most participants stated that because they were dealing with diabetes, they would rate their health at a six or seven on a scale of one to 10.
- Some of the participants reported that after being diagnosed with diabetes, they realized they needed to change their lifestyle.
- One participant who rated her health as seven or eight on a scale of one to 10 said, “I have always been healthy. Diabetes runs in my family—my mother and father have it—[so I] started taking care of myself and losing weight and taking whole foods [and] vitamins.”
- Another participant said, “[I’d rate it a] 10. I just started taking insulin. It’s been challenging, but right now I feel good; my sugar is maintained and I have good insurance.”

Hispanic/Latino Spanish-Speaking

- Participants in these groups generally rated their personal health from good to fair, with occasional ratings at the extremes (excellent or poor).

Caucasian

- Participants rated their overall health from poor to very good, but mostly in the average range.
- A good to very good health status for many participants depended on whether their diabetes was under control.

Frequency of healthcare professional visits

African American

- Participants said that they normally visit their healthcare professionals between every three months (quarterly) and yearly, depending on their specific health needs.

Hispanic/Latino English-Speaking

- Most participants reported being proactive in getting routine exams to help maintain their health.

Hispanic/Latino Spanish-Speaking

- There were no discernible patterns in how often participants in these groups saw their healthcare professionals, ranging from “just last month” to more than 10 years ago.

Caucasian

- Most participants in these groups saw their primary care physician once or twice a year, and several also saw specialists for their diabetes.

Types of healthcare professionals they see

African American

- Primary care physician.
- Gynecologist.
- Chiropractor.
- Endocrinologist.
- Urologist.
- Internal medicine.

Hispanic/Latino Spanish-Speaking

- General practitioner, internist, or family physician.
- County clinic or a nurse for regular care.
- Endocrinologist or diabetes specialist.
- Gynecologist.
- Cardiologist.
- Eye care professional.

Caucasian

- Primary care physician.
- Pulmonologist.
- Endocrinologist.
- Eye care professional (either optometrist or ophthalmologist).

Where they get information on health issues

African American

- TV (Dr. Oz, The Doctors).
- Magazines/Books (*Diabetic Monthly, Men's Health*).
- Internet (WebMD, Google, Mayo Clinic Website, Diabetic Connect).
- Family members and friends.
- Healthcare professionals.

Hispanic/Latino English-Speaking

- Primary care physicians.
- TV (Health Channel).
- American Diabetes Association (ADA).
- Diabetes magazines and pamphlets from healthcare professionals' offices.
- Pharmacy.
- Ads in magazines.
- Church.
- Family members.
- Amazon.com.
- Support groups.

Hispanic/Latino Spanish-Speaking

- Internet.
- TV (Dr. Oz).
- Primary care physicians.
- Classes through the local clinic or hospital.
- Family and friends.
- Radio (Caracol).
- Supermarket or pharmacy.
- Diabetes support group.
- Magazines.

Caucasian

- Internet (Google, Doctors.com, Diabetes.org).
- Direct mailings.
- Personal experiences.
- Books (*Johns Hopkins Guide to Diabetes, A Touch of Diabetes, 1001 Things You Can Do if You're Diabetic*).
- Diabetes magazines.

- ADA.
- TV (Oprah, Dr. Oz, The Doctors, Dateline specials, the news).
- Family members with diabetes.

IV. Vision

What they know about vision

African American

- “You get blurry vision with diabetes.”
- “You can get diabetes in your eyes.”
- “The longer you have diabetes, the worse your vision gets.”
- “My vision is not bad but is getting worse; I know the importance of getting my eyes checked.”

Hispanic/Latino English-Speaking

- Participants reported that their vision became blurry when their glucose level was high.
- Each group had several participants who appeared to be more knowledgeable about diabetes and vision than most of the others in the group.
- One participant stated, “When the sugar gets to your eyes, the blood vessels start to explode.”
- Most of the participants said they have a good relationship with their eye care professionals.

Hispanic/Latino Spanish-Speaking

- Participants stated that vision is important for everything they do.

Why vision is important to them

African American

- Reasons participants gave were deteriorating vision, having seen family members go through the symptoms of diabetes, or wanting to stay healthy for the sake of their children.

Direct Quotes:

- “My uncle [with diabetes] died in his 20s; it started with his foot, then his leg. My mother and grandmother had it, so I’ve seen a lot.”
- “I have young children and I can’t afford to have this, so I make sure I do what I need to do.”
- “I don’t know if I want to live without sight.”
- “I’m glad I’m not one of them. I know two people who are legally blind, but I just don’t think I would like to live like that; I get so much pleasure [from] reading.”

Hispanic/Latino English-Speaking

- All participants felt that vision was important, and all had some type of issue with their sight.
- Participants in several groups expressed the fear of going blind.

Hispanic/Latino Spanish-Speaking

- Some participants shared personal stories about family members who lost their vision because of diabetes.
- Participants thought that vision was important for independence and mobility.

Direct Quotes:

- “Vision is the most important thing.”
- “Vision is necessary for living.”
- “Vision is important for everything.”
- “If people couldn’t see, they couldn’t work.”

Caucasian

- Participants in all of these groups noted that vision was very important to them, and several expressed fear of losing their sight because of diabetes.

Frequency of eye exams

African American

- Most participants reported having had their eyes examined within the past year, and most had seen an ophthalmologist; only a few had gone to an optometrist.
- Some participants mentioned that their insurance automatically schedules an appointment with an eye care professional for them.

Hispanic/Latino English-Speaking

- The frequency of seeing an eye care professional ranged from having gone “yesterday” to “haven’t been to an eye doctor in several years and a real doctor in years.”
- Several participants reported being unable to see an eye care professional because they had lost their jobs or did not have insurance.
- All agreed that people with diabetes should see an eye care professional at least once a year.

Hispanic/Latino Spanish-Speaking

- Frequency varied widely, from once every six months to “can’t remember the last time.”
- Several participants in each group said that they have had their eyes examined once or twice a year since being diagnosed with diabetes.

Caucasian

- In general, participants in these groups reported having their eyes examined once or twice a year.
- Participants in one group said that if someone has diabetes, he or she should see an eye care professional twice a year or more, depending on the individual.

Motivation/disincentives to get eyes examined

African American

- One participant reported that he went blind, with total blurred vision for three weeks, and didn't know the cause. He later discovered that it was due to diabetes. After he got his sugar levels under control, his vision returned.
- Most participants felt that their eyesight was worsening with age.
- Disincentives participants mentioned to having their eyes examined were the lack of health insurance and the high cost of exams.

Hispanic/Latino English-Speaking

- Some participants reported that they receive a reminder from their health insurance provider to get their eyes examined.
- Participants admitted being aware that vision is important but that when they lack funds, it becomes secondary.
- In one group, participants said that their motivation for getting their eyes examined was the fear of what could happen in the future.
- Participants mentioned the following disincentives related directly to cost factors:
 - Several participants related that Humalog and Lantus are so expensive that they had to save up to purchase a bottle.
 - Several said that their jobs do not offer insurance so it is very hard to purchase the prescriptions they need.
 - One participant said that test strips are “about \$600” at Walmart.
 - Another participant reported trying to find out about the Gold Card in Houston to get some assistance with prescriptions.
 - The participants who have the Gold Card said that it has significantly helped them with the cost of their prescriptions. Some got their strips, Lantus, meter, and medications for \$25. Another participant, who had been laid off, reported getting a Gold Card and that the co-pay had been \$10.

Hispanic/Latino Spanish-Speaking

- Participants mentioned the following as incentives to having their eyes examined:
 - The serious consequences of blindness.
 - Headaches.
 - Blurry vision.
 - Other specific symptoms.
 - Relationship between diabetes and eye disease.

Caucasian

- Some participants said that they would be motivated to have their eyes examined if they had serious problems seeing or if “everything started to look fuzzy.”
- Participants stated that learning about the connection between diabetes and possible blindness was an incentive to see an eye care professional.
- One participant said, “If you wait until something is wrong, they [doctors] may be able to fix it, but it may cost more.”
- Participants in one group said that receiving reminder calls and notices in the mail motivated them to have their eyes examined.

- Participants said that they would get eye care more regularly if it was more affordable.
- Having insurance coverage was an important factor in whether or not participants had regular eye exams or bought new glasses.
- Participants noted that most insurance plans pay for new eyeglasses once a year at most, and this factor influenced their eye health decisions.
- A disincentive for getting one's eyes examined was having the “puff of smoke”/glaucoma test.
- Some participants said time was also a barrier for eye care.

Topics discussed with eye care professionals during visits

African American

- Participants said they discuss types of tests and side effects, as well as test results from previous years compared with current results.

Hispanic/Latino English-Speaking

- Some said they discuss anything about diabetes.
 - “Anything and everything.”

Hispanic/Latino Spanish-Speaking

- For some, communication with their eye care professional is “lacking.”
- Others said they discuss glaucoma and macular degeneration.

Caucasian

- Participants said they discuss blood sugar levels, blood sugar fluctuations, and vision.

Views on having eyes dilated

African American

- Most participants felt that people with diabetes should have their eyes dilated at least annually and those without diabetes should have their eyes dilated every two years.
 - “I know that it’s important to have your vision checked, especially if you are a diabetic.”
 - “If you have cataracts and diabetes, you can get them back every three months; that’s why you need to get checked constantly.”

Hispanic/Latino English-Speaking

- Participants in one group felt that eyes should be dilated depending on the specific needs of the individual.
- In another group, there was a wide variety of responses to this question:
 - “Every time I go.”
 - “Once a year.”
 - “Every four months.”
- One participant didn’t know what dilation was.

- Another participant asked, “How [long does it] take you to get your eyesight back once you get your eyes dilated?” Several participants replied that it took one or two hours.

Hispanic/Latino Spanish-Speaking

- Participants gave a wide variety of answers on how often people should have their eyes dilated, from “every time” you see an eye care professional to “never.”
- Others said that the eye care professional should determine how often eyes should be dilated.

Caucasian

- Participants in several groups mentioned that they dislike having their eyes dilated.
- One participant noted that eye care professionals have a machine that allows them to take a picture of the eye instead of having to dilate the eye.
- Participants stated they would like eye care professionals to find a way to “undilate” eyes more quickly.
- Most participants said they have their eyes dilated once a year.
- Others said that they get their eyes dilated every time they see their eye care professional and on an as-needed basis.
- Participants in two groups said that people with diabetes should get their eyes dilated more often than the general population.

V. Knowledge of DED

Diabetes and vision

African American

- Participants mentioned the following as ways diabetes affects vision:
 - Vision deteriorates over time.
 - Diabetes causes blindness.
 - Vision blurs.
 - Lights become more intense.
 - Diabetes causes headaches.
 - Diabetes causes tunnel vision and dimness.

Hispanic/Latino English-Speaking

- Most participants said that their physicians were direct when telling them the risks of losing vision due to diabetes. Participants stated that either their physicians or their family members informed them about the relationship between diabetes and vision.
- One participant said that one of the symptoms of DED is blurriness.
- A few participants reported that driving at night was a problem because of the glare from lights.
- Participants in one group said that DED is a serious health problem that needs to be treated, that there is no “reversible” treatment for diabetes, but that there is preventive care.
- One or two participants in each group had been diagnosed with DED.

Hispanic/Latino Spanish-Speaking

- Although all participants in these groups had diabetes, only two (in all five groups) had heard the term “diabetic eye disease” prior to these groups.
- One participant said that diabetes can affect the eyes by making blood vessels rupture, resulting in bleeding that leads to vision loss, shadows or white spots, or pressure in the eyes.
- A participant in another group said, “When you have sugar in your blood, it gets thicker, which increases pressure in your eyes.”

Caucasian

- Participants knew that diabetes can cause blindness and can affect eye blood vessels.

How they learned about the relationship between diabetes and vision

African American

- Participants said they learned about the relationship between diabetes and vision from reading medical journals and other publications; from talking with their primary care physicians, friends, and relatives; from the Internet; and from taking classes.

Hispanic/Latino English-Speaking

- Respondents got most of their information about DED from their regular physician, along with other information about diabetes complications.
- One participant said that information on diabetes was “overwhelming at times because diabetes affects so many other parts of the body.”

Hispanic/Latino Spanish-Speaking

- Participants said they received information about DED from their eye care professional, diabetes specialist, and friends and family members who have diabetes.
- Others said they got their information from a video at the eye care professional’s office and pamphlets.

Caucasian

- Participants reported learning from their healthcare professional and the Internet about the relationship between diabetes and vision.
- Several participants said they learned about the connection between diabetes and vision via classes for people with diabetes in their local communities and through the Internet.

Motivation to keep diabetes under control

African American

- Participants gave a variety of responses when asked what factors encouraged them to keep their diabetes under control:
 - “Don’t want to lose my vision.”
 - “Just want to live.”

- “The possibility of what can happen, so I made sure I got all the bad things down.”
- “My general health, vision, nerves, because of possible nerve damage in your legs, causes problems with your eyes and your feet.”
- “I’m dealing with a tingly feeling right now.”
- “I have a personal experience. My mom had her leg cut off, so I know how important it is, because mother couldn’t remember. And that’s in my mind—getting my leg cut off and my vision.”
- “I have diabetes in my family; my brother had his leg cut off and went into a coma.”
- “Just from hearing older people talking about touching the sugar.”
- “Knowing people who have had eye problems. A guy moved a file cabinet and the cabinet fell on his foot. He had to get it amputated, so things like that stick with you.”
- “Being self-sufficient.”

Hispanic/Latino English-Speaking

- Participants reported being motivated to keep their diabetes under control so they can watch their children and grandchildren grow up, enjoy life, and go out with friends.
- Others said they wanted to live longer than family members who have died young from not taking care of themselves and to have a satisfactory quality of life.

Hispanic/Latino Spanish-Speaking

- Participants reported being motivated to keep their diabetes under control because they want to stay healthy for friends and family.
- Some said that seeing others with diabetes suffer the consequences encouraged them to avoid those problems, if possible.

Caucasian

- Factors participants stated that encouraged them to keep their diabetes under control were the fear of going blind, a desire to live long, fear of amputation, and fear of pain and needing insulin.
- Others said they wanted to be able to see their family, for personal health reasons, and to enjoy quality of life.
- Participants said that physicians stress that diabetes is a balancing act.

Familiarity with the term “diabetic eye disease”

African American

- Most participants had heard of the terms “diabetic eye disease” and “diabetic retinopathy,” although in one group, none of the participants had heard the terms.
- Only a few participants had been diagnosed with DED.
- Participants made the following comments about DED:
 - “Bleeding in your eye; I had it and they removed that scar tissue out and I couldn’t see for a while after the surgery.”
 - “I have to confess I don’t know how that disease affects your vision.”

- “I don’t know, either. I’m a research person but I think I don’t want to know; I’m scared of it.”
- “I haven’t been diabetic for very long, maybe six years; everything has been fine so far, so maybe that’s why I haven’t worried about it.”
- Some participants mentioned that DED could be prevented by drinking carrot juice, getting a yearly examination, exercising and dieting, and keeping one’s sugar under control.
- One participant said that DED can accelerate macular degeneration.

Caucasian

- Participants in most groups were not familiar with the term “diabetic eye disease.” One participant “did not think of it as a disease but as a condition. More of a symptom or something that can happen.”
- Participants said that there are many diseases.
- Some participants said DED had something to do with circulation.
- Some participants were familiar with diabetic retinopathy but not with the term “diabetic eye disease.”

Knowledge of symptoms of DED

African American

- Participants in all groups said they learned about the relationship between diabetes and vision from their primary care physician.

Caucasian

- Symptoms of DED that participants mentioned included blindness, specks in the field of vision, blurriness, loss of peripheral vision, and worsening eyesight.
 - “[I had] flashing lights.”

Views on preventing vision loss from DED

African American

- In general, participants said that DED cannot be prevented, just treated.
 - “Let’s put it this way, no one has told me that it can be prevented; they say what meds to take and what not to drink but not that it can be prevented.”
 - “My doctor just told me that if I could keep my cholesterol down, I would be fine.”

Hispanic/Latino English-Speaking

- Participants stated that vision loss from DED can be prevented by keeping their “sugar under control,” exercising, and getting a second opinion if they felt they had been misdiagnosed.
- Participants in one group said that people with diabetes should drink water, “either Fiji or get a water purifier.”

Hispanic/Latino Spanish-Speaking

- Participants in this group stated that vision loss from DED could be prevented by controlling blood sugar, leading a healthy lifestyle, and visiting their healthcare professional regularly.
- Others said they try not to get too stressed, maintain a healthy weight, and take medications regularly.

Caucasian

- Participants in this group stated that vision loss from DED could be prevented by controlling diabetes and blood sugar, maintaining a good diet and getting exercise (“taking care of yourself,” said a participant in one group), and getting regular examinations (twice a year).
- Others said they control stress and anxiety and keep their eyes moist by using natural tear eye drops.

VI. Health Information Preferences

Level of comfort in communicating with primary care physicians

African American

- Most participants expressed the need for having a good relationship with their physicians.
- The majority of participants said they felt comfortable when communicating with their healthcare professionals; only a few mentioned having felt healthcare professionals didn’t understand them.
- Participants who had trouble communicating with physicians said that they would just change physicians.
- A few participants thought that communication issues were due to personality differences, while others opined that getting information from other sources can improve communication with healthcare professionals, since it shows the healthcare professionals that they are interested in health issues.
 - Participants reported appreciating when healthcare professionals took extra time to communicate with them and follow up on their health issues.
 - “I don’t fare well with Caucasian male doctors and Pakistan doctors. I don’t think they’re racist; they just don’t have cultural sensitivity.”
 - “A good doctor realizes that the patient is more than just a number.”
 - “[I] haven’t had any issues; I go to an African American doctor.”
 - “People need to speak up.”
 - “It’s like building a relationship.”
 - “When I go to the doctor, I make sure that they are looking for specific things and make sure it’s covered.”

Hispanic/Latino English-Speaking

- Participants said they had open communication with their healthcare professionals, including receiving calls from them and sharing e-mails.
- Participants also said they receive additional health-related information from their physicians, such as brochures and referrals to see other professionals.

- “I get a lot of good information from my doctor; she takes her time with me.”
 - “When I see my doctor, I have my list of questions and we discuss each and every one.”
- In one group, when asked whether or not they perceived physicians to be culturally insensitive or discriminating, some responded yes and some no; whereas in other groups, no one said that their physicians were culturally insensitive or discriminated against them.
- Some participants reported being very comfortable with their primary care physicians; however, one said, “You have some doctors that will just treat you like a number.”
- A participant in one group felt that physicians might “miss something” and stated that “older doctors seem to care more and keep up with technology and really know what can happen versus the younger doctors.”

Hispanic/Latino Spanish-Speaking

- Some participants reported feeling comfortable talking with their healthcare professionals.
- Others stated that sometimes healthcare professionals seem too busy to talk.
- Some participants stated being afraid to ask questions because they are afraid of the answers.
- One participant said his healthcare professional did not understand him because the healthcare professional was American.
- Another participant said, “With Hispanics, we do not get a Spanish-speaking doctor and we do not understand what they are saying. Government doctors are a problem.”

Caucasian

- Participants in one group stressed the need for having a good, open relationship with one’s primary care physician and endocrinologist (for those who see one).
- Participants who said they have a good relationship with their physician reported good levels of diabetes management, sugar monitoring, and sugar maintenance.
- Some participants were unsure about whether or not they can trust their physicians. Others in the group then advised them saying, “Then you should get a new doctor.”

Level of comfort in communicating with eye care professionals

African American

- When participants were asked to describe their level of comfort in communicating with their eye care professional, their responses varied:
 - “I don’t have a specific eye care professional.”
 - “Some are insensitive to what my needs were.”
 - “They use technical words. You’re your own advocate and can’t put all your faith in the doctor.”
 - “My doctor pays attention. I used to have blood pressure problems, so my doctor takes me right away.”
 - “I don’t have a relationship with my eye care professional.”

Hispanic/Latino English-Speaking

- Several participants said they love their eye care professionals and are very comfortable with them.
- One participant indicated that he or she sees someone higher than an ophthalmologist, depending on where he or she goes.
- Another participant indicated that he or she sees an optometrist when getting his or her eyeglasses.

Caucasian

- One participant said that her eye care professional shared pictures of the aging eye, showing what can happen if diabetes gets out of control, as well as pictures of diabetic eyes that have not been taken care of.
- Three other participants mentioned being shown a picture of how vessels in the eye change due to diabetes.

Beliefs, attitudes, myths, or feelings about going to an eye care professional

Hispanic/Latino English-Speaking

- One participant stated, “I don’t go to the doctor and feel that no matter what happens, then it’s going to happen. I’d rather burn down the whole house.”
- Some participants said that some people are fortunate to have good insurance and can get a good primary care physician, while others have a gold card and have to sit for hours to see a primary care physician.

Hispanic/Latino Spanish-Speaking

- One participant said, “Many times they will give you all the information, but they really do not care. Other doctors will really try and explain things to you.”
- Another participant said, “I think the white doctors discriminate against you. The minute you give them your name, they make you wait longer than necessary. They would pass you from one place to the next and pass you until the translator came. I could see their rejection.”

Barriers to receiving eye care services

African American

- Participants mentioned time and money as factors that get in the way of receiving eye care services.
 - “It is true. You put it on the bottom of the list because you have to wait for the insurance.”
 - “Money can get in the way.”
- Participants suggested the following to overcome a few of the obstacles some have experienced:
 - Find another healthcare professional.
 - Take care of oneself and find out what’s really going on.
 - Perform research.

Hispanic/Latino English-Speaking

- One participant said he was taking old insulin because he did not have insurance to cover prescriptions.
- In another group, participants said that affordability was a problem. One participant reported receiving a bill for \$150 from the eye care professional, which he considered to be very high for the services received.
- In order to overcome obstacles, some participants felt that healthcare professionals should “have the right knowledge to disburse the information to you.”
- A participant said, “If you’re not comfortable with your physician, you need to take care of it by doing surveys, writing letters, because if you don’t do anything, then they won’t, either.”
- Another participant said, the “doctor gave me a stack of prescriptions and when I left, I threw them in the trash [because I couldn’t afford to fill them]. I went to another doctor who told me to go to the lab, and we’ll take care of it from here. So that’s the doctor I stuck with.”

Hispanic/Latino Spanish-Speaking

- One participant reported changing eye care professionals because he was trying to get more money out of the insurance company than he was entitled to for the services provided.
- Some participants said language was a barrier to receiving services.
- Participants said a physician’s lack of caring was also a barrier to receiving services.
- Participants stated that healthcare professionals are not comfortable dealing with patients who do not speak English.

Caucasian

- One participant said that eye care professionals need to decrease the wait time and the “whole ordeal” needed when preparing to dilate eyes. This participant suggested that eye care professionals offer nighttime or weekend hours so that dilation doesn’t disrupt the day or that eye care professionals bring eye dilation to the patient’s home or work.
- One participant said that healthcare professionals need to improve communication among themselves. This person suggested that all healthcare professionals fill out a form regarding each visit with a patient and send it back to the primary care physician. This participant also requested that more education be provided to healthcare professionals on how to talk with patients and how to share information with patients.

Information seen in the media about vision

Hispanic/Latino English-Speaking

- Participants in one group had heard about eye health by watching stations like LiveWell.
- Several had heard of Lasik or laser surgery. One brought it up with the eye care professional, who immediately said, “No, that wouldn’t be good for you.”

Caucasian

- Participants in one group noted not seeing anything on eye health except in Internet pop-ups and an advertisement of a free screening at Walgreens.
- Participants in another group said they had not seen much in the media but had seen or heard the following:
 - Commercials for Dr. Allison (a local optometrist) treating dry eyes.
 - Ads for laser surgery on the radio.
 - Posters on eye diseases hanging in the eye care professional's office and at the Veterans Administration.
 - Articles in the paper.
- Participants in another group reported seeing or hearing the following in the media:
 - Commercials on dry eye.
 - Ads online about diabetes.
 - Articles on vision in the newspaper.

Major sources of health information

African American

- TV (Dr. Oz, shows on CNN and TLC, Diabetic Living).
- Internet (WebMD, Google).
- Ophthalmologist.
- Checkup calls from healthcare providers.
- Family.
- Physicians and nurses.
 - "When I have a list of questions to ask, I ask for literature about it, and then check the sources."
- Across most groups, social media does not appear to be a good source for health information:
 - "It is not used for information and I use it more to play games."

Hispanic/Latino English-Speaking

- Primary care physicians.
- Health insurance newsletters.
- National Public Radio.
- ADA and the ADA website.
- WebMD.
- Walmart.
- Pearle Vision.
- Family.
- FitTV (programs on types of food to eat for eye health).

Hispanic/Latino Spanish-Speaking

- Healthcare professionals.
- Internet.
- Magazine about diabetes.
- Spanish-language health information.

Caucasian

- Medical professionals:
 - Diabetes specialist.
 - Endocrinologist.
 - Eye care professional.
 - Nurse practitioner.
 - Dietician.
 - Primary care physician.
 - Pulmonologist.
- Family members in the health profession.
- Diabetes education class.
- Internet (Google, WebMD).
- Books and pamphlets.
- Personal experience.
- Insurance companies.

Types of information regarding eyesight/vision they have looked for

Hispanic/Latino Spanish-Speaking

- Information on glaucoma and on how diabetes affects vision.
- Information in Spanish.

Caucasian

- Information on safety goggles.
- Books on diabetes from Barnes and Noble and Walmart.
- Newsletters that give information on current health topics.
- Health information offered by phone from a health coach, made available through employer.
- ADA website.
- Weekly phone calls from a nurse through the health insurance company.

Need for further information about vision

African American

- Most participants said they could use much more information on eye health. They said it would be helpful to have a website to visit, e-mails sent to them, and printable materials that they can highlight and share with their healthcare professionals regarding their concerns.
 - “It’s extremely important.”
 - “If there is literature out there and things that we should be looking at, then it needs to be brought to our attention.”

Caucasian

- Participants noted needing more education on vision in laymen's terms. They would like to receive it online and to be able to call a national hotline where they can ask questions. They would also like someone to speak with them in a tone that scares them—so that they will do what healthcare professionals tell them—and who provides information that makes them feel like they are in control and doing something about it.

VII. Summary

“One thing” that NEI could do for people with diabetes

African American

- Offer more information about eye care for people with diabetes.
- Provide ways for people to get their eyes treated who can't afford it (mobile clinics that do eye exams).
- Support nonprofit health organizations that are geared toward promoting eye health.
- Help one participant's church with the printing and distribution of materials they are currently producing that are specifically for African Americans who have diabetes.
- Promote eye health more in healthcare professionals' offices, radio, and television; educate people before they are affected by diabetes, not after.
- Produce more commercials.
- Hold seminars.
- Exhibit billboards.
- Post more information in stores, pharmacies, and offices.
- Hold onsite seminars in hospitals.
- Increase visibility by partnering with eye care professionals.
- Hand out brochures.

Direct Quotes:

- “Share more research results like success rates on surgery versus holistic medicine and prevention.”
- “I'd like to see this organization provide information to those who don't have computers because there are a lot of seniors who don't have access to computers and don't have access to information about diabetic eyes and it's important that they try to reach the seniors; there should be a way to put the information into the community.”
- “A coordinated effort with med associations, diabetes associations, if they get together, it will be easier to spread the info.”
- “PSAs to reinforce the eye institute because I would have never thought about them and now that you mention them, I feel like ‘duh’. I would prefer a website, but you have to think about the older people who might not have electronic access.”
- “More clarity and less technical stuff. We want it quick and get out. Clear and concise.”

Hispanic/Latino English-Speaking

- Organize an event that offers free eye exams and eyeglasses.
- Bring more awareness to the public.
- Show the effects that diabetes has on people.
- Provide affordable ways to help people who don't have insurance.
- Make medicine and supplies affordable and available.

Hispanic/Latino Spanish-Speaking

- Offer ways to get inexpensive eye examinations.
- Find eye care professionals who will see patients without insurance or for a nominal fee.
- Advertise if there are NEI eye care professionals who could see patients.
- Provide information through the following venues:
 - Internet.
 - Magazines.
 - PSAs.
 - Personal mailings from NEI.
 - E-mail and mail.
 - In person.
 - Messages on the phone (like text messages or voicemails).
 - Chats on a website.
 - Phone calls with someone knowledgeable about eye care for people with diabetes.
- Provide funding:
 - Lasik operations.
 - Insurance to cover eye examinations.
 - Eyeglasses.
 - Workshops where eye care professionals discuss eye health.
 - Preventive exams.
- Provide physicians with publications to give to patients with diabetes.
- Sponsor an event, like the diabetes walk or cancer walks, for which the proceeds go toward people who cannot pay for eye exams.
- Open a local office.
- Offer "membership" in NEI to a diabetes support group.
- Promote NEI and promote affordable eye care professionals.

Caucasian

- Provide education for professionals.
- Provide continuing education courses for pharmacists and optometrists, including Walmart optometrists.
- Educate primary care physicians, because people tend to see primary care physicians more than specialists, and primary care physicians need education on communicating with patients and being more knowledgeable.
- Influence patient/healthcare professional communication and education for healthcare professionals.
- Educate the general public.
- Advertise through radio PSAs, because people listen to the radio when not on their phone.

- Post on billboards.
- Stress eye disease through commercials on TV, including the importance of having eyes examined (like the kidneys, they are a “silent killer”).
- Provide more information, not just on the Internet, but in TV commercials that explain a little bit and provide a website.
- Go to schools and speak with children about eyes and provide screenings.
- Add eye information to prescriptions and medications from the pharmacy.
- Have Oprah do a show on eye health.
- Provide information through pop-up ads, because everyone sees those.
- Provide information in healthcare professionals’ offices, on the radio, on billboards, through pamphlets, on posters on the wall, and on wall plaques.
- Provide education about different kinds of tests and whether they are helpful and/or harmful.
- Provide information in schools because there are “a lot of kids getting type 2 diabetes. Kids hearing that, maybe hearing more of the complications. Just providing more information and the kids can take it home.”
- Address funding issues.
 - Provide patients with coverage.
 - Help pay for costs.
- Build awareness.
 - Be more specific with problems people may have or may be experiencing (problem examples include noticing cloudy vision, having a hard time reading, and needing bright light when you didn’t need it before).
 - Scare “the hell out of them.”
 - Offer more information.
 - Build awareness, like the American Heart Association (“I haven’t heard of them doing any events”).
 - Raise funds.
 - “Do they fundraise? ‘Cause when [the American Cancer Association] solicits contributions, they give pamphlets.”
- Find a cure for diabetes.
 - “It’s been around for so long. If there’s gonna be one in four people predicted to be diabetic, they need to cure the disease.”

VIII. Other Comments

Hispanic/Latino English-Speaking

- One participant suggested using a celebrity spokesperson with diabetes, such as Patty LaBelle, to encourage people with diabetes to pay attention to the issue.
- Another participant said, “Diabetes is a cultural thing and people should get rid of processed food.”
- Participants said they really enjoyed the groups and are glad to see a government agency doing something on this topic and would like to see more.