Prevent Blindness

Diabetes + The Eyes:

Increasing Access and Addressing Bias

Final Report | March 15, 2024

Executive Summary

ABOUT THIS STUDY

- This Diabetes + The Eyes Report is the result of a qualitative study with Prevent Blindness stakeholders (patients and providers). Using narrated stories, SLR gathered feedback through interactive exercises to help respondents explore their experiences and potential biases.

WHAT'S WORKING WELL?

- From the **patient** perspective, many respondents shared that they appreciate the professionalism and responsiveness of their doctors in caring for their emotional wellbeing by providing education and information.
- **Provider** respondents reported that they find their work rewarding, fulfilling and dynamic. Many enjoy the diverse experience of working on a care team.

WHAT CAN BE IMPROVED?

- Key opportunities in the **patient** experience include the time required to plan and see a provider, feeling ignored, and gaps in understanding medical terms and insurance coverage.
- **Provider** improvement areas are schedule adherence pressure, knowledge alignment with patients, and negative impacts of bias on the patient experience.

Key Findings: What's Working Well?

- **From the patient perspective, many respondents shared that they appreciate the professionalism and responsiveness of their doctors in caring for their emotional wellbeing by providing education and information.**

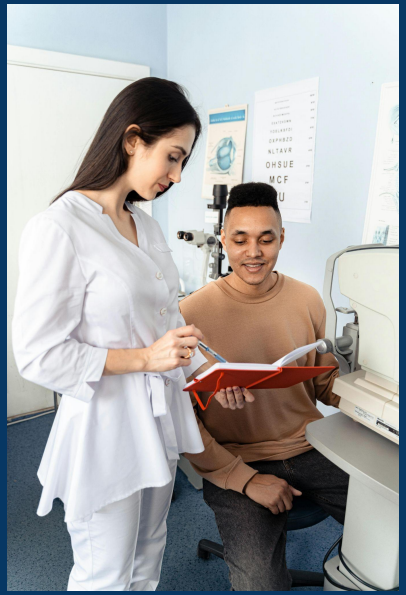
  "I was thankful because they showed me how to wear [my] prescription glasses. They listened. I'm grateful, more than anything, for the kindness they showed me. A lot of people will thank [providers] because they don't know where to go or what to do when our vision is not doing well." Spanish speaker

  "I've been going to my doctor now for about 30 years. I've had very good experiences and this last time was no exception. I met with the doctor, was able to get my prescription, also able to get other exams that I like to get, just to check for glaucoma, etc." - English speaker

- **Provider respondents reported that they find their work rewarding, fulfilling and dynamic. Many enjoy the diverse experience of working on a care team and take pride in educating patients.**

  "It's fulfilling because I know that I'm making a difference in the lives of the patients that I am assigned to help." - Optometrist

  "I feel like having that ability to quickly educate and show them is a very helpful way to have this patient care interaction." - Ophthalmologist



Key Findings: **Pain Points**

KNOWLEDGE GAP

- Lack of health literacy/knowledge disadvantages & scares patients
- Lack of patient health literacy takes time from providers they could instead spend getting to know patients as individuals, which would mitigate bias

TIME CRUNCH/WAIT

- Providers work under intense pressure to see many patients a day in short visits & spend valuable time educating patients about disease basics
- Patients have to take off work for appointments and travel to providers but agonize during long waits at provider offices and feel rushed through their visits

EMPATHY GAP

- Providers make assumptions about patients' knowledge level, language fluency, disease compliance, life circumstances, ability to pay and other factors
- Patients want to feel more heard/ seen and feel need to advocate for themselves but lack skills/ knowledge
- Many patients are inclined to defer to physicians, even when this goes against their best interests

PATIENTS

"My recommendation to better train providers is to ensure that in your practice or in your clinic, there is someone who has mastered Spanish perfectly." Spanish speaker

PROVIDERS

"I think each of us really needs to examine ourselves to see that we have some implicit bias that we really don't even realize we have. It can help us to create a great patient rapport and to prevent losing patients if we hurt their feelings." - Optometrist

BIAS

- Similar pain points were experienced among all patients
- Most participants were Black and Latino
- When reviewing the video stories, some Latino patients expressed a tendency to blame the patient and give the doctor the benefit of the doubt

Detailed Findings: Spanish-speaking Patient Experience Differences

Language

- Spanish-speaking patients have varying levels of language proficiency and preferences for which language they want to conduct their appointment in
  - Some prefer to use Spanish for their appointment even if they understand English
  - Speaking some English doesn't mean they are completely fluent or prefer English
- Patients want to be addressed directly even if they have a translator with them
- Some patients find it less embarrassing to discuss personal medical information through an external (even remote) translation service

Deference to provider

- Spanish-speaking patients seem especially likely to defer to providers out of respect, which may keep them from advocating for themselves

"Sometimes we have to tell them personal things and it's embarrassing. First, because you have to tell your problems to somebody else and then I don't know if they are telling me the truth." , Spanish speaker

"Kevin would have had a better experience if from the first visit with the doctor he had told him I have these questions and he wouldn't have had that fear or those thoughts that he can't question the doctor. Maybe that means bringing my medical history from my last visit, like "this is what the doctor said" and show it at the end of the appointment so as not to give the doctor any arguments." - Spanish speaker

SHARED RESPONSIBILITY

- Problems and solutions require participation from both patients and providers
- Information sharing should be coordinated among the full care team: PCPs, specialists, and other providers

TIME

- Waiting room time offers an opportunity to educate, comfort, and connect with patients while providers see other patients

KNOWLEDGE

- Comprehensive educational materials should be available at key touchpoints during eye visits
- Patient stories shared regularly via social media and email can build provider empathy across cultural and socioeconomic differences

Methodology: **Research Design**

- Led key informant interviews with Prevent Blindness stakeholders (real stories of bias witnessed from patient and provider perspectives)
- Used the collected stories to create narrated stories for patient and provider feedback
- Launched interactive exercises to help respondents explore their experiences and potential biases by responding to the audio stories (listen and discuss what went well or not so well)
- Asked respondents how to improve outcomes from the patient and provider perspectives via co-creation activities (scenario + potential ways to solve)
- Assessed participant comfort with web-based and voice-assisted technology

Patient Breakdown:

Language:
- **18** English-speaking
- **15** Spanish-speaking

Ethnicity:
- **3** Asian/ Asian American
- **11** Black/ African/ African American
- **16** Latinx/ Hispanic
- **3** White/ Caucasian

Age range:
- **2** 18-34
- **13** 35-49
- **13** 50-64
- **5** 65+

Vision status:
- **19** Have vision loss
- **14** Do not have vision loss

Provider breakdown:

Specialties:
- **7** optometrists | **6** ophthalmologists

Ethnicity:
- **2** Asian/ Asian American
- **4** Black/ African/ African American
- **2** Latinx/ Hispanic*
- **6** White/ Caucasian* [*One identified as Latina **&** White]

Regions:
- **10** in urban areas | **3** in suburban areas

Practice location:
- **8** in private practice
- **3** in university
- **2** in community health center or clinic

DETAILED FINDINGS: PATIENTS

Three words I would use to describe what it is like to go to an eye doctor are ____, _____, and _____.

Positive themes

PROFESSIONALISM AND RESPONSIVENESS

Patients used words such as ”professional,” “punctual,” “communicative” and “respectful” to describe their experience and many of those words referred to the respect and efficiency with which they were treated.

EMOTIONAL WELL-BEING

Using words like “rewarding,” “healthy” and “hopeful,” 8 patients showed a positive association in regards to their visits to the eye doctor.

EDUCATIONAL AND INFORMATIVE

A few others (4) used words that showed they considered their eye doctor an important educational experience where they would be able to learn about their eye health.

Negative themes

NEGATIVE EXPERIENCES

A large number of patients (13) recalled aspects of previous negative experiences and used them as one of their three words. Some examples are: “uncomfortable,” “feeling like a number,” “lacking compassion,” “Get-in-get-out,” “ignored” and “hurried.”

STRESS AND ANXIETY

Many patients (11) used words associated with anxious feelings like “fear,” “stressful,” and “nerve-wracking” to describe their eye doctor visits.

SENSORY IMPAIRMENTS

A few patients decided to describe their health challenges when remembering their eye doctor visits. They used the words “near-sighted,” “glaucomatous,” and “semi-blind.”

TIME-RELATED CHALLENGES

A few other patients decided to use words related to challenges they’ve experienced when waiting for their appointment or during their appointment: “time-consuming,” “long,” “anticipatory.”

Detailed Findings: Maria Video Feedback (“see her jump”)

English and Spanish-speaking patients had similar reactions to the video, with most feeling either very upset or unhappy with the story. A few felt neutral or thought the visit went well.

CONDESCENDING, INSENSITIVE DOCTOR

Other patients were **upset** by the story and described the behavior of the doctor as “humiliating” and “mind-boggling.” Some recognized that the problem was related to the language barrier.

UNPLEASANT AND UNPROFESSIONAL

Many patients across both languages used the word unpleasant, especially Spanish-speaking patients.Other words such as uncomfortable and unprofessional were also used to describe how **unhappy** they were with the outcome of the story.

NO WRONGDOING, INTERACTION WAS ADEQUATE

A few patients felt **neutral** about the story. They either did not seem to understand the story or saw no wrongdoing on the doctor’s part. A few others felt the visit went completely well.

VIDEO STORY 1:

MARIA VISITS THE EYE DOCTOR

Q8: If I were describing Maria's experience to a friend, I would describe it as ____.

Detailed Findings: Maria Video Feedback (“see her jump”)

English-speaking patients

- Patients want providers to understand that getting eye care can be stressful
- Patients want providers to be more comforting, especially during difficult parts of the exam
- Patients need reassurance on what to expect for their appointment

“When the doctor arrived, the tone seemed a bit flippant and sarcastic. I would like to think that a doctor would assume that anyone who's getting any test may have apprehension. Use verbiage to make sure the patient feels comfortable.” - English Speaking Patient

“I’ve had that test before, having that puff, you almost feel like when it comes like they're gonna stab you in the eye with a needle or something so everybody flinches. But definitely that doctor should have been more welcoming and calming to her, maybe rub her on the shoulder and say, ‘ok, this is the part nobody likes, but we have to do this’ and just alleviate her fears.” - English Speaking Patient

“I think Maria would have had a better experience if the doctor continued the same train of thought that Maria's friend had, the whole reassuring, telling you what to expect. Don't be nervous. This is what's going to happen… because it gives you some sort of confidence when you know what you should be looking forward to. Then the doctor tells you, ‘oh, you're going to see her jump.’ What, why? That's, that's so ridiculous.”- English Speaking Patient

Detailed Findings: Maria Video Feedback (“see her jump”)

Spanish-speaking patients

- Patients feel eye care should be not treated as a joke
- Patients feel Maria’s experience was unpleasant, even though she came prepared
- Patients feel providers should speak to them directly, even if they have an advocate with them

“I would describe Maria's visit to the eye doctor as unpleasant. It is not fun to go to the eye doctor since it is tedious and the exams are unpleasant. You feel uncomfortable for so many reasons and you are afraid that they will hurt you or that something will happen to your eyes. It is something very important to not be taken as a joke.” - Spanish Speaking Patient

“I do feel that Maria's experience was quite unpleasant. She had some anticipation of what to expect when seeing her medical provider. However, even though she had taken initiative and prepared for that medical appointment, it turned out to be in a negative way, an unpleasant surprise.” - Spanish Speaking Patient

“Even though you might understand the language or you might speak the language, sometimes you falter on the words that you're trying to say. If you have somebody there instead of, you know, speaking to you directly as the patient and speaking to the person that is there with you, it could definitely make you feel uncomfortable or... out of the conversation.” - Spanish Speaking Patient

Detailed Findings: Kevin Video Feedback (helping Dad navigate)

Patients provided mixed answers, with some putting the blame on the doctor for making assumptions about inability to cover test costs or not looking further into the patient's medical history. Others criticized the patient for not being more proactive.

Blame on doctor

PREJUDICE FROM DOCTOR

Patients were **blaming doctor** for prejudice based on his race or type of insurance held and not suggesting necessary tests because of perceived ability to cover costs.

DOCTOR MAKES ASSUMPTIONS

Patients also **blamed doctor** for making assumptions and not looking further into medical history, communicating with previous doctor, or asking more questions, assuming patient will speak up about previous conditions.

Blame on patient

PATIENT NEEDS TO ADVOCATE FOR HIMSELF

For others the **blame is put on the patient** for not asking more questions, standing his ground re: the tests he needed, talk more about his medical history instead of waiting for doctor to ask those questions or make recommendations.

Detailed Findings: Kevin Video Feedback (helping Dad navigate)

English-speaking patients

- Patients want providers to not make assumptions about insurance and other factors that impact treatment
- Patients feel they should advocate for themselves and make decisions with the provider
- Treat patients based on their health needs, not the color of their skin

"I think Kevin would have had a better experience if his doctors had not made assumptions about him and his situation and had either went ahead and ordered the necessary tests to ensure that Kevin got the best level of care... or spoken with Kevin about the test and let him know what tests were needed, what tests were required and what tests would benefit him at his stage in life and his current level of vision."- English Speaking Patient

"He would have had a better experience if he had advocated for himself from the first appointment, instead of waiting to talk to his son. The doctor should have not made assumptions about what he possibly could or could not have afforded. That's something you discuss with the patient and make the decisions together if it's important or not." - English Speaking Patient

"The doctor's idea that he only bills a certain insurance company... this whole thing could be taken... as systemic racism in healthcare. I've been in positions where I was treated differently than the other patients and I didn't understand why. "
- English Speaking Patient

Detailed Findings: Kevin Video Feedback (helping Dad navigate)

Spanish-speaking patients

- Patients think Kevin should feel empowered to ask questions and bring medical history documentation to inform the provider
- Patients want to be treated without prejudice
- Patients feel it is the provider and their staff's responsibility to have insurance on file and know the patient's options

"I think Kevin would have had a better experience if he told the doctor 'I have these questions' and he wouldn't have had that fear or those thoughts that he can't question the doctor. Maybe that means bringing medical history from the last visit, like "this is what the doctor said" and show it at the end of the appointment so as not to give the doctor any arguments. I think Kevin would have had a better experience if the doctor had said 'yes, we can test you for glaucoma' because as a patient, I prefer to have tests done. I need to make sure I'm safe and sound, or else I'll question myself. " - Spanish Speaking Patient

"I think Kevin would have a much better experience if there was no prejudice towards his age, which is ageism and also by race, ethnic backgrounds, misjudgment." - Spanish Speaking Patient

"Kevin's experience would be better if the staff had done their job by obtaining insurance at first, that way they know what medical options Kevin could receive and continue taking so his health would not be interrupted. It is very, very important. So it's not just the doctor's fault, it's also the staff's fault." - Spanish Speaking Patient

DETAILED FINDINGS: PROVIDERS

Three words I would use to describe a day in my life as a provider are ____, ____, and ____.

Positive themes

REWARDING

"Rewarding" was the top positive word (6) used by providers. "Fulfilling" and "gratifying" were also mentioned. Providers feel they are a valuable member of their patients' care team and are happy when they can detect issues early and improve vision using various treatments.

MULTI-FACETED

A mix of words were used to describe the positive aspects of their day. Words such as "diverse", "fun", "unique", "dynamic", "teamwork" and "humbling" were shared as providers reflected on the many layers to their patients and diagnoses.

Negative themes

CHALLENGING

"Challenging" was the top word (8) used by providers. Challenges include working with a "spectrum of patient encounters", deciding treatment for complicated diseases such as diabetes and educating patients.

TIME MANAGEMENT

Staying on time while providing quality care is a common theme among providers. "Busy" (5) and "fast-paced" were used to describe their days, with some having up to 70 patients daily and only 10 minutes with each.

What are the most important things to include in an empathy training?

Themes	Quotes
START WITH THE "WHY" Providers feel it's important to educate about why an empathy training is important with statistics to support the need.	"Starting with the why…why is this important? Maybe a few statistics on challenges with empathy, or loss of empathy medical professionals as we go on in training." -
UNDERSTAND PATIENT JOURNEY Stage demonstrations, role playing, active listening skills and nonverbal communication are recommended techniques in understanding how conditions impact communities differently and how health disparities lead to lack of access or other barriers.	"Stage demonstrations would be helpful to start with as well as hearing stories from patients that have had problems with their doctors. Then some sort of role playing to give essentially hands-on experience and practice."
ADDRESS UNCONSCIOUS BIAS THROUGH SELF-REFLECTION Providers feel it's important to be aware of one's assumptions or biases and managing their emotions during the training.	"You need to attack and address your unconscious subconscious biases as well as possibly talking to other people who have experiences where they suffered." -

What are the challenges to look out for in an empathy training?

Themes	Quotes
PROVIDERS MAY NOT UNDERSTAND THE NEED Providers are concerned that their colleagues won't see why empathy is integral to care and that the empathy topic could seem "wishy washy" and not practical. Providers think a training should be careful not to come off as condescending.	"I think a lot of physicians might feel like it's patronizing, not really a true problem or they're not giving any real ideas for how to correct the issue."
IMPLICIT BIAS MAY IMPACT TRAINING Providers acknowledge that implicit bias exists around how they view their patients and whether patients are following treatment. Providers think it could be helpful to explore more about their own biases and their patients' social determinants of health.	"Maybe some pre work can be assigned to help identify any biases that may exist. I think that would be helpful as it would prepare the person for the training." -
CHALLENGE OF COVERING PATIENT EXPERIENCE IN A WORKSHOP Given that every individual is different and their unique experiences may be complex, providers feel it could be difficult to address the empathy needs for patients in one workshop.	"There are so many different perspectives of what humans go through. It's difficult to encompass the human experience in a training session. But I think it's very important for people to go outside their comfort zone and think about what other people can go through from a financial hardship perspective, from different cultures, language barriers that reduce access to health care."

Detailed Findings: Maria Video Feedback (“see her jump”)

Providers

- Providers felt the doctor in the video was unprofessional, insensitive and inappropriate
- Providers are grateful Maria had an advocate
- Providers feel it’s important for patients to trust them and to treat patients regardless of language/ understanding barriers

“Maria’s experience was less than stellar. It was a good thing that she did have Janet there as an advocate to help her process and navigate through the eye exam. It was good that she was able to speak in a way that she felt comfortable with and she had someone there to tell her what to expect from the exam. However, the doctor's interaction with Maria was insensitive and it was not in the best interest of Maria. He should have been speaking directly to her and obviously he should never have said what he said about her, to jump from the tonometer. It was very insensitive.” - Optometrist

“I definitely would describe it as unprofessional. I think it's important to treat the patient regardless if there was any type of language barrier or understanding barrier. I think it’s important for them to trust you and feel comfortable in your recommendations and treatment plan as well.” - Optometrist

Detailed Findings: Gift Certificate Video Feedback (provider only)

Providers understood how embarrassed the patient felt and suggested training topics like unbiased customer care and communication skills for staff to avoid situations like these. Some mentioned these type of videos were a good reminder to focus on empathy in patient care.

LACK OF EMPATHY

Providers commented on the need to treat patients with compassion and dignity, being "sensitive to their backgrounds." Most mentioned the word "embarrassment" when referring to how the patient felt on the video.

TRAINING NEEDS

Many providers suggested training staff in communication skills (respecting patients' privacy and being tactful), unbiased customer care, insurance coverage, standard of care across all languages and races.

OPTIONS

Providers thought that patients should be offered options and let them decide for themselves which exams they can afford.

VIDEO STORY 3:

THE GIFT CERTIFICATE

Detailed Findings: Gift Certificate Video Feedback

Providers

- Providers feel patients should be given options
- The standard of care should be the same for all patients, regardless of race or insurance
- Providers should treat patients as family

"If I were that provider's supervisor, I would tell them never x-ray a patient's pocket, nor should we limit the care to a patient based on our perception. First and foremost, we would give the patient options, and also see if there's a way to get as much care to that patient as possible. Never would I limit my patient's care because of what I think that the insurance or whatever outside entity, entities would pay for top care." - Optometrist

"There should be a standard of care across all people, all races, regardless of insurance. I think that when you discriminate and don't test based on individuals and insurances, this increases health disparities, particularly in communities that may be less insured or underinsured." -ophthalmologist

"I like to think of every patient in the chair as being my own family member. How would I want that family member to be treated? I think that really helps bring down any barriers including lack of empathy or making assumptions." - Optometrist

Detailed Findings: Gift Certificate Video Feedback

Providers

- Providers feel patients should be given options
- The standard of care should be the same for all patients, regardless of race or insurance
- Providers should treat patients as family

"If I were that provider's supervisor, I would tell them never x-ray a patient's pocket, nor should we limit the care to a patient based on our perception. First and foremost, we would give the patient options, and also see if there's a way to get as much care to that patient as possible. Never would I limit my patient's care because of what I think that the insurance or whatever outside entity, entities would pay for top care." - Optometrist

"There should be a standard of care across all people, all races, regardless of insurance. I think that when you discriminate and don't test based on individuals and insurances, this increases health disparities, particularly in communities that may be less insured or underinsured." - Ophthalmologist

"I like to think of every patient in the chair as being my own family member. How would I want that family member to be treated? I think that really helps bring down any barriers including lack of empathy or making assumptions." - Optometrist