### **Preventing vision loss and blindness:**

What people with diabetes know about their eyes Results from nationwide focus groups





### **Today's presenters**







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### **Diabetes today**

- 26 million people affected.
- 79 million with pre-diabetes.
- All people with diabetes at risk for diabetic eye disease.
- Diabetic eye disease is a serious complication of diabetes.
  - Leading cause of vision loss and blindness in adults ages 20-74.





### What is diabetic eye disease?

#### **DIABETIC RETINOPATHY**





Normal vision

Vision with DR

- Most common form of diabetic eye disease.
- Diabetes damages the blood vessels in the retina, the light-sensitive tissue at the back of the eye.

#### **CATARACT**





Normal vision

Vision with Cataract

 Clouding of the lens of the eye.

#### **GLAUCOMA**





Normal vision Vision with Glaucoma

 Increase in fluid pressure inside the eye that leads to optic nerve damage and loss of vision.





### **Preventing vision loss**

 People with diabetes should have a comprehensive dilated eye exam at least once a year.

- No early warning signs or symptoms.
- 90% of vision loss can be prevented.
- In addition to eye exams, keep your health on TRACK:







- ake your medications.
- Reach and maintain a healthy weight.
- Add physical activity to your daily routine.
- control your blood sugar, blood pressure, and cholesterol.
- ick the smoking habit.







# Purpose of the focus groups

Gather information from people with diabetes on the following:

- Importance of eye health
- Knowledge of diabetic eye disease
- Sources of eye health information
- Health information preferences





### The surveyed

Spanish-speaking

Ages 18-70

Visited doctors yearly

Caucasians

Cleveland, OH

People with diabetes

Houston, TX

**English-speaking** 

**Hispanics/Latinos** 

Visited doctors every 3 months

Washington, DC

**African Americans** 

Atlanta, GA

Mixed low literacy

Miami, FL





### Eye health

- Participants aware of impact of diabetes on their vision:
  - Blurry vision
  - Deterioration of vision over time
  - Blindness
  - Intense light
  - Headaches
  - Tunnel vision and dimness







### Knowledge

- Doctors direct in telling risk of losing vision due to diabetes.
- Lack of familiarity with the term "diabetic eye disease."
- Many recognize is a serious health problem that needs to be treated.







### Their "symptoms"

**Tunnel vision** 

Reduced field of vision

Flashing lights

Headaches

**Blindness** 

**Floaters** 

Blurred Vision





### **Prevention**

**Awareness** 

Some knowledge

Understanding

Distrust

- "Diabetic eye disease cannot be prevented, just treated."
- "Diabetic eye disease can be treated by cooperation between ophthalmologists and primary care physicians."
- "It can be prevented with drops, surgery, medication controls, and diet."
- "Drink lots of water or have a water purifier."
- "Not sure if certain tests are necessary."
- "Getting a second opinion if I don't like results."

  National Eye Heal Education Progra

### **Treatment**

#### **KNOWLEDGE**

- Awareness of treatment options.
- Awareness it can be treated.
- A balancing act.

#### **BELIEFS**

- No treatment options for diabetic eye disease.
- Blindness inevitable.
- "At eye exam, doctor can't detect disease. I notice if vision is blurrier."





## What they said Biggest concerns

- "Losing eye sight."
- "Not knowing if it's going to get worse."
- "Possibility of blindness."
- "Lack of vision without glasses."
- "If I can't see, I can't work."
- "Independence and mobility."







### What they said

#### Reasons to keep diabetes under control

- "Don't want to lose my vision."
- "I just want to live."
- "The possibility of what can happen; get all the bad things down."
- "My general health, vision."
- "Have a "normal life"."
- "Knowing people who have had eye problems."
- "Being self-sufficient."







### Key findings from diabetes groups

#### Caucasian

- Awareness of relationship between diabetes and eye health, but no familiarity with term "diabetic eye disease."
- More emphasis on vision in diabetes education programs, materials.
- Information from doctors and family members in health professions.
- Better communication between health providers to improve health care for patients.

#### Spanish-speaking H/L

- Onset of diabetes a wake-up call for many.
- Little knowledge of diabetic eye disease.
- Information from doctors and others with diabetes.
- Some comfort with doctors.
- Some discrimination by non-Hispanic doctors.

#### **African American**

- Vision of high importance.
- Lack of knowledge regarding consequences of diabetes and eye health.
- Some familiarity with terms "diabetic eye disease" and "diabetic retinopathy."
- General perception that diabetic eye disease can't be prevented.
- Cost of eye care of concern.





### Their suggestions

#### Caucasian

- More education on vision and latest treatments for eye diseases.
- Importance of a good doctor/patient relationship for managing diabetes.
- Decreased wait time and "whole ordeal" of dilating, waiting, then waiting for the eyes to get back to normal.
- Visual aids on what happens to eyes after diabetes to help explain the importance of managing the condition.

#### Spanish-speaking H/L

- More affordable eye care services.
- Improvement in way eye care professionals communicate with patients.
- Appreciation of doctors who understand them.
- Information on diabetes through video and print materials helpful when newly diagnosed.

#### **African American**

- Better doctor/patient relationship, from extra time with patients to interest and followup.
- More information on eye health and education.
- Print materials.
- Non-traditional outreach, like pharmacies.
- Community events and coordinated efforts with diabetes groups.

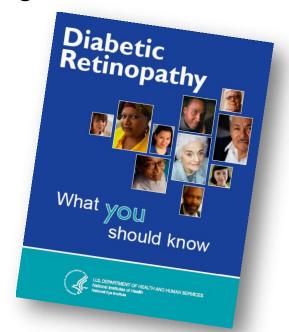




## Whom do they trust? Sources of eye health information

- Physicians
- Diabetes specialists
- Newsletters from insurance companies
- Google
- Friends and family with diabetes
- Videos at doctors' offices
- Supermarkets

- Nurses
- Ophthalmologists
- Pamphlets
- Magazines
- Radio
- WebMD







### Where do they seek information?

#### Their health information preferences

- Doctors' offices
- Support groups
- Diabetic Living
- National Public Radio
- American Diabetes
   Association

- Church
- Magazines
- Internet
  - Google, Mayo Clinic, WebMD, Wikipedia
- Information in Spanish
- Dr. Oz show





# Opportunities for increasing eye health knowledge

- More eye health information from doctors.
  - More patient materials, videos.
  - Newsletters.
  - E-mails.
  - Reminders, calls.
- Facilitation of behavior change and advocacy through participant knowledge.
  - Information in the hands of the community.
  - · Brochures.
  - · Resources in Spanish.







#### **Common threads**

- Vision taken for granted unless something goes wrong.
- Diabetes a major impetus for taking better care of self and eyes.
- Most positive about relationship with doctors.







### Common threads (cont.)

- Lack of awareness/understanding of diabetic eye disease.
- Interest, concern about eye health and desire to have eyes examined.
- Importance of repeated messages about seeing an eye doctor to people with diabetes.





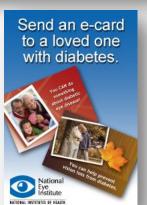


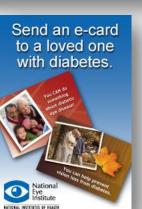
### Diabetic eye disease resources

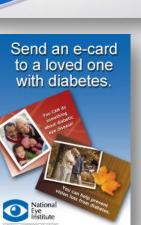
www.nei.nih.gov/NEHEP



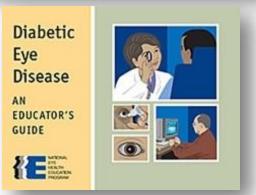
















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### **Questions?**

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