

TELL US WHAT YOU THINK!

What questions do YOU want answered about diabetic eye diseases?

A global Priority Setting Partnership



**James
Lind
Alliance**

Priority Setting Partnerships



**The Fred
Hollows
Foundation**

Our Goal

To improve the well-being of people at risk of vision loss from diabetes.

We would like to know what questions you have about the eye health of people with diabetes.

We are looking for questions that will make a real difference to people who may lose their sight from diabetes.

We are looking for questions about symptoms, day-to-day life, health care, and treatments.

Did you know?

- One in three people with diabetes around the world have eye problems from diabetes.
- Vision loss from diabetes can be prevented or at least managed.

Why You?

- You are someone who is living with diabetes; **OR**
- You are someone who is caring for someone living with diabetes; **OR**
- You are a healthcare professional who works with people with diabetes.

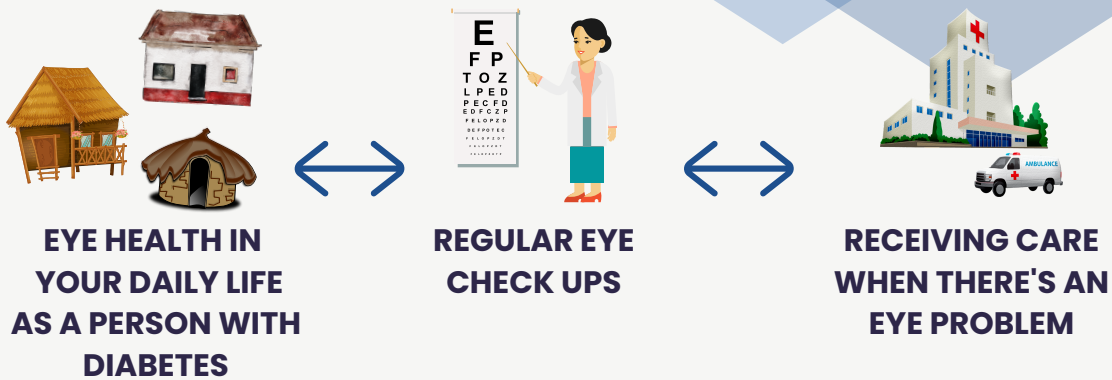
What will we do with YOUR questions?

- We will create a long list of questions that matter to you and others from around the world.
- We will then ask you and other people with diabetes, their carers, and health care professionals to put these questions in order from the most important to the least important.
- We will then have a final list of the Top 10 questions about eye health that are most important to people like yourself.

Who are we?

This initiative is a collaboration between the Diabetic Retinopathy Work Group of the International Agency of the Prevention of Blindness, the James Lind Alliance, and The Fred Hollows Foundation. We are working closely with partners from Ethiopia, Kenya, Fiji, Nepal, Pakistan, and Vietnam and we're extending an invitation to participate to low- and middle-income countries globally.

Let's think about what questions you might have about eye health.



It may be helpful to think about what questions you have about eye health in the day-to-day life of a person with diabetes, for example when they are at home.

You may also have questions about regular eye check-ups. People with diabetes are recommended to have these check-ups regardless of whether they have any problems with their eyes or not.

Finally, you may have questions about receiving care when someone with diabetes has eye problems. This may include seeing more doctors and receiving eye treatment.

But remember, it is also Ok if you don't have a question about all of these things or if you have questions about anything else that has to do with eye health!

EYE HEALTH IN THE DAILY LIFE OF A PERSON WITH DIABETES



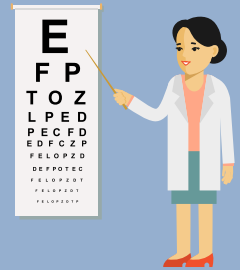
Is there anything you are unsure about when it comes to EYE HEALTH and DAY-TO-DAY LIFE for a PERSON WITH DIABETES?

Here's some examples of the type of questions you might want to ask. We are using headaches just as example, not because they are related to eye health.

- "I have heard that being stressed gives you headaches. Is it true?"
- "Is there anything I can do to prevent headache?"
- "What puts my patient at greatest risk of headaches?"
- "How can I make sure that my patients can manage their headaches at home?"

Please write as much or as little as you like or just go to the next question if you're not sure what to write here

REGULAR EYE CHECK-UPS



Is there anything you are unsure about when it comes to having REGULAR EYE CHECK-UPS?

Here's some examples of the type of questions you might want to ask. We are using headaches just as example, not because they are related to eye health.

- "Do I need to go to the referral hospital for a check-up if I don't have a headache?"
- "I don't have a headache, why do I need to get checked?"
- "Is it safe for the junior staff at my clinic to triage people with headaches?"

Please write as much or as little as you like or just go to the next question if you're not sure what to write here.

RECEIVING CARE WHEN THERE IS AN EYE PROBLEM



Is there anything you are unsure about when it comes to RECEIVING CARE WHEN THERE IS AN EYE PROBLEM?

Here's some examples of the type of questions you might want to ask. We are using headaches just as example, not because they are related to eye health.

- "What type of tests should I do if I get headaches?"
- "I can't afford all the medicines prescribed for my headache. Will my headache go away if I only take half?"
- "Is it safe for the junior staff at my clinic to triage people with headaches?"
- "I don't have the recommended equipment to diagnose headaches in my practice. Are there effective alternatives?"
- "Are there reliable tests that are cheaper than MRIs to make a diagnosis?"

Please write as much or as little as you like or just go to the next question if you're not sure what to write here.

ANYTHING ELSE?



Is there anything else that you are unsure of related to eye health problems?

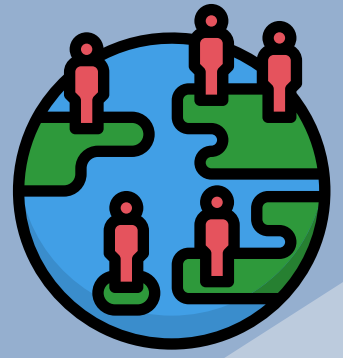
Here's some examples of the type of questions you might want to ask. We are using headaches just as example, not because they are related to eye health.

- "Why do I get headaches, but my siblings don't?"
- "What are the signs that my headaches need medical attention?"

Please write as much or as little as you like or just go to the next question if you're not sure what to write here.

A little about you:

- We want to understand questions asked by different groups of people.
- So we'd like to know a little more about you. We would be grateful if you could answer these questions:



Which of the following best describes you?

A person living with diabetes

A carer or family member of someone living with diabetes

A healthcare professional

If you're a healthcare professional, which best describes you?

Nurse

General Practitioner

Diabetologist/Endocrinologist

Dietician

Allied Ophthalmic Personnel

Optometrist

Ophthalmologist

Other (please specify): _____

If you're a healthcare professional, do you provide:

Diabetes care

Eye care

Both

If you are a person living with diabetes, when were you diagnosed?



Less than one year ago.

Between one and five years ago.

Between five and ten years ago.

More than ten years ago.

I don't have diabetes.

If you are a person living with diabetes, have you had an eye check-up since you were diagnosed?

Yes.

No.

I don't have diabetes.

If you are a person living with diabetes, do you have eye health problems?

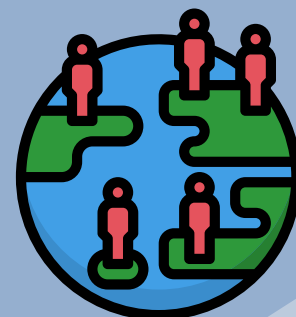
Yes, but not due to diabetes (for example, you have been wearing glasses but from before you had diabetes.)

Yes, due to diabetes (that means that a doctor told you that you have diabetic retinopathy or diabetic eye disease.)

No, my eyes are fine.

Not sure.

I don't have diabetes.



What is your gender?

Man

Woman

Other (please specify): _____

I prefer not to say

What is your age?

Under 20

20–29

30–49

50–69

70–89

90+

What is your highest level of education?

No formal schooling

Completed primary school

Completed secondary school

Completed bachelor degree or higher

What country do you live in?

Do you live in an urban or rural area?

Urban

Rural

What is your cultural identity?



By taking part in this initiative, you are agreeing that we can use and may publish some of your questions. **BUT NO ONE WILL KNOW THAT IT IS YOU WHO HAS ASKED THESE QUESTIONS.**

WHAT'S NEXT?

Would you like to help us to decide the Top 10 questions in the next stage?

- If yes, please provide your email address on this page.
- We will not share your email address with anyone else and we will only use your email address to contact you about this initiative.
- We'll keep your address separate from your answers, so this survey won't be linked to you.

Your email address: