

Participant ID: _____

Interviewer: _____

Date: ____/____/____

Hello, my name is _____ and I'm a medical student calling from SLUCare Ophthalmology Clinic. Is this Mr./Ms.____?

We are conducting a survey to help us understand why a patient may not be able to make a follow-up appointment for their diabetic retinopathy. Can I tell you a bit more about this survey and how you can help us?

Like I mentioned earlier, we want to understand some of the reasons why patients may not be able to attend their follow-up visits, whether that be because of job complications, transportation, or some other reason. Your participation in this study will involve answering questions from a survey about your eye health, your understanding of diabetic retinopathy, as well as any situations that may prevent you from getting to the clinic. We are trying to interview all patients who have come through the clinic, whether or not they have actually missed an appointment.

This will be a one-time survey that should only take around 25 minutes of your time and will be conducted through the phone. With this study, we hope to better understand the reasons why patients are unable to make it to the clinic so that in the future, we can help more people stay on schedule with their appointments and maintain their eye health.

If you choose to participate, all your answers will be stored under a random participant ID and remain confidential. This means that your answers will not be connected to your name. You may also choose to withdraw from the study at any time.

Do you have any questions?

Would you like to participate in the survey?

Okay, great. Let's go ahead and get started.

1. Have you ever had an exam when the doctor put drops in your eyes that made your pupils large?

*If yes, when was your last exam like that? **If participant is unsure** whether they were dilated, give them a more detailed description (e.g., vision may have been blurry) before checking DK (doesn't know).*

- _____ Never [0]
- _____ Within the past year [1]
- _____ Within the past 2 years [2]
- _____ More than 2 years ago, but less than 5 years ago [3]
- _____ More than 5 years ago [4]
- _____ More than a year ago, but unsure of the exact time [5]
- _____ DK [777]

2. Within the past year, have you missed a scheduled follow-up eye appointment for your diabetic retinopathy?

- _____ Yes
- _____ No

For the next part of the survey, I am going to read many statements. Most of the statements are about your eye health, but there are a few about your general health. After I read each statement, please tell me how much you disagree or agree with the statement. To do this, I will ask you to use a scale that ranges from 1 to 5: 1 means strongly disagree and 5 means strongly agree. A 3 means that you neither disagree nor agree; in other words, you are in the middle or don't have an opinion either way. For some questions, you will have an additional option to reply with Not Applicable instead of using a number.

Do you have any questions? The first statement is...

Read items from the self-administered survey packet and record participant's responses.

Strongly Disagree (1), Disagree (2), No Opinion/Don't Know (3), Agree (4), Strongly Agree (5)

1. My eyes are healthy.
2. Early diabetic eye disease usually causes changes in vision.
3. Having an eye exam is not pleasant.
4. I am confident in my ability to make an appointment for an eye exam.
5. Having an eye exam once a year can help me prevent losing my eyesight.
6. I have trouble reading a book or newspaper, even if I use my glasses or contacts.

7. Over the past 4 weeks I have felt blue, downhearted, or depressed.
8. I know someone who has lost some or all of his/her eyesight because of problems from diabetes.
9. I know a lot about diabetes and the effect it can have on health.
10. Diabetes can result in a loss of visual function (e.g., difficulty reading, driving).
11. I think I will lose some or all of my eyesight because of diabetes.
12. I am confident I can keep a scheduled appointment with an eye doctor.
13. I do not want to know if I have an eye disease.
14. People who have good control of their diabetes are unlikely to have eye problems.
15. Diabetes can cause severe eye problems.
16. I would benefit from having an eye exam every year.
17. My medical provider (i.e., doctor, nurse, nurse practitioner) talks to me about the importance of eye exams.
 - a. 6 = *Not applicable*
18. Eye exams cost too much.
19. There is no treatment for diabetic eye diseases.
20. It is hard for me to travel to an eye doctor.
 - a. How do you travel to the eye doctor (car, bus, friend/family)?
 - b. Why is it difficult for you to travel to the clinic?
21. There are many things that make it hard to get an eye exam every year.
22. I do not like having my eyes dilated with eye drops that make my pupils large.
23. I think it is important to have an eye exam every year.
24. My overall general health is excellent.
25. Diabetic eye disease can be seen with an eye exam.
26. Diabetes can damage the blood vessels in the eye.
27. There are many eye doctors where I live.
28. My family members or friends help me make doctor appointments.
29. Eye exams can find many different kinds of eye problems.
30. I am confident I can control my blood sugar.
31. Having a yearly eye exam will help me to save the eyesight I have now.
32. People with diabetes are unlikely to get an eye disease.
33. I cannot afford an eye exam.
34. My insurance covers most of the cost of an eye exam.
 - a. 6 = *Not applicable*
35. There are things I can do to prevent losing my vision from diabetes.
36. Diabetic eye diseases often cause blindness.
37. I have medical problems from diabetes.
38. I want to get an eye exam every year.
39. I only seek eye care when I am having trouble with my vision.
40. Getting an eye exam every year is not one of my top priorities.

41. I have an eye doctor I can go to for diabetic eye exams.

_____ Yes (**Go to Q42**) [1]

_____ No (**Go to Q45**) [0]

If **YES**

42. I receive a reminder from my eye doctor's office when it is time to schedule an exam.

43. I am happy with the care I get from my eye doctor.

44. Visiting the eye doctor takes too much time.

Covid-19 Addition to CADEES Questionnaire

Instruct patients that the following questions are related to the Covid-19 pandemic:

45. My family or friends were able to take me to my appointments during the Covid-19 pandemic.

a. 6 = Not applicable

46. I was able to take public transportation to my appointment during the Covid-19 pandemic.

a. 6 = Not applicable

47. I was able to travel to my appointment using a ride-share service during the Covid-19 pandemic.

a. 6 = Not applicable

48. I was worried I would get Covid-19 if I went to the eye clinic.

49. My eye clinic had available appointments during the pandemic.

50. Maintaining my eye health has been a top priority during the pandemic.

51. Have you ever tested positive for Covid-19?

If yes,

51a. I missed an eye appointment because I was quarantining.

52. I did not go to my eye appointment because I thought I may have had Covid-19.

53. My treatment for diabetic retinopathy was important to me before the pandemic.

54. My treatment for diabetic retinopathy has been important to me during the pandemic.

55. We are interested in why some people do not have yearly eye exams. Can you think of any reasons we did not ask about in this survey?

ADDITIONAL DEMOGRAPHIC/CLINICAL INFORMATION (Interviewer-Administered)

3. How many years ago were you diagnosed with diabetes? *If participant was diagnosed less than one year ago, ask how many months ago they were diagnosed; then convert number of months into years and round to the nearest quarter year (e.g., 3 months = .25 years; 10 months = .83 = .75 years).*

_____ years ago [enter number of years]

_____ DK [777]

_____ RF [999]

4. Most doctors follow diabetes with a blood test that measures long-term blood sugar control. This test measures something called Hemoglobin A1c. Do you know what your Hemoglobin A1c level was the last time you were tested? ***If participant doesn't know, count this as a NO response.***

_____ Yes [1]

_____ No [0]

If YES

5. What was your last A1c level and when was that test?

_____ (A1c Level)

___ / ___ (month/year)

_____DK [777]

6. How many years ago were you diagnosed with diabetic retinopathy?

_____ years ago [enter number of years]

_____DK [777]

Injection/laser photocoagulation therapy:

7. Have you ever had VEGF injections or laser surgery for your diabetic retinopathy?

a. **Yes for injections:**

- i. Was laser surgery ever suggested as a treatment option for you? If so, why did you choose injections over surgery?

- ii. Have you ever cancelled or missed an appointment for your monthly injections?

b. Yes for surgery:

- i. Why did you choose to get surgery over injections?

c. No for injections/surgery:

- i. Has your physician ever recommended or told you that you need injections or laser surgery to treat your diabetic retinopathy?
- ii. What prevented you from following through with either type of treatment?

8. Do you have health insurance?

_____ Yes [1]

_____ No [0]

_____ DK [777]

9. Sex _____ *Male* [1] _____ *Female* [2]

_____ DK [777]

10. How old are you? _____ Years Old [enter number of years]

_____ DK [777]

11. What is your relationship status? Are you:

If participant reports being single, check to see if they were previously married; if so, they should be categorized as separated, divorced or widowed.

_____ Single [0]

_____ Married [1]

_____ Separated [2]

_____ Divorced [3]

_____ Widowed [4]

_____ Domestic Partnership [5]

_____ DK [777]

12. What is the highest level of education you have finished?

_____ None [0]

_____ Primary School (grades 1-6) [1]

_____ Secondary School (grades 7-12) [2]

_____ High School Graduate (diploma) or GED [3]

_____ Some College (1-4 years after high school; includes trade school, associate's degree) [4]

_____ College Graduate (bachelor's degree) [5]

_____ Some Post-Graduate (1-3 years after college) [6]

_____ Post-Graduate Degree (master's degree or higher) [7]

_____ DK [777]

13. The next question will ask about your race and ethnicity.

Are you:

American Indian or Alaska Native

Hispanic or Latino

Asian

African American or Black

Pacific Islander or Native Hawaiian

White

Other

(Please List: _____)

_____ DK [777]

14. What is the total combined annual income, before taxes and deductions, of everyone who lives in your home?

\$ _____ [enter amount, no commas]

_____DK [777]