Please indicate if you are:
Radio button
An adult with an inherited retinal dystrophy (IRD) completing this survey by myself; A support person completing this survey on behalf of an adult with an inherited retinal dystrophy (IRD). All answers reflect only the perspective of the adult with IRD; Neither of the above

> Neither of the above --> exit from survey with message, "Thank you for your time; you are not eligible to participate in this study."

Personal Information

What is your assigned sex at birth?
Radio button
Male, Female, Intersex

What year were you born in?
YYYY

What race best describes you?
Radio button
White, Black or African American, Asian, American Indian/Alaska Native, Native Hawaiian or Other Pacific Islander, More than One Race, Unknown

What ethnicity best describes you?
Radio button
Hispanic or Latino, Not Hispanic or Latino, Unknown

What country do you live in?
Dropdown
Country list
United States --> What is your zip code?
#####

What is the highest level of education you have completed?
Radio button
Highschool or equivalent, Associate degree, Some college coursework completed, Bachelor's degree, Master's degree, Doctorate degree, Professional degree, None of the above

What is your retinal dystrophy diagnosis?
Radio button

- achromatopsia
- Best disease
- choroideremia
- cone dystrophy
- cone-rod dystrophy
- congenital stationary night blindness
- Gyrate atrophy
- Leber congenital amaurosis

- macular dystrophy – juvenile inherited only
- pattern dystrophy
- retinitis pigmentosa (rod-cone dystrophy)
- retinoschisis
- Stargardt disease
- Vitelliform dystrophy
- Other
  --> *Free text*
- Unsure

Is your retinal dystrophy related to one of the following syndromes (please select if so)?
Radio button

- Alstrom disease
- Bardet-Biedl syndrome (Laurence-Moon syndrome)
- Jalili syndrome
- Refsum syndrome
- Usher syndrome unspecified
- Usher syndrome – type I
- Usher syndrome – type II
- Usher syndrome – type III
- Other
  --> *Free text*
- I do not have a syndrome diagnosis
- Unsure

What year were you diagnosed (or an estimate)?
YYYY

Have you participated in a clinical trial before?
Radio button
Yes, No, Unsure

Yes --> What year(s) did you participate in a clinical trial?
YYYY-YYYY

An individual meets criteria for **legal blindness** when:

- central visual acuity in their better eye, with correction, is 20/200 or less
- visual field is less than 20 degrees

Do you meet criteria for legal blindness?
Radio button
Yes, No, Unsure

Sources of Information

I have obtained information about clinical trials from (select all that apply):
Multiple select
My ophthalmologist, Other medical or health professional, A genetic counselor, Registry (e.g., My Retina Tracker), Research group, Newspapers, Internet, Social media, Patient support group, Family/friends, Other

Other --> *Free text*

Would you be interested in learning more about the clinical trial process?
Radio button
Yes, No, Unsure

Yes --> Would you prefer to receive written or verbal information about the clinical trial process?
.

Radio button
Written, Verbal

Written → Would you prefer to receive written information about the clinical trial process online or with a hard copy (flyer, brochure, etc.)?

Radio button
Online, Hard copy

Verbal → Would you prefer to receive verbal information about the clinical trial process one-on-one or in a group of people?

Radio button
One-on-one, Group

Verbal → Would you prefer to receive verbal information about the clinical trial process in-person, through a video call, or through a phone call?

Radio button
In-person, Video, Phone call

Yes → Would you prefer to receive information about the clinical trial process one time or on a regular basis (monthly, annually, etc.)

Radio button
One-time, Regular basis

If there is a way of communicating information that we have not discussed and you would be interested in, please tell us about it here:
Free text

Perceived Knowledge

I have a good understanding about how clinical trials work.
Rank radio button 1-5 (strongly disagree, disagree, neutral, agree, strongly agree)

Knowledge Assessment

This last part of the survey includes statements about the clinical trial process. Select whether you think the statement is:

4 = Definitely True
3 = Somewhat True
2 = Uncertain
1 = Somewhat False
0 = Definitely False

Please answer to the best of your ability without using outside resources.

1. A clinical trial is a research study that involves people.
2. Clinical trials test strategies designed to improve health.
3. An intervention is a new treatment or strategy that is being tested by the research team.
4. The goal of a clinical trial is to find out if an intervention works.
5. The goal of a clinical trial is to find out if an intervention is safe.
6. A research team is led by a principal investigator.
7. Clinical trials can be funded by universities.
8. Clinical trials can be funded by private companies.
9. Clinical trials be funded by the government.
10. Clinical trials can take place at a hospital or doctor's office.
11. Clinical trials can take place in a doctor's office.
12. Clinical trials can take place in my community.
13. Clinical trials follow a research plan called a protocol.
14. The research plan is explained to the participants before the start of the study.
15. The risks of research are explained to the volunteers before they agree to take part in the research study.
16. The potential benefits are explained to the volunteers before they agree to take part in the research study.
17. Participation in a clinical trial is voluntary.
18. You can choose to leave the research study at any time.

19. Research participants are kept updated as the study goes on.
20. Patient medical information is kept private during a clinical trial.
21. The institutional review board exists to protect the patient's rights during a clinical trial.
22. The institutional review board is an ethics group that reviews the research plan before the start of a clinical trial.
23. If a clinical trial is found to be unsafe, the research study will stop.
24. If an intervention is found to be unsafe during a clinical trial the intervention will be discontinued.
25. Research is important to improve health of people of color.
26. Clinical trials have criteria that must be screened for before a volunteer is allowed to participate.
27. A volunteer's vision level may impact whether they are allowed to participate in a clinical trial.
28. A volunteer's genetic test results may impact whether they are allowed to participate in a clinical trial.
29. Clinical trials often include appointments before and after the intervention.