



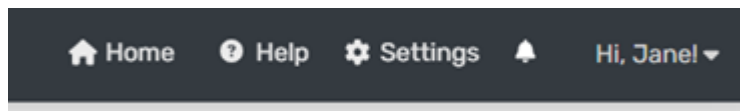
Participant User Guide

Language Selection

- To change your platform language selection on the login/register page, select the dropdown that says “English”, and choose your preferred language.

A screenshot of the IAMRARE login page. At the top right, there is a dark header bar with a white dropdown menu labeled "English". The main content area has a light blue and orange gradient background. In the center, there is a white box containing the text "IAMRARE®" and "LOGIN" below it. Below the text are two input fields: "e-mail" and "password". The "password" field has a small eye icon to its right.

- To change your platform language selection after you’ve logged in, click “Settings”, and choose your preferred language.




- This study is available in English, French, and Spanish.


Register for an Account


- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.


Featuring



ocular melanoma


Registration


Terms & Conditions


Contact Info


Notifications


Review & Submit


Confirmation

Below are links to the iAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

Acknowledgements:

☐

You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐

You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *

☐

You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *

☐

You agree to the [Terms and Conditions](#) & [Privacy Policy](#) *

[Return to login](#)

Next

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

ACUREINSIGHT.org
ocular melanoma

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) [Previous](#) [Next](#)

- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

Featuring

ACUREINSIGHT.org
ocular melanoma

Registration

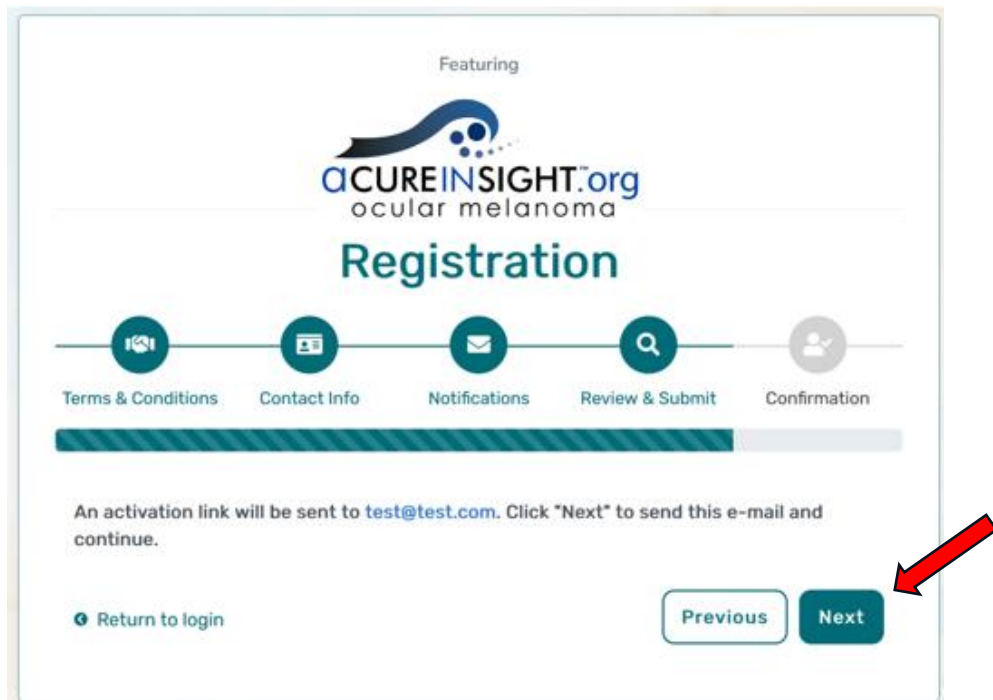
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

I am interested in NORD contacting me regarding available studies. *

☒ Yes ☐ No

[Return to login](#) [Previous](#) [Next](#)

- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



Featuring

ACUREINSIGHT.org
ocular melanoma

Registration

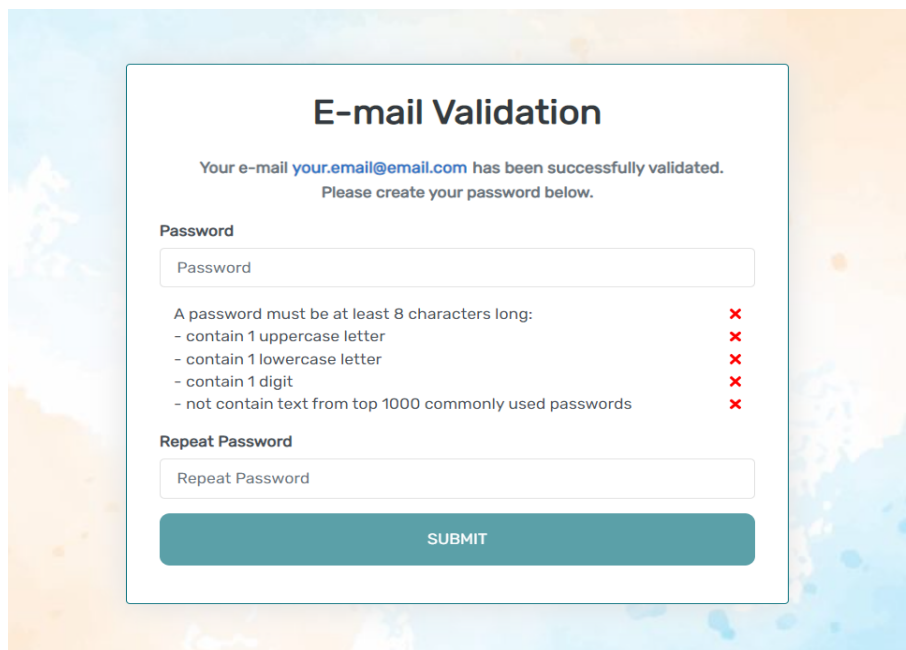
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to test@test.com. Click “Next” to send this e-mail and continue.

[Return to login](#) [Previous](#) [Next](#)

A red arrow points to the "Next" button.

- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

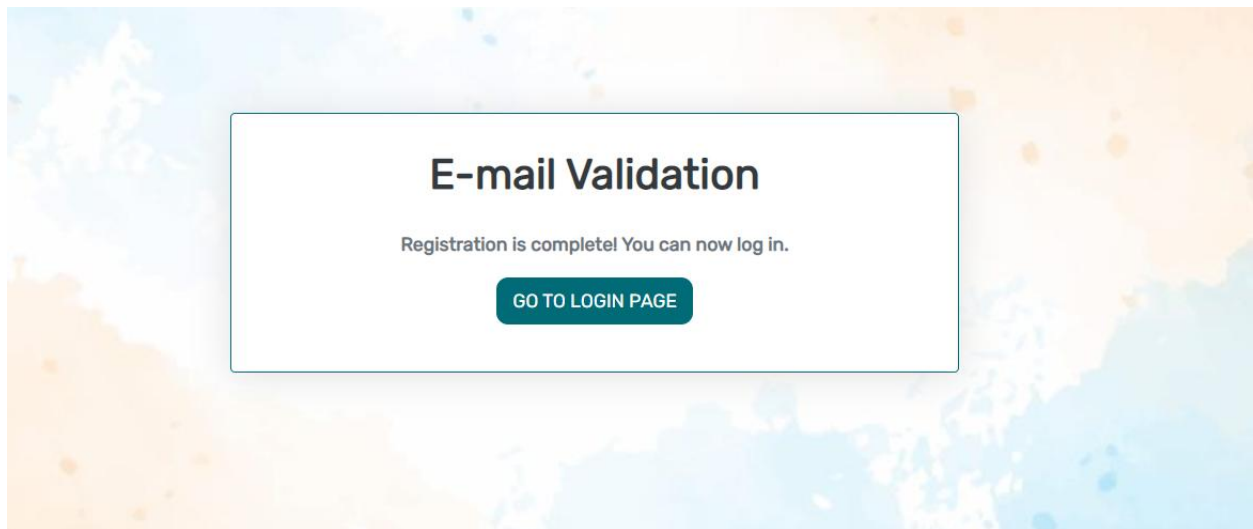
Password

A password must be at least 8 characters long: ×
- contain 1 uppercase letter ×
- contain 1 lowercase letter ×
- contain 1 digit ×
- not contain text from top 1000 commonly used passwords ×

Repeat Password

[SUBMIT](#)

- Step 6: Your validation is now complete. Select “Go to Login Page”.




- Step 7: Log in using your new e-mail and password.

IAMRARE®


LOGIN


e-mail

password 

☐ Keep me logged in

➔ LOGIN

 Forgot Password

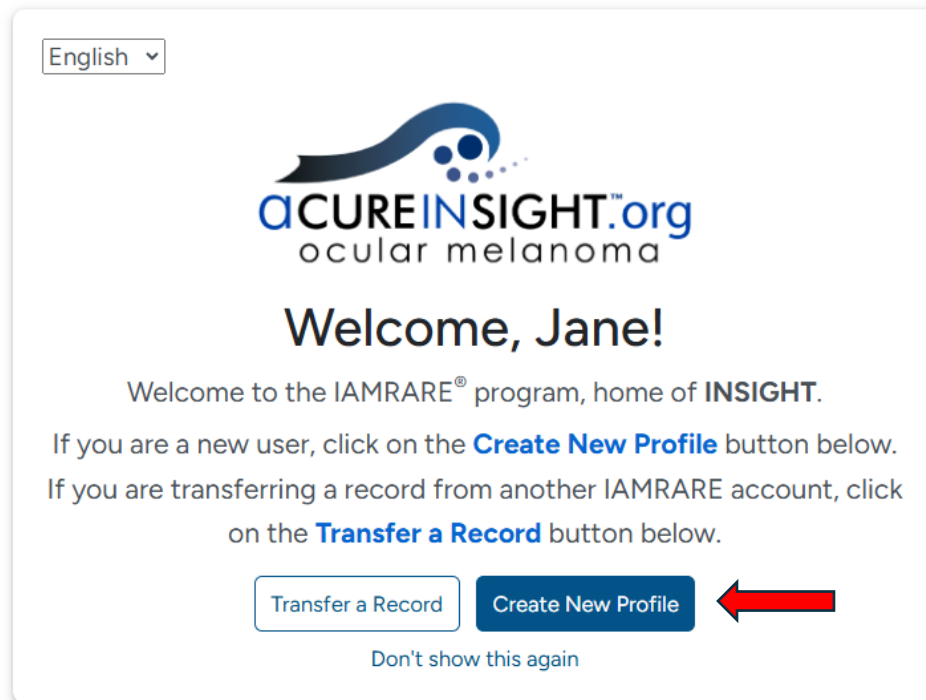
 Create an Account

By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)

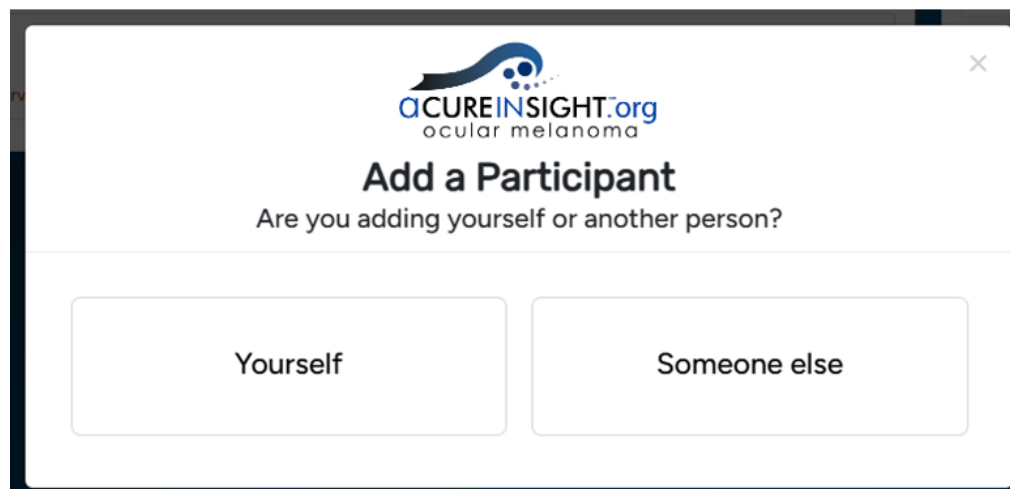


Add a Participant

- Step 1: To start, click Create New Profile.



- Step 2: Select who you will be providing information about.



- Step 3: Fill out the Participant's information.

Add Participant



Who Is Being Added as a Participant?

☐ Self

☒ Other

Preferred First Name *

Preferred First Name

Current Last name *

Current Last Name

First Name on Birth Certificate *

First Name on Birth Certificate

Middle Name on Birth Certificate *

Type 'NA' if none

Last Name on Birth Certificate *

Last Name on Birth Certificate

Date of Birth *

mm/dd/yyyy



Sex Recorded on Birth Certificate *

Sex Recorded on Birth Certificate

Country of Residence *

Choose country

State/Province/Region of Residence *

Type 'NA' if none

Country of Birth *

Choose country of birth

City/Municipality of Birth *

City/Municipality of Birth

What Is Your Relationship to ? *

Choose relationship

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”



Thank you for registering your first participant!

Would you like to consent to participate in INSIGHT?

Not right now

Yes, complete consent for this participant.



- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”

Consent to INSIGHT

Jane Smith

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Ocular Melanoma who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.
Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years of age and the age of majority in their state, province or country.
Designated Representative: A legal adult who was the caretaker of an individual who passed away from Ocular Melanoma, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Ocular Melanoma and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Please tell us about the Participant you would like to enroll in this study. *

☐

They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.

☐

They were a patient with Ocular Melanoma. I participated in their medical care.

Next

Consent to INSIGHT

Jane Smith

Consent for a Person with a Legally Authorized Representative (Caregiver)

Title: Insight Registry
Principal Investigator: Armin Afshar, MD
Phone: 415-514-8722
Email: Armin.Afshar@ucsf.edu
Sponsor: A Cure In Sight

Key Information
You are invited to take part in a research study for individuals with Ocular Melanoma (OM) on behalf of the person in your care. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.
Things you should know:
We are doing this research to study Ocular Melanoma and its effects on patients.
If you choose to participate on behalf of the participant, you will be asked to complete the listed surveys and upload medical records (when available) the Insight registry through the NORD platform.
You may experience some discomforts or inconveniences participating in this registry, such as remembering difficult times and describing situations of trauma.

Previous

Next

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

You will be asked to acknowledge:

- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- That you have explained the study to the Study Participant to the extent they are able to understand; and
- That you are of legal age.

This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering "Yes" to all of the following statements, you are giving your consent to participate in Insight Registry on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed to you. If you cannot comfortably answer "Yes" to these statements, please do not check the consent boxes in the following section.

- ☒ I have read this Consent and Authorization Form to provide the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about the Insight Registry have been answered to my satisfaction, and I understand the purpose of the Registry and the risks of participation.

[Previous](#)[Next](#)

- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Please continue to select your opt-ins. Once you have made your selections, please click Save and Review. You will then be ready to take surveys and participate in this study.

[Previous](#)[Continue to Opt-Ins](#)

- Step 4: Once you click "Continue to Opt-Ins" read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click "Save and Review".

Opt-Ins for INSIGHT

Select Opt-Ins for this study

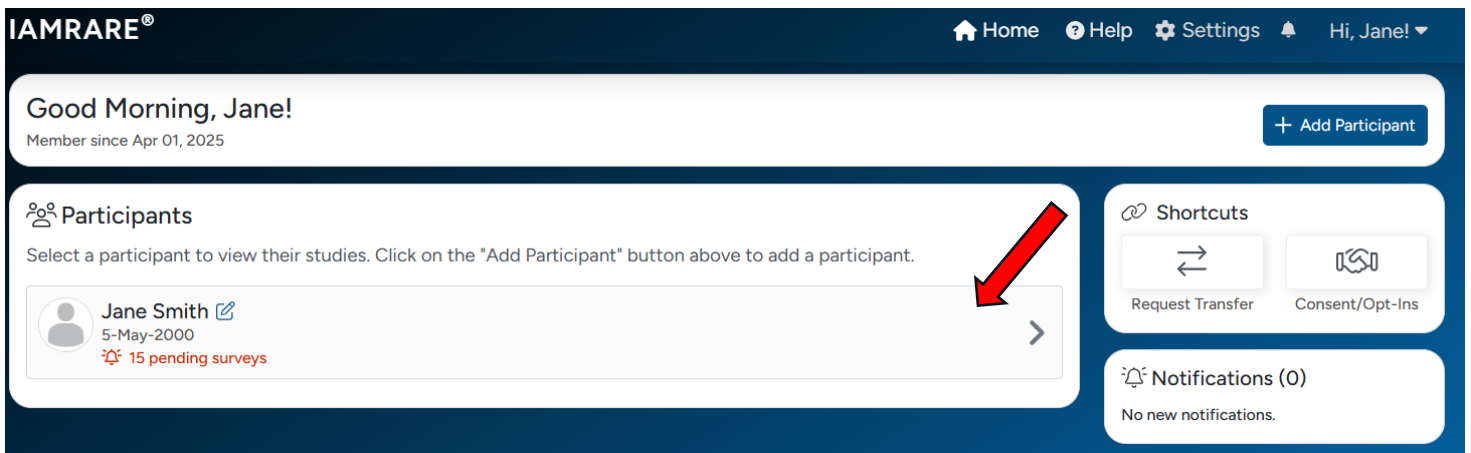
- ☐ Interest in hearing about other studies from [A Cure In Sight](#)
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about [A Cure In Sight](#)
- ☐ Interest in signing up for [A Cure In Sight's](#) newsletter
- ☐ Support from [A Cure In Sight](#) Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving [A Cure In Sight's](#) merchandise that would be sent via electronic or postal mail

[Save and Review](#)

- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

Taking Surveys

- Step 1: Click on your Participant.



IAMRARE® Home Help Settings Hi, Jane! ▼

Good Morning, Jane!
Member since Apr 01, 2025

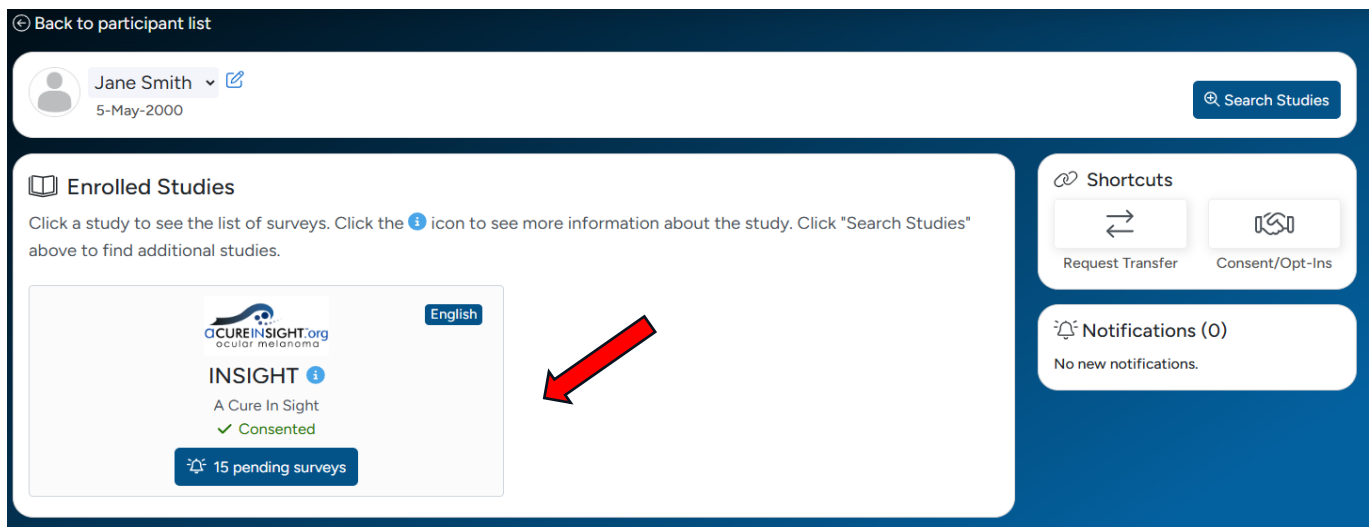
Participants
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith 5-May-2000
🔔 15 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.



← Back to participant list

Jane Smith 5-May-2000 Search Studies

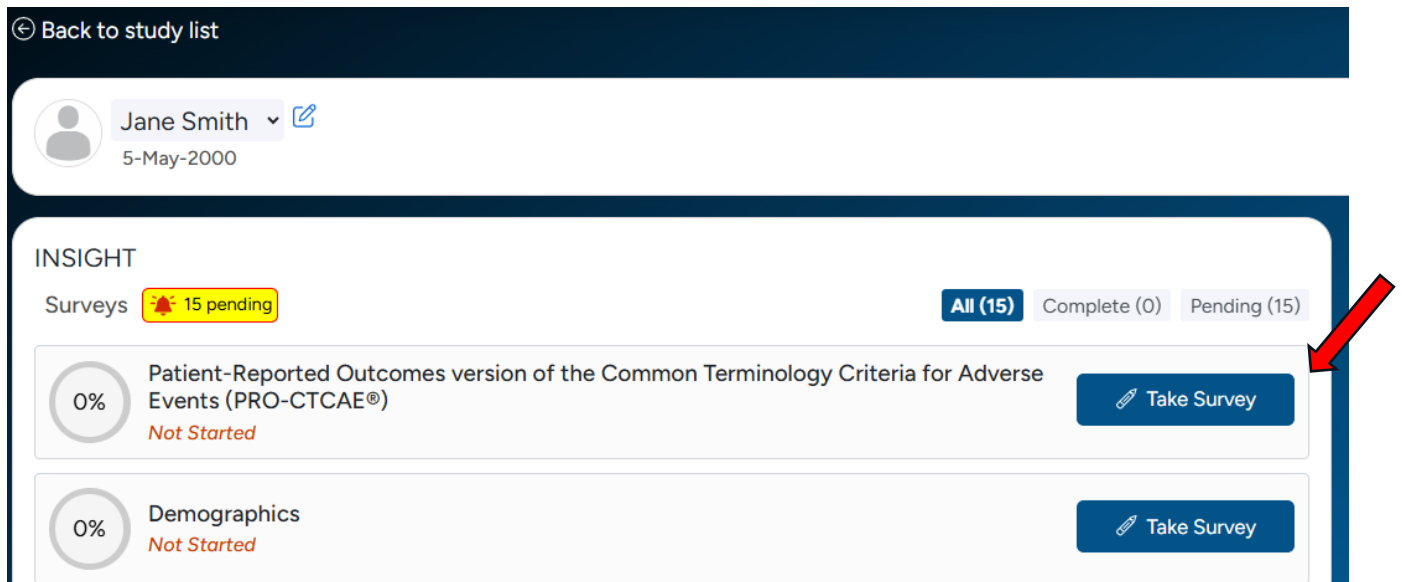
Enrolled Studies
Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click "Search Studies" above to find additional studies.

INSIGHT ⓘ
A Cure In Sight
✓ Consented
🔔 15 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 3: Click "Take Survey" for an available survey.



← Back to study list

Jane Smith 5-May-2000

INSIGHT

Surveys 🔔 15 pending All (15) Complete (0) Pending (15)

0% Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE®) Not Started Take Survey

0% Demographics Not Started Take Survey

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.

Jane Smith 5-May-2000

INSIGHT

Surveys 🔔 13 pending All (15) Complete (2) Pending (13)

✓ Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE®)
Completed on 1-Apr-2025

View Responses 1

Reports

✓ Demographics
Completed on 1-Apr-2025

View Responses 1

Reports

View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins.

Back to participant list

Jane Smith 5-May-2000

Search Studies

Enrolled Studies

Click a study to see the list of surveys. Click the i icon to see more information about the study. Click "Search Studies" above to find additional studies.

Shortcuts

Request Transfer

Consent/Opt-Ins

- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

Back to study list

Jane Smith 5-May-2000

Consents/Opt-Ins

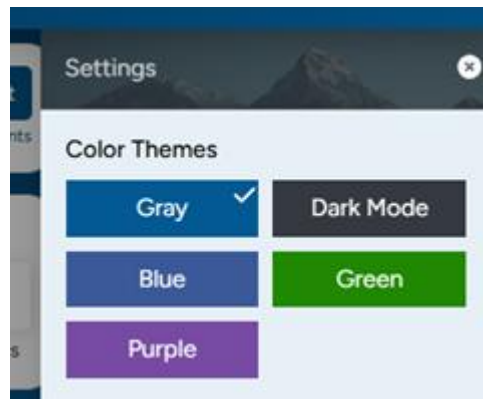
Study Name	Consent Status	Consented On	Actions
INSIGHT	✓ Consented	1-Apr-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

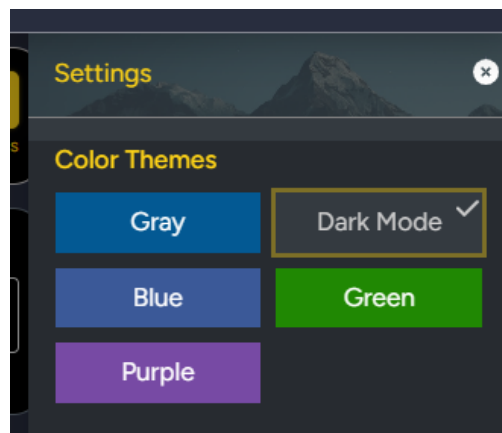
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



- Step 3: Exit the Settings menu, and your selection will be saved.

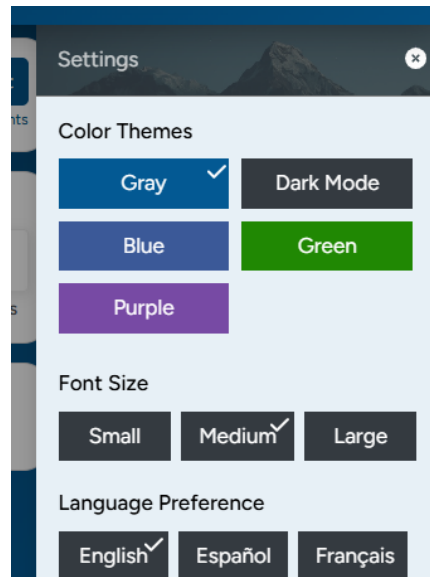


Display Settings

- Step 1: You can change the platform display settings. First, click Settings.



- Step 2: Select a color theme, a font size, or language preference.



- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite (<https://insight.iamrare.org/>) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.



For Researchers

Drive Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

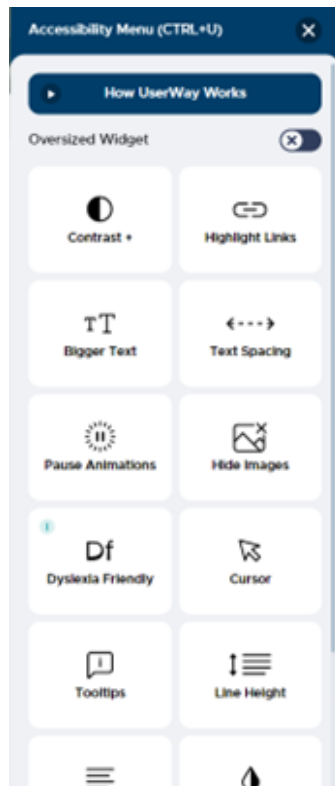


For Patients

Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.





Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

A screenshot of a mobile application's "Have a question?" form. The form has a blue header with the title "Have a question?" and a close button (X). Below the header is a paragraph of text: "Please enter your message below and click submit. We will be in touch shortly. We cannot provide medical advice or answer specific medical questions – to find out about resources to support people with your rare disease, please visit the NORD website at [rarediseases.org](\"http://rarediseases.org\")." Below this text are two input fields: "Inquiry Type *" with a dropdown menu showing "-- Select Inquiry Type --" and "Message *" with a text area containing "Your message". At the bottom of the form are two buttons: "Cancel" and "Submit".

- Step 3: Click Submit.

- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.

View Responses 1


Reports

View Responses 1


Reports

Take Survey

Take Survey

ACUREINSIGHT.org
ocular melanoma

A Cure In Sight

acureinsight.org

Contact

Hanna Hulick

Phone

2146053059

E-mail

Insightregistry@acureinsight.org

IRB E-mail

info@northstarreviewboard.org

Social Media

