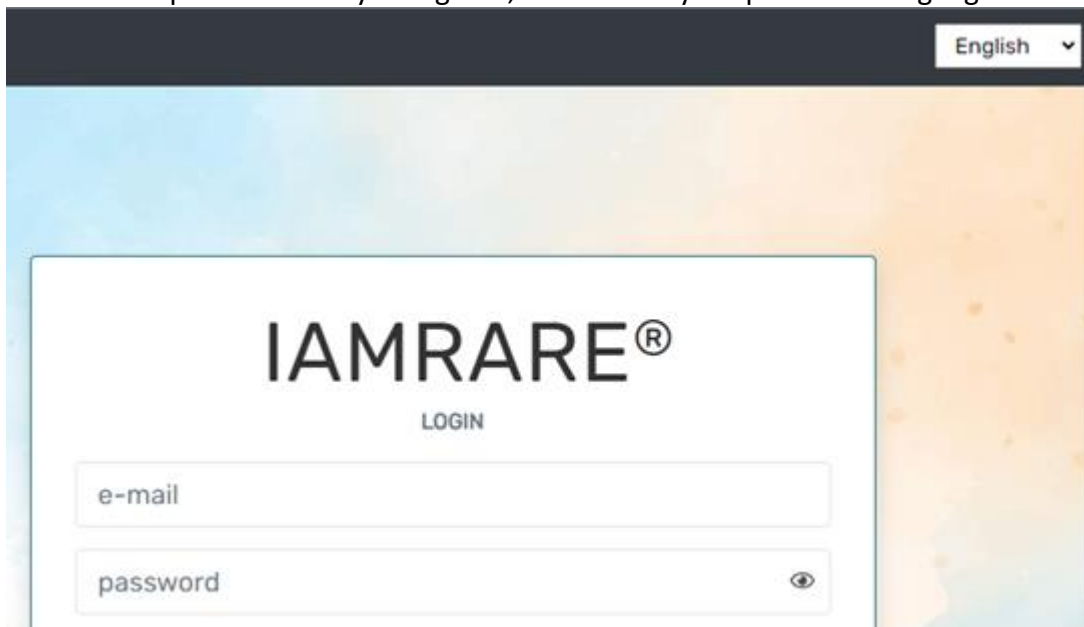


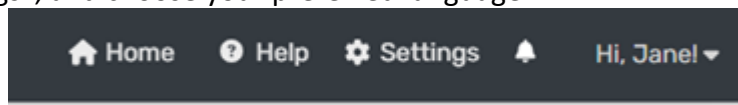
Participant User Guide

Language Selection

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



- 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: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
 - If you have a diagnosis of Wolfram syndrome select **Participant Account**.
 - If you are entering information for someone else who has Wolfram syndrome, select **Caregiver Account**.
 - If you are entering information for a Wolfram syndrome patient who has passed away, select **Caregiver Account**.

Featuring



Select Account Type

I have a rare disease, condition, and/or diagnosis.

Participant Account


I am a family member or guardian of someone with a rare disease.

Caregiver Account

[Return to login](#) [Not sure? Help me choose.](#)

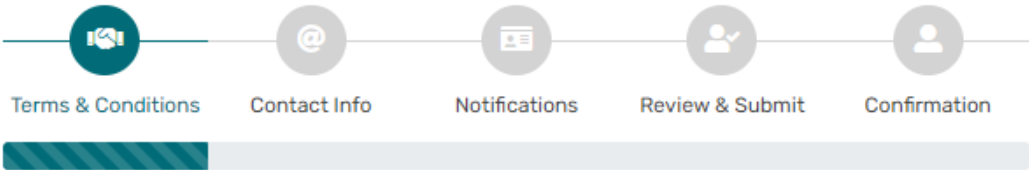
- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

Featuring



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A GLOBAL VOICE FOR RARE DISEASE

Participant 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.

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

Featuring



Participant Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

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Participant 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 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

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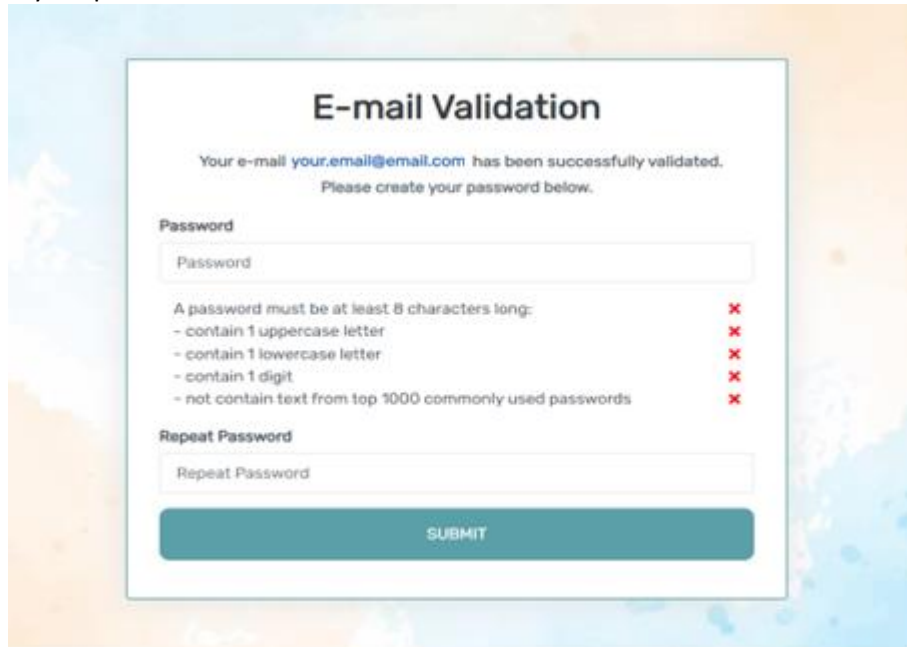
Participant Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to mail and continue. Click "Next" to send this e-

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

- Step 6: 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

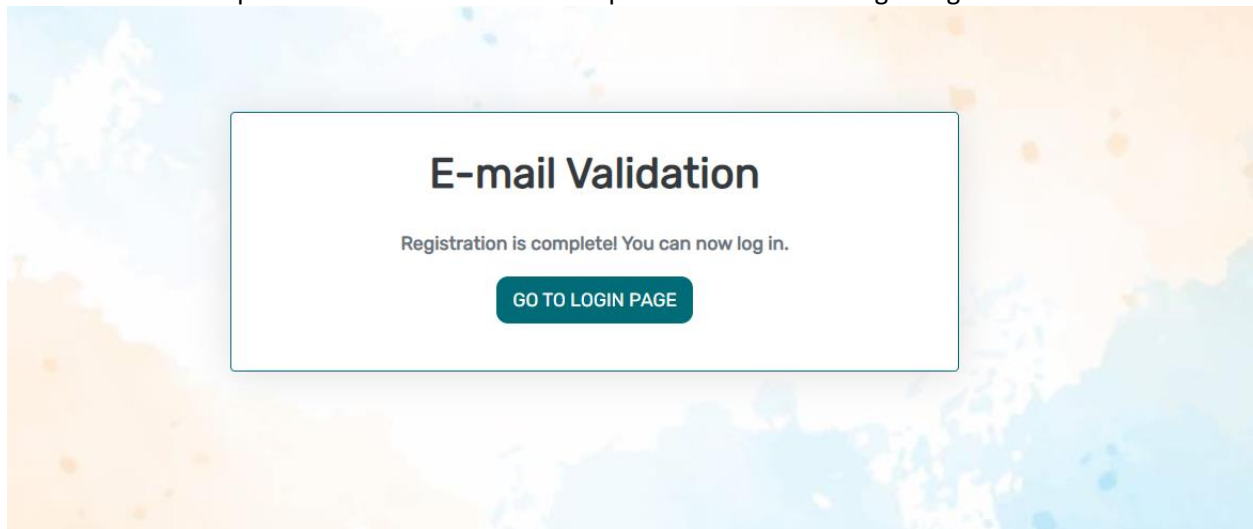
A password must be at least 8 characters long: ✘

- contain 1 uppercase letter ✘
- contain 1 lowercase letter ✘
- contain 1 digit ✘
- not contain text from top 1000 commonly used passwords ✘

Repeat Password

SUBMIT

- Step 7: Your validation is now complete. Select “Go to Login Page”.



E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

- Step 8: Log in using your new e-mail and password.

IAMRARE®

LOGIN

 Keep me logged in

[➔ LOGIN](#)

[⚠ Forgot Password](#) [+ Create an Account](#)

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

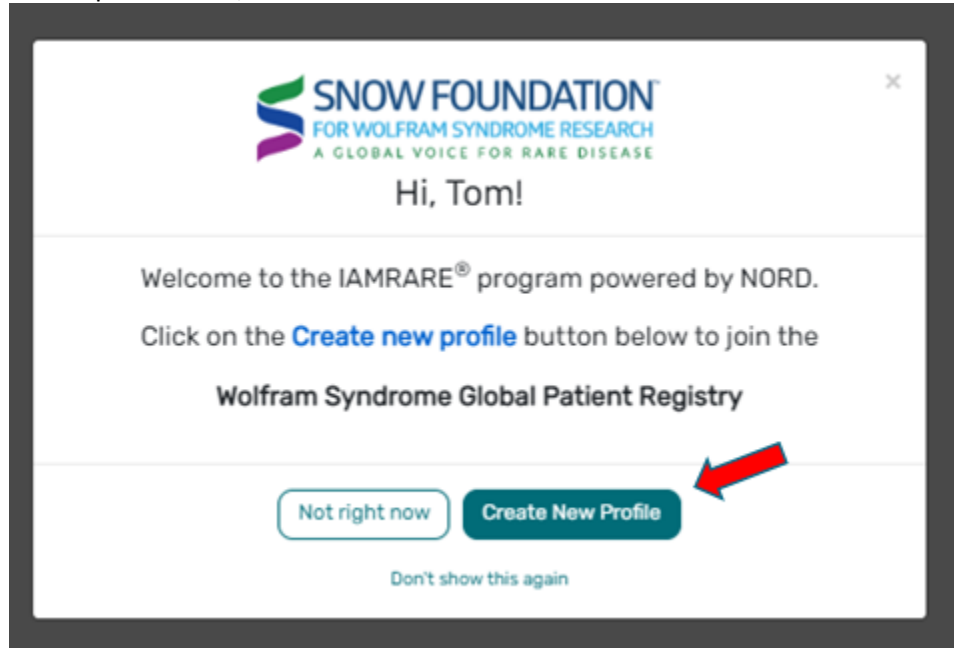
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Create Your Profile

- Step 1: To start, click Create New Profile



- Step 2: Fill out your information.

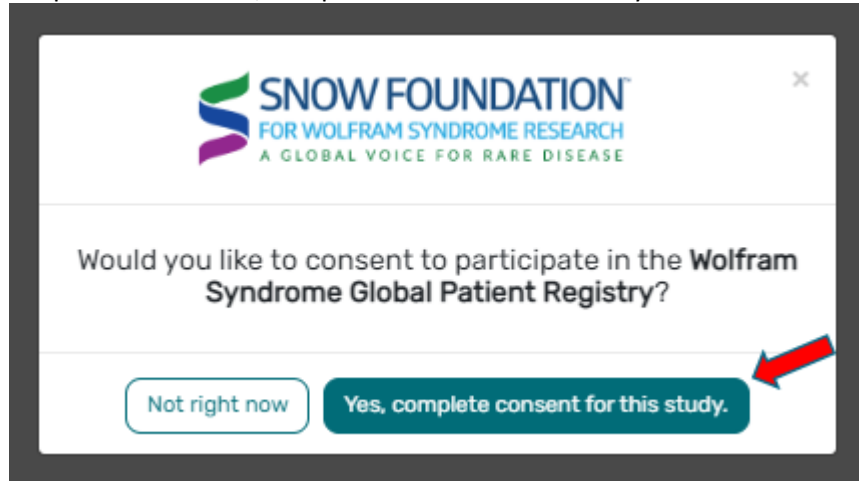
The screenshot shows a form titled "Complete Participant Profile". The form contains the following fields and options:

- Preferred First Name ***: Text input field containing "Jane".
- Current Last Name ***: Text input field containing "Smith".
- First Name on Birth Certificate ***: Text input field containing "First Name on Birth Certificate".
- Middle Name on Birth Certificate ***: Text input field containing "Type 'NA' if none".
- Last Name on Birth Certificate ***: Text input field containing "Last Name on Birth Certificate".
- Date of Birth ***: Date picker field showing "mm/dd/yyyy".
- Sex Recorded on Birth Certificate * ⓘ**: Dropdown menu.
- Country of Residence ***: Dropdown menu showing "United States".
- State/Province/Region of Residence ***: Dropdown menu.
- Country of Birth ***: Dropdown menu showing "Choose country of birth".
- City/Municipality of Birth ***: Text input field containing "City/Municipality of Birth".
- Profile Image**: Two options: "Choose Avatar" (with a person icon) and "Upload Your Own Image" (with a camera icon). Below these options, it says "No image selected".

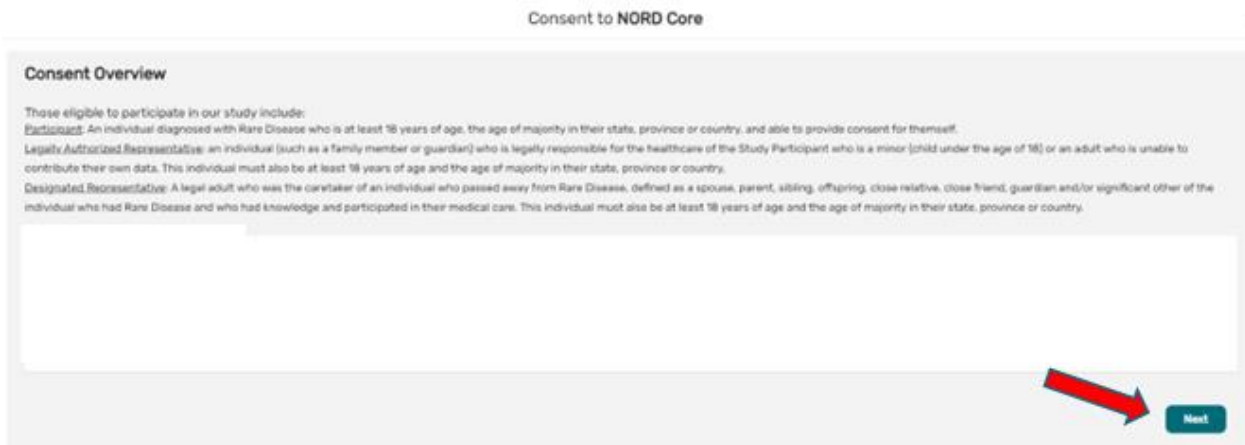
At the bottom of the form, there are two buttons: "CANCEL" and "SUBMIT".

Consent to the Study

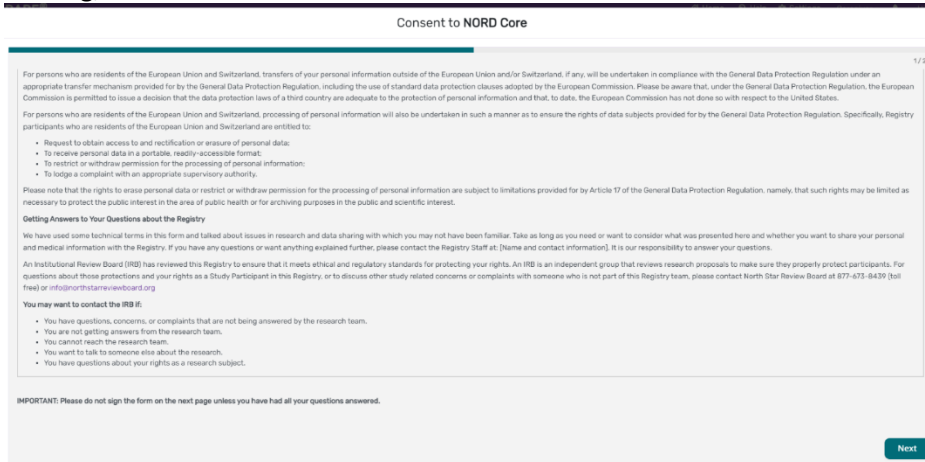
- Step 1: Click on “Yes, complete consent for this study.”



- Step 2: Read through the consent overview and answer any questions.



- Step 3: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button



- Step 4: Once you click “Next” and 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 “Complete.”

The screenshot shows a web browser window titled "Consent to NORD Core". The page is labeled "Authorization" and "2 / 2". It contains the following text: "The following statements are intended to ensure that you have had the time and opportunity to consider whether you 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:" followed by three bullet points: "Read the consent form and have no further questions about the Registry and your participation", "That you wish to provide personal data to the registry for the purposes of the Study", and "And that you wish to provide your pseudonymized data for future research". Below this, it states: "This is a web-based form and by answering Yes to all of the following statements, you are giving your consent to participate in the NORD Core, just as if you had signed your name to a paper document. After signing, a copy of the consent form will be emailed to you. If you cannot comfortably answer 'Yes' to these three statements and you have no further questions, please do not check the boxes below:". There are three checkboxes, all of which are checked: "I have read (or someone has read to me) this Consent and Authorization Form to provide my personal and medical data to be shared for the purpose of research. All my questions about the Registry have been answered to my satisfaction and I understand the purpose of the Registry and the risks of participation.", "I wish to provide my research data to the NORD Core for the purposes described above under Study Aims.", and "I wish to provide my research data that has been pseudonymized to the NORD Core for future research within recognized ethical standards for scientific research, as described under How We Use Your Data." At the bottom right, there are two buttons: "Previous" and "Complete".

- Step 5: Click Continue to Opt-ins.

The screenshot shows a web browser window titled "Consent to NORD Core". The page contains the following text: "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." At the bottom right, there are two buttons: "Previous" and "Continue to Opt-ins". A red arrow points to the "Continue to Opt-ins" button.

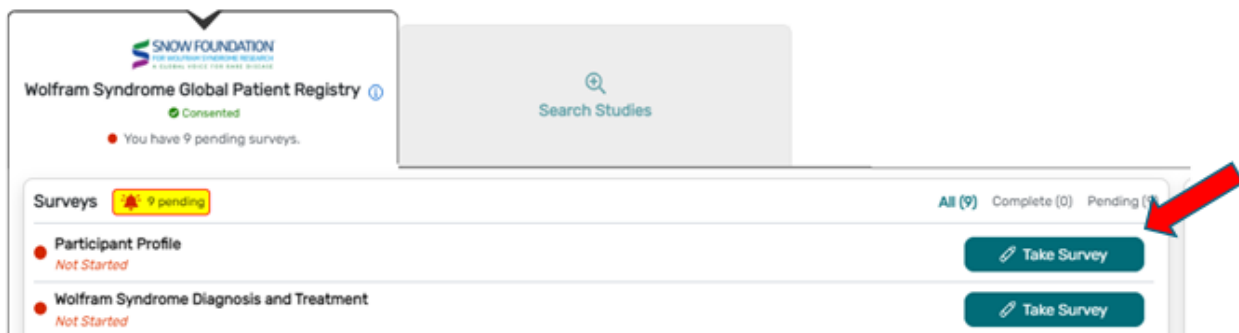
- Step 6: Select your Opt-ins and click Save and Review.

The screenshot shows a web browser window titled "Opt-Ins for NORD Core". The page contains the following text: "Select Opt-Ins for this study". Below this, there are three checkboxes, all of which are unchecked: "Interest in hearing about other studies from", "Interest in hearing about relevant clinical trials", and "Interest in donating specimens or DNA (biobanking) for future research". At the bottom right, there is a button labeled "Save and Review". A red arrow points to the "Save and Review" button.

- Step 7: Download a copy of your consent or click Close.

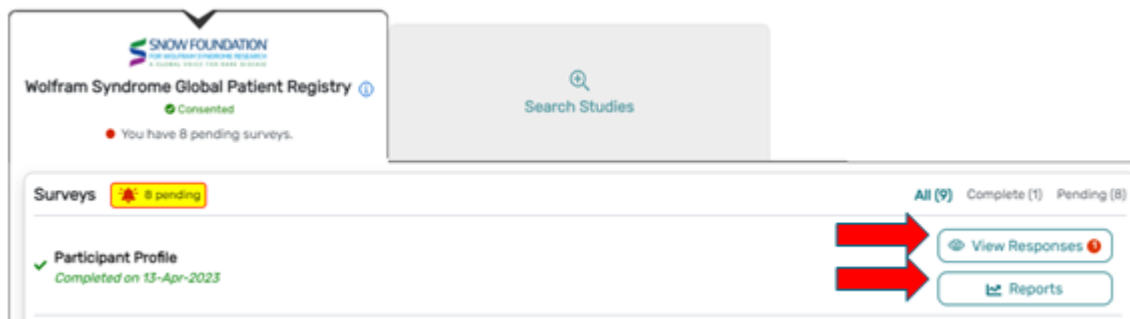


- Step 8: You will now have access to start taking surveys.



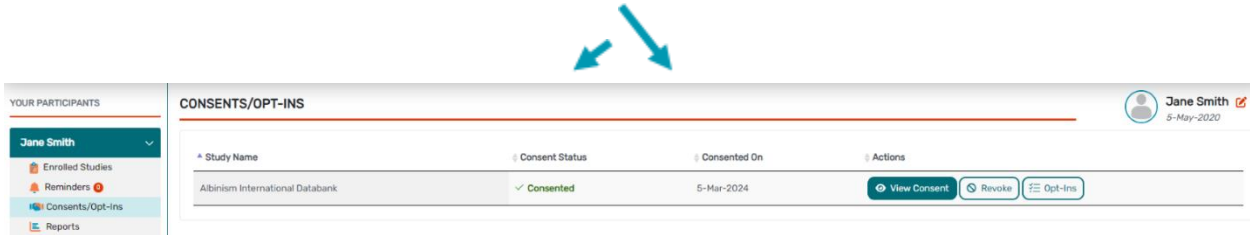
View Responses and Reports

- 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.



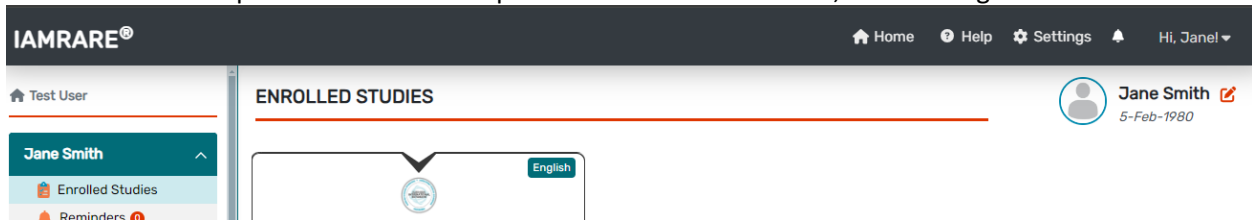
View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Click “Consents/Opt-Ins” to see your consent and opt-ins. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

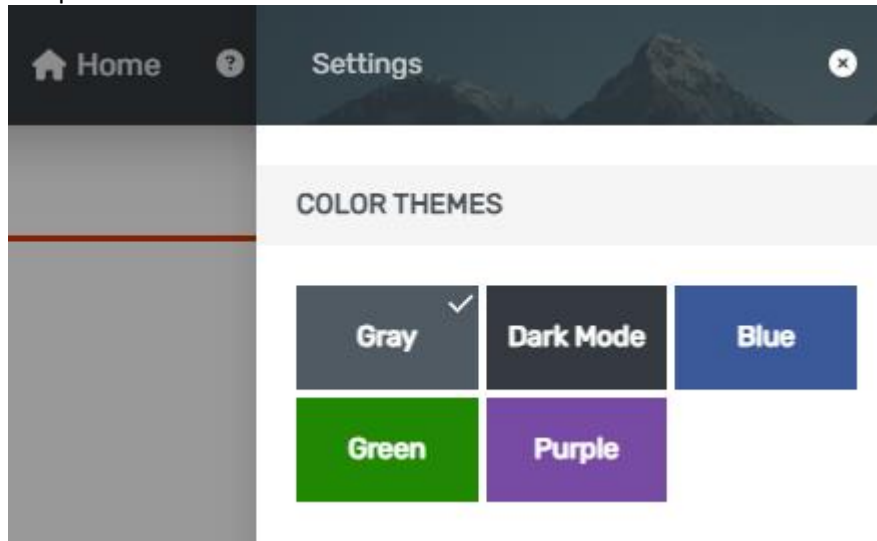


Dark Mode Settings

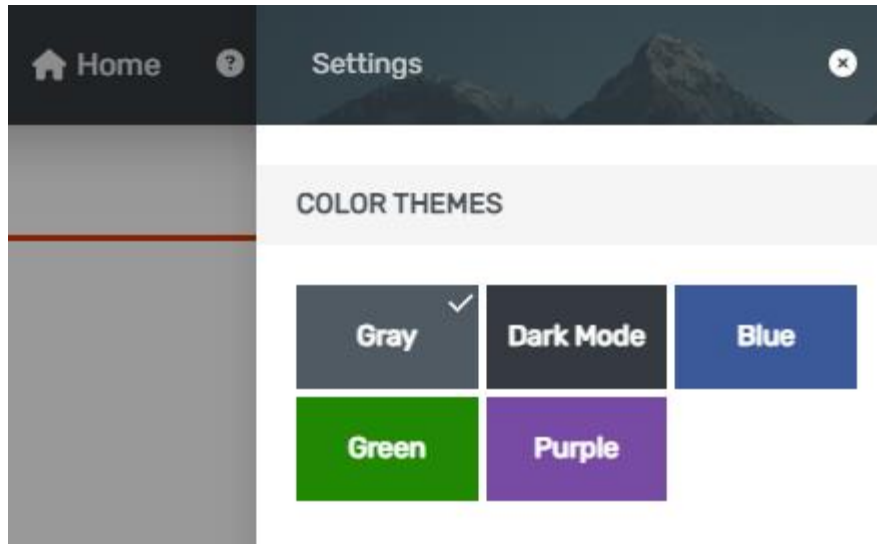
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.

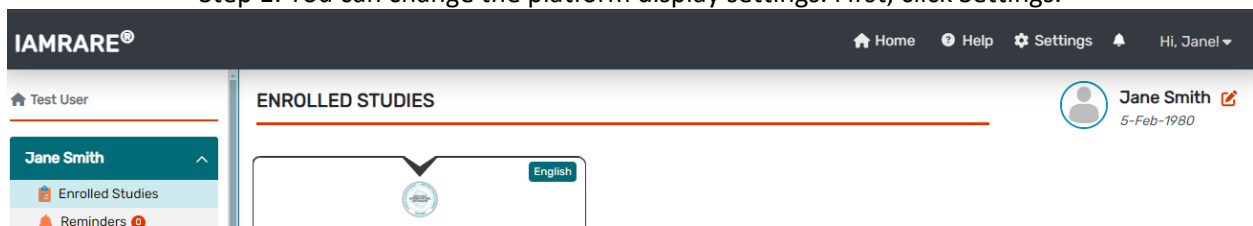


- Step 3: Exit the Settings menu, and your selection will be saved.

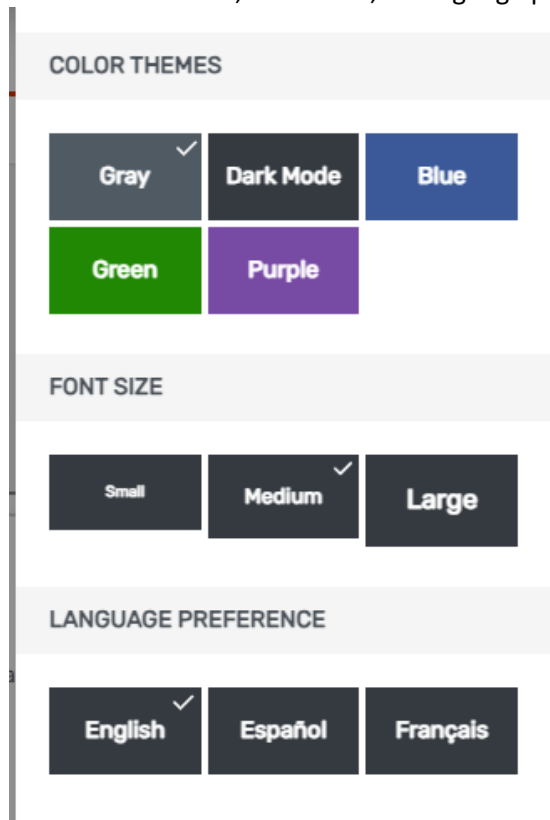


Display Settings

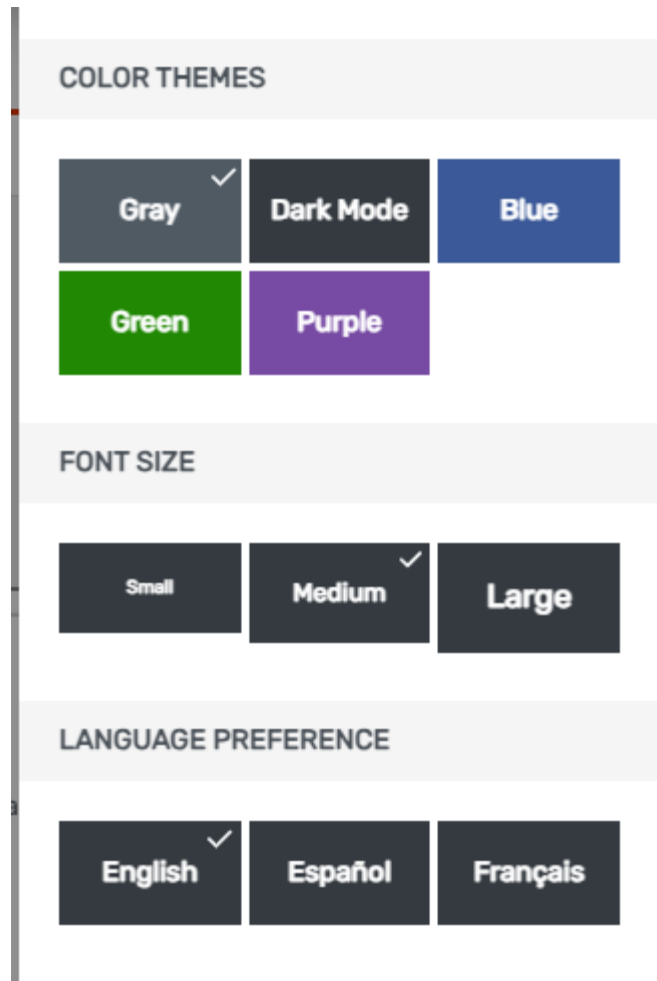
- Step 1: You can change the platform display settings. First, click Settings.



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





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

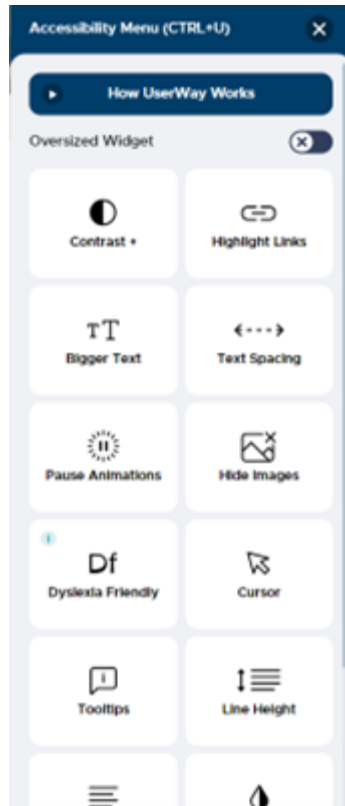


Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] 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.

 <p>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?</p> <hr/>	 <p>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.</p> <hr/>
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Need Assistance?

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

Home Help Settings

Have a question? ✕

Alternatively, to send us a message, please enter it 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.

Inquiry Type *

-- Select Inquiry Type --

Message *

Your message

Cancel Submit

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onsor
12 Foundation
ntact
Fourie
mail

- 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.

All (4) Complete (2) Pending (2)

 View Responses 1

 Reports

 View Responses 1

 Reports

 Take Survey

 Take Survey

Contact



Sponsor

Aardvark Foundation

Contact

Timothy Aardvark

E-mail

taardvark@gmail.com

Study available in:

English