

**RARE**X



**DATA  
COLLECTION  
PROGRAM**

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**User Guide**



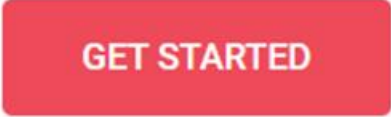
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# The Enrollment


## Getting Started From Your Community Page

Step 1. From your organization's Community Page Click the links to review RARE-X's Terms of Use and Privacy Policy.




By clicking Get Started, you are agreeing to the [RARE-X Terms of Use and Privacy Policy](#).

Step 2. Click Get Started


[HOME](#)   [GETTING STARTED](#)   [FAQ](#)Powered by 

### AHC - Data Collection Program




AHC patients, families, and communities are excited to participate in data collection to expand and improve medical research. By coming to this site, you can begin the first step in making your patient information available to researchers. By generating the most comprehensive AHC Data Collection Program, we can accelerate research and the development of new drugs, devices, or other therapies. Only you hold the key to unlock future discoveries.

Start Your Journey

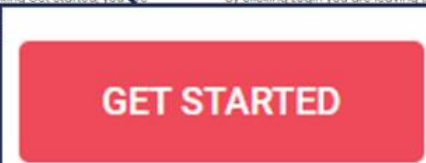


By clicking Get Started, you are agreeing to the [RARE-X Terms of Use and Privacy Policy](#).

Already Enrolled?



By clicking Login you are leaving the [RARE-X](#) website.



# Enrolling in the DCP

## Step 1. Complete Access Request Form

In order to proceed with your account creation, please acknowledge the following:

- I am at least 18 years of age (or at least the Age of Majority in my State/Country)
- I acknowledge that I am located in the United States; OR
- I acknowledge that I am located outside of the United States, and that the information I am providing will be transmitted to the United States for account creation.

Please check all that apply:

- Patient Participant**  
*A Patient Participant is a person with a rare disease who will be able to answer surveys and provide information about themselves.*
- Caregiver Participant**  
*A Caregiver Participant will be able to answer surveys and provide information on a patient(s) with a rare disease, for whom they are the Parent or Legally Authorized Representative.*
- Person who has lost a loved one to a rare disease**  
*This user will be able to answer surveys and provide information on a loved one with rare disease who is now deceased.*

**Remember check all roles that apply.**



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### RARE X Request Access

Join us and get connected today!

Your Information:

*This information will be used to create access credentials for the patient who will be accessing the platform themselves, or the caregiver/guardian who will be providing information on behalf of a patient.*

Your First Name \*  Your Last Name \*

Enter Letters Only

Email \*

Mobile Phone \*  Your Date of Birth \*

Enter Numbers Only

In order to proceed with your account creation, please acknowledge the following:

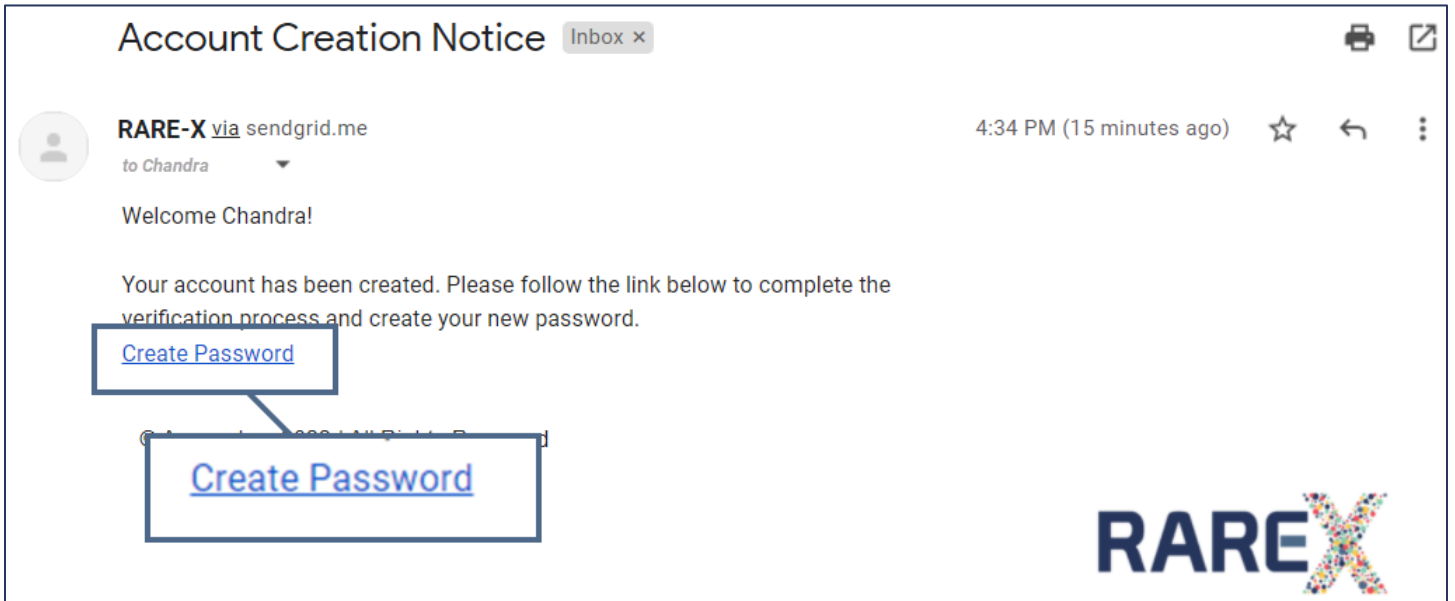
- I am at least 18 years of age (or at least the Age of Majority in my State/Country)
- I acknowledge that I am located in the United States; OR
- I acknowledge that I am located outside of the United States, and that the information I am providing will be transmitted to the United States for account creation.

Please check all that apply:

- Patient Participant**  
*A Patient Participant is a person with a rare disease (already diagnosed or still on their diagnostic journey) who will be able to answer surveys and provide information about themselves.*
- Caregiver Participant**  
*A Caregiver Participant will be able to answer surveys and provide information on a patient(s) with a rare disease, for whom they are the Parent or Legally Authorized Representative.*
- Person who has lost a loved one to a rare disease**  
*This user will be able to answer surveys and provide information on a loved one with rare disease who is now deceased.*

[PRIVACY POLICY](#)  [GO TO LOGIN](#)

## Step 2. Create your password



*If you do not receive a response within a few minutes, check your spam/junk folder.  
If you still don't receive an email, contact support@rare-x.org*

## Step 3. Request your verification code

### Create Password

Enter Your Email Here

[Send verification code](#)

Continue

Cancel

## Step 4. Email Verification

### Create Password

Verification code has been sent to your inbox. Please copy it to the input box below.

Enter Your Email Here

Enter Your Verification Code

[Verify code](#)

[Send new code](#)

Continue

Cancel


## Step 5. Create your password

### Create Password

The password must be between 8 and 64 characters.  
The password must have at least 3 of the following:

- a lowercase letter
- an uppercase letter
- a digit
- a symbol

## Step 6. Login to the DCP



Sign in with your email address

[Forgot your password?](#)

[PRIVACY POLICY](#) [TERMS OF USE](#)

## Completing the Consent Process

**When first logging into the Data Collection Program (DCP) you will be led through a required consenting process. You will be asked to complete an informed consent for each role you requested (caregiver, patient, or both) and each patient added.**

### Step 1. Matrix Terms of Use

This is like other terms of use you would agree to when downloading an application for personal use.

- ❖ Your Actions – **Review** and click **ACCEPT**

### Step 2. Informed Consent

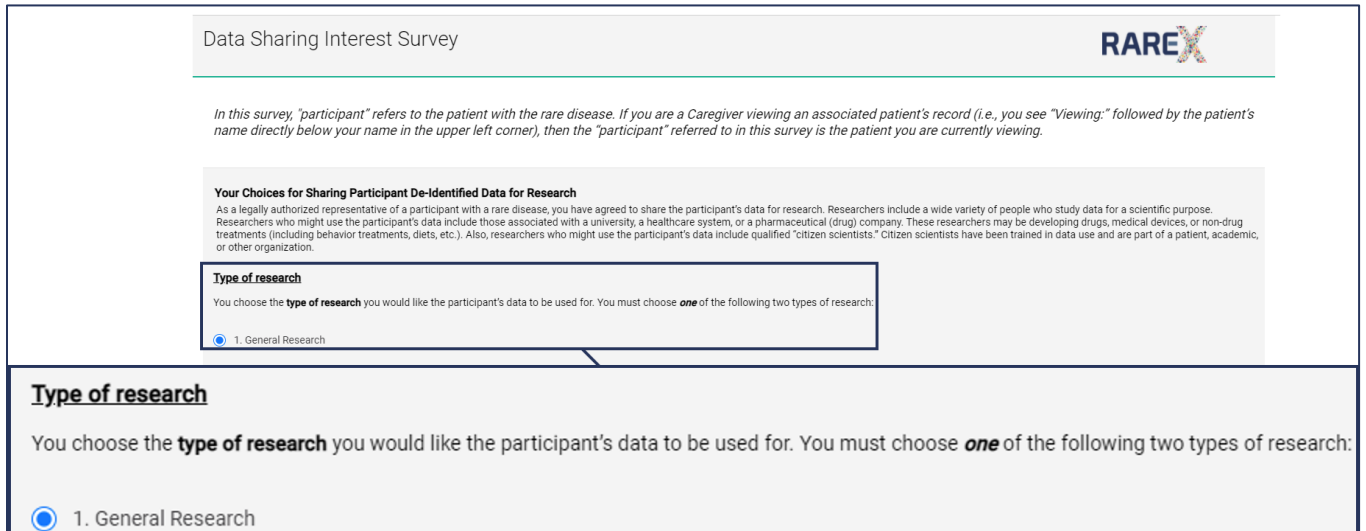
Informed consent is the process through which a researcher obtains, as well as maintains, the permission of a person or a person's authorized representative to participate in a research study.

- ❖ Your Actions – **Indicate** if someone is reading the consent to you. **Carefully Review** the Informed Consent. Click **I UNDERSTAND** at the bottom of each page. **Answer** the questions on the last page and **enter** your electronic signature. Click **COMPLETE**.

### Step 3. Data Sharing Survey

This part of the consenting process allows you to designate how your data will be shared.

**1. General Research.** Select this type of research to allow your data to be used for the broadest types of research.



The screenshot shows a web form titled "Data Sharing Interest Survey" with the RAREX logo in the top right. Below the title is a paragraph explaining that "participant" refers to the patient with the rare disease. A section titled "Your Choices for Sharing Participant De-identified Data for Research" contains a detailed explanation of the research types. Below this, a "Type of research" section asks the user to choose one of two options: "1. General Research" (which is selected with a radio button) and "2. Health/Medical/Biomedical Research". A larger, zoomed-in view of the "Type of research" section is shown below the main screenshot, highlighting the text and the selected radio button.

Data Sharing Interest Survey **RAREX**

*In this survey, "participant" refers to the patient with the rare disease. If you are a Caregiver viewing an associated patient's record (i.e., you see "Viewing:" followed by the patient's name directly below your name in the upper left corner), then the "participant" referred to in this survey is the patient you are currently viewing.*

**Your Choices for Sharing Participant De-identified Data for Research**  
As a legally authorized representative of a participant with a rare disease, you have agreed to share the participant's data for research. Researchers include a wide variety of people who study data for a scientific purpose. Researchers who might use the participant's data include those associated with a university, a healthcare system, or a pharmaceutical (drug) company. These researchers may be developing drugs, medical devices, or non-drug treatments (including behavior treatments, diets, etc.). Also, researchers who might use the participant's data include qualified "citizen scientists." Citizen scientists have been trained in data use and are part of a patient, academic, or other organization.

**Type of research**  
You choose the **type of research** you would like the participant's data to be used for. You must choose **one** of the following two types of research:

1. General Research

**Type of research**  
You choose the **type of research** you would like the participant's data to be used for. You must choose **one** of the following two types of research:

1. General Research

**2. Health/Medical/Biomedical Research.** Select this type of research if you prefer your data to be used for fewer types of research. Carefully read and select from the restrictions that follow.

The last page of the Data Sharing Survey asks permission for RARE-X to contact you or share your information in specific instances. For example, when new data sharing opportunities have been released.

❖ Your Actions: **Review** and **Select** your data sharing preferences. **Click COMPLETE** and then **FINISH**.

# The Dashboards

## Navigating the Caregiver Dashboard

Adding a Patient to the Caregiver Dashboard

Step 1. To add a patient to the DCP click the **ADD PATIENT** button in the upper left on your Caregiver Dashboard.

Step 2. Complete the Add Patient form

Step 3. Complete the consenting process.

Step 4. The patient will be added to your patient list. Click the Book icon to open the Patient's Dashboard.

The screenshot shows the 'My Patients' section of a dashboard. On the left, there is a sidebar with navigation options. The main content area has a header 'My Patients' and an 'ADD PATIENT' button. A callout box points to this button with the text 'To add another patient'. Below the button is a table with columns: First Name, Last Name, DOB, and Rare Disease. The table contains two rows of patient data. To the right of the table, there is a 'Logout' button and a 'Book' icon. A callout box points to the 'Book' icon with the text 'Click the book to open the patient's Dashboard'.

First Name	Last Name	DOB	Rare Disease
Macy	Lucus	Oct 11, 2011	4H Leukodystrophy (hypomyelination)
Mary	Lucus	Jul 13, 2017	Homocystinuria without methylmalon...

How to know what Dashboard I am on

The screenshot shows the user profile section of a dashboard. The user's name 'Sophia Hudson' and role 'CAREGIVER' are displayed. Below this, it says 'Viewing: Sam Hudson'. A callout box points to the user's name and role with the text 'Indicates the role you are logged in with and whose surveys you are viewing'. The dashboard shows a list of surveys/studies with columns for 'New/In-Progress', 'Completed', and 'Published On'. The first survey is 'Other Names Survey' published on 'Jan 05, 2022'. The second survey is 'Race and Ethnicity Concep...' published on 'Jan 05, 2022'.

Surveys/Studies - Level 1	Published On
Other Names Survey	Jan 05, 2022
Race and Ethnicity Concep...	Jan 05, 2022

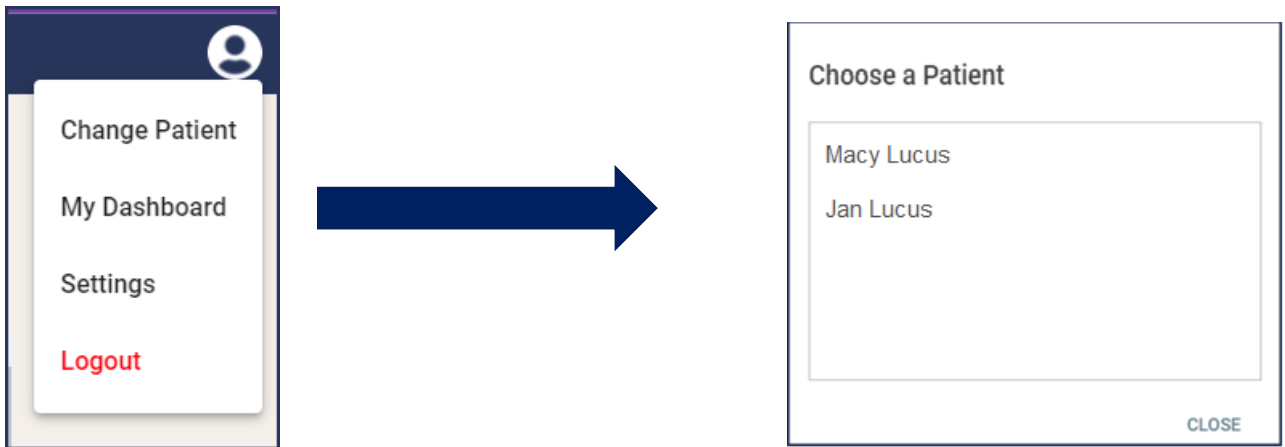
How to change Dashboards

STEP 1. Click the **Profile** icon in the upper right corner of the screen.



Step 2. Select **Change Patient** from the list.

Step 3. Select the patient's name from the **Choose a Patient** window.



## Navigating the Patient Dashboard

The screenshot shows the 'Dashboard' interface. At the top, there are two tabs: 'New/In-Progress' and 'Completed'. A callout box points to the 'Completed' tab with the text: 'Click the Completed tab to view, edit or print completed surveys.' Below the tabs are two tables of surveys.

**Surveys/Studies - Level 1**

Surveys/Studies - Level 1	Expiration Date	Time To Complete	Questions	Status
Diagnosis Survey	Jan 14, 2022	15-30 minutes	13	CONTINUE
Other Names Survey	Jan 05, 2022	2-4 minutes	1	START
Race and Ethnicity Concep...	Jan 05, 2022	5-8 minutes	2	START

**Surveys/Studies - Level 2**

Surveys/Studies - Level 2	Published On	Expiration Date	Time To Complete	Questions	Status
Blood and Bleeding Survey	Jan 05, 2022		5-10 minutes	11	START
Eyes and Vision Survey	Jan 05, 2022		10-15 minutes	13	START
Heart and Blood Vessels S...			10-15 minutes	11	START

At the bottom left, there is a 'VIEW: Category' dropdown menu. A callout box points to the 'Time To Complete' and 'Questions' columns with the text: 'Plan your DCP time by referring to the Time to Complete & Question columns'. Another callout box points to the 'START' buttons with the text: 'Click Start or Continue to open a survey'.

# The Surveys

## Completing Surveys

### Answering Level 1 Surveys

#### The Health and Development Survey

#### **\*\* Begin with the Health and Development Survey.\*\***

This is a head-to-toe survey indicating the body systems that are or that may be affected by the patient's rare disease.

Answer options include: Yes, No, or Unsure.

When a question is answered with Yes or Unsure, and there is an associated Level 2 survey the additional survey will be automatically added to the patient's dashboard. As additional Level 2 surveys become available, they will also be added to the patient's dashboard based on the Health and Development Survey responses.

The Health and Development survey can be updated as the patient's disease changes. Additional Level 2 surveys if applicable will be added to the Dashboard based on the updated survey responses.

The remaining Level 1 surveys are optional and only need to be completed if applicable to the patient.

The screenshot shows a survey form with several sections and annotations:

- Radio buttons - only select 1 answer:** A callout box points to a question: "Did the participant have genetic testing? \*". Below it are three radio button options: "Yes" (selected), "No", and "Unsure".
- Asterisks indicate required questions:** A callout box points to the asterisk on the question "What was the reason for genetic testing? \*".
- Check-boxes - Select all answers that apply:** A callout box points to a list of five check-box options under the question "What was the reason for genetic testing? \*". The options are: "The participant has had symptoms of a genetic condition.", "The doctor/I/the participant wanted to confirm a diagnosis that was suspected based on the participant's symptoms.", "The participant has a family history of a genetic disorder and was showing symptoms of that disorder - wanted to confirm diagnosis.", "The participant has a family history of a genetic disorder and was NOT showing symptoms of the disorder - wanted to assess the participant's risk.", and "The participant is healthy and wanted to be proactive about their health." The fifth option, "Unsure", is not checked.
- Click X to close the survey with an option to save your answers:** A callout box points to a red "X" icon in the top right corner, next to a "GLOSSARY" button.
- Click Next to save your response & move to the next page:** A callout box points to a "NEXT" button at the bottom right.
- Do you have genetic reports or summaries to upload? \*** A callout box points to a question with three radio button options: "Yes (The participant has had testing and I have a copy)" (selected), "No (The participant has had testing but I do NOT have a copy)", and "Unsure".
- Page 2 of 7:** A footer at the bottom left.
- Navigation buttons:** "PREVIOUS" and "NEXT" buttons are located at the bottom left and right respectively.

No survey with data will ever be removed from the patient's Dashboard based on updates to the Health & Development Survey

## Answering Level 2 Surveys

These surveys have more in-depth questions.

Answer options include: Yes, No, or Unsure.

Answers Yes or Unsure allow you to provide additional information regarding the age symptoms first appeared and the age a diagnosis was made.

What specific **EYE/VISION** issues has the participant had? At what age did the **EYE/VISION** issues begin, and when were they diagnosed by a healthcare provider?

	Do you see this symptom *	Age symptoms first appeared	Age at Diagnosis
<b>Eye movement issues</b> - Eyes have unusual movement such as "lazy eye" (strabismus), or eye tremors (nystagmus), etc..	Yes <input type="button" value="v"/>	2 years old <input type="button" value="v"/>	2 years old <input type="button" value="v"/>
<b>Visual Impairment</b> - Vision loss that cannot be corrected by conventional means, such as refractive correction, medications, or surgery.	Unsure <input type="button" value="v"/>	Unsure <input type="button" value="v"/>	Unsure <input type="button" value="v"/>
<b>Difference in eye size</b> - Eye size differs from what is usual such as a small eye size (microphthalmia) or lack of eye development (anophthalmia), etc.	No <input type="button" value="v"/>		

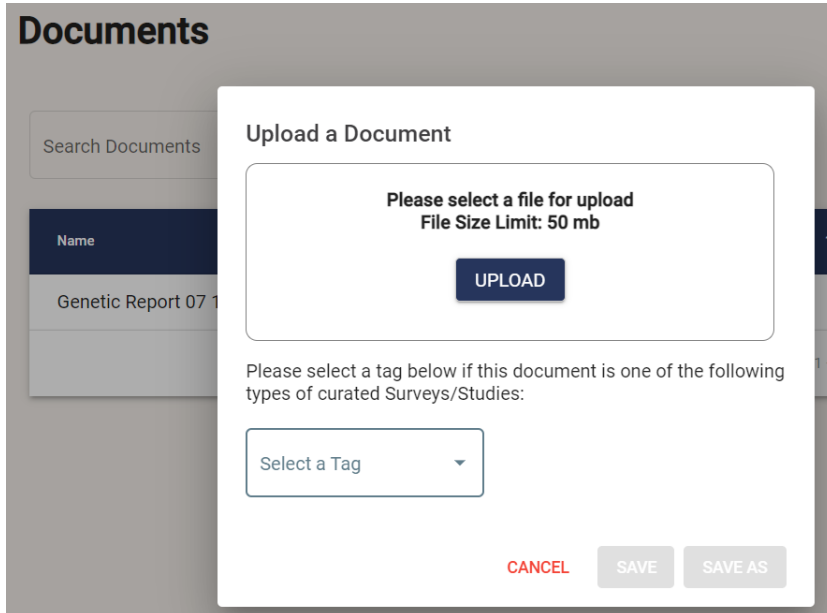
  

Age symptoms first appeared	Age at Diagnosis
2 years old <input type="button" value="v"/>	2 years old <input type="button" value="v"/>
Unsure <input type="button" value="v"/>	Unsure <input type="button" value="v"/>

# Documents

## Uploading Genetic Reports

Step 1. Select **Documents** from the left side menu & click the **UPLOAD** button on the far right of the screen. The window below will open.



The screenshot shows a web application interface with a 'Documents' section. A modal dialog box titled 'Upload a Document' is open. The dialog contains a search bar, a table with a 'Name' column and one entry 'Genetic Report 07 1', and a text prompt: 'Please select a tag below if this document is one of the following types of curated Surveys/Studies:'. Below this is a dropdown menu labeled 'Select a Tag'. At the bottom of the dialog are three buttons: 'CANCEL', 'SAVE', and 'SAVE AS'. The 'UPLOAD' button is visible in the background of the dialog.

Step 2. Click **UPLOAD**. Select the genetic report from your saved files.

Step 3. Click **Select a Tag** and choose Genetic report from the drop-down list.

Step 4. Click **SAVE** to save the file or **SAVE AS** if you would like to edit the file name.

# Frequently Asked Questions

## I forgot my password and other frequently asked questions

### ***How do I contact RARE-X support?***

Contact support by emailing us at [Support@rare-x.org](mailto:Support@rare-x.org). We will respond to your email within 24 hours, Monday – Friday, except on nationally designated holidays. You may also call at (716) 427 2739 and press 1 for Support.

### ***How do I reset my password?***

Click the *Forgot your Password?* link on the *Login* screen. Enter your email address and click *Send verification code*. Follow the requested steps. Refer to *Creating Your Account* for more detailed information.

### ***What are the preferred web browsers?***

Chrome, Edge, and Safari v14 or higher are the preferred browsers. Firefox is not compatible with the DCP.

### ***How do I update a survey?***

Navigate to the *Completed* tab on the *Dashboard*. Click the ellipses to the far right of the survey you would like to update. Select *Edit* from the list that opens and make your updates.

### ***How long will it take my level 2 surveys to load?***

First you must have answered yes or unsure to the related questions on the *Health and Development Survey*. This is a web-based application so there are several variables that affect the time it takes for the surveys to load. A few include:

- Your internet speeds
- The device you're using
- The number of surveys loading

### ***Why are there so many consents?***

We know the initial registration process can be confusing. We are working to make the process more streamlined. In the meantime, let's break down the documents you are asked to review.

- RARE-X Terms of Use and Privacy Policy – Similar to other terms of use and privacy policies you are asked to accept when adding an application to your

laptop or phone. These are links on the GET STARTED and LOGIN buttons on your community page.

- Matrix Terms of Use – Matrix is the software vendor that hosts RARE-X's DCP. Matrix requires you to accept their terms of use.
- Consents – Both caregiver participants and patient participants must give consent to enter or have their data entered in the DCP. You are asked to complete the caregiver consent and as each child or participant is enrolled you will be asked to complete their consent. There will be caregiver specific surveys in the future.
- Data Sharing – RARE-X encourages you to share your data as widely as possible to further the development of possible treatments and cures. We understand not everyone is comfortable with or wishes to provide their data this broadly. The Data Sharing survey allows you to share what you want with whom you want and can be updated at any time. Be aware, depending on the restrictions placed on your data RARE-X may not be able to contact you for clinical trials or treatments.