GLOBAL PRADER-WILLI SYNDROME REGISTRY

We invite you to login to your account in the Global PWS Registry and update the answers to surveys. Some symptoms may have improved, new milestones may have been reached, and there may be new challenges. Many things can change including medications, therapies, and schooling. Capturing each individual's story of PWS contributes to the power of the data in the Registry.

Using the instruction below, you will be able to login, view your previous answers to surveys, and make any changes or updates!

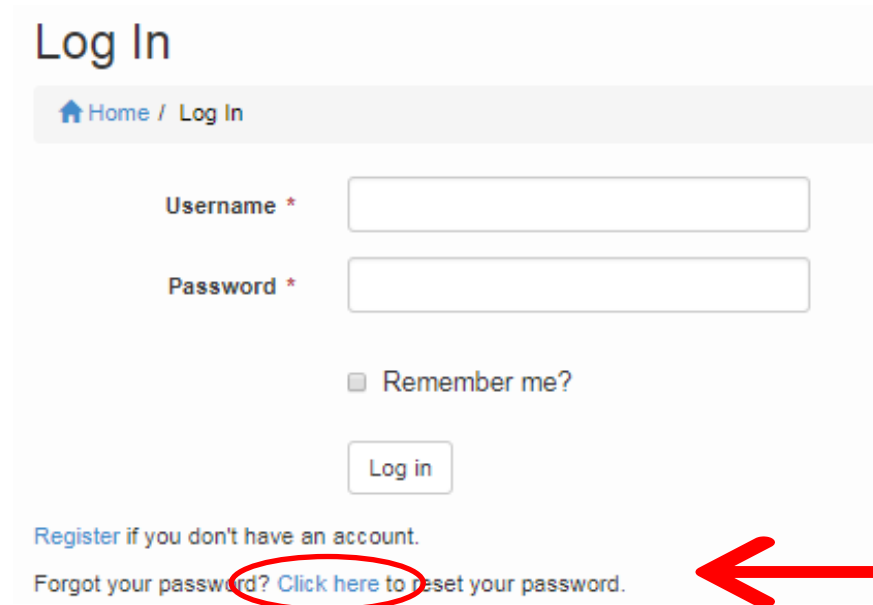Please contact us at info@pwsregistry.org with any questions or concerns.

STEP 1: Login to your account

a) **Go to the Registry homepage: https://pwsregistry.org/**

b) **Click the "Log In" link in the top right corner of the page**

c) **Your "Username" is an e-mail address**

If you don't remember the e-mail address used, contact us at info@pwsregistry.org. If you don't remember your password, click the reset link.

STEP 2: Access surveys

a) **After login, the name of the person with PWS should be listed as an Active Participant. If this is NOT correct, click 'Edit' to correct the information, or contact us at info@pwsregistry.org**

b) **Click "Take Surveys"**

STEP 3: Update previously completed surveys

a) **Surveys are divided into categories**

"Initial surveys"	= have not been completed
"Results"	= where you can view the information entered in survey retakes
"Updatable"	= have been completed and can be updated with new information
"Graph results"	= shows aggregate data from the community for any surveys you have completed
"Surveys to Retake"	= surveys that can be retaken every 6 months, starting from scratch

Initial Surveys (42)	Results (2)	Updatable (3)	Graph Results (2)	Surveys to Retake (1)

b) **Click the "Updatable" tab to see a list of surveys available for update. Click "edit" next to the name of survey to be updated. The submitted date shows when the survey was last updated.**


Initial Surveys (42)   Results (2)   Updatable (3)   ~~sults~~ (2)   Surveys to Retake (1)

Updatable Responses

You have completed these surveys and may now view your answers by clicking on the **View** button next to the survey title. You can update a previously completed survey by clicking on the **Edit** button.

| Survey Title		Survey Version Date	Submitted Date	Last Updated Date	
Getting Started	👁 View	September 18, 2017	March 26, 2020	Never	✏ Edit
Consent for Future Use of De-identified Data	👁 View	April 26, 2017	November 6, 2018	Never	✏ Edit
Research Trials	👁 View	April 26, 2017	March 26, 2020	Never	✏ Edit

c) The survey will load with all of the prior answers. Make changes, add new information, and when complete, submit the updated survey, by clicking "I'm Finished" in the bottom right-hand corner _even if no changes were made._
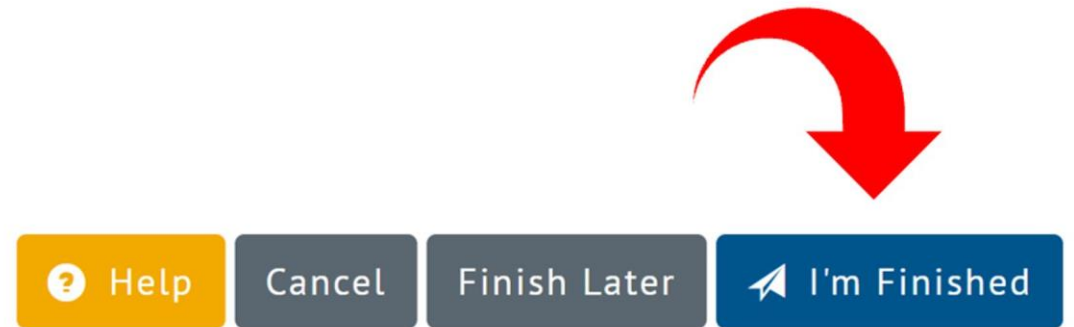
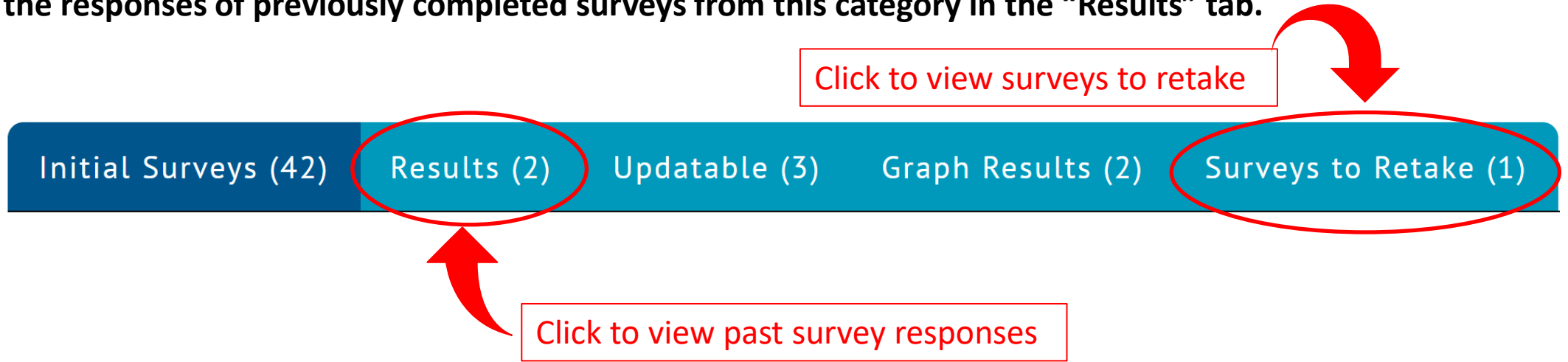**d)** Confirm survey submission by clicking "Yes, I'm Finished"
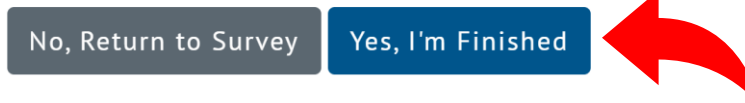
STEP 4: Complete survey retakes

a) **"Surveys to Retake" are surveys that are scheduled to be taken from scratch every 6 months. You can view the responses of previously completed surveys from this category in the "Results" tab.**

Click to view surveys to retake

Initial Surveys (42)   Results (2)   Updatable (3)   Graph Results (2)   Surveys to Retake (1)

Click to view past survey responses

b) **Click the "Surveys to Retake" tab to see a list of surveys available for retake. Click "Retake" next to the name of the survey due for retake. The "Next Follow-Up" column shows the date when the survey will be available for retake.**

Initial Surveys (42)   Results (2)   Updatable (3)   Graph Results (2)   Surveys to Retake (1)

Click Here

Surveys to be Retaken

These surveys are a part of the study schedule and require completion at varying intervals. A survey can be completed according to the date displayed in the Next Follow-Up column.

| Survey Title		Last Taken Version Date	First Taken	Last Taken	Next Follow-Up
Hyperphagia and Food Behavior	✏ Retake	March 9, 2020	March 26, 2020	August 25, 2020	August 26, 2020

Click to open survey

c) Complete the survey and submit by clicking "I'm Finished" in the _bottom right hand corner_. Surveys can be saved as drafts and completed at a later time by clicking "Finish Later"
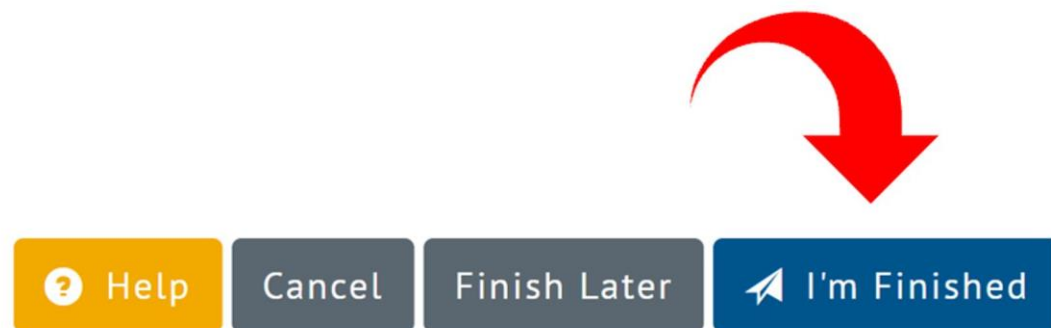
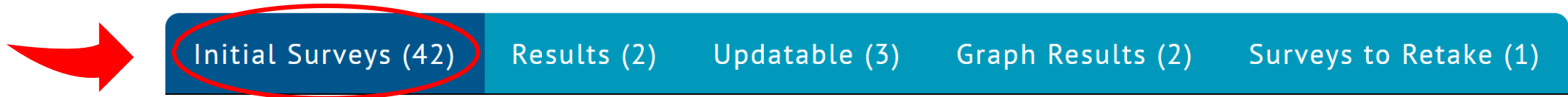**d)** Confirm survey submission by clicking "Yes, I'm Finished"
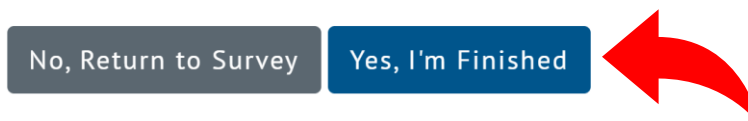
BONUS STEP 5: Complete any surveys not yet taken

a)   **From Step 3a, click the tab for "Initial Surveys" to see a list of surveys not yet taken.**

Initial Surveys (42)	Results (2)	Updatable (3)	Graph Results (2)	Surveys to Retake (1)

b)   **Click the blue "Take" button to access each survey**

Surveys Not Taken

Survey Title

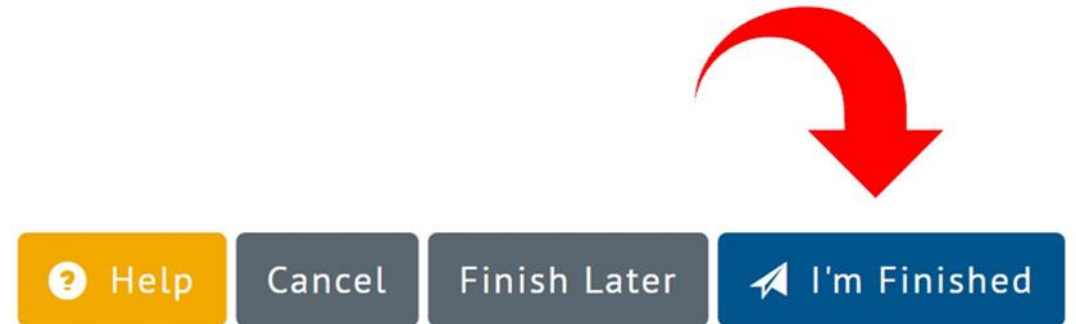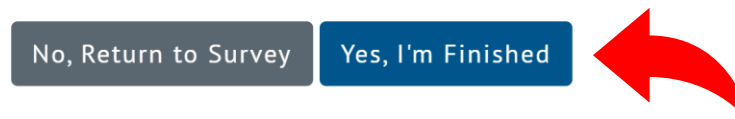|	
Food Safe Zone	✏ Take
Pregnancy Hstory	✏ Take
Biological Family History	✏ Take
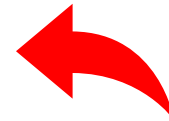
c) **Complete the survey and submit by clicking "I'm Finished" in the _bottom right hand corner_. Surveys can be saved as drafts and completed at a later time by clicking "Finish Later"**

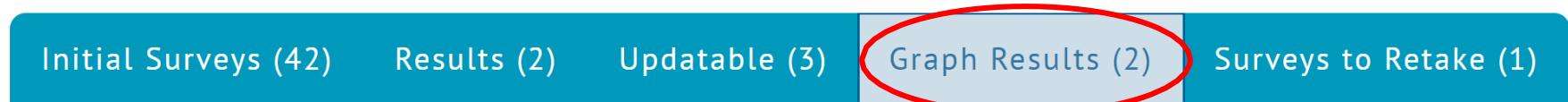d) **Confirm survey submission by clicking "Yes, I'm finished"**

BONUS STEP 6: Visualize results to see how your answers compare to the rest of the community

a) From Step 3a, click the tab for "Graph Results". Note that this is only available for surveys that have been completed

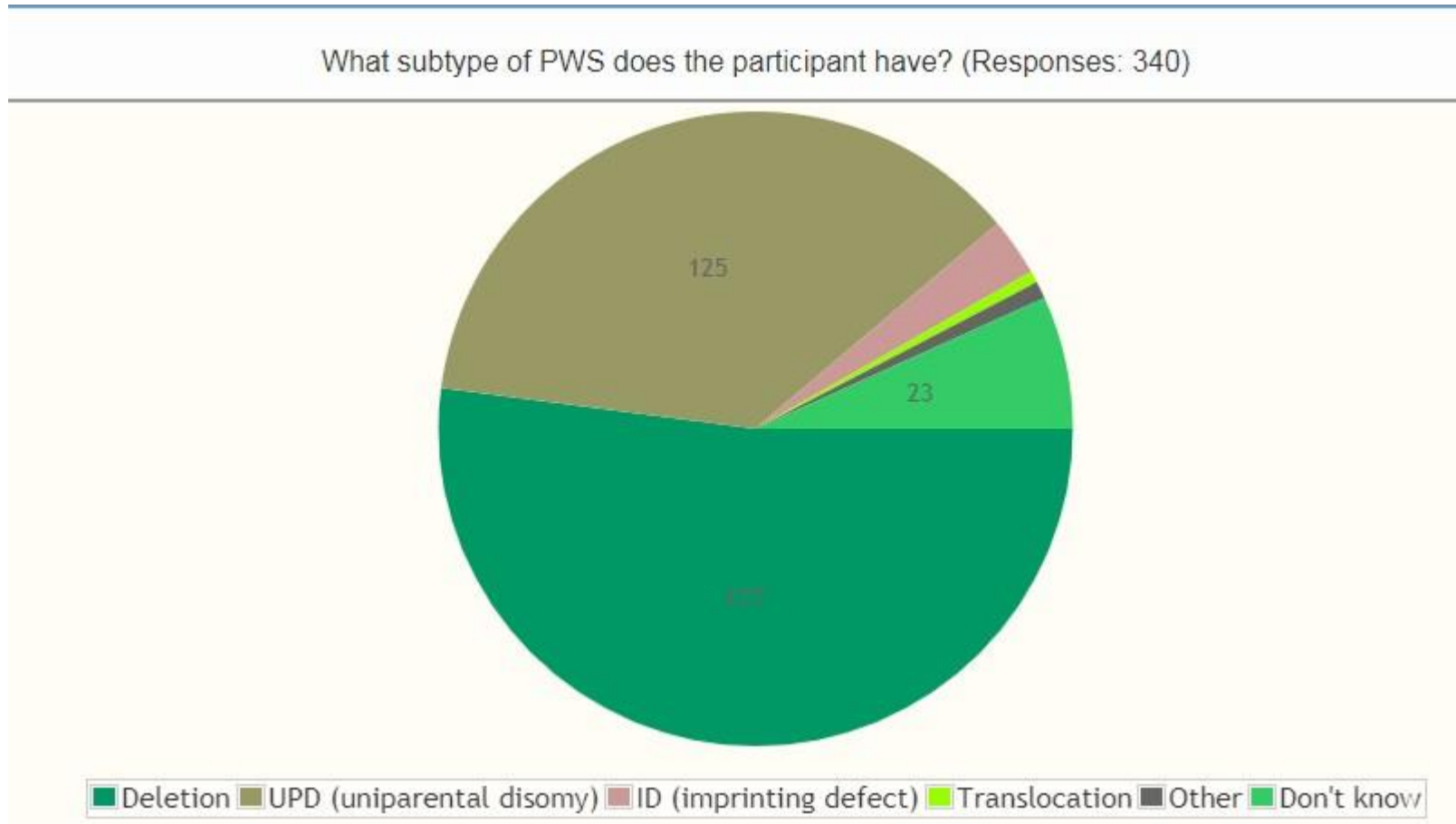| Initial Surveys (42) | Results (2) | Updatable (3) | Graph Results (2) | Surveys to Retake (1) |

b) Click "Graph Results"

Graph Results

You have completed these surveys and may now view your answers by clicking on the **View** button next to the survey title. Visually compare your answers against those of other participants by clicking on the **Graphed Results** button.

Survey Title		Sub-Study	Survey Version Date	Submitted Date	Updated Date	
Consent for Future Use of De-identified Data	👁 View		June 6, 2017	May 4, 2021	May 4, 2021	📊 Graph Results
Getting started	👁 View		May 1, 2015	May 4, 2021	May 4, 2021	📊 Graph Results
Contact information	👁 View		May 1, 2015	May 4, 2021	May 4, 2021	📊 Graph Results

Sample Figure of Visualized Data

What subtype of PWS does the participant have? (Responses: 340)

125

23

Deletion   UPD (uniparental disomy)   ID (imprinting defect)   Translocation   Other   Don't know

Thank you!

Your participation in the Global PWS Registry is vital to accelerating PWS research!

Please contact us at info@pwsregistry.org with any questions