

Are there genetic restrictions to enrolling in the DataHub?

Any person with a diagnosis of PMS (or their representative on behalf of the person with a PMS diagnosis) is eligible to enroll in the DataHub, including individuals with interstitial deletions.

How long will it take to fill out all DataHub information?

45 minutes to an hour. This will vary depending on how complicated the medical history is. You can exit out of surveys at any time and return at a later date.

What do I need handy to enroll in the PMS DataHub?

(All for the individual with PMS):

- Genetic report(s)
- Medical records could be helpful for answering questions on the general health about when symptoms started and when a diagnosis was made
- Any medications or symptoms you would like to track (considered bonus information)

I was enrolled in the previous PMS International Registry (PMSIR), do I need to enroll again in the DataHub? What will happen to my old data?

Yes, please enroll in the new PMS DataHub, since there are new surveys on the platform. But your old data will still be useful. If you uploaded a genetic report to the PMSIR, your report will be curated into the same format as the new DataHub platform. All of your old survey data will also be available to researchers.

Is the platform accessible in multiple languages? Can I enroll from a country other than the U.S.?

Right now, the information in the surveys is only available in English, but our goal is to translate the surveys in the future. The DataHub is not restrictive by country, but please keep in mind that privacy laws regarding medical information may vary by country, and this platform is based in the U.S.

Can I see how others answered survey questions in the DataHub?

The General Health Survey has an analyze function which will allow enrollees to see how many people answered Yes or No to each question. This will not show any personal information. To learn how to use the analyze function, please see the step-by-step DataHub user guide.

There are several things to fill out in the DataHub; what is most important?

The most critical information for researchers are:

- the genetic report
- the general health survey
- medications

All other information - such as symptom and activity data, is considered a bonus.

How is my information kept safe?

Your name and other personal identifiers will be removed and replaced with a special code before your data is shared with qualified researchers. Only PMSF staff and contractors who receive special training will have access to your identified data and only for authorized purposes. Researchers must apply to have access to the DataHub, which will be reviewed and vetted by PMSF staff based on expertise, relevance of their research to PMS, and completion of training in protecting human data.

Should I come back to update data in the future?

The DataHub is designed to be easy to return to and update any new information, while saving your previously entered data. We will send you reminders periodically to update your information if symptoms, medications, etc. have changed, or if a new survey is added. Updating this information is crucial to ensuring quality data is recorded.

How can I be contacted about new studies in PMS?

To stay up to date on survey updates and recruitment for new research studies, please turn notifications on. To do this, click the person icon in the upper righthand corner of the DataHub platform. Click “edit” and turn on notifications for new surveys and messages by toggling on text and/or email.

What are the risks of taking part in the DataHub?

As with all online data collection, there is a small risk that someone who does not have permission could see the data you have entered. We will do our best to protect your information from being seen by people who should not have it. The PMSF will do this by removing information that could be used easily to identify you. The risk that your identifiable information will go to someone who should not have it is very small. All relevant details are included in the Informed Consent document upon enrolling. Enrollment is entirely optional.

I want to be involved in a clinical trial. If I enroll, is this guaranteed?

Although one of the goals of the DataHub is to make it easier for patients to participate in research, there is no guarantee that you or your family member will be eligible for a trial. The DataHub serves as a sign up to be directly contacted about studies. (Please note that eligibility for a clinical trial can change at any time. Please also be aware that if we inform you about the existence of a trial, this does not mean we support it. In order to participate in any trial, you will need to fill out a separate Informed Consent form provided by the clinical trial site).

Why does the General Health Survey seem non-specific to PMS? Is there a place for me to add more detail about medical issues?

This survey is standardized so it can be used across disease, to learn more about similarities and differences between PMS and other neurodevelopmental disorders, and other rare diseases. We have received feedback from researchers that this is a powerful method to understand underlying factors in disease. More surveys specific to PMS will be added in the future to dig deeper. If you wish to add a condition that is not listed, or add more detail, there are free text fields where you can add this information at the bottom of the page.