



Special Announcement for PXEers

Your Data in PXE International Studies

Dear Sharon,

Did you finish your surveys? Please do. Pretty please?

What if I did not do the surveys?

There is no better time than now. We ask you to create an account and do all of the surveys you see at this link. (Ignore any request for DNA files or medical records.)

**Do the
surveys**

What if I did some but not all?

You are mostly amazing. Go for 100% amazing:

Finish the Surveys



What is most important?

Log in, copy your participant number, and send it to Mary@pxe.org - deadline February 2.

The screen will look like this, and your participant number is where I have circled in red. If you have any trouble, please email Mary@pxe.org and she, Ian, Catt will help you.

Click any of the big red buttons - we need the number on that main screen.

The screenshot shows the Luna dashboard for a study. At the top, there is a navigation bar with the Luna logo, a dashboard icon, 'DASHBOARD', 'MY DATA', 'ALL STUDIES', and a 'MENU' button. Below the navigation bar, there is a section for 'ALL STUDIES > GENERAL PXE STUDY'. On the right side of this section, there are two status indicators: 'STUDY ENROLLMENT OPEN' and 'DATA COLLECTION OPEN', both with green checkmarks. Below this, there is a summary bar with four metrics: '0 STUDY PARTICIPANTS', '0 SURVEYS COMPLETED', '0 DNA FILES SHARED', and '0 HEALTH RECORDS SHARED'. To the right of these metrics is the date '1/6/24' and the text 'LAST UPDATED'. Below the summary bar, there is a red circle around the text 'PARTICIPANT CODE: LN-PM66DNVB'. At the bottom of the dashboard, there is a progress bar with four steps: 'OVERVIEW' (with a plus icon), 'CONSENTS' (with a gear icon), 'PREREQUISITES' (with a checkmark icon), and 'DATA REQUESTS' (with an envelope icon).

Log in and copy your
participant code

We are DONE with surveys for a while (take a bow, raise a glass, and don't worry, we will be back with an easier survey system) and into the exciting phase of publishing the results. Once you send us your **participant code**, we can include you in the results.

Thanks to all of you for contributing your piece of the puzzle. Our consortium of scientists is so excited to see these data!

[PXE International](#)



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