PIN Data Portal

PUT PATIENT REPORTED DATA TO WORK FOR YOU

As an interested stakeholder you have access to charts, graphs and see aggregate data on the medical conditions of interest to you.

Create an account here:  https://pindata.invitae.com/

Click “SIGN UP” to create your account.

Select the medical conditions of interest on your account set-up screens.

You will be notified by email of account approval within 2 business days.

Then, return as an “Existing User”
PIN Data Portal

**SURVEY GRAPHS AND CHARTS**

Choose Medical Condition  
Choose Survey  
Choose Topic

Map - Export

At what age was the diagnosis made?

- 0 - 3 months old
- 4 - 7 months old
- 8 - 11 months old
- 1 year old
- 2 years old
- 3 years old

52 people provided 52 responses

See Charts and Graphs
PIN Data Portal

DATA AND CONTACT EXPORT

• Click on DATA PORTAL to see the menu displayed above.
• Choose Export Contacts to export email address of participants that wish to share.
• Choose Export Data to download row level de-identified survey data.
PIN Data Portal – data export screens

Select demographic fields, survey sessions and survey questions desired.

Export Data

The following fields are available for you to export data from the datasets assigned to your account and the source of information selected on the previous screen. Select the fields you would like included in your file. Scroll to the bottom of the page and enter a file name. After hitting Submit, you will receive a notification that your export is ready. You may also check the status of your export from the Manage Export link. If you have any questions, please contact PatientCrossroads at connect@patientcrossroads.com

Options Defined:

- No Option Selected - Export of survey responses for the most recent survey session (regardless of whether the session is incomplete or complete).
- Most Recent Survey - Export of the survey responses for the most recently completed survey session. If no complete survey session exists, then export the most recent incomplete survey session.
- All Completed surveys - Export of the survey responses for all the complete survey sessions, present and past (previously called historical or longitudinal export).
- All Complete and Incomplete Surveys - Export of the survey responses for all complete and incomplete survey sessions, present and past.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>_UE_HEALTH_REASON_FOR_REGISTRATION</td>
<td>Diagnosis - Page 1</td>
</tr>
<tr>
<td>_UE_GENDER</td>
<td>At what age was the diagnosis made?</td>
</tr>
<tr>
<td>_UE_AGE</td>
<td>What type of doctor or healthcare provider diagnosed this condition?</td>
</tr>
<tr>
<td>_UE_RACE (SELECT_ALL_THAT APPLY)</td>
<td>What led to the initial medical evaluation?</td>
</tr>
<tr>
<td>_UE_ETHNICITY</td>
<td>(Select all that apply.)</td>
</tr>
<tr>
<td>_UE_FAMILY_GROUP_CODE</td>
<td>At what age did the participant first begin experiencing symptoms of the condition?</td>
</tr>
<tr>
<td>_UE_STATE (USA ONLY)</td>
<td>Which of the following symptoms led to the participant’s initial medical evaluation? (Select all)</td>
</tr>
<tr>
<td>_UE_COUNTRY</td>
<td></td>
</tr>
</tbody>
</table>

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