




Pentaho Business Analytics has designed a platform for you to use and get real time Dystonia Coalition data.

Use the following link: [http://clinportalquery.wustl.edu/pentaho/Home?userid=DYSTONIA\\_OPENI&password=DYSTONIA](http://clinportalquery.wustl.edu/pentaho/Home?userid=DYSTONIA_OPENI&password=DYSTONIA). The recommended browsers are Firefox or Chrome. **If you encounter Error messages when moving Filters up or down, try clearing your CACHE. Click Ctrl + Shift + Delete to clear CACHE.**

Take a few minutes to practice using different filters. Click and drag the **Filter(s)** you are interested in up to **Rows**. The default Filter is Primary dystonia. You can also drag filter(s) down to the section called Filters. When you drag a filter up or down, wait a second before unclicking the filter. You can start over at any time using the green refresh button in the upper right hand corner of the screen.  .

You can filter by Body Regions Affected, Body Regions with Tremor, Burke-Fahn Marsden scores by body part, Family History of Dystonia, GDRS scores by body part Tremor type, Gender, Primary Dystonia, Primary Dystonia Subtype, Psychiatric Disorders, Sensory Trick Effective, Sites of Onset and Task Specific.

The Dystonia Coalition encourages researchers to use the data that has been collected by the coalition. If you would like to do a study using the Dystonia Coalition data and would like more information, please contact Gamze Kilic Berkmen at Emory University, [gamze.kilic.berkmen@emory.edu](mailto:gamze.kilic.berkmen@emory.edu) or (Laura) Jo Wright [wrightl@npg.wustl.edu](mailto:wrightl@npg.wustl.edu) at Washington University in St. Louis. A Data/Sample request form will be emailed to you.

In addition to the data found on Pentaho, study questionnaires (Beck Depression, Hospital Anxiety and Depression, Liebowitz, PHQ9 and SF36 Quality of Life) are available. Additional questionnaires were also required and available for 3 sub-studies within the coalition on Cervical Dystonia, Laryngeal Dystonia and Blepharospasm. Study videos and DNA are also available.

## Pentaho Default screen

The default filter is **Primary dystonia**.

The screenshot shows the Pentaho BI Desktop interface. The main window title is 'Dystonia'. The interface is divided into several sections:

- Columns:** Contains the measure 'Measures'.
- Rows:** Contains the filter 'Primary dystonia'.
- Filter:** A list of available filters including 'Age at onset of dystonia', 'Age in years', 'Best clin diagnosis', 'Body regions affected', 'Body regions with tremor', 'Dystonia ethnicity', 'Dystonia race', and 'Fahn marsden total'.
- Table View:** Shows a table with the following data:

	Measures
<b>Primary dystonia</b>	<b>Ppi</b>
<input type="checkbox"/> <b>All Primary dystonias</b>	3,447
<b>--Select--</b>	61
<b>Focal Dystonia</b>	2,289
<b>Generalized Dystonia</b>	137
<b>Hemi Dystonia</b>	14
<b>Multi-focal Dystonia</b>	198
<b>Not Specified</b>	306
<b>Segmental Dystonia</b>	689

Additional interface elements include a menu bar (File, View, Tools, Help), a toolbar with various icons, and a settings area with options like 'Swap Axes', 'Hide Empty Rows/Cols', 'Hierarchy', and 'Drill: Hierarchy'.

**Example 1. Body Region Affected**

If you want to know how many people in the coalition are affected by body region, drag **BODY REGIONS AFFECTED** up to Rows. (Drag Primary dystonia down to Filters). Click the “plus” sign to the Left of **ALL BODY REGIONS AFFECTED**

The screenshot shows a data analysis interface. On the left, there is a 'Filter' section with a list of filters. 'Body regions affected' is highlighted in blue. Below it, 'Primary dystonia' is also highlighted in blue. Other filters include 'Age at onset of dystonia', 'Age in years', 'Best clin diagnosis', 'Body regions with tremor', 'Dystonia ethnicity', 'Dystonia race', 'Fahn marsden total', 'Family history of dystonia', 'Fm eyes total', 'Fm left lower limb total', 'Fm left upper limb total', 'Fm mouth total', and 'Fm neck total'. On the right, there is a 'Table' view of a pivot table. The table has two columns: 'Body regions affected' and 'Measures'. The 'Measures' column contains 'Ppi'. The table shows a total of 3,348 for 'All Body regions affected' and a breakdown by body region.

Body regions affected	Measures
<input type="checkbox"/> All Body regions affected	3,348
Foot	168
Hand	723
Jaw	282
Larynx	573
Lower Face	617
Neck	2,239
Pelvis	43
Shoulder	638
Tongue	122
Trunk	190
Upper Arm	314
Upper Face	822
Upper Leg	83

**Example 2. Gender**

If you want gender breakdown, drag Gender up to Rows. Click the “plus” sign to the Left of **ALL GENDERS**.

**Dystonia**

Swap Axes  Hide Empty Rows/Cols  Hierarchy  Show Table

Table Chart

Drill:  Hierarchy  Replace  Data Report **Slicers :**

	Measures
<b>Gender</b>	<b>Ppi</b>
<input checked="" type="checkbox"/> <b>All Genders</b>	3,447
<b>Female Gender</b>	2,401
<b>Male Gender</b>	1,021
<b>Not Specified</b>	21
<b>Unspecified</b>	4

**Example 3. Gender by Primary Dystonia**

If you want Gender breakdown by Primary Dystonia, drag Primary Dystonia up to Rows. Then click the “plus” sign to the Left for each optio, **All Primary dystonias**, Female, Male, Not Specified, Unspecified.

Gender	Primary dystonia	Measures
<b>All Genders</b>	<b>All Primary dystonias</b>	3,447
	--Select--	61
	<b>Focal Dystonia</b>	2,289
	<b>Generalized Dystonia</b>	137
	<b>Hemi Dystonia</b>	14
	<b>Multi-focal Dystonia</b>	198
	<b>Not Specified</b>	306
	<b>Segmental Dystonia</b>	689
<b>Female Gender</b>	<b>All Primary dystonias</b>	2,401
	--Select--	34
	<b>Focal Dystonia</b>	1,623
	<b>Generalized Dystonia</b>	74
	<b>Hemi Dystonia</b>	11
	<b>Multi-focal Dystonia</b>	137
	<b>Not Specified</b>	179
	<b>Segmental Dystonia</b>	511
<b>Male Gender</b>	<b>All Primary dystonias</b>	1,021
	--Select--	27
	<b>Focal Dystonia</b>	666
	<b>Generalized Dystonia</b>	63
	<b>Hemi Dystonia</b>	3
	<b>Multi-focal Dystonia</b>	61
	<b>Not Specified</b>	102
	<b>Segmental Dystonia</b>	178
<b>Not Specified</b>	<b>All Primary dystonias</b>	21
<b>Unspecified</b>	<b>All Primary dystonias</b>	4

**Example 4. Race and Ethnicity**

If you want to know breakdown of race, drag **Dystonia Race** to Rows.

The screenshot shows a data visualization interface. On the left, the 'Rows' pane contains 'Dystonia race'. Below it, the 'Filter' pane lists several fields: 'Age at onset of dystonia', 'Age in years', 'Best clin diagnosis', 'Body regions affected', 'Body regions with tremor', 'Dystonia ethnicity', and 'Fahn marsden total'. On the right, the 'Table' view is active, showing a table with 'Dystonia race' in the column headers and 'Ppi' in the measures column. The table data is as follows:

Dystonia race	Measures
All Dystonia races	3,447
American Indian or Alaska Native	32
Asian	51
Black or African American	172
Native Hawaiian or other Pacific Islander	2
Not Reported	6
Other	45
Unknown	25
White	3,132

**Example 5.** If you want to know breakdown for race and ethnicity, drag **Dystonia Ethnicity** up to Rows under **Dystonia Race**

**Rows**

- Dystonia race
- Dystonia ethnicity

**Filter**

- Age at onset of dystonia
- Age in years
- Best clin diagnosis
- Body regions affected
- Body regions with tremor
- Fahn marsden total

**Table** | **Chart**

Drill:  Hierarchy  Replace  Data Report    **Slicers :**

Dystonia race		Measures
Dystonia race	Dystonia ethnicity	Ppi
- All Dystonia races	+ All Dystonia ethnicitys	3,447
American Indian or Alaska Native	+ All Dystonia ethnicitys	32
Asian	+ All Dystonia ethnicitys	51
Black or African American	+ All Dystonia ethnicitys	172
Native Hawaiian or other Pacific Islander	+ All Dystonia ethnicitys	2
Not Reported	+ All Dystonia ethnicitys	6
Other	+ All Dystonia ethnicitys	45
Unknown	+ All Dystonia ethnicitys	25
White	+ All Dystonia ethnicitys	3,132

Then click the “plus” sign to Left of **All Dystonia ethnicity** for each race. (Partial screen shot below).

The screenshot shows a data analysis tool interface. On the left, there are two panels: 'Rows' and 'Filter'. The 'Rows' panel contains two filters: 'Dystonia race' and 'Dystonia ethnicity'. The 'Filter' panel contains a list of filters including 'Age at onset of dystonia', 'Age in years', 'Best clin diagnosis', 'Body regions affected', 'Body regions with tremor', 'Fahn marsden total', 'Family history of dystonia', 'Fm eyes total', 'Fm left lower limb total', 'Fm left upper limb total', and 'Fm mouth total'. The main area displays a table with 'Table' and 'Chart' tabs. The table is titled 'Table' and has a 'Drill' section with options for 'Hierarchy' (checked), 'Replace', and 'Data Report'. Below this, there are 'Slicers' and a table with columns 'Dystonia race', 'Dystonia ethnicity', and 'Measures'. The 'Measures' column contains 'Ppi'. The table data is as follows:

Dystonia race	Dystonia ethnicity	Ppi
- All Dystonia races	- All Dystonia ethnicitys	3,447
	Ashkenazi Jewish	12
	Hispanic or Latino	109
	Not Hispanic or Latino	2,689
	Not Reported	55
	Other	267
	Unknown	294
American Indian or Alaska Native	+ All Dystonia ethnicitys	32
Asian	+ All Dystonia ethnicitys	51
Black or African American	+ All Dystonia ethnicitys	172
Native Hawaiian or other Pacific Islander	+ All Dystonia ethnicitys	2
Not Reported	+ All Dystonia ethnicitys	6
Other	+ All Dystonia ethnicitys	45
Unknown	+ All Dystonia ethnicitys	25
White	+ All Dystonia ethnicitys	3,132

Remember: Take a few minutes to practice dragging up and down different filters. Simply click and drag the **Filter(s)** you are interested in up to the section called **Rows**. When you drag a filter up or down, wait a second before unclicking the filter. You can start over at any time using the green refresh button in the upper right hand corner of the screen.