



Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

Priapism Impact Profile (PIP) Questionnaire

During the past 2 weeks:

Quality of Life

1. Worry about my overall health has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

2. My distress about my priapism has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

3. The effect of priapism on my daily activities has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

4. The negative effect of priapism on my feelings have been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate

- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

Sexual Function

5. The effect of priapism on my sexual satisfaction has been:

- 1 [] None
- 2 [] Minimal
- 3 [] Slight
- 4 [] Moderate
- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

6. The effect of priapism on my relationship with my partner has been:

- 1 [] None
- 2 [] Minimal
- 3 [] Slight
- 4 [] Moderate
- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

7. The effect of priapism on my sexual confidence has been:

- 1 [] None
- 2 [] Minimal
- 3 [] Slight
- 4 [] Moderate
- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

8. Having trouble getting an erection has been:

- 1 [] None
- 2 [] Minimal
- 3 [] Slight
- 4 [] Moderate
- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

9. Problems with my sexual desire have been:

- 1 [] None
- 2 [] Minimal
- 3 [] Slight
- 4 [] Moderate
- 5 [] Substantial
- 6 [] Extreme
- 7 [] Very Extreme

Physical Wellness

10. Physical discomfort caused by my priapism has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

11. The level of pain in my penis caused by my priapism has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

12. The abnormal shape of my penis caused by priapism has been:

- 1 None
- 2 Minimal
- 3 Slight
- 4 Moderate
- 5 Substantial
- 6 Extreme
- 7 Very Extreme

Protocol source: <https://www.phenxtoolkit.org/protocols/view/850602>