

## Autosomal Dominant Polycystic Kidney Disease – Pain & Discomfort Scale (ADPKD-PDS<sup>®</sup>)

**This questionnaire asks about different types of pain related to ADPKD:**

- **Dull kidney pain** refers to chronic uncomfortable ache or discomfort, often felt in the lower to middle back, abdomen, or sides.
- **Sharp kidney pain** refers to intense, acute pain that may be caused by a burst cyst or infection in your kidney(s).
- **Fullness/discomfort** refers to feeling full or bloated pressure, as if you had eaten a very large meal. This feeling may restrict flexibility in the stomach area, and require you to eat small portions or not eat at all.

Please mark one box per question to indicate your response over the **past 7 days**, unless otherwise noted. Please respond to every question. Please provide only one answer for each question.

<b>Dull kidney pain</b> refers to chronic uncomfortable ache or discomfort, often felt in the lower to middle back, abdomen, or sides.					
Over the past 7 days...	None	Mild	Moderate	Substantial	Extreme
1. Please rate your <i>dull kidney pain</i> <u>at its worst</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Please rate your <i>dull kidney pain</i> <u>on average</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Over the past 7 days...					
	Not at all	1 time	2 – 3 times	Almost daily	Constantly
3. How frequently did you experience <i>dull kidney pain</i> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Sharp kidney pain</b> refers to intense, acute pain that may be caused by a burst cyst or infection in your kidney(s).					
Over the past 7 days...					
	None	Mild	Moderate	Substantial	Extreme
4. Please rate your <i>sharp kidney pain</i> <u>at its worst</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Please rate your <i>sharp kidney pain</i> <u>on average</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Over the past 7 days...					
	Not at all	1 time	2 – 3 times	Almost daily	Constantly
6. How frequently did you experience <i>sharp kidney pain</i> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>Fullness/discomfort</b> refers to feeling full or bloated pressure, as if you had eaten a very large meal. This feeling may restrict flexibility in the stomach area, and require you to eat small portions or not eat at all.					
Over the past 7 days...					
	None	Mild	Moderate	Substantial	Extreme
7. Please rate your <i>fullness/discomfort</i> <u>at its worst</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Please rate your <i>fullness/discomfort</i> <u>on average</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Over the past 7 days...					
	Not at all	1 time	2 – 3 times	Almost daily	Constantly
9. How frequently did you experience <i>fullness/discomfort</i> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Autosomal Dominant Polycystic Kidney Disease – Pain & Discomfort Scale (ADPKD-PDS<sup>®</sup>)

**Dull kidney pain** refers to chronic uncomfortable ache or discomfort, often felt in the lower to middle back, abdomen, or sides.

<i>Over the past 7 days...</i>	Not at all	Slightly	Somewhat	Very Much	Completely
10. Has your <i>dull kidney pain</i> interfered with your ability to perform your <u>routine daily activities</u> such as walking, bending, light lifting or housework?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. Has your <i>dull kidney pain</i> interfered with your ability to engage in <u>leisure activities</u> such as gardening, doing hobbies, traveling, playing with kids?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input checked="" type="checkbox"/> 5
12. Has your <i>dull kidney pain</i> interfered with your <u>relationships with other people</u> such as limiting social activities, not spending time with other people?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input checked="" type="checkbox"/> 4	<input type="checkbox"/> 5
13. Has your <i>dull kidney pain</i> interfered with your <u>sleep</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input checked="" type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. Has your <i>dull kidney pain</i> interfered with your <u>enjoyment of life</u> ?	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Sharp kidney pain** refers to intense, acute pain that may be caused by a burst cyst or infection in your kidney(s).

<i>Over the past 7 days...</i>	Not at all	Slightly	Somewhat	Very Much	Completely
15. Has your <i>sharp kidney pain</i> interfered with your ability to perform your <u>routine daily activities</u> such as walking, bending, light lifting or housework?	<input checked="" type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Fullness/discomfort** refers to feeling full or bloated pressure, as if you had eaten a very large meal. This feeling may restrict flexibility in the stomach area, and require you to eat small portions or not eat at all.

<i>Over the past 7 days...</i>	Not at all	Slightly	Somewhat	Very Much	Completely
16. Has your <i>fullness/discomfort</i> interfered with your <u>ability to perform mild physical activities</u> such as walking, lifting/carrying light objects?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
17. Has your <i>fullness/discomfort</i> interfered with your <u>ability to perform moderate physical activity</u> such as brisk walking, dancing, walking up stairs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
18. Has your <i>fullness/discomfort</i> interfered with <u>bending/stretching</u> such as tying shoes, household chores, gardening?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
19. Has your <i>fullness/discomfort</i> interfered with <u>eating or your appetite</u> ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
20. Has your <i>fullness/discomfort</i> interfered with your <u>relationships with other people</u> such as limiting social activities, not spending time with other people?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5