

Attention - DO NOT enter patient data on this form if the header does not contain preprinted CRISP ID number, clinical center ID, and visit number.

Participant ID: \_\_\_\_\_ pkdid

Clinical Center: \_\_\_\_\_ pccn

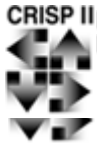
visit:

## Pain Questionnaire

Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains and toothaches). We are interested in finding out if you have pain or other symptoms related to your polycystic kidney disease. We also want to find out if the pain affects you day to day.

Please answer each question by marking the appropriate response with an "X",  
Thank you for your help.

<b>Date of visit:</b> <i>dvdate</i>			/			/			
1. Since your diagnosis of PKD, have you <b>ever</b> experienced nagging or chronic pain in the following locations?									
<i>(Choose one response for each line)</i>									
<b><u>Location</u></b>									
Back <i>backpn</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes			
Back radiating into buttocks, hips or legs <i>radipn</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes			
Abdomen <i>abdopn</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes			
2. For each location above, please indicate whether you believe the pain is related to your polycystic kidney disease. Choose "N/A" (not applicable) for locations that you marked "NO" in question #1. If you answered "NO" to all locations in #1, please go to #3.									
<b><u>Location</u></b>									
Back <i>backpkd</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes	<input type="checkbox"/>	N/A	
Back, radiating into buttocks, hips, or legs <i>radipkd</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes	<input type="checkbox"/>	N/A	
Abdomen <i>abdopkd</i>	0	<input type="checkbox"/>	No	1	<input type="checkbox"/>	Yes	<input type="checkbox"/>	N/A	



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## Pain Questionnaire

### BACK PAIN

3. Over the past 3 months, how often did you experience back pain? *bkpnfrq*

(Choose one response only)

1

Never

2

Rarely

3

Sometimes

4

Often

5

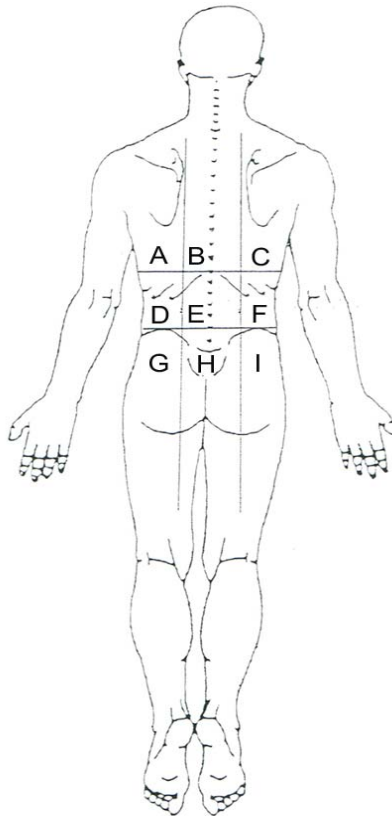
Usually

6

Always

(Go to #9)

If you answered "Never" please go to #9



4. Choose one or more letters from the diagram above that indicate where your back pain was located **over the past 3 months.**

A  
*bkloca*

B  
*bklocb*

C  
*bklocc*

D  
*bklocd*

E  
*bkloce*

F  
*bklocf*

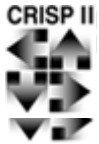
G  
*bklocg*

H  
*bkloch*

I  
*bkloci*

Unsure  
*bklocu*

If you choose only one letter in #4, please go to #6



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5. If you chose more than one letter in #4, is **one** location the **primary** or main location? *bkprim*

0  No    1  Yes     Unsure  
(Go to #6)

If "YES", indicate one letter that is the **primary** location of your pain. *bkprimloc*

A     B     C     D     E     F     G     H     I

6. Check the one number that best describes how you would rate your back pain at its worst in the past 3 months. (A rating of 10 would indicate pain so severe as to prohibit all activity: the worst pain you can imagine.) *bkpnwrst*

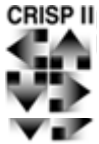
No Pain     0     1     2     3     4     5     6     7     8     9     10    Pain as bad as you can imagine

7. Check the one number that best describes how you would rate your back pain on average in the past 3 months. *bkpnavg*

No Pain     0     1     2     3     4     5     6     7     8     9     10    Pain as bad as you can imagine

8. Was your back pain associated with visible blood in the urine (that you saw yourself) **in the past 3 months**? *bkpnbl*

0  No    1  Yes



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## Pain Questionnaire

### BACK PAIN RADIATING TO YOUR BUTTOCKS, HIPS OR LEGS

9. **Over the past 3 months, how often did you experience back pain radiating to your buttocks, hips or legs?** *rdpnfrq*

*(Choose one response only)*

1

Never

2

Rarely

3

Sometimes

4

Often

5

Usually

6

Always

**(Go to #12)**

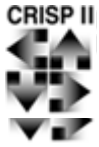
*If you answered "Never", please go to #12*

10. Check the one number that best describes how you would rate your back pain radiating into your buttocks, hips or legs at its worst in the past 3 months. *rdpnwrst*

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
No Pain	0	1	2	3	4	5	6	7	8	9	10	Pain as bad as you can imagine

11. Check the one number that best describes how you would rate your back pain radiating into your buttocks, hips or legs on average in the past 3 months. *rdpnavg*

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
No Pain	0	1	2	3	4	5	6	7	8	9	10	Pain as bad as you can imagine



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## Pain Questionnaire

### ABDOMINAL PAIN

12. Over the past 3 months, how often did you experience abdominal pain? *abpnfrq*

(Choose one response only)

1

Never

2

Rarely

3

Sometimes

4

Often

5

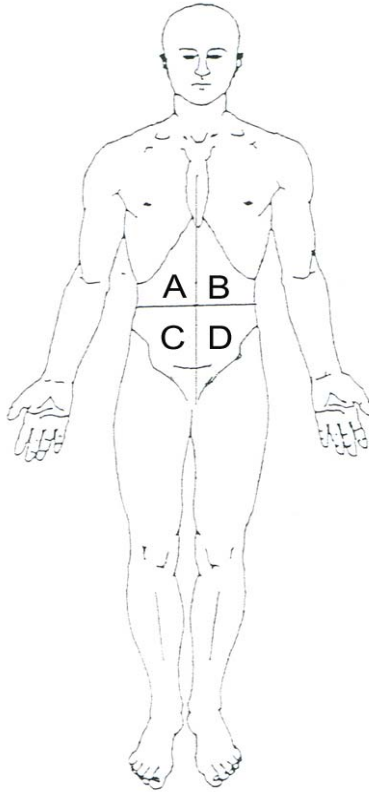
Usually

6

Always

(Go to #18)

If you answered "Never", please go to #18



13. Choose one or more letters from the diagram above to indicate the location of your abdominal pain over the past 3 months.

**A**

*abloca*

**B**

*ablocb*

**C**

*ablocC*

**D**

*ablocd*

**Unsure**

*ablocu*

If you chose one letter only in #13, please go to #15



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14. If you chose more than one letter in #13, indicate the **primary** location of your pain **over the past 3 months**. *abprmloc*

**A**       **B**       **C**       **D**       **Unsure**

15. Check the one number that best describes how you would rate your abdominal pain at its worst in the past 3 months. *abpnwrst*

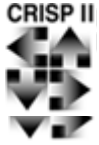
0    1    2    3    4    5    6    7    8    9    10   Pain as bad as you can imagine  
No Pain

16. Check the one number that best describes how you would rate your abdominal pain on average in the past 3 months. *abpnavg*

0    1    2    3    4    5    6    7    8    9    10   Pain as bad as you can imagine  
No Pain

17. Was your abdominal pain associated with visible blood in the urine (that you saw yourself) **in the past 3 months?** *abpnblld*

0  No      1  Yes



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## Pain Questionnaire

### ABDOMINAL FULLNESS

18. How often did abdominal fullness interfere with your ability to perform your usual physical activities **over the past 3 months?** *abffrq*

(Choose one response only)

1  Never      2  Rarely      3  Sometimes      4  Often      5  Usually      6  Always

19. How often did you eat less than your usual meal size because of abdominal fullness **in the past 3 months?** *eatles*

(Choose one response only)

1  Never      2  Rarely      3  Sometimes      4  Often      5  Usually      6  Always

20. How often was your appetite poor because of nausea **in the past 3 months?** *nausea*

(Choose one response only)

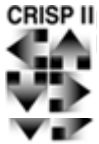
1  Never      2  Rarely      3  Sometimes      4  Often      5  Usually      6  Always

21. Has your abdomen gotten bigger since this time last year? For example, have you required an increase in clothing size? *gotbig*

0  No      1  Yes

22. If you experience abdominal fullness, do you think that is caused by your polycystic kidney disease? *abflpkd*

0  No      1  Yes       Unsure



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## Pain Questionnaire

### PAIN TREATMENT

23. What medications or treatments are you receiving for your pain?

(Choose all that apply)

- |                                  |   |   |                                     |                              |  |                            |
|----------------------------------|---|---|-------------------------------------|------------------------------|--|----------------------------|
| 1 <input type="checkbox"/>       | 2 <input type="checkbox"/>                          | 3 <input type="checkbox"/>                        | 4 <input type="checkbox"/>          | 5 <input type="checkbox"/>   | 6 <input type="checkbox"/>                             | 7 <input type="checkbox"/> |
| No<br>treatment<br><i>pnmeda</i> | Over the<br>counter<br>medications<br><i>pnmedb</i> | Prescription pain<br>medications<br><i>pnmedc</i> | Massage<br>therapy<br><i>pnmedd</i> | Acupuncture<br><i>pnmede</i> | Heat or<br>cold<br>applied<br>locally<br><i>pnmedf</i> | Surgery<br><i>pnmedg</i>   |
| <b>(Go to #26)</b>               |   |   |                                     |                              |  |                            |
| <input type="checkbox"/>         | Other   |   |                                     |                              |  |                            |
| <i>pnmedh</i>                    | Other specify: _____                                |   |                                     |                              |  | <i>pnmedhdes</i>           |

If you answered "No Treatment", please go to #26

24. Check the one number that best describes how much relief is provided by the pain medications or treatments that you use. *pnrelif*

No Relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Complete Relief
	0	1	2	3	4	5	6	7	8	9	10	

25. In general, how satisfied are you with:

(Choose one response for each line)

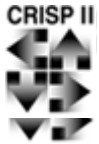
- |  | Completely<br>dissatisfied | Very<br>dissatisfied       | Somewhat<br>dissatisfied   | Somewhat<br>satisfied      | Very<br>satisfied          | Completely<br>satisfied    |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a. Your current treatment<br>of your pain? <i>curtrtpn</i>             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> |
| b. Your physical ability to<br>do what you want to?<br><i>dowhtwnt</i> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> |

26. **During the past 3 months** how much did pain (all locations) interfere with the following things:

(Choose one response for each line)

- |  | Not at all                 | A little bit               | Moderately                 | Quite a bit                | Extremely                  |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Mood <i>pnintrfr1</i>                        | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Relations with other people <i>pnintrfr2</i> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Walking ability <i>pnintrfr3</i>             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Sleep <i>pnintrfr4</i>                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |





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	Not at all	A little bit	Moderately	Quite a bit	Extremely
Work (part or full time job, homemaker, student, etc.) <i>pnintrfr5</i>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Strenuous physical activity (jogging, heavy lifting, etc.) <i>pnintrfr6</i>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Social activities or hobbies <i>pnintrfr7</i>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Enjoyment of life <i>pnintrfr8</i>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
27. Do you have any other comments about pain or its effect on your daily life that this questionnaire did not address? <i>pncmmnt</i>	<hr/> <hr/> <hr/>				

CRISP Member completing this form \_\_\_\_\_ *cdidnum*

Date Form Completed \_\_/\_\_/\_\_\_\_/\_\_\_\_ *cddate*

Data Entry Status: Please check to indicate that the above information has been entered

Primary Entered by: \_\_\_\_\_ Date: \_\_/\_\_/\_\_\_\_ *deidnum dedate*

Secondary Entered by: \_\_\_\_\_ Date \_\_/\_\_/\_\_\_\_