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.

Date of visit: *dvdate* ☐☐/☐☐/☐☐☐☐

1. Since your diagnosis of PKD, have you **ever** experienced nagging or chronic pain in the following locations?

(Choose one response for each line)

Location

Back *backpn*	0 ☐ No	1 ☐ Yes	9998 ☐ Missing
Back radiating into buttocks, hips or legs *radipn*	0 ☐ No	1 ☐ Yes	9998 ☐ Missing
Abdomen *abdopn*	0 ☐ No	1 ☐ Yes	9998 ☐ Missing

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**.*

Location

Back *backpkd*	0 ☐ No	1 ☐ Yes	☐ N/A	9998 ☐ Missing
Back, radiating into buttocks, hips, or legs *radipkd*	0 ☐ No	1 ☐ Yes	☐ N/A	9998 ☐ Missing
Abdomen *abdopkd*	0 ☐ No	1 ☐ Yes	☐ N/A	9998 ☐ Missing

Pain Questionnaire

BACK PAIN

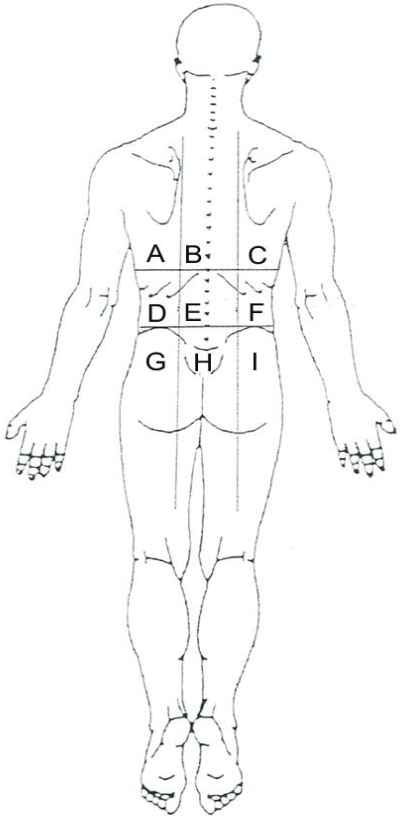
3. **Over the past 3 months,** how <u>often</u> did you experience back pain? *bkpnfrq*

(Choose one response only)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998 ☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

(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 *bklocl*	☐ Unsure *bklocu*	☐ Missing *bklocm*

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

Pain Questionnaire

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

0 ☐ No 1 ☐ Yes ☐ Unsure ☐ Missing
(Go to #6)

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

☐ A ☐ B ☐ C ☐ D ☐ E ☐ F ☐ G ☐ H ☐ I ☐ Missing

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 ☐ Missing

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 ☐ Missing

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

0 ☐ No 1 ☐ Yes 9998☐ Missing

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 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998 ☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

(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*

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

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*

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

Pain Questionnaire

ABDOMINAL PAIN

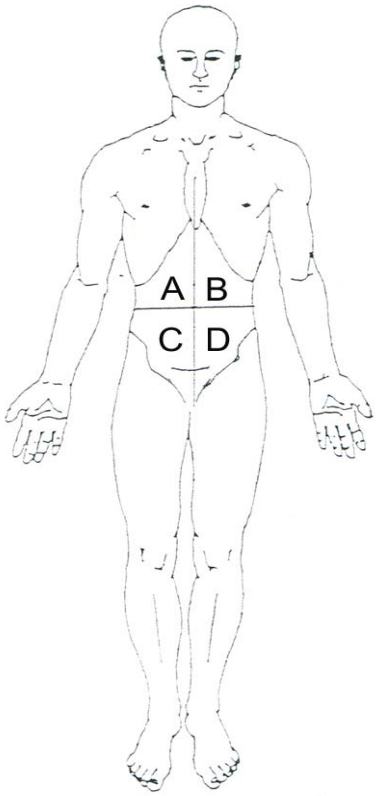
12. **Over the past 3 months,** how often did you experience abdominal pain? *abpnfrq*

(Choose one response only)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998 ☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

(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	**B**	**C**	**D**	**Unsure**	**Missing**
abloca	*ablocb*	*ablocc*	*ablocd*	*ablocu*	*ablocm*

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

Pain Questionnaire

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** ☐ **Missing**

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

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

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

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

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

0 ☐ No 1 ☐ Yes 9998 ☐ Missing

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?** *abflfrq*

(Choose one response only)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

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

(Choose one response only)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

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

(Choose one response only)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998☐
Never	Rarely	Sometimes	Often	Usually	Always	Missing

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

0 ☐ No 1 ☐ Yes 9998☐ Missing

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

0 ☐ No 1 ☐ Yes ☐ Unsure 9998☐ Missing

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Pain Questionnaire

PAIN TREATMENT

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

(*Choose all that apply)*

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
No treatment *pnmeda* ***(Go to #26)***	Over the counter medications *pnmedb*	Prescription pain medications *pnmedc*	Massage therapy *pnmedd*	Acupuncture *pnmede*	Heat or cold applied locally *pnmedf*	Surgery *pnmedg*

☐ Other *pnmedh* Other specify:_____ *pnmedhdes*

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 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Complete Relief ☐ Missing

25. In general, how satisfied are you with:

(Choose one response for each line)

		Completely dissatisfied	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied	Completely satisfied	Missing
a.	Your current treatment of your pain? *curtrtpn*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998☐
b.	Your physical ability to do what you want to? *dowhtwnt*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	9998☐

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	Missing
Mood *pnintrfr1*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
Relations with other people *pnintrfr2*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
Walking ability *pnintrfr3*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
Sleep *pnintrfr4*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐

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		Not at all	A little bit	Moderately	Quite a bit	Extremely	Missing
	Work (part or full time job, homemaker, student, etc.) *pnintrfr5*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
	Strenuous physical activity (jogging, heavy lifting, etc.) *pnintrfr6*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
	Social activities or hobbies *pnintrfr7*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
	Enjoyment of life *pnintrfr8*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9998☐
27.	Do you have any other comments about pain or its effect on your daily life that this questionnaire did not address? *pncmmnt* _____ _____ _____						

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: __ __/__ __/__ __ __ __ *dedate*
deidnum

Secondary Entered by: _____ Date __ __/__ __/__ __ __ __