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

Participant ID: ___________ *haltid* **Clinical Center:** ________ *clinic* **Date of Visit:** ___/___/______
month *dvm* day *dvd* year *dvy*

visit:

___**Form was not completed** *misfrm*

HALT – PKD PAIN QUESTIONNAIRE

Form # 39

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.

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

Location			
Back *backpkd*	0 ☐ No	1 ☐ Yes	2 ☐ N/A
Back, radiating into buttocks, hips, or legs *radipkd*	0 ☐ No	1 ☐ Yes	2 ☐ N/A
Abdomen *abdopkd*	0 ☐ No	1 ☐ Yes	2 ☐ N/A

BACK PAIN

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

(Choose one response only)

0 ☐	1☐	2 ☐	3 ☐	4 ☐	5 ☐
Never ***(Go to #9)***	Rarely	Sometimes	Often	Usually	Always

If you answered "Never", please skip to #9.

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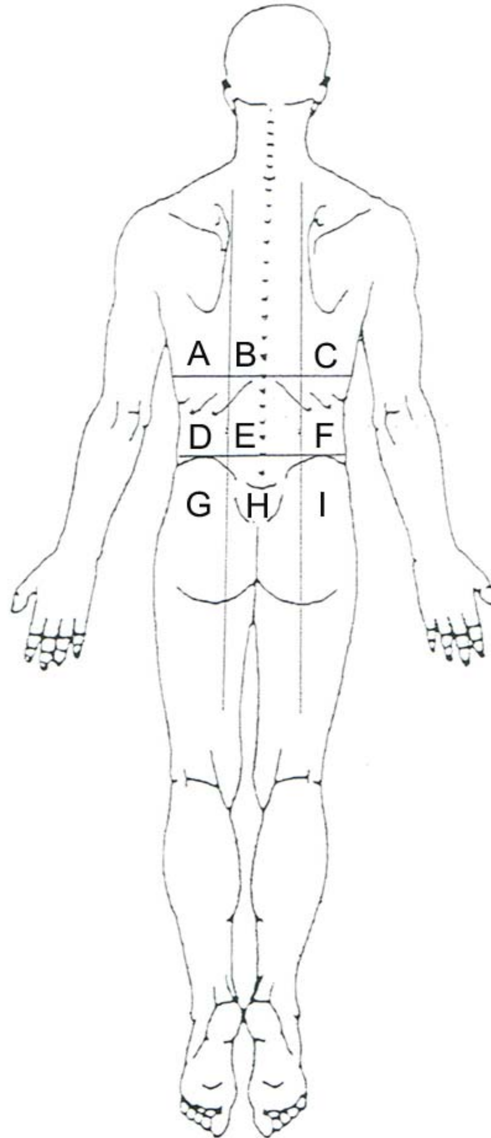
Participant ID: ___________ *haltid* **Clinical Center:** ________ *clinic* **Date of Visit:** ___/___/______
month *dvm* day *dvd* year *dvy*

visit: ___**Form was not completed** *misfrm*

HALT – PKD PAIN QUESTIONNAIRE

Form # 39



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

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
A	B	C	D	E	F	G	H	I	Unsure
bkloca	*bklocb*	*bklocc*	*bklocd*	*bkloce*	*bklocf*	*bklocg*	*bkloch*	*bkloci*	*bklocu*

*If you chose only one letter in **#4, please skip to #6.***

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

1 ☐ Yes 2 ☐ No ***(Go to #6)*** 3 ☐ Unsure ***(Go to #6)***

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

0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐
A	B	C	D	E	F	G	H	I

HALT – PKD PAIN QUESTIONNAIRE **Form # 39**

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?** *bkpnbld*

1 ☐ Yes 0 ☐ No

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)

0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Never ***(Go to #12)***	Rarely	Sometimes	Often	Usually	Always

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

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

ABDOMINAL PAIN

12. **Over the past 3 months,** how often did you experience abdominal pain? *abpnfrq*
(Choose one response only)

0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Never ***(Go to #18)***	Rarely	Sometimes	Often	Usually	Always

If you answered "Never", **please skip to # 18.**

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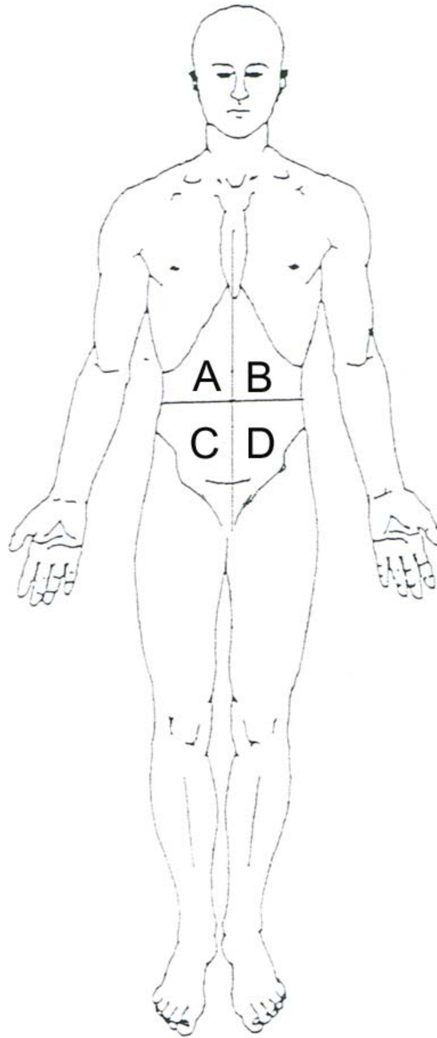
month *dvm* day *dvd* year *dvy*

visit: ___**Form was not completed** *misfrm*

HALT – PKD PAIN QUESTIONNAIRE

Form # 39



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 skip to #15.**

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

0 ☐ **A**	1 ☐ **B**	2 ☐ **C**	3 ☐ **D**	4 ☐ **Unsure**

15. Check the <u>one</u> number that best describes how you would rate your abdominal pain <u>at its worst</u> **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

HALT – PKD PAIN QUESTIONNAIRE **Form # 39**

16. Check the <u>one</u> number that best describes how you would rate your abdominal pain <u>on average</u> **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

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

1 ☐ Yes 0 ☐ No

<u>ABDOMINAL FULLNESS</u>

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)

0 ☐ Never 1 ☐ Rarely 2 ☐ Sometimes 3 ☐ Often 4 ☐ Usually 5 ☐ Always

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)

0 ☐ Never 1 ☐ Rarely 2 ☐ Sometimes 3 ☐ Often 4☐ Usually 5 ☐ Always

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

(Choose one response only)

0 ☐ Never 1 ☐ Rarely 2 ☐ Sometimes 3 ☐ Often 4 ☐ Usually 5 ☐ Always

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

1 ☐ Yes 0 ☐ No

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

1 ☐ Yes 2 ☐ No 3 ☐ Unsure

<u>PAIN TREATMENT</u>

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

(*Choose all that apply)*

☐ 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***

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month *dvm* day *dvd* year *dvy*

visit: ___**Form was not completed** *misfrm*

HALT – PKD PAIN QUESTIONNAIRE — Form # 39

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	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	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 dissatisfied	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied	Completely satisfied
a. Your current treatment of your pain? *curtrtpn*	0 ☐	1☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Your physical ability to do what you want to? *dowhtwnt*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

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 *pnintrfr1*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Relations with other people *pnintrfr2*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Walking ability *pnintrfr3*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Sleep *pnintrfr4*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Work (part or full time job, homemaker, student, etc.) *pnintrfr5*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Strenuous physical activity (jogging, heavy lifting, etc.) *pnintrfr6*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Social activities or hobbies *pnintrfr7*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Enjoyment of life *pnintrfr8*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

27. Do you have any other comments about pain or its effect on your daily life that this questionnaire did not address? *pncmmnt*

____

____

____

****

Reviewed by Designated Personnel (signature required): ___________________ **Date:** _____/_____/_____
cmidnum Month *cdm* Day *cdd* Year *cdy*

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

Primary Entered by: __________________________________ *deidnum* Date: __ __/__ __/__ __ __ __ *dem /ded / dey*