

Patient ID

Date:

For each statement, please circle the response that comes closest to how you feel. If any of the statements do not apply to you please circle 'does not apply'.

**Can you say how often the following statements about digestion and diet applied to you IN THE LAST FOUR WEEKS?**

1	I was able to eat what I liked <b>Symptoms</b>	Never 5	Rarely 4	Sometimes 3	Most of the time 2	Always 1	
2	I ate or drank only a small amount, and still felt bloated <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	
3	I felt unwell when I drank alcohol <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	Did not apply /never drink alcohol 0

**And IN THE LAST FOUR WEEKS, how often did you experience any of the following?**

4	I had discomfort in my right side <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	
5	I had dry eyes <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	
6	My mouth was very dry <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	
7	I had aches in the long bones of my arms and legs <b>Symptoms</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	

**Some people with PBC experience itching. How often did you experience itching IN THE LAST FOUR WEEKS? If you did not itch, please circle 'does not apply'**

8	Itching disturbed my sleep <b>Itch</b>	Never 1	Rarely 2	Sometimes 3	Most of the time 4	Always 5	Did not apply/ no itch 0
---	---	------------	-------------	----------------	-----------------------	-------------	-----------------------------

9	I scratched so much I made my skin raw <b>Itch</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>	Did not apply/no itch <b>0</b>
10	I felt embarrassed because of the itching <b>Itch</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>	Did not apply/no itch <b>0</b>

***Fatigue can also be a problem for many people with PBC. How often did the following statements apply to you IN THE LAST FOUR WEEKS?***

11	I had to force myself to get out of bed <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
12	I had to have a sleep during the day <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
13	Fatigue interfered with my daily routine <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
14	I felt worn out <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
15	I felt so tired, I had to force myself to do the things I needed to do <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
16	I felt so tired, I had to go to bed early <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
17	Fatigue just suddenly hit me <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
18	PBC drained every ounce of energy out of me <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>

***The next section is about the effort and planning that can be involved in living with PBC. Thinking about THE LAST FOUR WEEKS, how often did the following statements apply to you?***

19	Some days it took me a long time to do anything <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
20	If I was busy one day I needed at least another day to recover <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>

21	I had to pace myself for day-to-day things <b>Fatigue</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
----	--	-------------------	--------------------	-----------------------	------------------------------	--------------------

*The following statements are about the effects that PBC may have on things like memory and concentration. Thinking about THE LAST FOUR WEEKS, how often did the following statements apply to you?*

22	Because of PBC I had to make a lot of effort to remember things <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
23	Because of PBC I had difficulty remembering things from one day to the next <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
24	My concentration span was short because of PBC <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
25	Because of PBC, I had difficulty keeping up with conversations <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
26	Because of PBC, I found it difficult to concentrate on anything <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>
27	Because of PBC, I found it difficult to remember what I wanted to do <b>Cognitive</b>	Never <b>1</b>	Rarely <b>2</b>	Sometimes <b>3</b>	Most of the time <b>4</b>	Always <b>5</b>

*Now some more general statements about how PBC may be affecting you as a person. How much do the following statements apply to you?*

28	Because of PBC, I get more stressed about things than I used to <b>Emotional</b>	Not at all <b>1</b>	A little <b>2</b>	Somewhat <b>3</b>	Quite a bit <b>4</b>	Very much <b>5</b>	
29	My sex life has been affected because of PBC <b>Social</b>	Not at all <b>1</b>	A little <b>2</b>	Somewhat <b>3</b>	Quite a bit <b>4</b>	Very much <b>5</b>	Does not apply <b>0</b>
30	Having PBC gets me down <b>Emotional</b>	Not at all <b>1</b>	A little <b>2</b>	Somewhat <b>3</b>	Quite a bit <b>4</b>	Very much <b>5</b>	
31	I feel I neglect my family because of having PBC <b>Social</b>	Not at all <b>1</b>	A little <b>2</b>	Somewhat <b>3</b>	Quite a bit <b>4</b>	Very much <b>5</b>	Does not apply <b>0</b>

32	I feel guilty that I can't do what I used to do because of having PBC <b>Social</b>	Not at all 1	A little 2	Somewhat 3	Quite a bit 4	Very much 5
33	I worry about how my PBC will be in the future <b>Emotional</b>	Not at all 1	A little 2	Somewhat 3	Quite a bit 4	Very much 5

***These statements relate to the possible effects of PBC on your social life. Thinking of your own situation, how much do you agree or disagree with them?***

34	I sometimes feel frustrated that I can't go out and enjoy myself <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
35	I tend to keep the fact that I have PBC to myself <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
36	I can't plan holidays because of having PBC <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
37	My social life has almost stopped <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1

***The next section is about the impact that PBC may be having on your life overall. How much do you agree or disagree with the following statements?***

38	Everything in my life is affected by PBC <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
39	PBC has reduced the quality of my life <b>Social</b>	Strongly agree 5	Agree 4	Neither agree nor disagree 3	Disagree 2	Strongly disagree 1
40	I can still lead a normal life, despite having PBC <b>Social</b>	Strongly agree 1	Agree 2	Neither agree nor disagree 3	Disagree 4	Strongly disagree 5