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’.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was able to eat what I liked</td>
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<tr>
<td>2. I ate or drank only a small amount, and still felt bloated</td>
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<tr>
<td>3. I felt unwell when I drank alcohol</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. I had discomfort in my right side</td>
<td></td>
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<td></td>
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<tr>
<td>5. I had dry eyes</td>
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<td>6. My mouth was very dry</td>
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<tr>
<td>7. I had aches in the long bones of my arms and legs</td>
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</tbody>
</table>

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’

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Itching disturbed my sleep</td>
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<tr>
<td>9. I scratched so much I made my skin raw</td>
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<tr>
<td>10. I felt embarrassed because of the itching</td>
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</tbody>
</table>
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
   Never  Rarely  Sometimes  Most of the time  Always

12 I had to have a sleep during the day
   Never  Rarely  Sometimes  Most of the time  Always

13 Fatigue interfered with my daily routine
   Never  Rarely  Sometimes  Most of the time  Always

14 I felt worn out
   Never  Rarely  Sometimes  Most of the time  Always

15 I felt so tired, I had to force myself to do the things I needed to do
   Never  Rarely  Sometimes  Most of the time  Always

16 I felt so tired, I had to go to bed early
   Never  Rarely  Sometimes  Most of the time  Always

17 Fatigue just suddenly hit me
   Never  Rarely  Sometimes  Most of the time  Always

18 PBC drained every ounce of energy out of me
   Never  Rarely  Sometimes  Most of the time  Always

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
   Never  Rarely  Sometimes  Most of the time  Always

20 If I was busy one day I needed at least another day to recover
   Never  Rarely  Sometimes  Most of the time  Always

21 I had to pace myself for day-to-day things
   Never  Rarely  Sometimes  Most of the time  Always

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
   Never  Rarely  Sometimes  Most of the time  Always

23 Because of PBC I had difficulty remembering things from one day to the next
   Never  Rarely  Sometimes  Most of the time  Always

24 My concentration span was short because of PBC
   Never  Rarely  Sometimes  Most of the time  Always
Because of PBC, I had difficulty keeping up with conversations
Never  Rarely  Sometimes  Most of the time  Always

Because of PBC, I found it difficult to concentrate on anything
Never  Rarely  Sometimes  Most of the time  Always

Because of PBC, I found it difficult to remember what I wanted to do
Never  Rarely  Sometimes  Most of the time  Always

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
Not at all  A little  Somewhat  Quite a bit  Very much

29 My sex life has been affected because of PBC
Not at all  A little  Somewhat  Quite a bit  Very much  Does not apply

30 Having PBC gets me down
Not at all  A little  Somewhat  Quite a bit  Very much

31 I feel I neglect my family because of having PBC
Not at all  A little  Somewhat  Quite a bit  Very much  Does not apply

32 I feel guilty that I can’t do what I used to do because of having PBC
Not at all  A little  Somewhat  Quite a bit  Very much

33 I worry about how my PBC will be in the future
Not at all  A little  Somewhat  Quite a bit  Very much

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
Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

35 I tend to keep the fact that I have PBC to myself
Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

36 I can’t plan holidays because of having PBC
Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

37 My social life has almost stopped
Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree
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

39 PBC has reduced the quality of my life

40 I can still lead a normal life, despite having PBC

The next few questions are about your general health and well being:

A In general, would you say your health is:

B And how would you have rated it before you had PBC?

C COMPARED TO ONE YEAR AGO, how would you rate your health in general now?

THANK YOU FOR TAKING THE TIME TO COMPLETE