

PBC KNOWING YOUR NUMBERS

A critical part of “owning the problem and owning the solution” in PBC is for you to know and understand your test values so that you can ask your doctor or nurse what their future management plans are. This way you can make sure you get the best possible care. Use this simple table to help you collate your results. I suggest you copy it and take a version every time you go to the clinic.

Test	Target Value in 2023	Likely Future Target Value	YOUR Values Date	YOUR Values Date	YOUR Values Date	YOUR Values Date
<i>Blood Tests</i>						
<i>Alkaline Phosphatase</i>	Under 217	Under 130				
<i>Bilirubin</i>	Under 20	Under 12				
<i>Alanine Transaminase</i>	NA	Under 40				
<i>Fibroscan</i>	Under 15.1	Under 7.7				
<i>Symptoms</i>						
<i>Itch (Scale 0-10)</i>	Under 4	Under 4				
<i>Fatigue (Scale 0-10)</i>	Under 4	Under 4				

Explanation: For the ***Blood tests*** the “target values in 2023” are the values that clinics should be working towards based on current treatment guidelines. The alkaline phosphatase and bilirubin thresholds are the POISE criteria which were used in the key trial which led to the licensing of obeticholic acid. Alanine transaminase currently doesn’t form part of these criteria. It is likely that, over the next few years, the treatment target will move to normalization of alkaline phosphatase, alanine transaminase and bilirubin. This change will occur because it is increasingly clear that anything other than normal blood test values (the thresholds given for future use in the table) is associated with some ongoing disease activity. We can and must be more ambitious about our goals for treatment in PBC. Note that the values given are for the Newcastle laboratory. There may be small differences between different labs so check with your clinician as to your local values.

Fibroscan should now be a routine part of follow-up for everyone with PBC. The suggested 2023 threshold is the value for increased risk. A value above this suggests a high risk of presence already of, or progression in the future to, cirrhosis. In the future we should aim for the lower threshold of 7.7. Below this value PBC is very low risk indeed. That is what we should all be aiming for.

For ***Symptoms*** it is difficult to give accurate cut-offs because symptoms are all about individual impact. For both the symptom types the scales are 0-10 (“where zero is no symptom and 10 is the worst severity you can imagine”). Conventional wisdom is that a value below 4 is associated with low (or at least tolerable) symptom impact.