Primary Biliary Cholangitis (PBC)

Patient Clinic Visit Questionnaire

Patient Name: _____ DoB: _____

Consultant / Clinic: _____ Date: _____

This checklist helps patients raise key symptoms, concerns, and priorities in advance, so they can be addressed more effectively during the consultation.

Do you have any of these core PBC symptoms?

Itching (Pruritus)	**Fatigue**	**Pain / Physical Discomfort**
☐ Worse at night ☐ Disturbs sleep ☐ Causes skin damage / bleeding ☐ Not controlled with current treatment 0 1 2 3 4 5 6 7 8 9 10 None - Worst	☐ Limits daily activities ☐ Affects work / study ☐ Brain fog / poor concentration ☐ Need frequent rest ☐ Safety concerns (e.g. driving) 0 1 2 3 4 5 6 7 8 9 10 None - Worst	☐ Upper right abdominal discomfort ☐ Muscle pain ☐ Joint pain ☐ Generalised aches 0 1 2 3 4 5 6 7 8 9 10 None - Worst

Any Dryness Symptoms?

Eyes	**Mouth**	**Other dryness**
☐ Gritty sensation ☐ Redness ☐ Blurred vision ☐ Require daily eye drops	☐ Dry mouth ☐ Difficulty swallowing dry food ☐ Dental problems	

Any other symptoms or medical conditions?

Digestive & gastrointestinal symptoms	**Mental health & emotional wellbeing**	**Cognitive & sleep issues**
☐ Nausea ☐ Poor appetite ☐ Bloating ☐ Diarrhoea ☐ Pale stools ☐ Dark urine	☐ Low mood / depression ☐ Anxiety or constant worry ☐ Irritability ☐ Loss of motivation or enjoyment ☐ Feeling overwhelmed by illness ☐ Feel my symptoms are not always fully acknowledged ☐ I am receiving mental health support ☐ I would like support or advice	☐ Memory problems ☐ Difficulty concentrating ☐ Poor sleep quality ☐ Reversal of sleep pattern (awake at night, sleepy by day)

Bone & musculoskeletal Health	**Quality of life impact** *(Tick all that apply)*	**Other autoimmune conditions** *(Tick all that apply)*
☐ Bone pain ☐ Back pain ☐ Loss of height ☐ History of fractures ☐ Falls in past year DEXA scan previously performed ☐ Yes ☐ No ☐ Unsure When: ☐ I have never been advised about bone health in PBC	☐ Difficulty working or studying ☐ Reduced hours or stopped working ☐ Difficulty with daily tasks ☐ Social withdrawal ☐ Impact on relationships ☐ Reduced independence ☐ Financial stress related to illness **Overall quality of life since last visit:** ☐ Improved ☐ Stable ☐ Worse	☐ Sjögren's syndrome ☐ Autoimmune thyroid disease ☐ Rheumatoid arthritis ☐ Coeliac disease ☐ Psoriasis / psoriatic arthritis ☐ Inflammatory bowel disease ☐ Autoimmune hepatitis overlap ☐ Other autoimmune condition(s):

Other medical conditions	**Symptoms that may need urgent attention**	
☐ Osteopenia / Osteoporosis ☐ Anaemia / Iron deficiency ☐ Vitamin D deficiency ☐ Diabetes ☐ Heart disease ☐ Kidney disease ☐ Asthma / COPD ☐ Fibromyalgia ☐ Other condition(s):	☐ New or worsening jaundice ☐ Abdominal swelling ☐ Leg / ankle swelling ☐ Easy bruising or bleeding ☐ Confusion or mental changes ☐ Black stools or vomiting blood ☐ None of the above	

What medications are you currently taking?

PBC-specific medications:	Symptom treatments	Supplements
☐ Ursodeoxycholic acid (UDCA) Dose: ☐ Please check that my dose is right for my weight **Other medications:**	☐ Itch treatment: ☐ Fatigue-related treatment: ☐ Eye / sicca treatment: ☐ Bone medication:	☐ Vitamin D ☐ Calcium ☐ Iron ☐ B12 / Folate ☐ Other:

Medication side effects or difficulties	Other Liver Assessments
☐ Nausea ☐ Diarrhoea ☐ Mood changes ☐ Sleep disturbance ☐ Poor tolerance ☐ Difficulty taking medication as prescribed ☐ Other: **Concerns about medication?** ☐ I have concerns about my medications. ☐ I feel one or more of my current medication aren't working ☐ Other	Ultrasound scan previously performed? ☐ Yes ☐ No ☐ Unsure When: Result: FibroScan® scan previously performed? ☐ Yes ☐ No ☐ Unsure When: Result: ELF (Enhanced Liver Fibrosis) test previously performed? ☐ Yes ☐ No ☐ Unsure When: Result:

Please select one or more Care, Communication or Information needs you have?	
☐ Allow more time to hear my main concerns ☐ Make sure my symptoms are fully considered ☐ Allow time to discuss new or worsening symptoms ☐ Can we review whether I need calcium or fat-soluble vitamins (A, D, E, K)? ☐ Help me decide which symptoms need attention now ☐ Explain my test results in clear language ☐ Explain my current care plan clearly	☐ Discuss a dietary plan with me ☐ Explain what treatment options are available ☐ Tell me which symptoms I should report between visits ☐ Tell me who to contact between visits if problems arise ☐ Point me to reliable sources of information ☐ Other

What else would you like to discuss at today's appointment?

My Priority Statement

The symptom or issue affecting my quality of life the most right now is: