

HEPATOLOGY

Development of a Question Prompt List for People Living With Primary Biliary Cholangitis: A Delphi Study



Ellen Werner,¹ Maria C. B. van Hooff,¹ Gemma H. X. Weijsters,¹ Nadir Abbas,^{2,3,4} Alessio Gerussi,^{5,6} José A. Willemse,⁷ Robert Mitchell-Thain,⁸ Angela Leburgue,⁹ Gideon M. Hirschfield,¹⁰ Christophe Corpechot,¹¹ Christoph Schramm,¹² Cynthia Levy,¹³ Frederik Nevens,¹⁴ Jef Verbeek,¹⁴ Andrew L. Mason,¹⁵ George Dalekos,¹⁶ Nora Cazzagon,¹⁷ George F. Mells,¹⁸ Kris. V. Kowdley,¹⁹ Marco Carbone,⁵ David E. Jones,²⁰ Bettina E. Hansen,¹ Palak J. Trivedi,^{2,3,4,21} and Adriaan J. van der Meer,¹ on behalf of the Global PBC Study Group/ERN RARE-LIVER/Question Prompt List

¹Department of Gastroenterology and Hepatology, Erasmus Medical Center, Rotterdam, the Netherlands; ²National Institute for Health and Care Research Birmingham Biomedical Research Centre, Centre for Liver and Gastrointestinal Research, University of Birmingham, Birmingham, United Kingdom; ³Liver Unit, University Hospitals Birmingham, Birmingham, United Kingdom; ⁴Institute of Immunity, Immunology and Immunotherapy, College of Medical and Dental Sciences, University of Birmingham, Birmingham, United Kingdom; ⁵Division of Gastroenterology, Center for Autoimmune Liver Diseases, IRCCS Fondazione San Gerardo dei Tintori – Monza, Monza, Italy; ⁶Department of Medicine and Surgery, University of Milano-Bicocca, Monza, Italy; ⁷Dutch Liver Patient Association, Hoogland, the Netherlands; ⁸PBC Foundation, Edinburgh, United Kingdom; ⁹Association pour la Lutte contre les maladies inflammatoires du foie et des voies Biliaires, Versailles, France; ¹⁰Toronto Centre for Liver Disease, Division of Gastroenterology and Hepatology, University of Toronto, Toronto, Ontario, Canada; ¹¹Reference Center for Inflammatory Biliary Diseases and Autoimmune Hepatitis, INSERM UMR_S938, Saint-Antoine Research Center, Saint-Antoine Hospital, Assistance Publique–Hôpitaux de Paris, Sorbonne University, Paris, France; ¹²1st Department of Medicine and Martin Zeitz Center for Rare Diseases, University Medical Center Hamburg–Eppendorf, Hamburg, Germany; ¹³Division of Digestive Health and Liver Diseases, University of Miami School of Medicine, Miami, Florida; ¹⁴Department of Gastroenterology and Hepatology, University Hospitals KU Leuven, Leuven, Belgium; ¹⁵Division of Gastroenterology and Hepatology, University of Alberta, Edmonton, Alberta, Canada; ¹⁶Department of Medicine and Research Laboratory of Internal Medicine, National Expertise Center of Greece in Autoimmune Liver Diseases, General University Hospital of Larissa, Larissa, Greece; ¹⁷Department of Surgery, Oncology and Gastroenterology, University of Padua, Padua, Italy; ¹⁸Academic Department of Medical Genetics, University of Cambridge, Cambridge, United Kingdom; ¹⁹Liver Institute Northwest, Seattle, Washington; ²⁰Translational and Clinical Research Institute, Newcastle University, Newcastle Upon Tyne, United Kingdom; and ²¹Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham, United Kingdom

Development Of A Question Prompt List For People Living With Primary Biliary Cholangitis

Aim To create a **question prompt list (QPL)** for individuals with primary biliary cholangitis (PBC) including key questions (directed) to their treating physician which are most likely to improve their outcome.

Study design



Delphi Study

Digital Survey and in-person meetings



Participants

Health care providers and patient representatives with special interest in PBC



Target group

People with PBC and their treating physician

Questions on



Diagnosis



Monitoring



Symptoms



Liver-related co-morbidity



1st-line
2nd-line



Extra-Hepatic Manifestations



Disease severity



Other

Results



108 respondents

- From 23 countries
- 56.5% with >10 years of experience in PBC



11 of 43 questions were rated important by >70%



Two in-person discussion meetings resulted in a final QPL of 8 questions



Clinical Gastroenterology and Hepatology

Abbreviations used in this paper: BCQ, best candidate question; HRQoL, health-related quality of life; OCA, obeticholic acid; PBC, primary biliary cholangitis; QPL, question prompt list; UDCA, ursodeoxycholic acid; VCTE, vibration-controlled transient elastography.

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- BACKGROUND & AIMS:** Clinical practice guidelines support caregivers to manage liver diseases. However, people with lifelong conditions often lack guidance to understand what aspects of care are most important and how their disease should be managed. This study aimed to create a question prompt list (QPL) for individuals with primary biliary cholangitis (PBC) including key questions (directed) to their treating physician that are most likely to improve their outcome.
- METHODS:** International PBC professionals including patient representatives rated and ranked questions related to 9 aspects of PBC care. Questions rated by >70% as moderately/very important were considered best candidate questions (BCQs) for the QPL. Results of the survey were discussed during 2 in-person meetings, upon which the questions and/or QPL were amended.
- RESULTS:** Based on 108 respondents, 11 of 43 questions were considered BCQs. After 2 in-person meetings (64 attendees), the final QPL contained 8 questions and was unanimously approved by 19 members of the study team during the consensus meeting. The included questions referred to the risk of disease progression, presence of cirrhosis, need of second-line therapy, need of repeated liver stiffness measurements, bone health, and availability of patient information and support. Two BCQs addressing options to manage pruritus and fatigue were combined on the QPL. In addition, one question regarding first-line therapy was included despite being rated as moderately/very important by 68.5%.
- CONCLUSIONS:** The PBC patient question prompt list serves as a user-facing document, to enhance the patient experience, and drive value-based healthcare in routine clinical practice.

Keywords: Quality of Care; Patient Participation; Symptoms; Ursodeoxycholic Acid; Second-Line Therapy.

Primary biliary cholangitis (PBC) is a chronic immune-mediated cholestatic disease with a variable clinical course, which, if left untreated, leads to cirrhosis and need for liver transplant.^{1–3} Additionally, individuals may experience several debilitating symptoms, with fatigue, cognitive impairment and pruritus having particular impact on health-related quality of life (HRQoL).³ People with PBC should be well managed to optimize both their long-term outcome and current HRQoL. This requires a continuous and holistic approach to care delivery, particularly as treatment paradigms evolve and the goals of treatment change.^{4–6} Optimal care may therefore be challenging, especially considering PBC is a rare disease and the majority of individuals with PBC are managed outside of expert centers. Despite efforts to inform and educate physicians on disease management, there are substantial gaps in the quality of PBC care as evidenced in recent population-based audits.^{7,8}

In this regard, several physician-directed approaches have been developed including the PBC integrated care pathway (a practical guide for clinicians) and the PBC review tool (which allows physicians to check adherence to available guidelines for the individual patient).^{7,9} Additionally, healthcare quality may be improved by empowering patients to take ownership over their condition and address individual clinical need. The need to improve knowledge on PBC management was recently highlighted by the finding that people with PBC frequently underestimate or overestimate their prognosis and/or need for add-on therapy.^{10,11} Many organizations developed information leaflets

on PBC to help individuals better understand their liver disease. Some of these leaflets also provide a long list of potential questions which people with PBC could ask their physician during consultation.¹² This is relevant as an adequate question may trigger a physician to (re)consider and discuss the optimal care for the individual patient. However, people with PBC are not currently guided with respect to the prioritization of these questions, which is relevant given the limited time offered in routine outpatient appointments.

This study aimed to develop a question prompt list (QPL) for people with PBC, containing key questions that are felt most likely to elicit optimization of PBC care.

Materials and Methods

We drafted a survey that included 43 questions related to various aspects of PBC care, which individuals could ask their physician ([Figure 1](#); [Supplementary Table 1](#)).

Healthcare professionals with a special interest in managing PBC, and representatives from multiple PBC patient associations were asked to indicate how important each question was on a 7-point Likert scale ([Supplementary Table 2](#)). When deciding on the importance of each question, participants were asked to consider (1) the probability that the specific aspect of care is not optimally managed and (2) their confidence that optimizing the specific aspect of care will benefit patient outcomes. In addition, participants had to rank their top 3 questions within various aspects of care, in order of importance.

Questions in the survey that were rated by >70% of respondents to be moderately important or very important were considered best candidate questions (BCQs) for the QPL.¹³⁻¹⁵ Results of the survey were discussed during 2 in-person meetings.

Thereafter, the results of the survey and any suggestions based on the in-person meetings were evaluated by the core study team in a consensus meeting (the number of questions on the final QPL was not predefined). During the latter, it had to be decided whether consensus was reached with respect to the final list of questions on the QPL, or whether an additional survey round would be required.

Statistical Analyses

Descriptive analyses were performed using IBM SPSS Statistics version 28.0. Frequencies are presented as both number and percentages. To assess the degree of variation among the responses to the questions in the survey, z scores were calculated based on interquartile ranges and standard deviations of questions within the same aspect of care. More details are provided in the [Supplementary Materials](#).

Results

Survey Respondents

In total, 108 respondents from 23 countries spread across 4 continents completed the survey. Of these respondents, 61 (56.5%) were men and 52 (48.1%) were between 35 and 50 years of age. Patient representatives formed 5.6% of the respondents, 61 (56.5%) respondents had more than 10 years of experience in the field of PBC, and 71 (65.7%) were working in a tertiary hospital or transplant center. Further details of respondent characteristics are shown in [Table 1](#).

General Survey Results

Overall, 11 questions were rated as moderately/very important by >70% of the respondents (range, 70.4%–86.1%) ([Figure 1](#)). These BCQs could be assigned to 6 out of the 9 predefined aspects of care. Similar results were seen in a sensitivity analysis based solely on physicians and/or researchers (data not shown). All had z scores <1, indicating moderate variation ([Supplementary Table 3](#)). Additional suggested questions are listed in [Supplementary Table 4](#).

Symptoms

The question “What are the options to treat my pruritus?” was mostly rated as moderately/very important by the respondents of the survey (n = 93 [86.1%]), and was commonly ranked as the most important question regarding

What You Need to Know

Background

Medical care for the population with primary biliary cholangitis (PBC) can be improved. While continuing physician-directed educational efforts, empowering people with PBC to be involved in their clinical care may benefit their outcomes.

Findings

Based on the opinion of over 100 PBC experts, 8 patient questions were selected that have the highest likelihood to positively impact the quality of PBC care.

Implications for patient care

The developed question prompt list can be used by individuals with PBC when preparing for consultation with their physician. The questions may trigger the evaluation of optimal patient management on key aspects of medical PBC care.

symptoms (by 47 [43.5%] respondents). In addition, 81 (75.0%) respondents considered “What can I do myself to reduce my fatigue?” a moderately/very important question. This BCQ was ranked as most important question by 1 (0.9%) respondent, while “What are the options to treat my fatigue?” was ranked as most important by 14 (13.0%) respondents but failed, however, to reach the predefined importance rating ([Figure 1](#)). During the in-person meetings, the discrepancy between rating and ranking was suggested to be related to similarity among the questions. Through the survey it was suggested to change the word *treat* into *manage*, which was supported by attendees of the in-person meetings to cover both medical treatment and non-medical interventions. Additionally, the word *pruritus* was changed into *itch*. Even though it was acknowledged that pruritus and fatigue are 2 distinct symptoms, the majority of attendees were in favor of combining these two symptoms of PBC in one question to keep the final QPL as concise as possible: “What are the options to manage my itching and/or fatigue?”

Second-Line treatment

While both the question focusing on the reason to start second-line treatment and the question regarding the pros and cons of different second-line treatment options reached the predefined level of importance ([Figure 1](#)), the attendees of the in-person meeting considered that these questions had limited added value next to the best ranked BCQ. The question “Do I need additional therapy beyond UDCA?” was most frequently rated as moderately/very important (n = 85 [78.7%]). This BCQ was also ranked by 73 (67.6%) respondents as the most important question within this aspect of care. There was agreement among attendees of the in-person meetings to include this question in the QPL, albeit

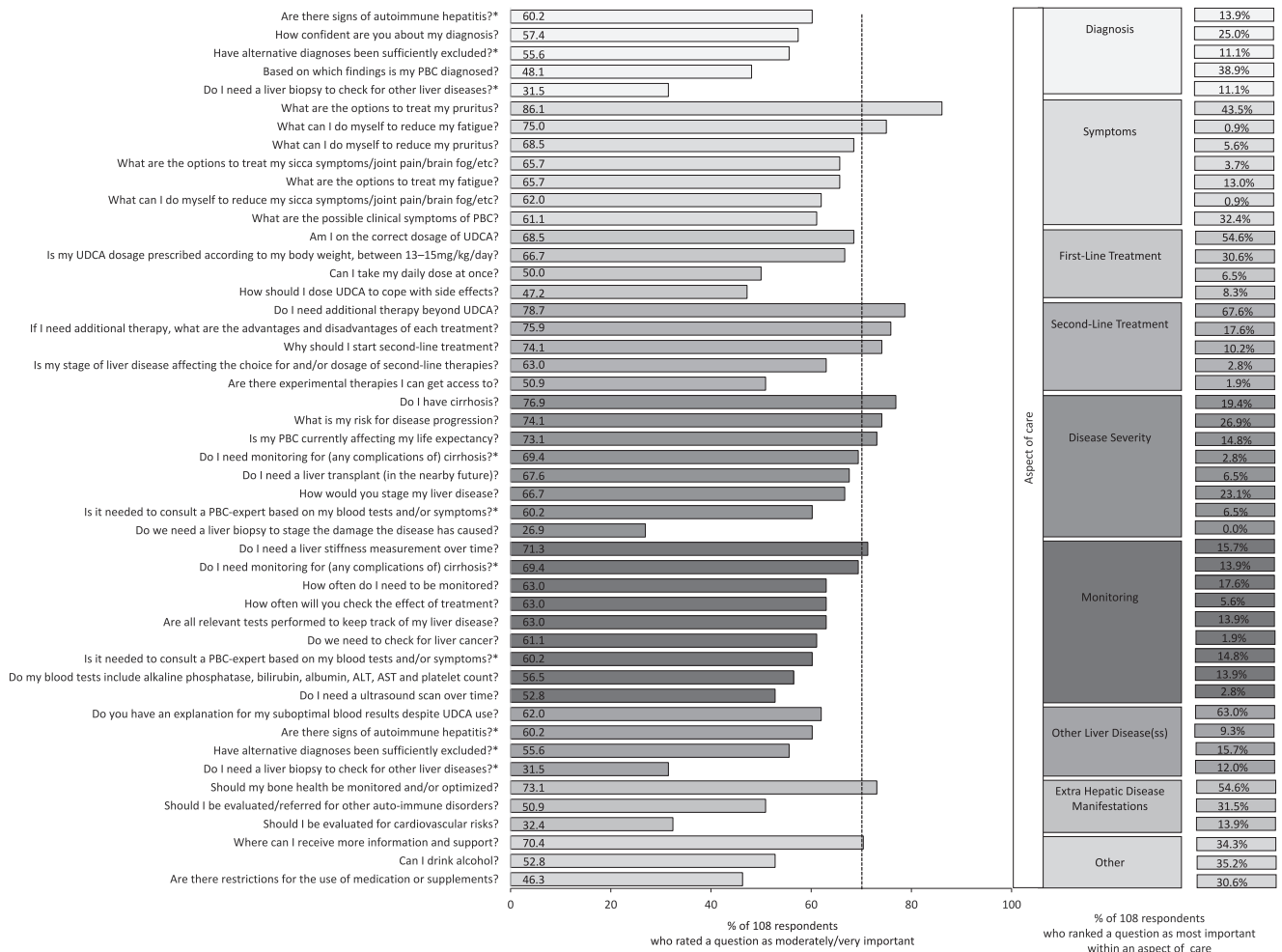


Figure 1. Rating and ranking of patient questions. This figure shows the percentage of respondents rating a question moderately/very important and the percentage of respondents ranking a question as most important question within an aspect of care. Each color represents a different aspect of care. Questions rated as moderately/very important by >70% of respondents were considered as best candidate questions to be included on the question prompt list. *Question was rated once, but was ranked in multiple aspects of care. ALT, alanine aminotransferase; AST, aspartate aminotransferase; UDCA, ursodeoxycholic acid.

with adjusted wording: “Do I need any therapy in addition to ursodeoxycholic acid?”

Disease Severity

During the meetings, it was mentioned that there was a considerable overlap between the different questions in this category. Three of the 8 questions assigned to this aspect of care reached the predefined definition of a BCQ (Figure 1) and were ranked highest by the majority of respondents. There was general agreement to focus on these questions for possible inclusion on the shortlist. The BCQ “What is my risk for disease progression?” was considered to be of relevance to potentially trigger a discussion on prognosis, treatment, and follow-up strategy, but attendees suggested to specify the wording to “liver disease progression.” The question regarding life expectancy was considered to have a more informative character and to be in line with the question on the liver

disease progression risk. Therefore, it was suggested to be left out of the QPL during the meetings. The BCQ “Do I have cirrhosis?” was considered to be important to set the stage for adequate disease management, even though questions related to specific topic of cirrhosis care would fall outside of the scope of this QPL.

Monitoring

The question “Do I need a liver stiffness measurement over time?” was rated as moderately/very important by 77 (71.3%) respondents (Figure 1). During the in-person meetings, there was a broadly supported suggestion to rephrase the BCQ to “How often do I need a liver stiffness measurement over time?” The main argument for rephrasing the question was that there is general consensus on the need to stage PBC-related liver disease but that physicians should be triggered to repeat disease staging during follow-up.

Table 1. Baseline Characteristics of Survey Respondents

| Characteristics | n | % |
|--|----|------|
| Sex | | |
| Female | 47 | 43.5 |
| Male | 61 | 56.5 |
| Age | | |
| <35 y | 10 | 9.3 |
| 35–50 y | 52 | 48.1 |
| 51–65 y | 38 | 35.2 |
| >65 y | 8 | 7.4 |
| Country | | |
| Argentina | 1 | 0.9 |
| Belgium | 3 | 2.8 |
| Canada | 7 | 6.5 |
| Croatia | 1 | 0.9 |
| England | 3 | 2.8 |
| Estonia | 1 | 0.9 |
| France | 8 | 7.4 |
| Germany | 3 | 2.8 |
| Greece | 4 | 3.7 |
| Iran | 1 | 0.9 |
| Israel | 1 | 0.9 |
| Italy | 30 | 27.8 |
| Japan | 1 | 0.9 |
| Lithuania | 1 | 0.9 |
| Luxembourg | 1 | 0.9 |
| Macedonia | 1 | 0.9 |
| Netherlands | 24 | 22.2 |
| Poland | 1 | 0.9 |
| Portugal | 1 | 0.9 |
| Spain | 4 | 3.7 |
| Sweden | 2 | 1.9 |
| Switzerland | 1 | 0.9 |
| United States | 8 | 7.4 |
| Primary role in field of PBC | | |
| Researcher | 5 | 4.6 |
| Hepatologist with special interest in managing PBC | 49 | 45.4 |
| Hepatologist/gastroenterologist | 44 | 40.7 |
| Patient representative | 6 | 5.6 |
| Other | 4 | 3.7 |
| Type of hospital | | |
| Secondary hospital | 25 | 23.1 |
| Tertiary hospital/Transplant center | 71 | 65.7 |
| Not applicable | 12 | 11.1 |
| Experience in the field of PBC | | |
| <5 y | 20 | 18.5 |
| 5–10 y | 27 | 25.0 |
| >10 y | 61 | 56.5 |
| Number of people with PBC under care | | |
| 0–25 | 28 | 25.9 |
| 26–50 | 28 | 25.9 |
| 51–100 | 26 | 24.1 |
| >100 | 26 | 24.1 |

PBC, primary biliary cholangitis.

Extrahepatic Disease(s)

The question related to bone health was rated as moderately/very important by 79 (73.1%) respondents and was also ranked as the number 1 question by 59

(54.6%) respondents (Figure 1). The other questions were not rated as moderately/very important by more than 70% of the respondents and did not raise comments.

Other/Miscellaneous

In this category, the question “Where can I receive more information and support?” was rated by 76 (70.4%) of the respondents as moderately/very important. The attendees during the meetings were unanimous in their view that this question should be added to the QPL.

Diagnosis, Other Liver Diseases, and First-Line Treatment

Within diagnosis, other liver diseases, and first-line treatment, no questions were rated as moderate/very important by more than 70% of the respondents (Figure 1), which was in line with the opinion of the attendees during the in-person meetings except for a question related to first-line treatment. The question “Am I on the correct dosage of UDCA?” was rated to be moderately/very important by 74 (68.5%) respondents but was ranked as the most important question within this category by 59 (54.6%) respondents (Figure 1). While discussing these survey results, it was commented that triggering physicians to evaluate adequate use of ursodeoxycholic acid (UDCA) is important because UDCA is frequently underdosed or not prescribed at all, although UDCA has a dose-dependent association with improved clinical outcome. With this argumentation, it was suggested to include “Am I on the correct dosage of UDCA?” in the final QPL. The attendees commented that caution was advised when specifying the dosage of UDCA within the question because the dosage may be adjusted based on individual factors.

Consensus Meeting

Based on the survey and in-person meetings, 8 questions were proposed to the study team to be included in the QPL (Table 2). Consensus was reached as it was unanimously agreed by 19 members of the study team that these questions formed the final QPL.

Discussion

Through this Delphi study, a QPL of 8 key questions which people living with PBC should consider asking their physicians was developed. According to the opinion of more than 100 stakeholders in the field of PBC, and their perspectives on the current gaps in PBC care delivery, these 8 questions are felt most likely to impact patient outcomes. The QPL is an user-friendly and inexpensive tool, which intends to increase awareness among both patients and their treating physicians on the most important aspects of PBC care. People living with PBC may

Table 2. Question Prompt List for Individuals With Primary Biliary Cholangitis

| Aspect of Care | Question |
|-------------------------|---|
| Symptoms | What are the options to manage my itching and/or fatigue? |
| First-Line Treatment | Am I on the correct dosage of ursodeoxycholic acid? |
| Second-Line Treatment | Do I need any therapy in addition to ursodeoxycholic acid? |
| Disease Severity | What is my risk for liver disease progression? Do I have cirrhosis? ^a |
| Monitoring | How often do I need a liver stiffness measurement over time? |
| Extrahepatic Disease(s) | Should my bone health be monitored and/or optimized? |
| Other/Miscellaneous | Where can I receive more information and support? |

^aPlease note that this is a question prompt list focused on primary biliary cholangitis management. In case you have cirrhosis, other questions related to specific aspects of cirrhosis care could be relevant. Consult your physician for extra information.

therefore use the QPL to prioritize their focus during consultation in the outpatient clinic. Physicians may be triggered by the questions to evaluate and, where needed, optimize the management of the individual patient.

One of the questions included in the QPL focuses on the options to manage pruritus and fatigue. Up to 70% of people with PBC are suggested to have pruritus during the course of their disease and around 50% experience fatigue, which result in impaired HRQoL.^{3,16} Various treatments are available and may relieve the severity of cholestatic pruritus.¹⁷ With respect to PBC-related fatigue, despite the recent promising results, pharmacological therapy remains an unmet need (EudraCT: 2022-000422-16).^{18,19} For now, aerobic and resistance-based exercise has been shown to attenuate fatigue severity in small groups of people with PBC (NCT04265235).²⁰ Considering the high symptom burden and availability of potentially effective management options, it is worrisome that recent studies indicated that fatigue and pruritus are not assessed in over a third of patients, and in case of pruritus, a third did not receive any treatment.^{7,8,21} The question “What are the options to manage my itching and/or fatigue?” in the QPL can improve the attention given to these symptoms.

An interesting finding of the survey was that none of the questions related to the use of UDCA reached the predefined level of importance to be considered for QPL inclusion. Therefore, in-person meetings within the Delphi methodology proved to be important. It was concluded that there is a substantial body of literature which argues for inclusion of a question regarding adequate use of UDCA on the QPL. Treatment with UDCA, usually well tolerated, is broadly known to reduce levels of alkaline phosphatase, which are

log-linearly associated with survival.^{22,23} In addition, real-world data indicate that UDCA use was associated with a more than 2-fold improvement of the survival free of liver transplantation.²⁴ This association was found to be dose-dependent, as patients receiving the guideline-recommended UDCA dose 13–15 mg/kg/day benefitted most.^{24–26} It is therefore difficult to accept that up to 30% of people with PBC are still not optimally dosed, if treated with UDCA at all.^{8,10,27}

With regard to second-line treatment, most of the questions were rated as moderately/very important. Depending on the biochemical response criteria chosen, 40%–70% of patients inadequately respond to UDCA and, consequently, are at heightened risks of disease progression.⁴ For those people, additional treatment options are now available of which obeticholic acid and off-label fibric acid derivatives are mostly commonly used.⁶ Although these drugs differ with respect to side effect profile and costs, both have been shown to lower serum alkaline phosphatase values among individuals with an incomplete UDCA response. In addition, treatment with either obeticholic acid or bezafibrate is associated with improved patient survival, free of developing hepatic decompensation or need for liver transplantation.^{28,29} Despite these results, many patients with an incomplete UDCA response are still without second-line therapy.⁸ Hence, it is important to address the possibility of prescribing add-on second-line treatment during consultation.

Additionally, repeated liver stiffness measurements were considered important. Disease stage is relevant to determine the need to monitor for cirrhosis-related complications, which is also one of the reasons to include the question regarding presence of cirrhosis. Moreover, the stage of liver disease is of influence on the preferred biochemical goals of anticholestatic treatment and may effect drug tolerability.³⁰ Recently, (the change of) liver stiffness measurement by vibration-controlled transient elastography (VCTE) was shown to be an independent predictor of the clinical outcome of people with PBC.^{5,31} While VCTE may not be accessible in all hospitals, a focus on the stage of liver disease remains relevant. Physicians may rely on alternative noninvasive markers of fibrosis or refer individuals with PBC to a clinic with availability of VCTE.

Although the literature on bone health in PBC is scarce and with limitations, it has been estimated that the risk of osteoporosis in PBC is 3–4 times higher than in control subjects.^{32,33} In line, people with PBC had an almost 2-fold higher fracture risk.³² Clinical practice guidelines therefore recommend regular bone mineral density measurements.^{25,26} The limited available audit data, however, indicate that in up to 55% of patients no bone mineral density measurement was recorded within the previous 5 years.⁸ Thus, agreement on the inclusion of the question related to bone health may have been expected.

Notably, generalizability can be considered a limitation of this QPL. Additional questions alongside the QPL may be very useful to optimize care in individual cases, or to better inform people with PBC on the course of

their liver disease. For example, besides physical symptoms, other aspects of HRQoL such as psychological distress and anxiety could be of great importance. The QPL is merely intended to be used as an added tool to prepare the patient for their consultation. Another limitation of the QPL is that the language of the questions may not necessarily be closest to the vocabulary of individuals. The optimal wording may also differ from country to country, or even from patient to patient. If adopted by national patient organizations, the QPL can be translated to best fit the specific populations and/or care settings. As an example, we included a QPL with alternative wording (Supplementary Table 5). Further, despite the large number of participants, it was not possible to assess for regional differences with respect to their registered opinion. Gaps in care delivery, however, might be country-specific, but there is lack of data to evaluate this in more detail. This limitation also applies to other characteristics of the participants of the survey, such as level of experience and health care setting in which they work. A challenge of current effort is how the QPL can reach people with PBC. Wallet-sized QPLs have been translated by coauthors and contributors in multiple languages (Supplementary Figure 1A–1L). In addition, these will be available from PBC/liver patient organizations who were participants of the study team. Furthermore, an explanation on the relevance for each question in the QPL in layman's language is provided (Supplementary Letter 1). It should, however, be acknowledged that the content of the QPL has not been validated by an independent international group of PBC experts. Further studies would also be needed, although complex in design, to evaluate the clinical impact of the QPL on the quality of PBC care in daily practice.

In conclusion, we created a QPL containing 8 key questions as an aid for people with PBC and their caregivers attending PBC clinics. It is hoped that the PBC QPL will serve as an additional tool to improve the quality of healthcare delivery in daily practice, maximize adherence to PBC guideline standards, and improve the patient experience.

Supplementary Material

Note: To access the supplementary material accompanying this article, visit the online version of *Clinical Gastroenterology and Hepatology* at www.cghjournal.org, and at <https://doi.org/10.1016/j.cgh.2025.01.037>.

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Correspondence

Address correspondence to: Adriaan J. van der Meer, MD, PhD, Erasmus MC, University Medical Center, Department of Gastroenterology and Hepatology, Doctor Molewaterplein 40, NA Building, Floor 6, 3015 GD Rotterdam, the Netherlands. e-mail: a.vandermeer@erasmusmc.nl.

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The contributor authors of the Global PBC Study Group/ERN RARE-LIVER/Question Prompt List are the following: Nadir Abbas, F. Adekunle, F. Azzaroli, L. Baiocchi, Y. de Boer, M.C. Bragazzi, T. Bruns, H.R. van Buuren, Marco Carbone, I. Cavalli, Nora Cazzagon, Christophe Corpechot, E. Culver, George Dalekos, E. Degasperis, E. Eggleton, A. Eshraghian, E. Falbo, A. Federico, A. Ferrase, N. Gatselis, A. Geerts, Alessio Gerussi, T.J.G. Gevers, E.G. Giannini, Bettina E. Hansen, M. Harms, J. Hercun, Gideon M. Hirschfield, Maria C.B. van Hooff, I. Houry, David E. Jones, H.H. Ko, Kris V. Kowdley, J. Kujvenhoven, E. Kuiper, Angela Leburgue, Cynthia Levy, A. Lleo, M.C. Londoño, V. Lygoura, E. Lytwyak, J. Madaleno, N. Maksimovic, Andrew L. Mason, T. Mayne, M. Mayo, George F. Mells, B. Merceska, Adriaan J. van der Meer, M. Miglanti, P. Milkiewicz, A. Minello, A. Molinaro, O. Morelli, F. Morisco, A. Mrzljak, L. Muratori, Frederik Nevens, V.P. Palitti, A. Pares, M. Pedersen, L. Pesci, B.T. Beretta-Piccoli, C. Ponsoen, S. Ravi, M. Russello, R. Salupere, Christoph Schramm, H. van Soest, P. Soret, M. Swain, S. R. Tajes, A. Tanaka, Robert Mitchell-Thain, I. van Thiel, M. Tielemans, Palak J. Trivedi, E. Vanni, Jef Verbeek, X. Verhelst, R. Verdonk, P. Veronica, G. Vettori, A. Villamil, J.M. Vrolijk, L. van de Waaij, Gemma H.X. Weijsters, Ellen Werner, José A. Willemsse, K. Zachou, and E. Zigmund.

CRedit Authorship Contributions

Ellen Werner (Conceptualization: Lead; Data curation: Lead; Formal analysis: Lead; Investigation: Lead; Methodology: Lead; Project administration: Lead; Visualization: Lead; Writing – original draft: Lead; Writing – review & editing: Lead)

Maria C.B. van Hooff (Conceptualization: Equal; Formal analysis: Supporting; Investigation: Supporting; Methodology: Supporting; Visualization: Supporting; Writing – original draft: Supporting; Writing – review & editing: Supporting)

Gemma H.X. Weijsters (Writing – review & editing: Supporting)
Nadir Abbas (Conceptualization: Supporting; Writing – review & editing: Supporting)

Alessio Gerussi (Conceptualization: Supporting; Methodology: Supporting; Writing – review & editing: Supporting)

José A. Willemsse (Writing – review & editing: Supporting)
Robert Mitchell-Thain (Writing – review & editing: Supporting)
Angela Leburgue (Writing – review & editing: Supporting)
Gideon M. Hirschfield (Writing – review & editing: Supporting)
Christophe Corpechot (Writing – review & editing: Supporting)
Christoph Schramm (Writing – review & editing: Supporting)
Cynthia Levy (Writing – review & editing: Supporting)

Frederik Nevens (Writing – review & editing: Supporting)
Jef Verbeek (Writing – review & editing: Supporting)
Andrew L. Mason (Writing – review & editing: Supporting)
George Dalekos (Writing – review & editing: Supporting)
Nora Cazzagon (Writing – review & editing: Supporting)
George F. Mells (Writing – review & editing: Supporting)
Kris V. Kowdley (Writing – review & editing: Supporting)
Marco Carbone (Writing – review & editing: Supporting)
David E. Jones (Writing – review & editing: Supporting)
Bettina E. Hansen (Writing – review & editing: Supporting)
Palak J. Trivedi (Conceptualization: Supporting; Methodology: Supporting; Writing – review & editing: Supporting)

Adriaan J van der Meer (Conceptualization: Lead; Methodology: Equal; Supervision: Lead; Visualization: Supporting; Writing – original draft: Supporting; Writing – review & editing: Supporting)

Conflicts of interest

The authors disclose no conflicts.

Data Availability

The dataset which was generated is not openly available for researchers outside of the study team. Please contact the corresponding author to inquire about the possibilities of collaboration.

Supplementary Methods

Survey

The aspects of care were based on clinical practice guidelines developed by the European Association for Study of Liver.^{e1} To some extent, the questions were allowed to overlap, when related to the same aspect of care.

Because the aim of study was to prioritize questions that might positively impact patient outcomes, informative questions on primary biliary cholangitis (PBC) and/or questions not related to the medical management were generally not considered in the survey. To minimize a potential question order bias, the order of the patient questions was randomized for each participant.

Participants had the opportunity to comment on the questions, for instance by suggesting alternative wording and/or to formulate additional questions that they considered to be lacking in the predefined list.

In-Person Meetings

In total, 64 PBC professionals attended the biannual meeting of the Global PBC Study group during the International Liver Congress of the European Association for Study of Liver (Vienna) in June 2023, and/or at the European Reference Network RARE-LIVER Members' Meeting (Hamburg) in September 2023. During these meetings, the ranking of questions guided selection of questions for the question prompt list (QPL) in case of overlapping candidate questions within the same aspect of care. In addition, comments and alternative wording suggestions were discussed and registered.

Statistics

The interquartile ranges (IQRs) that were used for calculating z scores were derived from individual scores (according to the 7-point Likert scale) appointed to the questions. The following formula was used: $z \text{ score} = [\text{IQR of a question} - \text{mean IQR of questions related to the same aspect of care}] / \text{SD of IQRs of questions related to the same aspect of care}$. A negative z score indicated small variation in the rating of the question by the respondents, a z score between 0 and 1 indicated moderate variation in the rating, and a z score >2 indicated large variation.

Question Prompt List

The final QPL for individuals with PBC will be accompanied by a clear description on its rationale, including a statement that the list is intentionally incomplete and should be used as an attributed tool to prepare for consultation. In addition, it was decided in advance to include a disclaimer for people with cirrhosis to indicate that questions related to specific aspects of cirrhosis care fall outside of the scope of this exercise. The aim here was to develop a QPL focused on management for the individual with PBC in general.

In total, 11 (10.2%) respondents suggested a total of 24 questions for people with PBC to ask their physician in addition to the questions in the survey. These questions are listed in [Supplementary Table 4](#). During the in-person meetings, none of these questions were considered of sufficient importance to be included in the QPL.

Supplementary Reference

- e1. [European Association for the Study of the Liver, EASL Clinical Practice Guidelines: The diagnosis and management of patients with primary biliary cholangitis. J Hepatol 2017;67:145–172.](#)

Supplementary Table 1. Questions Related to Various Aspects of PBC Care That Individuals Could Ask Their Physician

| Aspect of Care | Question |
|-------------------------------------|--|
| Diagnosis | <p>Are there signs of autoimmune hepatitis?^a</p> <p>How confident are you about my diagnosis?</p> <p>Have alternative diagnoses been sufficiently excluded?^a</p> <p>Based on which findings is my PBC diagnosed?</p> <p>Do I need a liver biopsy to check for other liver diseases?^a</p> |
| Symptoms | <p>What are the options to treat my pruritus?</p> <p>What can I do myself to reduce my fatigue?</p> <p>What can I do myself to reduce my pruritus?</p> <p>What are the options to treat my fatigue?</p> <p>What are the options to treat my sicca symptoms/joint pain/brain fog/etc.?</p> <p>What can I do myself to reduce my sicca symptoms/joint pain/brain fog/etc.?</p> <p>What are the possible clinical symptoms of PBC?</p> |
| First-Line Treatment | <p>Am I on the correct dosage of UDCA?</p> <p>Is my UDCA dosage prescribed according to my body weight, between 13 and 15 mg/kg/day?</p> <p>Can I take my daily dose at once?</p> <p>How should I dose UDCA to cope with side effects?</p> |
| Second-Line Treatment | <p>Do I need additional therapy beyond UDCA?</p> <p>If I need additional therapy, what are the advantages and disadvantages of each treatment?</p> <p>Why should I start second-line treatment?</p> <p>Is my stage of liver disease affecting the choice for and/or dosage of second line therapies?</p> <p>Are there experimental therapies I can get access to?</p> |
| Disease Severity | <p>Do I have cirrhosis?</p> <p>What is my risk for disease progression?</p> <p>Is my PBC currently affecting my life expectancy?</p> <p>Do I need monitoring for (any complications of) cirrhosis?^a</p> <p>Do I need a liver transplant (in the nearby future)?</p> <p>How would you stage my liver disease?</p> <p>Is it needed to consult a PBC expert based on my blood tests and/or symptoms?^a</p> <p>Do we need a liver biopsy to stage the damage the disease has caused?</p> |
| Monitoring | <p>Do I need a liver stiffness measurement over time?</p> <p>Do I need monitoring for (any complications of) cirrhosis?^a</p> <p>Are all relevant tests performed to keep track of my liver disease?</p> <p>How often will you check the effect of treatment?</p> <p>How often do I need to be monitored?</p> <p>Do we need to check for liver cancer?</p> <p>Is it needed to consult a PBC expert based on my blood tests and/or symptoms?^a</p> <p>Do my blood tests include alkaline phosphatase, bilirubin, albumin, ALT, AST, and platelet count?</p> <p>Do I need a ultrasound scan over time?</p> |
| Other Liver Diseases | <p>Do you have an explanation for my suboptimal blood results despite UDCA use?</p> <p>Are there signs of autoimmune hepatitis?^a</p> <p>Have alternative diagnoses been sufficiently excluded?^a</p> <p>Do I need a liver biopsy to check for other liver diseases?^a</p> |
| Extrahepatic Disease Manifestations | <p>Should my bone health be monitored and/or optimized?</p> <p>Should I be evaluated/referred for other autoimmune disorders?</p> <p>Should I be evaluated for cardiovascular risks?</p> |
| Other/Miscellaneous | <p>Where can I receive more information and support?</p> <p>Can I drink alcohol?</p> <p>Are there restrictions for the use of medication or supplements?</p> |

ALT, alanine aminotransferase; AST, aspartate aminotransferase; PBC, primary biliary cholangitis; UDCA, ursodeoxycholic acid.

^aQuestion was rated once, but was ranked in multiple aspects of PBC care.

Supplementary Table 2. 7-Point Likert Scale

| | |
|---|------------------------|
| 1 | Very unimportant |
| 2 | Moderately unimportant |
| 3 | Slightly unimportant |
| 4 | Neutral |
| 5 | Slightly important |
| 6 | Moderately important |
| 7 | Very important |

Supplementary Table 3. IQR z Scores of Questions Related to the Same Aspect of Care

| Aspect of Care | Question | z Score Based on IQR (Within Aspect of Care) |
|-------------------------------------|---|--|
| Diagnosis | Are there signs of autoimmune hepatitis? ^a | -0.65 |
| | How confident are you about my diagnosis? | 1.21 |
| | Have alternative diagnoses been sufficiently excluded? ^a | -1.11 |
| | Based on which findings is my PBC diagnosed? | 1.21 |
| | Do I need a liver biopsy to check for other liver diseases? ^a | -0.65 |
| Symptoms | What are the options to treat my pruritus? | -2.37 |
| | What can I do myself to reduce my fatigue? | -0.21 |
| | What can I do myself to reduce my pruritus? | 0.52 |
| | What are the options to treat my fatigue? | 0.52 |
| | What are the options to treat my sicca symptoms/joint pain/brain fog/etc.? | 0.52 |
| | What can I do myself to reduce my sicca symptoms/joint pain/brain fog/etc.? | 0.52 |
| | What are the possible clinical symptoms of PBC? | 0.52 |
| First-Line Treatment | Am I on the correct dosage of UDCA? | 0.58 |
| | Is my UDCA dosage prescribed according to my body weight, between 13 and 15 mg/kg/d? | 0.58 |
| | Can I take my daily dose at once? | 0.58 |
| | How should I dose UDCA to cope with side effects? | -1.73 |
| Second-Line Treatment | Do I need additional therapy beyond UDCA? | -0.82 |
| | If I need additional therapy, what are the advantages and disadvantages of each treatment? | -0.82 |
| | Why should I start second-line treatment? | 1.22 |
| | Is my stage of liver disease affecting the choice for and/or dosage of second line therapies? | 1.22 |
| | Are there experimental therapies I can get access to? | -0.82 |
| Disease Severity | Do I have cirrhosis? | -2.10 |
| | What is my risk for disease progression? | 0.14 |
| | Is my PBC currently affecting my life expectancy? | 0.14 |
| | Do I need monitoring for (any complications of) cirrhosis? ^a | 0.14 |
| | Do I need a liver transplant (in the nearby future)? | 0.14 |
| | How would you stage my liver disease? | 0.14 |
| | Is it needed to consult a PBC expert based on my blood tests and/or symptoms? | -0.42 |
| | Do we need a liver biopsy to stage the damage the disease has caused? | 1.82 |
| Monitoring | Do I need a liver stiffness measurement over time? | 0.38 |
| | Do I need monitoring for (any complications of) cirrhosis? ^a | 0.38 |
| | Are all relevant tests performed to keep track of my liver disease? | 0.38 |
| | How often will you check the effect of treatment? | -0.11 |
| | How often do I need to be monitored? | -1.58 |
| | Do we need to check for liver cancer? | -1.58 |
| | Is it needed to consult a PBC expert based on my blood tests and/or symptoms? | -0.11 |
| | Do my blood tests include alkaline phosphatase, bilirubin, albumin, ALT, AST, and platelet count? | 0.38 |
| | Do I need a ultrasound scan over time? | 1.85 |
| Other Liver Diseases | Do you have an explanation for my suboptimal blood results despite UDCA use? | 0.58 |
| | Are there signs of autoimmune hepatitis? ^a | 0.58 |
| | Have alternative diagnoses been sufficiently excluded? ^a | -1.73 |
| | Do I need a liver biopsy to check for other liver diseases? ^a | 0.58 |
| Extrahepatic Disease Manifestations | Should my bone health be monitored and/or optimized? | 0.71 |
| | Should I be evaluated/referred for other autoimmune disorders? | -1.41 |
| | Should I be evaluated for cardiovascular risks? | 0.71 |
| Other/Miscellaneous | Where can I receive more information and support? | 0.98 |
| | Can I drink alcohol? | 0.39 |
| | Are there restrictions for the use of medication or supplements? | -1.37 |

ALT, alanine aminotransferase; AST, aspartate aminotransferase; IQR, interquartile range; PBC, primary biliary cholangitis; UDCA, ursodeoxycholic acid.

^aQuestion was rated once, but was ranked in multiple aspects of PBC care.

Supplementary Table 4. Additional Questions as Suggested by the Survey Respondents

| Topic | Suggested Questions |
|--|---|
| Management | <p>Should I get vaccinated and how safe are vaccines for my PBC? (eg, against COVID, influenza, hepatitis A+B, pneumococci...)</p> <p>Do I need to change my diet because of PBC?</p> <p>How should I treat my lipid profile?</p> <p>Should I be evaluated for depression, anxiety or other issues?</p> <p>Why should I be treated for PBC when I don't have any symptoms?</p> <p>How do you protect me from unnecessary tests and treatment?</p> <p>I don't have medication, should I take medication?</p> <p>Is it important to control my weight and maintain an adequate metabolic control?</p> <p>What is the importance of exercise to improve my liver and bone health situation?</p> <p>Are there any over the counter medications or supplements which may support the current treatment?</p> <p>Should I be worried about my elevated cholesterol panel?</p> <p>Do we need to check my INR as well?</p> |
| Cirrhosis | <p>If I have cirrhosis, what is my MELD score?</p> <p>Do I need to check for liver cancer?</p> <p>Do I need a ultrasound scan over time if I have already established cirrhosis?</p> <p>Is it needed to consult a PBC expert based on my blood tests and/or symptoms and/or on fibrosis/cirrhosis?</p> |
| Informative | <p>Are my relatives at risk of developing PBC?</p> <p>Is there a significant risk to transmit my liver disease to my children or other family members?</p> <p>What is the chance of recurrence after liver transplantation?</p> <p>Will liver transplantation be a definitive cure for my liver disease?</p> <p>Is pregnancy not advised if I am still in childbearing age?</p> <p>What is the cause of my liver disease?</p> |
| Country-specific questions (the Netherlands) | <p>Should not all PBC patients in the Netherlands be centralized?</p> <p>Does Passende zorg have a place in PBC treatment to decrease low value care ?</p> |

INR, international normalized ratio; MELD, Model For End-Stage Liver Disease; PBC, primary biliary cholangitis.

Supplementary Table 5. Alternative Wording of the Question Prompt List for People With Primary Biliary Cholangitis

| Aspect of Care | Question |
|--------------------------------|--|
| <i>Symptoms</i> | What are the options to treat my itching and/or fatigue. How effective are these options likely to be? |
| <i>First-Line Treatment</i> | Am I taking the right amount of ursodeoxycholic acid? |
| <i>Second-Line Treatment</i> | Do I need any treatment in addition to ursodeoxycholic acid? |
| <i>Disease Severity</i> | Do you think that the risk for my liver disease getting worse is high or low? Do I have cirrhosis? ^a |
| <i>Monitoring</i> | How often do I need a FibroScan, or one of the other types of staging for my liver disease? |
| <i>Extrahepatic Disease(s)</i> | Do I need treatment for osteoporosis? |
| <i>Other/Miscellaneous</i> | Where can I receive more information and support? |

^aPlease note that this is a question prompt list focused on primary biliary cholangitis management. In case you have cirrhosis, other questions related to specific aspects of cirrhosis care could be relevant. Consult your physician for extra information.