Understanding the experience of people living with primary biliary cholangitis (PBC): Further development of an experience map

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THU-178

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Background

The experience of living with PBC is highly variable, and current data are limited.

PBC is a rare autoimmune disease of the liver.[1] A range of non-specific symptoms of varying severity are reported, which can impact quality of life (QoL).

The degree of symptom frequency/severity does not always correlate with liver biochemistry measures or disease progression.[1] This incongruence affects most of the PBC population; 50% of the population develops symptoms within 5 years of diagnosis, and 95% of the population report symptoms by 20 years post-diagnosis.[2]

Previous work has highlighted the methodology behind understanding the patient experience of PBC and has also been summarized in Figure 1.[3]

Objective

To further understand the patient experience, people living with PBC were consulted via a patient experience survey to capture their thoughts, feelings, symptoms, and impact on QoL.

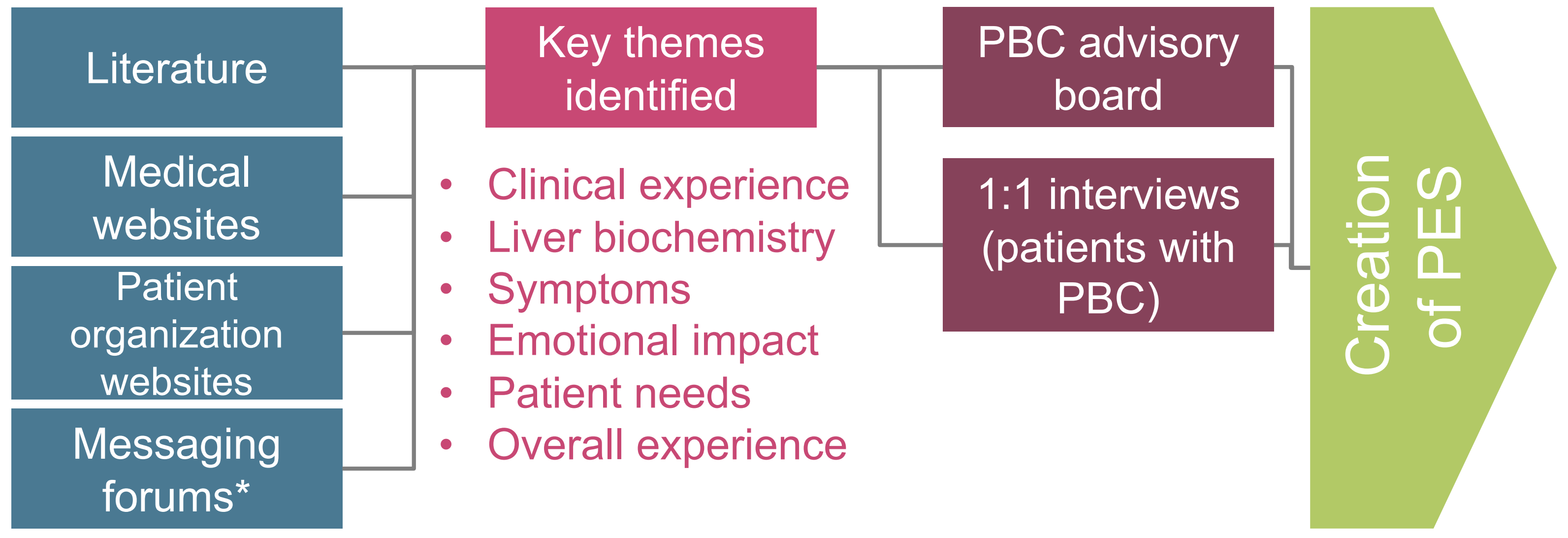
Methods

Multiple approaches were taken to refine understanding of the patient experience

Publicly available literature, medical and patient organization websites, and patient stories were reviewed to identify key themes of the PBC experience. These themes guided an international steering committee meeting of patient advocates and 1:1 interviews with patients. As a final step, insights were used to co-create a patient experience survey (PES) (Figure 1).

The aim was to validate prior findings and ensure an accurate representation of the PBC population. The survey was distributed in Europe and North America via a patient app for five weeks between October and November 2023, with findings discussed in the results section and Figure 2.

Figure 1. Methodology behind information gathering and PES development



Literature

Medical websites

Patient organization websites

Messaging forums*

Key themes identified

- Clinical experience
- Liver biochemistry
- Symptoms
- Emotional impact
- Patient needs
- Overall experience

PBC advisory board

1:1 interviews (patients with PBC)

Creation of PES

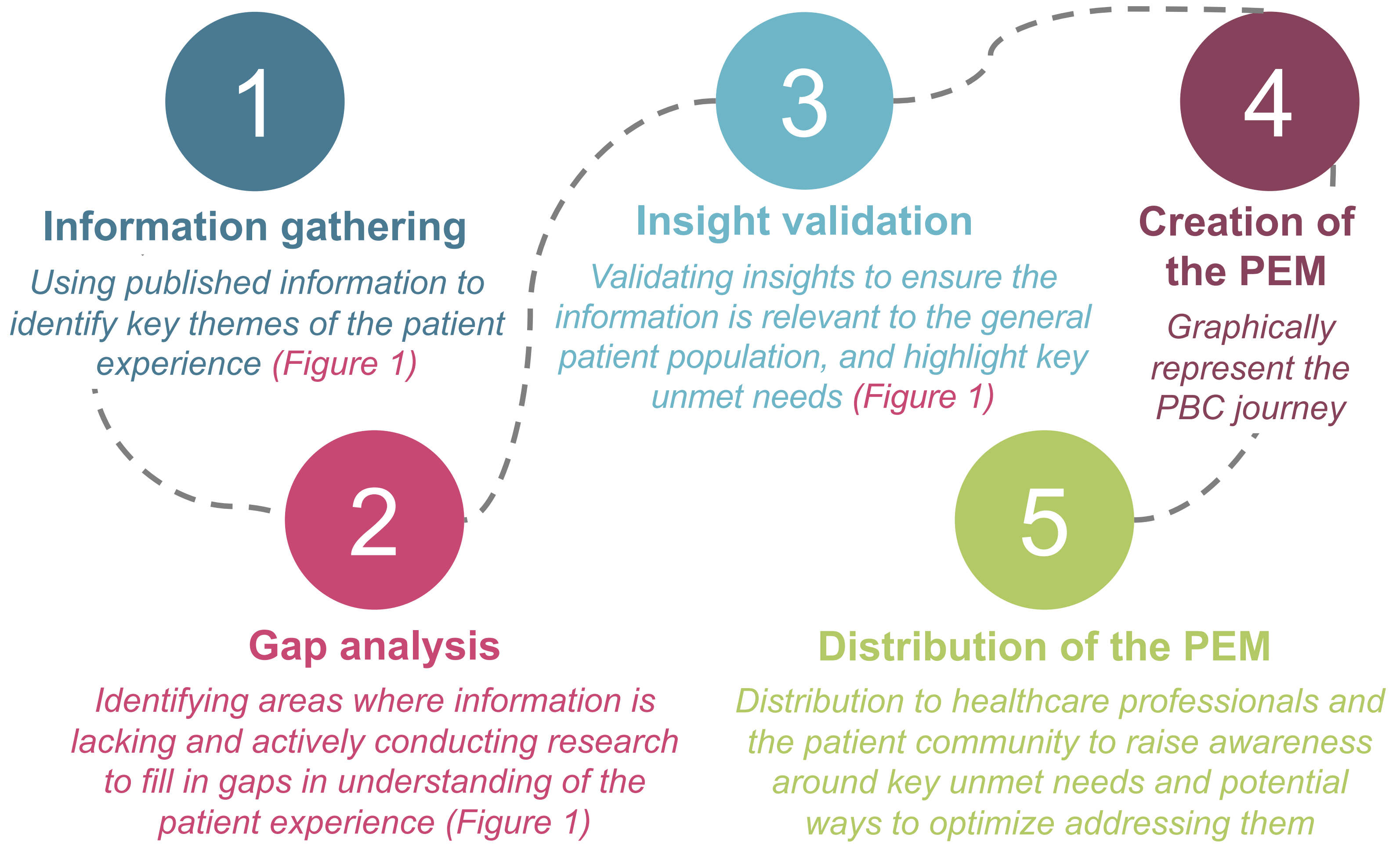
*Included social media

TAKE-HOME MESSAGE

Patient experience maps (PEMs) can be useful in aligning and informing healthcare and treatment approaches to address the substantial unmet needs of people living with a condition (Figure 3).

Insights into the PBC experience were gathered and validated through international steering committee meetings, 1:1 interviews, and a patient experience survey. This research will be used to create the first PEM for PBC to further understand the patient experience.

Figure 3. The creation process and benefits of a patient experience map



1 **Information gathering**

Using published information to identify key themes of the patient experience (Figure 1)

2 **Gap analysis**

Identifying areas where information is lacking and actively conducting research to fill in gaps in understanding of the patient experience (Figure 1)

3 **Insight validation**

Validating insights to ensure the information is relevant to the general patient population, and highlight key unmet needs (Figure 1)

4 **Creation of the PEM**

Graphically represent the PBC journey

5 **Distribution of the PEM**

Distribution to healthcare professionals and the patient community to raise awareness around key unmet needs and potential ways to optimize addressing them

Understanding the patient experience can help with providing personalized, patient-centric treatment. Insights can be gathered and validated to create a patient experience map where key unmet needs are prioritized.

CONCLUSIONS

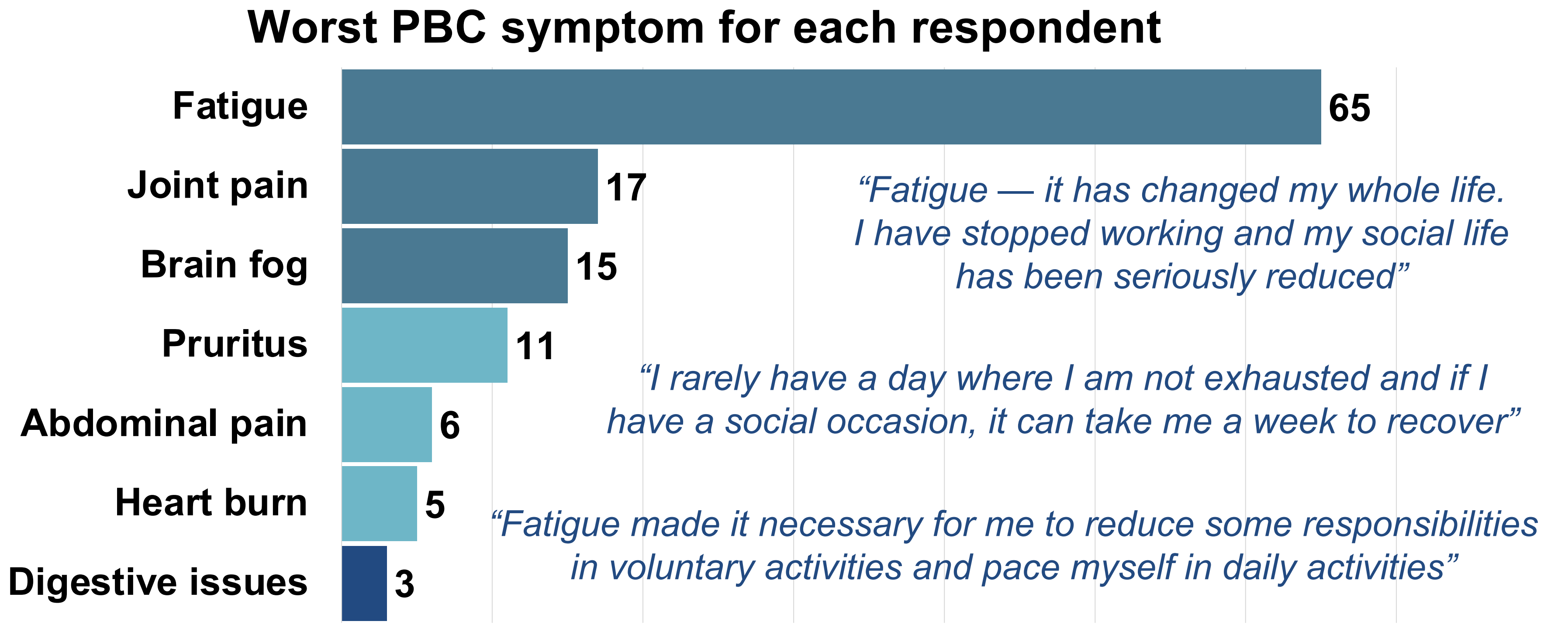
- Results highlighted the impact that symptoms, particularly fatigue, had on QoL and mental health
- The survey aimed to understand multiple domains of the patient experience; although patients received support from many sources, these were not sufficient to fully meet their needs
- A unique patient experience map for PBC will be created using validated insights from a range of people living with this progressive disease

Results

The survey results reflect the variability in different people's experiences of living with PBC.

- **113 respondents** filled in the survey; the demographics included:
  - **96%** of the respondents were **female**
  - **86%** of the respondents were **≥46 years old**
- The symptom reported as having the **biggest impac**t on QoL was **fatigue** (Figure 2)
  - **14–15%** of respondents reported experiencing **no symptoms**
  - **48%** of respondents were using **treatments** specifically **to alleviate symptoms**
- **Emotional responses were variable**, with a general trend from anxiety and fear at diagnosis towards more positive emotions at the initiation of treatment
  - When rating mental health on a scale of 1–10 (1=worst, 10=best), **25% consistently assigned a rating of 1–3** before and immediately after receiving a diagnosis of PBC
  - The proportion of people reporting the highest ratings of 7–10 **reduced from 48% before diagnosis to 37% after diagnosis**
- The survey investigated multiple domains of the patient experience; patients reported receiving **support from numerous sources** (spouse/partner, family, patient support organizations), but **these were insufficient for their needs**

Figure 2. Worst PBC symptoms and their impact on quality of life



"Fatigue — it has changed my whole life. I have stopped working and my social life has been seriously reduced"

"I rarely have a day where I am not exhausted and if I have a social occasion, it can take me a week to recover"

"Fatigue made it necessary for me to reduce some responsibilities in voluntary activities and pace myself in daily activities"

Survey participants were asked the question, "What is your worst symptom, and how does it affect you on a daily and long-term basis?" . Respondents could choose one option from a list or provide their own answers, which were tabulated.
Quotes highlighting the impact of fatigue on QoL have also been included.

Abbreviations

AALSD, American Association for the Study of Liver Diseases; EASL, European Association for the Study of the Liver.

References

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2. Prince MI et al. *Gut* 2004;53:865–870.
3. Artyomenko A et al. *Poster presented at AASLD 2023,* 4587-C.

Author Conflicts of Interest AA, MS: employee and shareholder of Ipsen; AB: employee of Health Unlimited; MC, RMT: employee of the PBC Foundation, PBC Foundation has been paid for their time and has received grants from pharmaceutical companies (not paid personally); MM: received payment for volunteer patient/advocate perspective at EASL and AASLD with any funds paid to the Canadian PBC Society; CR: PBCers Organization has received grants (not paid personally); SW: none.

Disclosures Conducted under a collaboration agreement between the PBC Foundation and Ipsen Pharmaceuticals. Financial support was provided to Health Unlimited for project co-ordination by Ipsen Pharmaceuticals.

Acknowledgements The authors thank Ingo van Thiel of Deutsche Leberhilfe e.V. for insights and contribution to survey development.

Medical Writing Support The authors thank Nadhrah Ali, PhD of Health Unlimited, London, UK for providing medical writing support, and Shimaila Siddiqui of Costello Medical, Manchester, UK, for editorial support, which was sponsored by Ipsen in accordance with Good Publication Practice guidelines.

Presented at EASL 2024 | Milan, Italy | 5 – 8 June 2024

This study was sponsored by Ipsen

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EASL CONGRESS 2024
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5–8 June

DOI: 10.3252/pso.eu.EASL2024.2024

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THU--178
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