

CASE STUDY:

A PATIENT-CENTERED APPROACH TO PBC RESEARCH

Primary Biliary Cholangitis (PBC) is a rare autoimmune liver disease that often presents with pruritus, a symptom that severely impacts quality of life and is difficult to quantify. Pulse Infoframe supported the design of the CHAPTER study, a non-interventional, ambispective registry that used a decentralized and accessible model guided by feasibility research and stakeholder input to capture the real-world experiences of adults with recent-onset pruritus related to primary biliary cholangitis (PBC).

CHALLENGE

Enabling Real- World Evidence Generation in a Rare Liver Disease

- Small and geographically dispersed patient population
- Cultural, language, and digital literacy barriers
- Difficulties linking symptom burden (e.g., pruritus, sleep disruption) to clinical and patient-reported outcomes

SOLUTION

Feasibility-Driven Design with a Patient-First Framework:

- Hybrid Study Participation
- Multilingual, Inclusive Design
- Stakeholder Collaboration
- Empowered Patient Experience
- Integrated Data Strategy

RESULT

Study Infrastructure Ready, Patient-Centric Model Validated

Platform Deployed: Fully configured, multilingual-enabled platform prepared for observational data collection

Site Readiness: Clinical sites in the US and Germany equipped to initiate recruitment and engagement

Participant Empowerment: Tools and interfaces designed to improve patient retention and experience

Global Feasibility Blueprint: A scalable approach applicable to future rare disease registries

CONCLUSION

Blueprint for Rare Disease Research Success

This case illustrates Pulse Infoframe's ability to bridge stakeholder input, platform flexibility, and patient empowerment in rare disease settings. Our feasibility-driven approach ensured that the CHAPTER study was not only compliant and technically ready but built around what matters most: the patient voice.

Email contact@pulseinfoframe.com to learn more.