



**Cholangiocarcinoma
Foundation®**

CONTACT

Amy Medley

Senior Director of Operations,
Cholangiocarcinoma Foundation

SOLUTION

Research Edition

Cholangiocarcinoma Foundation

The foundation leverages agile survey technology to amplify the patient voice in rare cancer research, driving real-world impact in oncology policy and practice.



OVERVIEW

CCF chose QuestionPro for its robust survey logic, ease of use, and real-time support, enabling quick collection of patient insights that shaped oncology research and policy discussions.

ABOUT CCF

- Founded in 2006
- Based in Utah

cholangiocarcinoma.org

GOALS

- Amplify the patient voice in clinical trial design.
- Identify and understand barriers to DFOT participation.
- Inform trial sponsors on how to make studies more inclusive and accessible for all patients.

Overview

The Cholangiocarcinoma Foundation (CCF) leads global efforts to support patients and researchers facing cholangiocarcinoma, a rare, aggressive bile duct cancer. Through advocacy, education, and funding, CCF is committed to elevating the patient voice in oncology.

To advance this mission, CCF relies on timely, accurate data, making their choice of survey technology a pivotal decision.

Navigating barriers in rare cancer research

In preparation for the ASCO oncology conference, CCF faced a critical challenge: rapidly collecting actionable insights from a diverse patient population about barriers to participating in dose-finding oncology trials (DFOTs). These trials are essential for developing safe, effective cancer therapies, but recruiting patients with rare conditions is uniquely complex.

The main challenges included:

- **Speed:** Only a few weeks to design, deploy, and analyze the survey.
- **Sensitivity:** Addressing deeply personal and logistical barriers faced by patients with rare cancers.
- **Data Security:** Ensuring compliance with HIPAA and other privacy regulations due to the sensitive nature of patient health information.

“With QuestionPro, we quickly designed and launched a tailored, accessible survey under a tight deadline. Its real-time analytics and advanced logic let us refine the survey on the fly, turning patient feedback into actionable insights that are shaping cancer research and trials.”



Amy Medley
Senior Director of Operations,
Cholangiocarcinoma Foundation

Selecting the right survey partner

After evaluating several platforms, the Cholangiocarcinoma Foundation selected QuestionPro for its unique blend of advanced features, security, and flexibility. The platform empowered CCF to:

- **Rapidly deploy sophisticated surveys:** Using over 30 advanced branching and skip logic rules, CCF tailored the survey experience to each respondent, ensuring relevance and sensitivity.
- **Guarantee data privacy and compliance:** QuestionPro's 100% HIPAA and GDPR compliance, ISO 27001:2022 certification, and robust security protocols provided peace of mind for handling sensitive patient data.
- **Reach patients anywhere, on any device:** With mobile-optimized surveys and seamless cross-platform functionality, over 85% of respondents completed the survey on mobile devices.
- **Leverage real-time analytics:** Live dashboards and AI-powered analytics enabled CCF to monitor participation, track completion rates, and surface actionable insights as responses came in.
- **Drive engagement with automated reminders:** Built-in reminder and follow-up tools boosted response rates to nearly 90% among those who started the survey.
- **Scale effortlessly:** Unlimited surveys and responses, multilingual support, and customizable branding allowed CCF to focus on patient engagement and data quality, not technical hurdles.

QuestionPro Research Edition overview:

- HIPAA compliant
- Multilingual surveys
- Advanced branching logic
- Looping logic
- Real-time dashboards
- Webhook Integrations
- 20+ survey themes
- 38+ question types
- Multi-channel distribution

And much more!

Learn more

questionpro.com/research-edition



Rapid deployment, real insight

Within just three weeks, CCF designed and launched a sophisticated survey with personalized flows, resonating with patients' unique journeys. Broad digital outreach generated nearly 300 responses, which is impressive given the rarity of the disease.

The survey uncovered critical barriers:

- 80% of respondents reported logistical and financial challenges, such as travel time, housing costs, and restrictive washout periods.
- Many patients expressed willingness to participate in trials if they were designed with greater flexibility and patient-centric considerations.

These insights informed a peer-reviewed manuscript and directly influenced research and policy discussions at ASCO.

A lasting impact

The Cholangiocarcinoma Foundation's experience with QuestionPro demonstrates how the right technology can accelerate research and amplify the patient's voice.

"We recommend QuestionPro to any mission-driven organization or research group that needs fast and actionable data. Their platform helped us translate patient voices into evidence that's shaping the future of oncology trials." — Amy Medley, Senior Director of Operations, Cholangiocarcinoma Foundation