Precision-BTC Clinical Registry

Overview

The **International Biliary Tract Cancer (BTC) Registry** is a collaborative, multi-center clinical initiative supported by the Precision-BTC Network. It brings together expert centers from **Europe**, **Latin America**, **Asia**, and **Africa**, with the goal of advancing research and clinical care in BTC. The registry is open to new participating centers worldwide.

This registry compiles **longitudinal**, **observational data**—both retrospective (from 2010) and prospective—from patients diagnosed with all types of BTC, including cholangiocarcinoma, gallbladder cancer and ampullary tumors. Together, this resource is designed to support **cross-institutional analyses**, facilitate **evidence-based clinical practices**, and serve as a central reference for the global BTC research community.

Primary Objective

To collect, harmonize, and share high-quality clinical data to support collaborative research, enable data sharing, and improve outcomes for patients with BTC.

Study Design

- **Type**: Observational, multi-center, retrospective and prospective
- **Data Sources**: Electronic health records, radiology/pathology reports, biosamples
- **Data Platform**: AEG-REDCap™ – Hosted by the *Asociación Española de Gastroenterología*
- **Data Governance**: Each Center retains ownership of its data and samples. Shared use requires approval and/or a Material-Data Transfer Agreement (MDTA)
- **Follow-up**: Prospective updates aligned with standard-of-care clinical visits and procedures

Registry Contents

The registry includes, but is not limited to:

- Patient demographics and clinical characteristics
- Diagnostic and staging information
- Treatment pathways and responses
- Molecular profiling data
- Follow-up and outcome measures

All data is pseudoanonymized and collected in accordance with ethical and data protection regulations.

Participation & Contact

Who Can Participate

Researchers and institutions affiliated with the Precision-BTC Action or related collaborative frameworks are welcome to contribute to and access the registry. Participation requires:

- Institutional ethics approval
- Signed data-sharing agreement and/or research contract
- Compliance with pseudoanonymization and data quality standards

How to Get Involved

To contribute data or request access to the registry, contact the coordination team directly (details below).

Data Utilization

The registry welcomes high-quality research proposals aimed at advancing knowledge in BTCs. Interested researchers must submit a written project proposal in English via email to the Registry Sponsor. Proposals are reviewed by a Scientific Evaluation Committee based on criteria such as scientific quality, feasibility, relevance, and patient impact.

Approved projects may gain controlled access to registry data, pending agreement from participating centers and compliance with ethical and legal standards.

Contact

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