PBC Ireland –Patient Registry

Information for Researchers

About the Registry

The PBC Ireland Patient Registry is a **patient-led, GDPR-compliant, ethically approved registry** collecting self-reported data from people living with Primary Biliary Cholangitis (PBC) in Ireland. It was launched in 2025 to support research, advocacy, and real-world understanding of the disease in an Irish context.

We are actively seeking academic researchers, either in Ireland or internationally, who are interested in using the PBC Ireland Patient Registry data for meaningful research. This includes studies on symptom burden, quality of life, pruritic, fatigue, quality of life, treatment access, health inequalities and other aspects of living with PBC. The data is fully de-identified, ethically approved, and collected directly from patients who provided consent. We welcome collaborations that lead to peer-reviewed publications, policy impact, or improved understanding of the disease, and we are happy to support ethics submissions, co-authorship, and access to structured datasets.

1. Ethics and Governance

- **IRB Approval**: The registry received full ethical approval from a U.S.-based Institutional Review Board (IRB) in 2025.
- **No Institutional Affiliation**: As a patient-led initiative, the registry is not hosted by an Irish university or hospital.
- **No Clinical Data**: The registry collects **self-reported data only**, no hospital records, no clinician-entered information, no interventions.
- **GDPR Compliance**: All data is securely hosted in Ireland, de-identified at source, and managed under strict privacy protocols.

2. Opportunities for Irish Researchers

Irish-based academics, clinicians, and health policy researchers are invited to:

- Conduct descriptive or exploratory analyses of anonymised registry data
- Co-author publications on symptom burden, quality of life, or unmet needs
- Use registry findings to support HTA submissions (NHS/NCPE), or policy advocacy
- Collaborate on joint studies (e.g. grant-funded, multi-country, or postgraduate work)

3. REC (Ethics Committee) Considerations

If your institution requires REC review:

- You may submit the project to your internal REC as the lead researcher.
- PBC Ireland will provide:
    - IRB approval documentation
    - Participant consent forms
    - Data dictionary and security details
    - Sample de-identified data
    - A signed Data Use Agreement (DUA)

We are committed to **working within your institution's governance framework** and supporting any ethics review process required on your end.

4. Contact

To discuss collaboration or request access:

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