Collaborative Working Executive Summary

Project title	Evolving Clinical Access and Care Pathways for Primary Biliary Cholangitis (PBC) Patients. A Collaborative Working Project between Ipsen & Hull University Hospitals Trust
Project rationale	PBC is a rare, chronic autoimmune liver disease affecting ~20,000 people in the UK, predominantly women aged 40–70 (ref 1,2). PBC can have a major impact on quality of life and can result in patients needing to be treated frequently in a hospital setting with a potential impact on healthcare utilisation including increased waiting times for care, alongside the wider social & economic impact of chronic disease management. This project aims to address inequities in access and care quality, aligning with the NHS 10-Year Plan. *Ref 1 : Tanaka T, Yamada H, Suzuki K, et al. The Lancet. 2024;404(10457):1053-1066.* *Ref 2: Epidemiology of Primary Biliary Cholangitis UK-PBC Consortium. Available from: https://www.uk-pbc.com/about/aboutpbc/epidemiology-of-pbc*
Project objectives	The primary objective of the project is to improve the equity of access to high quality clinical services across the Care Group for patients diagnosed with PBC. To achieve this objective the project will be designed to deliver the following: 1. Characterisation/ stratification of the PBC population across the Care Group to define the local service requirements and unmet clinical need. 2. Design and implement an enhanced group-wide PBC referral and management pathway. 3. Implement a group-wide multi-disciplinary PBC clinic. The anticipated benefits that are expected to be achieved on completion of the project are including but not limited to the following: **Patient Benefit**: Introduction of a new care pathway across the Care Group region, will deliver improved speed and equity of access to care for all patients across the locality.

	Indirect benefits of expanding the current service model will also support patients to receive care closer to home and reduce the travel time and expenditure for those patients who are currently referred to Hull. **NHS/Service Benefit**: Improvements in service efficiency through the enhancement and streamlining of appropriate patient referrals will reduce waiting times and contribute to the provision of optimal care against National Standards. **Ipsen Benefit**: A higher number of patients will be identified with PBC leading to increased numbers of patients treated with PBC medication, including Ipsen's treatment in line with National Guidelines.
Project period	Q4 2025 project start and 12 months duration
Financial arrangements	Ipsen UK will provide funding for clinical nurse support over a 12 month period. NHS: will provide Cross-functional support including but not limited to consultant, nursing, and project management time
Plans for publication	The project outcomes will be published within 6 months of project completion on the Ipsen website
Contact details	Ipsen: Matt Ferriday: Head of Neuroscience & Rare Diseases Mattew.ferriday@ipsen.com NHS: Peter Grant, Operations Director, NHS Humber Health Partnership Peter.grant7@nhs.net
Summary of the roles and responsibilities of each party	**Ipsen:** Manage project logistics and documentation. Provide expertise in stakeholder engagement and pathway design. Support corrective actions and business case development. Publish outcomes within 6 months post-project. **Hull University Teaching Hospitals NHS Trust (HUTH)** Lead planning, recruitment, and clinical decisions. Operate bi-monthly MDT clinics and maintain the PBC database.

	Track KPIs, implement improvements, and deliver final report. Publish outcomes within 6 months post-project.