

Collaborative Working Executive Summary

Project title	Case Finding for Patients at Risk or Previously Diagnosed with Primary Biliary Cholangitis (PBC) and Care Pathway Optimisation A Collaborative Working Project between Ipsen UK and Norfolk & Norwich University Hospital
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. Local and national PBC audits have revealed substantial variation in care delivery, with many patients lost to follow-up or receiving suboptimal treatment. This project aims to address these gaps by identifying undiagnosed or disengaged patients and optimising care pathways across the Norfolk & Waveney University Hospitals group. <i>Ref 1 : Tanaka T, Yamada H, Suzuki K, et al. The Lancet. 2024;404(10457):1053-1066.</i> <i>Ref 2: Epidemiology of Primary Biliary Cholangitis UK-PBC Consortium. Available from: https://www.uk-pbc.com/about/aboutpbc/epidemiology-of-pbc</i>
Project objectives	The primary objective of the project is to improve the equity of access to high quality clinical services across the Region for patients diagnosed with PBC. 1. Improve Patient Identification: Use NHS Eclipse analytics to identify undiagnosed and lost-to-follow-up PBC patients. 2. Enhance Equity of Access: Optimise the current care pathway to reduce variation in care and ensure consistent, guideline-based treatment across the region. 3. Create a Scalable Model: Develop a blueprint for similar initiatives across other NHS regions.

	The anticipated benefits that are expected to be achieved on completion of the project are including but not limited to the following: Patient Benefit: Use of NHS case finding methodology will enable PBC patients currently undiagnosed or lost to follow up to gain equitable 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 Norfolk & Norwich. 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 a Clinical Fellow post over a 12 month period. NHS: will provide Cross-functional support including but not limited to consultant, nursing, administration 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 and Rare Diseases – matt.ferriday@ipsen.com NHS: Mazen Jeha, Divisional Operations Manager, NNUH – mazen.jeha@nnuh.nhs.uk
Summary of the roles and responsibilities of each party	Ipsen: Project governance and milestone tracking Stakeholder engagement and communication planning Support pathway redesign and dissemination Provide publication subject matter expertise

	Publish outcomes within 6 months post-project Norfolk & Norwich University Teaching Hospitals NHS Trust (NNUH) Lead planning, recruitment, and clinical decisions. Manage case finding methodology and database updates 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.
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