

Collaborative Working Executive Summary

Project title	<p>Case Finding, Treatment Optimisation and Devolved Delivery of Second-Line Therapy for Primary Biliary Cholangitis (PBC) across the Royal Free Hepatology Network</p> <p>A Collaborative Working Project between Ipsen UK and Royal Free London NHS Foundation Trust</p>
Project rationale	<p>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.</p> <p>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 Royal Free Hepatology Network</p> <p><i>Ref 1 : Tanaka T, Yamada H, Suzuki K, et al. The Lancet. 2024;404(10457):1053-1066.</i></p> <p><i>Ref 2: Epidemiology of Primary Biliary Cholangitis UK-PBC Consortium. Available from: https://www.uk-pbc.com/about/aboutpbc/epidemiology-of-pbc</i></p>
Project objectives	<p>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.</p> <p>The anticipated benefits that are expected to be achieved on completion of the project are including but not limited to the following:</p>

	<p>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.</p> <p>Direct 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 whose care is currently managed from the Royal Free.</p> <p>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.</p> <p>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.</p>
Project period	Q3 2026 project start and 24 months duration
Financial arrangements	<p>Ipsen UK will provide funding for a Clinical Nurse Specialist post over a 24 month period.</p> <p>NHS: will provide Cross-functional support including but not limited to consultant, nursing, administration and project management time</p>
Plans for publication	The project outcomes will be published within 6 months of project completion on the Ipsen website
Contact details	<p>Ipsen: Jennifer Leng, Business Unit Director, Rare Disease – jennifer.leng@ipsen.com</p> <p>NHS: Sukhvinder Sandhu, Divisional Director of Operations, Royal Free – sukhvinder.sandhu2@nhs.net</p>
Summary of the roles and	<p>Ipsen:</p> <p>Project governance and milestone tracking</p>

responsibilities of each party	<p>Stakeholder engagement and communication planning Support pathway redesign and dissemination Provide publication subject matter expertise Publish outcomes within 6 months post-project</p> <p>Royal Free University Teaching Hospitals NHS Trust</p> <p>Lead planning, recruitment, and clinical decisions.</p> <p>Manage case finding methodology and database updates</p> <p>Enable spoke site delivery of specialist care including initiation and ongoing management of 2L treatments Track KPIs, implement improvements, and deliver final report. Publish outcomes within 6 months post-project.</p>
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