

## Collaborative Working Executive Summary

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| <b>Project title</b>      | <p>Improving Identification of Patients with PBC through Community Outreach and Integrated IT Systems</p> <p>A Collaborative Working Project between Ipsen UK and Mid &amp; South Essex NHS Foundation Trust</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Project rationale</b>  | <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 &amp; 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: <a href="https://www.uk-pbc.com/about/aboutpbc/epidemiology-of-pbc">https://www.uk-pbc.com/about/aboutpbc/epidemiology-of-pbc</a></i></p> |
| <b>Project objectives</b> | <p>The primary objective of the project is to address unwarranted variation and sub-optimal care across the ODN's geography for PBC patients.</p> <p>This project aims to provide improvements in equity of access to PBC risk stratification &amp; care provision across the ODN through utilising primary care clinic sites to provide a more accessible “one stop” service.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

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|                               | <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><b>Patient Benefit:</b> 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 Basildon.</p> <p><b>NHS/Service Benefit:</b> 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><b>Ipsen Benefit:</b> 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> |
| <b>Project period</b>         | Q3 2026 project start and 24 months duration                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Financial arrangements</b> | <p>Ipsen UK will provide funding for a Clinical Research Fellow 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>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Plans for publication</b>  | The project outcomes will be published within 6 months of project completion on the Ipsen website                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Contact details</b>        | <p>Ipsen: Jennifer Leng, Business Unit Director, Rare Disease – <a href="mailto:jennifer.leng@ipsen.com">jennifer.leng@ipsen.com</a></p> <p>NHS: Samantha Hayton, Head of Research, Mid &amp; South Essex NHS Trust – <a href="mailto:samantha.hayton@nhs.net">samantha.hayton@nhs.net</a></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |

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| <b>Summary of the roles and responsibilities of each party</b> | <p><b>Ipsen:</b></p> <p>Project governance and milestone tracking<br/> Stakeholder engagement and communication planning<br/> Support pathway redesign and dissemination<br/> Provide publication subject matter expertise<br/> Publish outcomes within 6 months post-project</p> <p><b>Mid &amp; South Essex Hospitals NHS Trust</b></p> <p>Lead planning, recruitment, and clinical decisions.<br/> Manage case finding methodology and database updates<br/> Establish new Clinical Fellow lead weekly PBC clinics in 4-5 Primary care locations to provide 1-stop accessible PBC care.<br/> Track KPIs, implement improvements, and deliver final report.<br/> Publish outcomes within 6 months post-project.</p> |