

A Declaration of Collaborative Working between Intercept Pharma UK & Ireland Limited and PBC Foundation (UK) Limited

The PBC Foundation and Intercept Pharma UK & Ireland Limited are engaged in a Collaborative Working project called “UK Experience Survey 2021” (the “Project”).

Overview:

The Project will survey patients with primary biliary cholangitis to understand their perspective and opinions on the management of their disease (the “Survey”).

The Project will start in December 2021 and will run for one (1) year. The Survey will be disseminated via PBC Foundation’s app to their registered members. Anonymised results will be analysed by PBC Foundation one (1) month from the date of the initial dissemination of the Survey. Both parties have contributed skills, experience and resources and have made a significant contribution for this initiative.

No clinical safety or outcomes will be measures as part of this project.

Objectives:

The objectives of this Project is to gather insight from patients on the following topics:

- (i) explore any changes in the patient experience in managing primary biliary cholangitis (PBC) since the PBC Patient Experience Survey 2019 and whether there has been an improvement in PBC services; and
- (ii) understand the impact of the COVID-19 pandemic on the patient experience in managing PBC.

Benefit to patients:

Using the results of the survey we plan to communicate and raise awareness of the patient’s perception of their disease and management to healthcare professionals that will provide the feedback to improve and enhance the patient management and care.

Benefits to the NHS:

Education on the patient perspective of their management that may highlight gaps and variation in clinical practice that potentially can be addressed.

Benefits to Intercept Pharma:

An understanding of the patient perspective to communicate to healthcare professionals through scientific publications. This could potentially lead to opportunities to collaborate with liver units to improve PBC patient care.