Association ALBI

- Representing **4 rare inflammatory liver diseases**: Primary biliary cholangitis, Primary sclerosing cholangitis, Autoimmune hepatitis, Low Phospholipid-Associated Cholelithiasis

- A community of **3000 people** (website, forum, Facebook, Twitter, newsletters...)

- **850 members**

- **20 volunteers** - regional ambassadors

- **Association certified** by the French Health Ministry to represent patients in health organisations

- Member of French Liver Network Filfoie and French network for inflammatory diseases of liver and biliary tracts - MIVB-H – equivalent to a pilar within the ‘filière’ and **ERN RARE-Liver**
Conducting surveys since 2005

- 2005: Quality of Life
  - Hierarchy of the symptoms and patients’ difficulties
- 2010: Quality of Life (with BVA – survey company)
  - 241 ALBI patients and 243 respondents from control group
  - Recognition of the problem of chronic fatigue
- 2014: Psychological impact
  - 50% anxiety, 25% depression
- 2017: Patients’ major concerns
  - Disease progression, treatments, not symptoms
- 2018: Quality of Life
  - Panorama of the 4 diseases
- 2018: Priorities for the PSC research
  - Common survey with UK and US patients groups
- 2020: Study about patients' experiences on PBC treatments
- 2021: Medical care in France – medical visits
  - Basis to re-certification of centres of expertise + progress plan
- 2021: Study about reimbursement expenses ALD
  - Quantity and reasons for a problem in the 100% reimbursements
MEDICAL CARE: EVALUATION OF CENTERS OF EXPERTISE

Assessing patients’ care in 35 centres of expertise (medical visits) and others
> Used in the re-certification of those centres as part of the French ‘filières’ (ref. networks).

Experience from the EURORDIS AMEQUIS group for the assessment, monitoring & evaluation of ERNs.

Questionnaires (26 closed-ended questions + several open-ended questions), sent by email, Facebook and added on the website (2 months fieldwork): 700 respondents

Use of the results
• Presentation to the French liver network and AILD network coordinators.
• Publication on website, Facebook, forum + sent by email to contacts.
• Exchanges with network coordinators and centre leads (ongoing)
• Used in personalised letters of support for the re-certification of French centres
• Used in progress plan to be implemented in 2023.
Develop a culture for people in the community to express themselves, be listened to and show them that their voice is taken into account:

• Regularly ask the community what they think and what they experience

• Make the community feel listened to e.g. by answering their comments in the open questions when they give their email, sending them results and telling them how those results are being used...

• Use the survey results for action: QoL (chronic fatigue), making sure that patients’ feedback is taken into account during visits...

• Take the experience into account when doing new surveys (zooms) and when dialoguing with clinicians and researchers, as well as supporting patients.