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## **Unmet Clinical Needs (UCN)**

### **Background/aims:**

This project aims to understand patients' difficulties in order to quantify and prioritize patients' problems and needs related to their disease that should be addressed by clinicians and medicine/science/research. The objective is to identify problems as well as potential topics that need to be further explored in detail.

### **Study design/Methods or/PROMS:**

- Ask patients with autoimmune liver disease which are their main problems and difficulties when dealing with their condition. Identify gaps and unmet clinical needs. Define which are possible threats and barriers for patients to have an improvement in their health condition.
- Survey with open questions about their uncovered needs will be performed.
- A sample of 10 to 20 persons from 5 countries will be used to test the understandability of the questions and its translations (Pre-Test). After checking and adjusting them, the EU platform survey will be used. The survey will be disseminated by named patient representatives (NPRs) and clinicians, as well as an announcement on the website.

### **Target population:**

All patients (rare liver diseases)

### **Languages:**

Dutch, English, Flemish, French, German

### **Countries:**

Belgium, France, UK, Germany, Netherlands, UK

### **Inclusion and exclusion criteria:**

Open to patients >18 years

### **Study period/begin/stage:**

Presently at pre-test phase, the online survey will be online in June 2022

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