Can you help us improve the diagnosis and management of liver disease?

Do you have lived experience of liver disease?

Can you help us ensure we use data from patient health records safely and effectively?

We are at the early design stage of our project and want to involve patients and the public.

Why is liver disease important?

- Liver disease is a growing problem in the UK. It is the leading cause of death in people aged 35 to 49.

Key facts about liver disease

- The most common liver disease is non-alcoholic fatty liver disease (NAFLD). More than 1 in 4 adults in the UK have NAFLD, usually in a mild form. Other causes of liver disease include alcohol, viruses, and autoimmune.
- Most people with liver disease don't know they have it because most symptoms only occur in when the liver is severely damaged (cirrhosis), and this takes several years to develop.
- Most cases of liver disease are treatable when diagnosed early.
- Only some people with liver disease will develop severe liver damage, also called cirrhosis, that means the liver stops working. This can lead to liver cancer and/or death.
- It is hard to predict who will develop severe liver damage (cirrhosis).
- The only cure for severe liver damage (cirrhosis) is a liver transplant, which is a scarce and costly treatment.

What we want to research

- We want to use national data from electronic health records to find clues about who is likely to develop severe liver damage (cirrhosis) and who is likely to have mild liver disease or no liver disease. We hope this will help us identify people who should be prioritised for testing, to help diagnose people with liver disease earlier.
- Many people with liver disease also have other medical conditions (multimorbidity), which means they use multiple healthcare services. We want to better understand how other medical conditions (multimorbidity) and liver disease interact. We also hope to improve the patient journey through the healthcare system, to reduce unnecessary tests and appointments.

How can you help?

- **We want to involve people with lived experience of liver disease to help us develop and prioritise research questions relating to liver disease.**
- **We would also like your thoughts on the use of 'big data' from electronic health records for research. For example, what are patients and the public's main concerns and questions about using this kind of data?**
- **The expected contribution would be in the form of either/both of: (1) online questionnaire (approx. 15-30 minutes), and/or (2) an online focus group session. Payment of £25 for attendance at online focus group.**

Please respond via the advertisement on www.peopleinresearch.org, or email dominic.crocombe@nhs.net to show your interest. Thank you!