# Hep-MoLo Study: Mongolian Community Liver Screening – Participant Information Sheet (Focus Groups and Interviews)

## We invite you to take part in a research study

- Before you decide to take part, it is important for you to understand why this project is being done and what it will involve.
- Please take time to read the following information carefully. You can discuss it with friends and relatives if you wish.
- Ask a member of the study team if anything is not clear or if you would like more information.
- You are free to decide whether to take part. If you choose not to take part, this will not affect care you receive in the future.

## Brief Summary

- We are a group of doctors, nurses and scientists working to diagnose, manage and improve our understanding of liver disease, which is very common in Mongolia.
- We want to understand more about what factors may encourage or prevent people from accessing testing and healthcare for chronic viral hepatitis.
- We want to understand your views and opinions by inviting you to take part in a one-to-one interview and/or a group discussion (focus group).

## Why are we doing this study?

- Long-term viral hepatitis infection, caused by hepatitis B, D and C viruses, affects around 300 million people globally.
- Viral hepatitis is very common in Mongolia leading to one of the highest rates of liver cancer in the world.
- Many people don't know they have viral hepatitis, as they often don't have symptoms. It is important to diagnose viral hepatitis because monitoring and treatment can prevent future liver disease.
- It is estimated that only 1 in 10 of those living with hepatitis B know their status, and we want to understand reasons why people might choose to seek or avoid testing for hepatitis B.
- Many people living with hepatitis B are not engaged in regular follow-up, which is important to monitor for liver cancer. We want to know your views and opinions on why people may or may not attend hepatitis clinics regularly.

## What would taking part involve?

- We will invite you to take part in a focus group or an interview, or both.
- The focus group will consist of 5-8 people from the Mongolian community. We will discuss attitudes to testing for chronic viral hepatitis. The group will be led by an experienced member of the research team and there will be an additional team member to assist on the day. This will take place in a private room in London. We will pay for your transport and light refreshments will be included.
- The interview will be held either in a private and confidential area or over the phone. You will only be offered an interview if you are living with chronic viral hepatitis, as we want to understand your views on accessing viral

hepatitis healthcare.

- We will record both the focus group and the interview so we can listen again and better understand the views and opinions expressed.

### Do I have to take part?

- No, you do not have to take part.
- Saying no to the research study will not affect any future care that you receive.
- If you choose to take part, we will ask you to sign a consent form to record this.
- You are free to withdraw at any time, without giving a reason. If any new relevant scientific information becomes available during this study, which may impact your ongoing participation, we will inform you.

### What are the possible benefits of taking part?

- You will also be contributing to improved knowledge and understanding of chronic viral hepatitis healthcare services, with an aim to help people in the Mongolian community and beyond.
- Learning from this project will help us and other teams to develop similar projects in future, so that we can reach more communities in the UK and elsewhere in the world.

### What are the disadvantages of taking part?

- There is a risk that some of the topics we may cover, for example your views on accessing healthcare or viral hepatitis testing, may be distressing for you to discuss. If you do feel distressed, you can stop the interview or leave the focus group. We will provide support and check that you are OK.
- We will make sure that participants know they must not share any information outside of the focus group, however there is always a small risk that this may not be observed by other group members. We ask people to consider this risk before taking part.

### How will information about me be kept confidential?

- The Data Controller for this study is University College London/University College London Hospital NHS Foundation Trust.
- We will always protect your privacy.
- Digital recordings will be anonymised and deleted once they have been transcribed.
- The following steps are taken to ensure confidentiality:
    - You will be given a unique identifier number so that we can keep your information anonymous (we do not need to use details such as your name or date of birth when analysing data).
    - All study data will be stored online in a secure database which conforms to NHS Digital Information Governance Standards and is restricted access to named researchers working on this study.
    - On rare occasions, if you disclose information that makes us concerned that you or others may be at risk, we may need to break confidentiality. If this is the case, we will warn you beforehand, and tell only people who need to know.

## How will we use information about you?

- We will transcribe the recordings into text so that we can analyse the themes that come up in the discussion.
- We aim to present the data at conferences and publish in medical journals. Direct quotes from your recordings may be used in our reports.
- We will not publish any information that will enable readers to identify you.

## What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason. If you do withdraw, we may still use the information collected so far in the final analysis.

## Where can you find out more about how your information is used?

You can find out more about how we use your information:

- Online: at www.hra.nhs.uk/information-about-patients/
- In person: by asking one of the research team
- By email: data-protection@ucl.ac.uk

## Who is organising and funding the study?

This study is organised by doctors and researchers from University College London NHS Foundation Trust, University College London and the Francis Crick Institute. It is funded by the British Research Council.
The sponsor of the study is University College London/ University College London NHS Foundation Trust Joint Research Office.

## Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, which is there to protect your safety, rights, wellbeing and dignity. This study has been reviewed and received a favourable outcome by the London-Brighton & Sussex NHS Research Ethics Committee (25/LO/0126).

## What will happen to the results of this study?

- We hope that the results of this study will be presented at national or international medical conferences and published in one or more medical or research journals, but no individual will be identifiable in any presentation or publication.
- We will send you a letter with the summary of the overall results of the study when it is finished.

## What if something goes wrong for me?

If you have any concerns about the way you have been approached or treated during the study then please contact the lead researcher, Professor Philippa Matthews, to discuss this (contact details below). You can also contact the Patient Advice and Liaison Service (PALS) at University College London Hospital:

PALS
Ground Floor Atrium
University College Hospital
London NW1 2BU
Telephone: 020 3447 3042
Email: uclh.pals@nhs.net
Website: https://www.uclh.nhs.uk/contact/patient-advice-and-liaison-service-pals

## How to contact us

If you have questions about this study, please talk to the lead researcher and the study team:
Philippa Matthews
Clinical Group Leader, The Francis Crick Institute, 1 Midland Road, London, NW1 1AT
*Study email*
You can contact the study sponsor University College London/ University College London NHS Foundation Trust Joint Research Office (uclh.randd@nhs.net)