Data Transparency Document

Study Title: Prognostic biomarkers in HCV cirrhosis

IRAS: 150126 / REC: 14/WM/1128

Principle Investigator:

Nottingham University Hospitals NHS Trust is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Nottingham University Hospitals NHS Trust will keep identifiable information about you for a minimum of 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information www.nuh.nhs.uk.

[NHS/other site] will collect information from you and your medical records for this research study in accordance with our instructions.

[NHS/other site] will use your name, NHS number and contact details [add other identifiers] to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Nottingham University Hospitals NHS Trust and regulatory organisations may look at your medical and research records to check the accuracy of the research study. [NHS site] will pass these details to Nottingham University Hospitals NHS Trust along with the information collected from you and your medical records. The only people in Nottingham University Hospitals NHS Trust who will have access to information that identifies you will be people who need to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

[NHS/ other site] will keep identifiable information about you from this study for a minimum of 15 years after the study has finished.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.
Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.