Fair Data Processing statement for study website (21/07/2017)

Thank you for taking part in the study: - **Liver transplantation as treatment for patients with hepatocellular carcinoma (HCC); a study using existing electronic data.** The study aim is to maximise the benefit of liver transplantation as a treatment option for patients with liver cancer.

The study aims to collect information (data) about you and we wish to clarify the organisations involved and what we do with the data.

The Clinical Effectiveness Unit (CEU) based at The Royal College of Surgeons (RCS) requires linked data from three large national databases containing information on all patients in the last two decades who have had HCC (HCC being the most common type of liver cancer) and of those patients who have subsequently received a liver transplantation.

We expect to include about 70,000 patients with HCC and about 17000 patients who underwent liver transplantation. Currently, about 2000 patients are being diagnosed annually with HCC in England and about 150 of these have a liver transplantation as their primary treatment.

The CEU is a collaborative research unit formed from both the RCS and London School of Hygiene & Tropical Medicine (LSHTM) and therefore both RCS and LSHTM are joint data controllers. The project is funded by the NIHR as part of a Doctoral Research Fellowship (DRF) grant.

The databases include (a) the liver cancer dataset, managed by the National Cancer Registration and Analysis Service (NCRAS) and used to identify all patients with HCC in England (b) the Hospital Episode Statistics (HES) database, managed by NHS Digital and used to determine comorbidities, treatments and outcomes, and (c) the UK Liver Transplant (UKLT) Registry, managed by NHS Blood and Transplant (NHSBT) and used to evaluate the outcome of liver transplantation.

NCRAS is run by Public Health England and is responsible for cancer registration. The UKLT Registry is run by NHSBT who manage blood and platelet donation, and organ, stem cell and tissue donation and transplantation.

The datasets from each of the following national databases are to be linked by NHS Digital: -

Liver cancer dataset: - records of patients diagnosed with HCC between 1996 and 2015, including date of diagnosis, TNM stage, cancer morphology, and treatment indicators will be used, including already linked: Chemotherapy (SACT) and Radiotherapy (RTDS) datasets supplied from NCRAS.

UK Liver Transplant (UKLT) Registry: - records of all patients who received a liver transplant since 1994 and all patients on the liver transplant waiting list, including 'standard liver dataset' and 'waiting list data', supplied from NHSBT.

Hospital Episode Statistics (HES) datasets (Admitted Patient Care (APC), Outpatients (OP), Critical Care (CC), Accident and Emergency (A&E) supplied from NHS Digital and ONS Mortality Data supplied by the Office for National Statistics via NHS Digital.

To obtain information from NHS Digital, NCRAS and NHSBT will need to provide them with your NHS number, date of birth, postcode, gender and your unique Liver Cancer or Liver Transplant person ID.

Information is collected from patient hospital records and national death records. The final linked dataset to be used by the study researchers contains **no data items** that could be used to directly identify individuals. Individual patient level data and will be stored in a secure environment at the Clinical Effectiveness Unit (CEU).

All relevant patients can opt to have their information removed from this project either at the time of listing for liver transplantation or at the point of NHS contact in the secondary care setting. However, you can always opt out if you no longer wish that we link your data obtained for this study with data held by these organisations. Contact details for opting out are listed below.

Outputs from this project will be displayed in an 'aggregate' non-identifiable format and will consist of publications to peer reviewed journals and presentations to patient groups, healthcare professionals and the international research community. When presenting information in research articles your personal information is never revealed.

If you have any other questions or wish to opt out, please contact **David Wallace (Tel: 020 7869 6600 or Email: david.wallace@lshtm.ac.uk)**