



The UK Collaborative HIV Cohort (CHIC) Study: Patient Information

THIS CENTRE CURRENTLY CONTRIBUTES TO THE UK CHIC STUDY, SO HERE IS SOME INFORMATION YOU MAY LIKE TO KNOW ABOUT THE STUDY:

What is the UK CHIC study?

Set up in 2001, the UK CHIC study has produced many important studies that have helped to guide the care of HIV positive individuals in the UK. The study makes use of data that are routinely collected in several HIV centres across the UK and is led by a team at the University College of London and the Medical Research Council Clinical Trials Unit. The study contains information on approximately 40,000 people with HIV who have attended for care since 1996.

What data are used and how?

Each year, participating centres send a dataset about their patients to the study co-ordinating team. This dataset contains all routinely collected information regarding antiretroviral treatment, CD4 cell counts, viral loads, survival, diseases and drug side effects. The dataset includes a clinic identifying number as well as an encoded version of a patient's name and first initial. This dataset is securely stored at the Medical Research Council Clinical Trials Unit and contains only enough patient identifiable data to allow the removal of errors in the dataset and to ensure patients aren't entered into the study twice.

Once any errors are removed, a duplicate dataset is created which removes patient identifiers and replaces them with a pseudonym or 'false name'. This means that by the time UK CHIC researchers get to see the data there are no patient identifiers other than gender and year of birth remaining. Sometimes researchers outside of the UK CHIC study may ask to use this data. Before this is allowed, a steering committee of consultants and a patient representative must approve the proposed research, and if approved, access will only be granted to the parts of the data relevant to the specific research question.

How are the data kept safe?

The dataset is encrypted before being uploaded onto a secure Medical Research Council server. Only one or two UK CHIC data managers who remove errors from the data have access to this version.

By removing original patient identifiers and giving each patient a pseudonym, we ensure that UK CHIC and other researchers have no information that could lead back to a patient's identity.

The encrypted dataset is stored for no longer than 2 years.

Do I need to give consent?

When the UK CHIC study was set up, the question of patient consent was carefully considered. The Medical Research Ethics Committee decided that patients did not need to give consent for their data to be re-used by UK CHIC because:

- The study makes minimal use of person identifiable data so **does not put patients' privacy at risk**
- The study does not influence patients' clinical care

The UK CHIC team understands the need to protect patient's data, so that they can only ever be used by the right people for the right purpose. A strict data protection policy was devised in 2007 and revised in 2011 with guidance from experts in data protection at the Medical Research Council and the British Medical Association.

If you want to know more about the UK CHIC, its research or its data protection visit www.ukchic.org.uk, or you can email us at ukchic@ctu.mrc.ac.uk.