

HIV RESEARCH AT THE ROYAL FREE: THE ROYAL FREE HIV COHORT STUDY

Why is HIV research needed?

Research into HIV contributes greatly to improvements in health and outcomes for people living with HIV. Much of this research is based on information from routine hospital records. This routine information is analysed to help answer questions about HIV care and treatment. The information helps to improve future care for people with HIV.

What is the Royal Free HIV Cohort Study?

A study of people with HIV who attend this clinic – the Ian Charleson HIV clinic.

Who is running the study?

The study is run by a team of UCL university researchers, along with the HIV clinic team. The university researchers work in the Royal Free Hospital and are in the Centre for Clinical Research, Epidemiology, Modelling and Evaluation (CREME), within the UCL Institute for Global Health.

What information is collected and what happens to it?

Only information already recorded as part of your HIV care is collected, such as HIV treatments received and test results. This information from everyone attending the Ian Charleson Centre is put together to create the Royal Free HIV Cohort Study. The data is analysed by UCL researchers working in the Royal Free Hospital. No individual can be identified during the analysis or when any results are presented. The data is only analysed for groups and not for individuals.

Is any personal information collected?

Yes, but we do NOT collect your name or address. We collect some personal information, such as your hospital number, NHS number, and date of birth, so we can link data from the clinic with hospital test results. All personal information is removed as soon as this linkage is done. The linkage is done inside a completely secure UCL system – one which meets the international information security standard, known as ISO 27001.

How do the results get presented?

The findings are submitted to medical journals and national and international health conferences. You can find out information on the study and research findings on our website:

<https://www.ucl.ac.uk/rfhcs>.

Who do I talk to if I have questions or concerns about this?

If you have any concerns or questions please discuss with your doctor or nurse.