

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

Why is HIV research needed?

HIV research is important. It is through research that we develop better treatments, as well as improve diagnosis, prevention, care and quality of life for everyone living with HIV. Much of this research is based on information from routine hospital records, which is analysed to help answer questions about HIV care and treatment. The information helps to shape future care for people with HIV.

What is the Royal Free HIV Cohort Study?

The Royal Free HIV Cohort Study (RFHCS) is an ongoing prospective study of individuals attending the Royal Free Hospital for HIV care. It addresses research questions relating to diagnosis, treatment, prognosis, management and experience of individuals living with HIV. Over 7000 individuals who attend the Ian Charleson Day Centre (ICDC) HIV are part of the study.

Who is running the study?

The study is run by a team of UCL (University College London) researchers and ICDC clinic staff at the Royal Free Hospital.

What information is collected?

Only information already recorded as part of your HIV care is collected, such as HIV medication and test results. This information is collected from everyone attending the Ian Charleson Day Centre and collated to create the Royal Free HIV Cohort Study.

Is any personal information collected?

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

What happens to the information?

Once all the personal information has been removed, the data is analysed to produce important evidence-based statistics about people living with HIV. The data is only analysed for groups and not for individuals. Even though no individual can be identified, the dataset is always stored and used according to strict security protocols.

How do the results get presented?

The findings are submitted to medical journals and national and international health conferences. Summaries of the research and a list of publications is available on the website for the Royal Free HIV Cohort Study (<https://www.ucl.ac.uk/rfhcs>). This information helps to improve the care given to people with HIV.

What if I want to opt-out of this study?

Everyone has the right to opt-out of the study. You can opt out at any time. If you have any questions, or you want to opt-out, please tell your ICDC doctor or nurse. They will give you an opt-out form to complete if you decide you do not want your data to be included.