

What if I don't want my data included in this project?

You have the right to opt out of your data being included in this research project. This will not impact the care you receive in any way.

If you have any questions or would like to notify us that you do not wish to have your records in CRIS and/or linked with the HARS datasets, please contact:

Address: CRIS Administrator, BRC Nucleus, Mapother House, South London and Maudsley NHS Foundation Trust, Denmark Hill, London, SE5 8AZ

Email: cris.administrator@slam.nhs.uk

Telephone: 020 3228 8553



Where can I find out more?

To find out more, please visit:

www.maudsleybrc.nihr.ac.uk/cris

www.slam.nhs.uk/about-us/privacy-and-gdpr

www.gov.uk/guidance/hiv-surveillance-systems

CRIS is a project supported by the National Institute for Health Research (NIHR) Maudsley Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London.

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Research Project: Severe Mental Illness and the Human Immunodeficiency Virus (HIV)

HIV in people with severe mental illness is an incredibly under researched area in the UK. We aim to conduct a programme of work which will investigate HIV in people with severe mental illness. In order to do this we have linked mental health data from the South London and Maudsley NHS Foundation Trust with information from HIV clinics held by Public Health England to create an anonymous dataset for research.

This data linkage provides a resource for investigating the health care of people with HIV and mental disorders. This research project has the potential to highlight areas of need in treatment and prevention of HIV in people with severe mental illness.

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What is the purpose of the project?

HIV (Human Immunodeficiency Virus) is an illness that damages the cells in your immune system and weakens your ability to fight everyday infections and disease. If it is not treated properly, it can have very negative health effects. There is currently no evidence in the UK on how having HIV and a severe mental illness might complicate health and treatment. Therefore, we aim to conduct a programme of work that will explore a number of factors including; estimating the number of people with HIV and severe mental illness, what challenges people face, and if there are better ways to treat and manage HIV.

What data is being looked at?

Data relating to mental health care from the South London and Maudsley NHS Foundation Trust (the Trust) and sexual health care data from the HIV and AIDS reporting system (HARS) provided by Public Health England is being examined. Mental health data from the Trust is contained in a computer system specifically designed for research called CRIS (Clinical Record Interactive Search). Once the data has been linked, all identifiable information is removed or masked by the computer before any researcher uses the data. This means that there are no names, addresses, or dates of birth in the dataset.



Whose data is being included?

Data from people who have had contact with the Trust since 2006 and have a diagnosis of HIV will be included in the study. We will also be including data from people who have HIV but have not had contact with the Trust and live in four London boroughs: Lambeth, Southwark, Lewisham, and Croydon.

Who can access this data?

The data are only available to approved researchers who have a contract with the Trust.

Can my doctor or nurse access this information?

No, this data is only available to researchers and will not affect the care you receive.

Can researchers see personal information about me?

No, data are transformed so that it is anonymous. There are no names, addresses, or dates of birth in the dataset once the data has been linked.

How is the data protected?

This project has received approval from an independent research ethics committee. The data linkage will be conducted by Public Health England. In order to carry out the linkage we use identifiable information (for example surname and date of birth). Once records have been linked all identifiable information is destroyed and the data are fully anonymised prior to being accessed by researchers. This linkage has been legally permitted by the Health Research Authority under section 251 of the NHS Act 2006. This approval enables temporary use of identifiers for accurate linkage. The information in the database is protected by strict information security. It cannot be accessed or taken outside the Trust in any form.

