What can I do if I want to find out more?

We are keen to share information about CRIS with service users, carers and staff. We hold open sessions to discuss CRIS with anyone who wants to know more. Information about these sessions can be found on our website:

www.maudsleybrc.nihr.ac.uk/CRIS

You have the right to opt out of your data being included in CRIS. This will not impact the care you receive in any way. If you have any questions or concerns, or if you would rather not have your records in CRIS and/or linked with external datasets, please speak with your mental health worker, or contact us at:

CRIS Administrator

Centre for Translational Informatics Institute of Psychiatry, Psychology & Neuroscience King's College London 16 De Crespigny Park, London SE5 8AZ

Email: cris.administrator@slam.nhs.uk

A Data Controller is the individual or organisation who controls and is responsible for how data is kept and used. South London and Maudsley NHS Foundation Trust (the Trust) is the Data Controller for CRIS. The Trust has a Privacy Notice which describes how data is kept and used in the organisation and your legal rights with regards to your data. This can be viewed on the Trust website:

www.slam.nhs.uk/personal-information-gdpr

CRIS is a project supported by the National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre, which is part of the NIHR and hosted by South London and Maudsley NHS Foundation Trust in partnership with King's College London.







How we use health records for research

The Clinical Record Interactive Search system, known as **CRIS**, is a computer system that allows us to carry out research using information from the Trust's clinical records.

CRIS is safe and secure. It does not reveal service users' personal details to Trust researchers.

CRIS makes a real and positive difference to future mental health treatments and care. Our aim is to put research at the core of everything we do, so we can continually improve our clinical care.

slam.nhs.uk /research

Version 1, 27/02/2024

What does CRIS help with?

CRIS helps us to look at real life situations on a large scale This means it's easier to see patterns and trends – e.g. what works for some patients and doesn't for others.

We may link information about your treatment and care in the Trust with other information sources relevant to your healthcare, this is called a data linkage. This will help to improve physical and mental health as a whole.

For example, information about patients who had both a mental health condition and cancer was linked to look at the impact of mental illness on cancer survival rates.

We have also created a linkage with local GP records to help us learn how to improve the physical health of patients.

We've explored:

- How do physical health conditions and medications affect people with Alzheimer's disease?
- Should pregnant women continue to take mental health medications?
- How do mental health conditions in children and teenagers affect their school performance?

How are your personal details protected?

CRIS transforms clinical information so that it is anonymous. Your clinical details can be used in research, but your personal details cannot. CRIS removes or covers up any information that can identify you. Your name, the name of your carer, your full date of birth, address, postcode and phone numbers are replaced with 'ZZZZZ' like this:

December 06 ZZZZZ ZZZZZ ZZZZZ ZZZZZ ZZZZZ Dear ZZZZZ Re: Anger Management Group I am writing to confirm that the next Anger Management Group will commence on Wednesday 27th December 2023 for 10 weeks.

In order to carry out data linkages we sometimes need to share identifiable information (for example NHS number, name, and date of birth) to trusted third parties, such as NHS England who supply information on general hospital care.

Data linkage with external organisations is 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. This is always done in a secure environment. Once records have been linked. all identifiable information is destroyed and the data are fully anonymised prior to it being used for any research. Patients who have chosen to opt out via the NHS National Opt-Out system are excluded from these linkages (Visit www.nhs.uk/your-nhs-datamatters for more details).

Full information on all data linkages with CRIS can be found on our website:

www.maudsleybrc.nihr.ac.uk/crisdata-linkages

CRIS has received ethical approval from an independent (non-Trust) research ethics committee, as a safe, secure and confidential information source for research.

We will continue to maintain approval from an independent research ethics committee. This is to make sure that the security of your information and your confidentiality is always protected.

Who can access CRIS?

CRIS is available only to researchers who have a contract with the Trust. These researchers might work in collaboration with other organisations (both 'not-for-profit' and 'for-profit'). The information in CRIS is protected by strict Trust information security.

How will CRIS affect individual care delivery right now?

We believe CRIS can make a real and positive difference to future treatments and care. However, the research made possible by CRIS is unlikely to impact directly on care right now.

