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 are holding a series of 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.

Alternatively, if you have any questions, or if you would rather not have your records in CRIS and/or linked with external datasets, please contact:

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

Email: cris.administrator@slam.nhs.uk
Telephone: 020 3228 8553

A Data Controller is the individual or organisation who controls and is responsible for how data is kept and used. The South London and Maudsley NHS Foundation Trust (SLaM) is the Data Controller for CRIS. SLaM 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 SLaM website: www.slam.nhs.uk/about-us/privacy-and-gdpr.

Introducing CRIS

We have developed a computer system that allows us to carry out research and Trust audits using information from the Trust’s clinical records.

We call this system CRIS: the Clinical Record Interactive Search system.

CRIS is safe and secure. It does not reveal your personal details to Trust researchers.

We believe CRIS can make a real and positive difference to future treatments and care.
What sort of things will CRIS help with?

CRIS helps us to look at real life situations in large quantities. This means it’s easier to see patterns and trends – e.g. what works for some and doesn’t for others.

We may link information about your treatment and care in the Trust with other aspects of your healthcare. This will help to improve physical and mental health as a whole. As an example, information about patients who had both mental health illness 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 with severe mental illness.

Here are a few of the things we’ve been looking at so far:

- How do physical health conditions and medications affect people with Alzheimer’s disease?
- Should women continue to take mental health medications during pregnancy?
- 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. The computer 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 ZZZZZZ
ZZZZZ Dear ZZZZZ Re: Anger Management Group I am writing to confirm that the next Anger Management Group will commence on Monday 14th January 2013 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 Digital.

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

www.maudsleybrc.nihr.ac.uk/cris-data-linkages/

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. It cannot be accessed or taken outside the Trust in any form.

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.

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.