HOW WILL MY DATA BE DE-IDENTIFIED?

CRIS transforms clinical information so that service users' clinical details can be used in research but personal details cannot. Information that could directly identify you is replaced with nonsense data. This process is called de-identification. For example, your name, date of birth, address, NHS number etc are replaced with the letters 'ZZZZZ'. Researchers accessing data would only see information which has been de-identified in this way which makes it very difficult to identify an individual.

This is an example of how the de-identified information would appear:

'January 6 2014 ZZZZZ ZZZZZ ZZZZZ ZZZZZ
Dear ZZZZZ Re: Mindfulness Group, I am writing to confirm that the next group will commence on Monday 3 February 2014 for 10 weeks.'

RE-IDENTIFICATION

The CRIS system keeps a separate 'look-up' table so that the Trust can re-identify patients where there is good reason to do so, including to ask patients if they would like to participate in a study, or where there is a clinical need. For example, if new research shows that a drug is unsafe when combined with another drug, CRIS can be used to identify where a patient is on both medications, and allow re-identification so that the patient's doctor can contact them.

Re-identification must be authorised; researchers are unable to do this without the Trust's approval.

CAN I OPT OUT?

Whilst we fully believe that the CRIS system will make a real difference to improve the services and treatments we provide, we understand that some people might have reservations about their data being used in this way.

Patients can opt out at any point and their data will not be transferred or if already transferred, will be removed from use. To opt out please email CRISOptOut@sussexpartnership.nhs.uk or speak to you lead practitioner. Your care will not be affected in any way. Please note, this is different to the GP data opt out (type 1 opt out) scheme.

Additionally, there is a national NHS data opt out which enables patients to stop their confidential patient information from being used for research and planning. If you choose to opt out of the national service, you will automatically be opted out for the CRIS system. For more information, go to www.nhs.uk/your-nhs-data-matters.

FOR MORE INFORMATION

If you have any questions or concerns about this project, please contact us at: CRISOptOut@sussexpartnership.nhs.uk or go to www.sussexpartnership.nhs.uk/CRIS.

This document is available in alternative formats on request, such as large print, easy read electronically or another language. Please email communications@sussexpartnership.nhs.uk.

NHS

Sussex Partnership
NHS Foundation Trust

HELP MAKE A DIFFERENCE TO THE FUTURE OF MENTAL HEALTH SERVICES IN YOUR AREA

Sussex Clinical Records Interactive Search (CRIS) System

Sussex Partnership is joining the Sussex Clinical Records Interactive Search (CRIS) System, a computer information system that will allow us to carry out research, assess the effectiveness of our treatments and identify ways we can improve our services.

The CRIS system will process our electronic clinical notes and records, de-identifying them so that we are able to look at real life situations and cases, without breaching patient confidentiality. Using this tool will allow us to see when there are patterns and trends emerging in mental health, service use and treatments. Our researchers will be able to use your data to help expand our understanding of medical conditions, and improve the treatments and services that are being provided by the NHS and other organisations.

WHAT IS CRIS?

We hold an electronic record of anyone who is using or has used our services. The CRIS system will use these records and remove all information that may directly identify a person (names, addresses, telephone number) and only allow access to de-identified data, such as symptoms and demographic information (age, gender and ethnicity) to be used for the purpose of research, audit and quality improvement.

On top of this, CRIS is able to identify key 'concepts' in free-text clinical notes, things like drug names, dosage, symptoms and diagnosis. This data is very useful to researchers and would otherwise be inaccessible.

WHAT ARE THE BENEFITS OF USING CRIS?

Approved studies can use CRIS to gain access to information collected routinely by the Trust. This enables clinical researchers to base their analyses and recommendations on large complete sets of real life data, which allows in depth evaluation of medical conditions and treatments and supports our services to plan accurately for treatments that meet our current and future patient needs.

EXAMPLES OF STUDIES USING CRIS

We believe CRIS can make a real and positive difference to future treatments and care. Looking at information available from a lot of different patients and services makes it easier to see patterns and trends; what works for some and does not for others. Here are some things that have been looked at using CRIS systems in other Trusts:

- Is there a test for those with Alzheimer's disease that can show if medication would be the best course of treatment?
- Do some drugs for schizophrenia affect physical health, for example diabetes?
- Do people's home living arrangements affect how long they spend in hospital wards?

IS THE DATA SAFE AND HOW IS IT BEING PROTECTED?

The information in CRIS is protected by strict information security and by law. NHS organisations store information on a dedicated national computer network called the Health & Social Care Network (HSCN) - your personal data will not leave this network. CRIS has also received ethical approval from an independent committee as a secure and confidential information source for research and is already running safely at different NHS Trusts in England.

CRIS will only be available for use by researchers who are working with Sussex Partnership on approved projects. These researchers may work within the Trust and/or in other collaborating organisations.

The Trust has also set up an Oversight Committee, consisting of clinicians and service users, to direct and regularly review the way CRIS is being used.