

Data Linkage Service User Advisory Group Newsletter

Issue 2, July 2016

Group Updates

First Meeting

Thank you to everyone who came along to our first proper meeting last month! At the meeting we heard from Professor Rob Stewart, who talked about why health data is useful for research as well as the role of patient and public involvement in our research, and Dr Murat Soncul, who gave us an introduction to Information Governance in the Trust. We also heard about a proposed project which aims to link mental health data with data from a national audit of heart attacks, and the group gave their thoughts and feedback on this project.

Recruiting Additional Members

We are looking to recruit additional members to the group, if you know of anyone who may be interested in joining then please feel free to pass on details of the group and they can contact us on the email address/ phone number below if they would like further information.

News

CRIS Blog

Dr Richard Hayes, Senior Lecturer at Kings College London, has written an interesting blog piece for the BRC website about investigating the impact of antipsychotic medications using CRIS and linked data from general hospitals. If you would like to read the post it can be found here:

<http://www.maudsleybrc.nihr.ac.uk/about-us/news-events/cris-blog-investigating-the-impact-of-antipsychotic-medications-used-to-treat-people-with-serious-mental-illness/>

FAQ

What is the Clinical Records Interactive Search (CRIS) system?

The CRIS system has been developed for use within the SLAM Biomedical Research Centre (BRC). It provides authorised researchers with regulated, secure access to anonymised information

extracted from SLaM's electronic clinical records system. CRIS helps us to look at real life situations on a large scale. This means it's easier to see patterns and trends, like what treatments work for some and don't work for others. Applications to access CRIS and the analyses carried out using CRIS are closely reviewed and monitored by an Oversight Committee, which is chaired by a service user. The Oversight Committee is responsible for ensuring all research applications comply with ethical and legal guidelines. The data is used in an entirely anonymised and secure format and all patients have the choice to opt-out of their anonymised data being used.

Why is Patient and Public Involvement (PPI) important in research?

Patient and Public Involvement (PPI) is important in improving the research we do at the BRC. PPI can offer unique and invaluable insights and by involving service users, carers and the public in our work we can help keep research relevant, make studies more effective, and encourage researchers to consider the patients' perspective when conducting research.

What impact does data linkage research have?

The data linkage research we do within the BRC will not have a direct impact on any one service user; this is because the data we use is fully anonymised so we don't know who the people are whose data we are using. Instead the research that is carried out can help to evaluate current services and make improvements where necessary, as well as adding to larger bodies of research which can directly impact policy and decision making within the area of mental health.

Upcoming

Next Meeting

The next meeting will be held on **Thursday 15th September**, from **4.30-6pm** at the BRC Nucleus Meeting Room. We look forward to seeing you then!

Future Newsletters

If there is anything that you would like to see in future newsletters or if you would like more information about something mentioned in a newsletter, you can contact Amelia or Megan via email: amelia.jewell@slam.nhs.uk / megan.pritchard@kcl.ac.uk, or phone: 020 3228 8554.