Maudsley
Biomedical Research Centre
Dementia Biomedical Research Unit

NHS
National Institute for
Health Research

Data Linkage Service User Advisory Group Newsletter

Issue 12, January 2018

Group Updates

Happy New Year

We hope you all had a fantastic Christmas and New Year! We are looking forward to continuing to work with you all over the next year!

Next Meeting

The next meeting will be held on Thursday 8th March from 4-6pm. We will send out an agenda the week before which will confirm which room in the Institute of Psychiatry, Psychology and Neuroscience building the meeting will be held in.

Research Spotlight

In each newsletter we will highlight recent research that has been conducted using linked data, if you would like to know more about any particular piece of work please let us know.

Linking Health and Education Data to Plan and Evaluate Services for Children

As some of you may already be aware CRIS has previously been linked to the National Pupil Database (NPD). The NPD contains information about pupils and students' educational performance, including information about test and exam results, special education needs, absences, and exclusions. The project to link CRIS with the education data was led by Dr Johnny Downs, who has presented to the group a couple of times in the past for various projects. Last year Johnny published a paper describing the linkage between health and education data, focusing on how this linkage can be used to evaluate the mental health services available for children.

As most of you are aware, the CRIS system was set up 10 years ago by the Maudsley Biomedical Research Centre (BRC) to enable research using deidentified information from the SLaM clinical record. CRIS has strict governance and security controls which are maintained by a service user led Oversight Committee. The CRIS system contains detailed information on mental health, including, for example diagnoses, appointments attended, outcome measures (such as Strength and Difficulties Questionnaires), risk assessments, and substance misuse.

The education data (NPD) is looked after by the Department for Education, it provides in depth information on childhood development and education, including indicators of ability (through

teacher based assessments and standardised tests or exams), special education needs such as physical problems like deafness and visual impairment, episodes of exclusion or absenteeism, and some information on social care, for example details of children place into out-of-home care.

The linkage between CRIS and the NPD took around 3 years to complete and involved applying for appropriate ethical and legal approval. The linkage itself was conducted by the Department for Education. The linked data is now stored within the South London and Maudsley NHS Foundation Trust and access to the data for research is provided only to researchers who have a project approved by the CRIS Oversight Committee and the Department for Education.

This linked data provides detailed information on patient pathways and can help to identify inequalities in services. It can be used to help flag gaps in existing healthcare provision and direct where new services are needed. Linkage of data from schools to mental health services offers the opportunity to study and target school-based prevention strategies. Findings can be used to prioritise schools which require help with developing preventative strategies. In the UK, there is a distinct lack of research into the link between educational achievement, self-harm and the potential impact of school-based interventions, this data provides an opportunity to study this better.

If you would like to know more about this linkage you can access the full article here: https://kclpure.kcl.ac.uk/portal/en/publications/linking-health-and-education-data-to-plan-and-evaluate-services-for-children(357849f2-98d9-4f1f-bed7-6a4c3805d16f).html

Work has been on-going using the linked mental health and education data. We will provide updates in future newsletters on the projects using this linkage as and when they are published.

Upcoming

Next Meeting

The next meeting will be held on **Thursday 8th March**, from **4-6pm**, in the Institute of Psychiatry, Psychology and Neuroscience. 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.