Maudsley
Biomedical Research Centre
Dementia Biomedical Research Unit

NHS
National Institute for
Health Research

Data Linkage Service User Advisory Group Newsletter

Issue 5, November 2016

Group Updates

Reminder, We Need Your Feedback

You may remember from the last newsletter that we are hoping to get some feedback from our members about the format of the meetings. If you have any general comments or would like to answer any of the below questions please feel free to email either Amelia (amelia.jewell@slam.nhs.uk) or Megan (megan.pritchard@slam.nhs.uk).

1. Do you think the presenters described their data linkage projects clearly? If not, what do you think would have helped?

2. Do you feel satisfied with the structure of the meeting i.e. short presentation followed by a discussion? If not, what do you think could be made better?

3. Do you feel able to share your ideas or suggestions that you have during group discussions? If not, what would help you feel more able to share your thoughts?

4. Any other comments?

News

Opportunity to take part in a workshop

Do you have thoughts and ideas about how technology could be used to improve mental health services? The South London and Maudsley NHS Trust and King's College London are running a workshop and want to hear your views on how technology can be used to improve mental health.

You don't need to be an expert in IT to attend, just someone with an interest in mental health and technology. The event will take place on Monday 28th November 2016 at 10 Windsor Walk, Camberwell. For more information and to register your interest please see: https://www.eventbrite.co.uk/e/mental-health-technology-ideas-generation-workshop-tickets-29278101590

Research Spotlight

Data Linkage with The Department for Work and Pensions

For this month's research spotlight we wanted to introduce you to a new linkage project, we will be discussing this project in more detail at the next meeting in December. BRC researchers are proposing to link information on employment and the receipt of benefits from the Department for

Work and Pensions (DWP) with mental health data from CRIS. We give some background for why we think this is an important area for future research.

The largest cause of long term occupational disability are mental health disorders. However, the DWP has surprisingly limited information on diagnosis and other clinical information associated with disability related benefits such as Employee Support Allowance. At the same time, health services are unable to state with any degree of confidence whether their interventions have had an impact on a patient's capacity to work.

Mental health researchers interested in studying the occupational impact of mental disorders have no routinely available data. Much of the evidence on mental health and occupational outcomes relies upon information which doesn't sufficiently include people with mental disorders. Health records are an unreliable source of information on benefit receipts or even occupational status, as these are not routinely collected or recorded.

The proposed linkage would be the first between an NHS electronic health record and the Department for Work and Pensions National Benefits Database. By making this linkage we will be able to answer questions of fundamental importance to patients, clinicians and policy makers. These include providing data on which clinical and treatment factors are associated with a good occupational outcome. These questions ultimately may have direct policy implications – for example, if we show some patients do not benefit from the DWP return to work packages, the response from DWP may be to lessen the emphasis on work capability assessments, which may reduce anxiety placed on patients with severe and enduring mental health problems.

We intend therefore to link and fully anonymise mental health clinical data on adults of working age, from the South London and Maudsley NHS Foundation Trust (SLaM) Biomedical Research Centre (BRC) Clinical Record Interactive Search (CRIS) system with data on benefits received from the Department of Work and Pensions (DWP) National Benefits Database (NBD).

Upcoming

Next Meeting

The next meeting will be held on **Thursday 1st December**, from **4.30-6pm**, location to be confirmed. 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.