

Data Linkage Service User and Carer Advisory Group Newsletter

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News

New CRIS Blog

Dr Marcella Fok and Dr Chin-Kuo Chang have written a CRIS blog describing their work using linked data from CRIS and Hospital Episode Statistics (<u>HES</u>) to look at the physical health of people with personality disorders. You can read it <u>here</u>.

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.

An Approach to Linking Education, Social Care and Electronic Health Records for Children and Young People in South London: a Linkage Study of Child and Adolescent Mental Health Service Data

The South London and Maudsley NHS Foundation Trust (SLaM) provide Child and Adolescent Mental Health Services (CAMHS) to a geographic catchment of approximately 190,000 children and young people resident in the four SLaM boroughs - Croydon, Lewisham, Lambeth, and Southwark, as well as highly specialist services that accept referrals from outside of the SLaM catchment area. In 2015, CAMHS data from CRIS was linked to the National Pupil Database (NPD) in order to provide a resource for investigating the relationship between mental health and educational outcomes.

The NPD, held by the Department for Education (DfE), is a pupil-level education database that contains details on personal and school characteristics (e.g. ethnicity, language spoken, type of school attended, etc.) linked to pupils' attainment and exam results over the lifetime of their school attendance. This linkage has been detailed in a recent publication led by Dr Johnny Downs.

The first step in creating the linked data resource involved obtaining the necessary legal and ethical approvals. Gaining the permissions to link the NPD to CRIS was complex as there was no precedent in England for such a linkage. The proposal underwent a robust and lengthy ethical, legal, governance, and technical review conducted by a number of local and national committees within both the NHS and the DfE.

Once all relevant approvals were obtained, the linkage was conducted by the DfE. A cohort of young people aged between 4 and 18 years who were referred to SLaM mental healthcare between 1st September 2007 and 31 December 2013 was identified using the CRIS system. Personal identifiers (i.e. date of birth, name, and address) were extracted and sent securely to the DfE for linkage. The DfE matched these against the NPD personal identifiers and created a unique non-identifiable ID variable for each pupil. NPD data was then sent securely back to SLaM with only the non-identifiable ID variable attached - all personal identifiers were securely destroyed. This matching process achieved an 82.5% linkage rate.

The team compared the demographic (e.g. age and gender), clinical (e.g. diagnosis), and administrative record factors (e.g. was postcode available for matching) between the matched and the unmatched group within the CRIS record. The purpose of this was to determine if there were any significant differences between people who matched to the NPD and people who didn't; as if the two groups were found to be different then this could introduce bias into the research. The team found that individuals who presented to services for the first time during late adolescence or outside of the school census timeframes were less likely to successfully match to the NPD. In order to check if these findings cause any bias, the team conducted an analysis looking at predictors of school absenteeism whilst controlling for the differences between the matched and unmatched group. Reassuringly, they found that linkage biases had little effect in this particular analysis.

The team concluded that linkage between health and education records offers a powerful tool for evaluating the impact of mental health on school function; however, biases due to linkage error may produce misleading results. Therefore collaborative research with the individuals who provide the data is needed in order to develop linkage methods that minimise any potential bias.

If you would like to read the article in full, it is available here.

Upcoming

Next Meeting

The next meeting will be held on **Thursday 20th June**, from **4-6pm**, in Seminar Room 6 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.