

Issue 25 August 2019

News

CRIS Linkage with the HIV and AIDS Reporting System

I am pleased to report that the proposed linkage between CRIS and the HIV and AIDS Reporting System (HARS), led by Dr Margaret Heslin and presented to the group in September last year, has now received ethical approval and provisional [Section 251](#) approval. In order to inform people about the project we have created a patient information leaflet and poster which will be displayed in relevant services around the Trust. We would like to get some feedback on these, if you have a spare few minutes we would really appreciate it if you could take a look and give us any feedback you may have on the design or the wording: www.surveymonkey.co.uk/r/JW9JWXT.

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.

Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study

Javiera Leniz, Irene J. Higginson, Robert Stewart and Katherine E. Sleeman

Dementia brings serious challenges for provision of care near the end of an individuals' life. Care can often become fragmented and people with dementia can experience distressing moves from one care setting to another, these are known as transitions. Transitions near the end of life can lead to physical and cognitive deterioration and many are avoidable. A team at the King's College London [Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation](#) used mental health data from CRIS linked to hospital and mortality data to investigate the frequency of end-of-life hospital transitions and factors associated with these transitions among people with previously diagnosed dementia.

Individuals with a diagnosis of dementia who had died between 2007 and 2016 were included in the study. Hospital data from [Hospital Episode Statistics](#) (HES) were used to identify hospital admissions in the last year of life. Two types of transition were defined: a late transition included any hospital admission in the last three days of life and an early transition included multiple hospital admissions in the last 90 days of life. A number of additional variables, including gender, ethnicity, subtype of

dementia, and dementia severity, were extracted from CRIS so that the team could see if these were associated with end-of-life transitions.

8,880 people were included in the study, of these 1,421 had at least one end-of-life transition. 505 had an early transition, 788 had a late transition and 128 had both types. The team found that individuals who had drinking or drug-taking problems were significantly more likely to have had late transitions. Whilst individuals who lived in a care home were less likely to have had late transitions. With regards to early transitions, people who were male, who had physical illness or disability, and experienced problems with depressed mood were more likely to have had early transitions. Whilst older people and those living in the least deprived areas or in care homes were less likely to have had an early transition.

Within the study, late transitions were more common than early transitions, however, they have decreased over time which may be partly due to policies aimed at improving end-of-life care over the past decade which focus on reducing deaths in hospital. In contrast early transitions showed no reduction and are associated with high levels of hospital use throughout the last year of life.

The team concluded that changes in care and support are required to reduce early end-of-life hospital transitions. High hospital use is associated with early transitions and therefore such changes have the potential to benefit both individuals and the health care system. The study identified a number of characteristics which are associated with early transitions, and these should be used to guide the development of interventions that reduce the reliance on hospital care for people with dementia in their last months of life.

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 12th September**, 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.