

## Data Linkage Service User Advisory Group Newsletter

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Issue 10, October 2017

### Group Updates

#### Next Meeting

Thank you for everyone who came along to our last meeting in September, as agreed previously, the next meeting will be held on Thursday 7<sup>th</sup> December 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.

#### Predictors of Emergency Department Attendance by People with Dementia in their Last Year of Life

Some of you may remember Dr Katherine Sleeman who presented her work on using routinely collected data to understand and improve end of life care in dementia at one of our early meetings. Katherine has recently published a paper on this so we wanted to provide an update on the project and give a summary of the findings from this recent paper.

Most people would prefer to die at home rather than in hospital. Over the past 10 years within the UK there has been a strong focus on good quality end-of-life care and one marker for this is not dying in hospital. By looking at place of death on death records it has previously been found that during the past 10 years there has been a fall in the number of people dying in hospital and an increase in the number of home deaths. However, the place of death does not give any indication about the care received by individuals during their last weeks and months. Visits to the emergency department can be distressing for patients and their families, and a high number of these visits are considered preventable. Therefore the aim of this project was to examine the frequency of visits to emergency departments among people with dementia in the last year of their lives and also to see if they could identify things which may predict whether or not somebody needs to attend the emergency department.

In order to do this, Katherine looked at mental health data from CRIS linked with hospital attendance data (known as Hospital Episode Statistics - HES) and Mortality data provided by the

Office for National Statistics. By linking these three datasets they were able to examine what care was received by an individual in the year prior to their death.

They found that the majority of patients (79%) visited the emergency department at least once during their last year of life and that the number of visits to the emergency department for people with dementia increased over time. They also found that individuals who were living in care homes were less likely to attend the emergency department whilst individuals living in more deprived areas were more likely to have to attend. The team concluded that policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death.

If you are interested in reading this paper in full you can access it here:  
[http://www.alzheimersanddementia.com/article/S1552-5260\(17\)32520-7/fulltext](http://www.alzheimersanddementia.com/article/S1552-5260(17)32520-7/fulltext)

## Upcoming

### Next Meeting

The next meeting will be held on **Thursday 7<sup>th</sup> December**, 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](mailto:amelia.jewell@slam.nhs.uk) / [megan.pritchard@kcl.ac.uk](mailto:megan.pritchard@kcl.ac.uk), or phone: 020 3228 8554.