Learning Disabilities Mortality Review (LeDeR) programme

University of Bristol Bulletin | July 2020

Contents:

LeDeR annual report published

The LeDeR programme produces an annual report every year. Our 2019 report has recently been published and is available at www.bristol.ac.uk/sps/leder/resources/annual-reports/.

Professor Pauline Heslop said: "The disparity between people with learning disabilities and the general population in relation to average age at death, causes of death, and avoidable causes of death remains substantial and urgent action is needed".

A webinar and presentation of the report's findings is here. An easy read copy of the report is here.

The report uses data from deaths reported to the programme up to the end of 2019 and prior to the onset of the COVID-19 pandemic in the UK. It does not include any deaths related to Coronavirus.

NHS England's action from learning report is here. It includes:

- a University of Bristol analysis of COVID-19 deaths to help prevent infections and deaths
- work to increase the uptake of Annual Health Checks to over 75%
- training for 5000 paid and unpaid carers to help them spot the early signs of deterioration in people with a learning disability
- work with the Race Equality Foundation and Learning Disability England to understand why people with a learning disability from BAME backgrounds face barriers in accessing services.

Reviews of deaths related to Covid-19

Our April bulletin reminded reviewers to be sure to include specific information when reviewing any deaths related to COVID19. This includes:

- how the early symptoms of illness were identified and responded to
- the treatment received, including admission to hospital and ITU
- the decision-making processes that guided a person's treatment plan
- DNACPR decisions made and their rationale; and any reasonable adjustments required and made.

It would also be helpful for reviewers to include information specific to risk factors for COVID 19 in the general population: if the person was obese; what, if any, underlying health conditions they had; if they were a smoker; if they had had previous episodes of respiratory disease; if they were being 'shielded'; and if they relied on others to help them to wash their hands and maintain social distance.

Please could we remind you that the best reviews take account of these factors wherever the person is supported - both in the community and in hospital - so that we can fully understand the different aspects of service provision for people with learning disabilities during the pandemic.

Tackling cyber threats in health and care

LeDeR team members recently tuned into a King's Fund web discussion on tackling cyber-threats in health and care, in which a panel of experts from NHS Digital, Imperial College, IBM and an international consultancy considered what we might learn from the Covid-19 situation. The overall theme was that security awareness has not kept up with the pace of digital growth, and the critical importance of this awareness at a time when working from home has created greater dependency on IT and cyber systems.

One key message was the reminder that whether we are working from home or not we are all still "custodians of patient data". It was rather alarming to learn that there had been a 6000% rise in spam phishing in March and April, with "Covid" routinely used as a keyword. A particular danger to guard against in health and care is a threat by hackers to shuffle or add data to records.

In terms of LeDeR this is a good time to remind partners of the importance of maintaining good "cyber hygiene" by not sending patient-identifiable information to our university inbox. We do have a secure nhs.net address for such information (ubh-tr.lederprogramme@nhs.net), and of course the web based platform is fully secure.

Uploading .zip or multiple files to LeDeR's web based platform

A reminder that our platform for notifying deaths is secure: confidential documents should only be viewed within it and not downloaded.

The contents of .zip files, or multiple files, can be easily added to our system.

To upload the contents of a .zip file, please first unzip it/extract its files; it's then possible to select multiple documents after pressing the "Browse..." or "Choose Files" button.

New LeDeR web based platform

NHS South Central and West (SCW) have been appointed to develop a new web-based system to support the LeDeR programme. The new platform is expected to be live in June 2021.

The development will be informed by a Technical Reference Group which includes representatives from key user groups including people with lived experience.

SCW will provide regular updates on the development's progress throughout the coming year. In the meantime if you have any queries or enquiries please contact Jim Atkinson on jim.atkinson@nhs.net or Paul Cavil paul.cavill@nhs.net.

Get this LeDeR bulletin sent directly to your inbox

If you've been forwarded this bulletin by a colleague, or friend, and want to have LeDeR bulletins sent direct to your inbox, you can add your name to our database by emailing the LeDeR team at the University of Bristol.

The next LeDeR monthly bulletin will be sent out on 23rd August 2020. Please email leder-team@bristol.ac.uk with any information to include by 9 August 2020.