

Learning Disabilities Mortality Review (LeDeR) Programme

- Update from the University of Bristol's LeDeR Team

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The LeDeR team at the University of Bristol are currently hard at work Update from the University of Bristol's LeDeR Team University of Bristol are developing the analysis that will underpin this year's LeDeR Programme annual report and preparing for the transition from the current notification system to the new web-based platform being developed by the South, Central and West Commissioning Support Unit.

The University of Bristol is just one of the partners in the Learning Disabilities Mortality Review (LeDeR) programme and, since the programme's inception in 2015, has played a key role in recording, managing and analysing programme data in order to make important service improvement recommendations to NHSE.

The University of Bristol's contract with the LeDeR Programme is due to come to a planned end on 31 May 2021.

Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

The new [LeDeR policy](#) has just been published. Importantly, the policy sees the responsibility for making sure that actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality moving from clinical commissioning groups to integrated care systems. Update from NHS England & Improvement

The policy has been co-produced with bereaved family members, people with a learning disability, health and social care professionals and people from across the LeDeR workforce.

In addition to the publication of the new Learning Disability Life and Death Review (LeDeR) programme policy, NHSE&I have provided a wider update on the programme:

- The contract with the University of Bristol to support LeDeR is due to come to an end 31 May 2021.
- A new LeDeR website and web-based platform for the management of reviews are currently being developed by South Central and West CSU and will be in place by 1 June 2021.
- The LeDeR web-based platform development is currently in private beta phase, and user testing has commenced.
- South Central and West CSU is developing comprehensive training to support the LeDeR workforce in implementing the new policy and using the new platform, which will be available before the platform launches.
- The transition to a new web-based platform should not impact on the completion of LeDeR reviews that are currently in progress.
- Deaths notified after the 1st March will be transferred to the new web-based platform when it is launched and reviews will be completed within six months of being notified.
- The annual LeDeR report from the University of Bristol is due to be published in late Spring 2021 along with the NHS England and NHS Improvement Action from Learning Report

- A tender is currently out to seek a new partnership of academics and quality improvement partners to support the National Learning Disability and Autism Programme including the analysis and ongoing examination of LeDeR data and promoting service improvement across the NHS and social care. It is currently anticipated this will be in place from June 2021.

SCW (South, Central and West Commissioning Support Unit) continues the development on the new web-based platform for the LeDeR programme, through a series of phases, which will deliver a product ready for use. We are working with people who already use the current system to test the new system, to ensure it will be easy to use when launched. SCW are working closely and effectively with the University of Bristol and NHSE to ensure a smooth transition, including an agreed transition plan and data transfer processes. The new web-based platform will be available by June 2021.

The Care Quality Commission (CQC) recently released a review of ‘Do not attempt cardiopulmonary’ (DNACPR) decisions during the coronavirus (COVID-19) pandemic. The report, titled [Protect, respect, connect – decisions about living and dying well](#), is available to download from the CQC website. Report findings include worrying variation in people’s experiences of do not attempt cardiopulmonary resuscitation (DNACPR) decisions during the pandemic. And, while there were some examples of good practice, some people were not properly involved in decisions, or were unaware that such an important decision about their care had been made.

Resources

Inclusion North, Dr George Julian and the Stop People with a Learning Disability Dying Too Young Group have created new Easy Read resources to support people with a learning disability and their families to understand what a coroner does, what an inquest is, and why the deaths of people with a learning disability are reported to a coroner less frequently. These Easy Read resources as well as short videos can be found on the Inclusion North website: https://inclusionnorth.org/our_work/stop-people-dying-too-young-the-leder-programme/

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 in April 2021. Please email leder-team@bristol.ac.uk with any information to include by 15 April 2021.

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