

Publications approval reference: PAR0028

To: CCG chief clinical officers
Directors of nursing

Ray James
National Director for
Learning Disabilities
NHS England and NHS Improvement
Skipton House
80 London Road
London
SE1 6LH

[t](#)

27 July 2020

Dear colleagues,

Re: The Learning Disability Mortality Review (LeDeR) programme 2020/21

You will be as concerned as I am about the continued health inequalities for people with a learning disability and wish to find ways to improve services to reduce premature mortality. LeDeR is a service improvement programme focussed on reducing health inequalities. It is about local systems, commissioned by clinical commissioning groups (CCGs), putting into action the changes that have been identified as important to reduce premature mortality and health inequalities for people with a learning disability. The NHS is committed to the LeDeR programme for at least the next five years and now more than ever, as a result of the COVID-19 pandemic, we need to ensure that we properly understand the circumstances leading up to a person's death and whether there are things that we could do differently to prevent deaths in a future wave of coronavirus.

This letter clarifies the expectations of CCGs and sets out national delivery arrangements for the LeDeR programme for 2020/21.

Expectations of CCGs

[NHS operational planning and contracting guidance](#) sets out the expectation of CCG's in the delivery of the LeDeR programme (see appendix).

The reviews of all eligible deaths notified to the LeDeR programme before 30 June 2020 are expected to be completed by the end of December 2020. CCGs should be developing plans now to achieve the 100% completion rate by December 2020.

Support for LeDeR reviews

As well as the additional capacity brought in to support CCGs via North of England Commissioning Support Unit (NECS) we are looking at how returning clinical staff, including experienced learning disability nurses, could be asked to support CCGs to deliver reviews. Additional money will be made available to support CCGs to complete the increased number of reviews as a result of COVID-19.

LeDeR annual reports

CCGs were expected to have published their annual LeDeR reports by the end of March 2020, however, we are aware that many were unable to do so as a result of COVID-19. CCGs are therefore now expected to publish their reports before the end of September 2020.

Black, Asian and minority ethnic (BAME) lead for every LeDeR steering group

Every LeDeR steering group is required to identify a BAME lead to ensure meaningful engagement with established local BAME networks, raising the profile of LeDeR and supporting people to overcome barriers to accessing services.

Engaging primary care

CCGs have a crucial role to play in ensuring that GP practices are aware of LeDeR and either release clinical notes to reviewers or have a meaningful conversation to give them the content of the notes. Without the cooperation of primary care LeDeR reviews cannot be completed. Some GP practices have expressed concerns about their ability to share this data. You should reassure them that the CAG S251 approval permits this data to be shared and encourage them to do so.

If you have any questions or queries about the LeDeR programme please email england.lederprogramme@nhs.net.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Ray James', with a long horizontal flourish extending to the right.

Ray James CBE
National Director for Learning Disabilities

NHS England and NHS Improvement

Appendix 1

[NHS operational planning and contracting guidance](#)

Summary of expectations:

- The completion of 100% of reviews of deaths of people with a learning disability aged four and above within six months of notification of the death.
- Collating learning from completed reviews and developing and delivering strategic and operational actions to address themes and individual recommendations affecting change in service delivery to reduce health inequalities.

LeDeR national delivery arrangements

NHS England and NHS Improvement have agreed a contract with the University of Bristol for a 12-month period to 31 May 2021 to support the ongoing delivery of the LeDeR programme.

The university will:

- manage the secure LeDeR web-based platform (the LeDeR review system)
- produce an annual report and two themed reports
- produce monthly CCG performance reports for NHS England and NHS Improvement
- work with NHS England and NHS Improvement to produce a monthly bulletin.

The redacting and coding of reviews will now be completed by South Central and West Commissioning Support Unit, who have been commissioned by the national team.

Information governance

The University of Bristol previously held approval, from the Confidential Advisory Group of the Health Research Authority under Section 251, for information to be shared for the purpose of the LeDeR programme. As of 1 June 2020, the approval transferred to NHS England and NHS Improvement. There is no change to the operational arrangements for the sharing of information for the purpose of the LeDeR programme. Details of the Confidentiality Advisory Group (CAG) S251 approval can be found on the [Health Research Authority's website](#).

The [General Medical Council's Confidentiality Guidance](#) (paragraphs 71b and 71c) advises that doctors should disclose relevant information about a patient who has died where disclosure is authorised under section 251 of the NHS Act 2006.

Working with NECS

NECS follow the established national LeDeR methodology and have an internal quality assurance process. GP practices have been particularly reluctant to release notes to NECS and CCGs are encouraged to do all that they can to ensure that their local practices support the completion of LeDeR reviews irrespective of the organisation conducting that review.