

Learning from Lives and Deaths

People with a Learning Disability and Autistic People (LeDeR)

Information for general practice

JULY 2021

This document is to let you know you about the Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) programme and how you might be asked to support it. It also explains the basis on which patient identifiable information can be shared with LeDeR review teams.

Your support is key in reducing premature mortality and improving health outcomes for people with a learning disability and autistic people.

Please distribute to appropriate staff within your practice for their information.

Learning from Lives and Deaths

People with a Learning Disability and Autistic People (LeDeR)

LeDeR

Evidence shows that people with a learning disability continue to experience significant health inequalities. The average age of death for women with a learning disability is up to 27 years below that of the general population; for men, it is up to 22 years below. Often, such deaths are from preventable and treatable causes.

LeDeR is a service improvement programme which helps local systems to address this inequality by reviewing information about the health and social care people received before their deaths, and:

- Delivering local service improvement, learning from LeDeR reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LeDeR reviews at a regional and national level.
- Influencing national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

From late 2021 the deaths of autistic adults will be included within the remit of LeDeR for the first time.

Requirements in general practice

Primary care records are key to understanding the person who has died and will always be needed to help us understand whether there are lessons to be learned from the death of an individual. A LeDeR reviewer will always either need access to primary care records or have a conversation with the GP of a person with a learning disability or autistic person who has died.

In developing the new LeDeR policy we have listened to GPs. To reduce the burden on GP practices we have recommended that local systems use smartcards to allow reviewers to access patient records. This means that when someone with a learning disability or an adult with a diagnosis of autism dies, you will be asked to give your permission for the LeDeR reviewer to access the clinical notes on your system for that individual for a limited period.

Where smartcards are not in place locally, your practice staff may need to share the patient notes directly with the LeDeR reviewer, in the same way as LeDeR has worked previously. In either case, instructions will be provided by the LeDeR review team. You can offer to have a detailed telephone conversation with the reviewer instead.

GP practices should always notify LeDeR about the death of any patient registered with the practice who has a learning disability or who is autistic. Notification takes moments and is via a [simple online form](#). Further information about LeDeR can be found online in the [national LeDeR policy](#) and on the [LeDeR website](#).

Appendix A: Legal basis for sharing patient identifiable information

NHS England and NHS Improvement hold approval from the Confidentiality Advisory Group (CAG) of the Health Research Authority under Section 251, for information to be shared for the purpose of the LeDeR programme.

Further details on the legal basis for sharing data with LeDeR reviewers can also be found in the [LeDeR policy](#).

Details of the CAG S251 approval (ref: 20/CAG/0067 (previously 16/CAG/0056)) can be found on the [Health Research Authority's website](#).

The General Medical Council's (GMC) confidentiality guidance 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.

Paragraph 137 of the [GMC guidance](#) advises:

“137 - Circumstances in which you should usually disclose relevant information about a patient who has died include:

- the disclosure is permitted or has been approved under a statutory process that sets aside the common law duty of confidentiality, unless you know the patient has objected.”

Paragraph 103 to 105 of the [GMC guidance](#) advises:

“103 - In England, Wales and Northern Ireland, statutory arrangements are in place for considering whether disclosing personal information without consent for health and social care purposes would benefit patients or the public sufficiently to outweigh patients' right to privacy. Examples of these purposes include medical research, and the management of health or social care services. There is no comparable statutory framework in Scotland.

“104 - Section 251 of the National Health Service Act 2006 allow the common law duty of confidentiality to be set aside for defined purposes where it is not possible to use anonymized information and where seeking consent is not practicable.

“105 - You may disclose personal information without consent if the disclosure is permitted or has been approved under regulations made under section 251 of the National Health Service Act 2006. If you know that a patient has objected to information being disclosed for purposes other than direct care, you should not usually disclose the information unless it is required under the regulations.”