

LeDeR Myth Busters for General Practice

1) Is the expectation that for every death notification received by a practice, the practice will review that person's notes to see if they have a coded LD? If this is the case, are practices then obliged to make a notification to the LeDeR.

Ideally Yes, LeDeR can accept multiple notifications of the same death. The case is then assigned a unique number to avoid duplication. Notifications are accepted via:-

0300 777 4774 (confidential) calls charged at local rate

<https://www.bris.ac.uk/sps/leder/notification-system>

2) Are there any statutory obligations?

The LeDeR programme was one of the recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).

Section 11 of the Health and Social Care Act 2001 places a duty on NHS organisations to make arrangements to involve and consult patients and the public in:

- Planning services that they are responsible for
- Developing and considering proposals for changes in the way those services are provided
- Decisions to be made that affect how those services operate.

3) Consent - do the family need to be made aware that this review is happening (we all thought they did) - if so, how is this going to be done and who would do this?

The LeDeR Review does not require the consent of the family. However, the LeDeR Programme place great emphasis on speaking with the deceased's family and carers in order to produce a review that reflects the persons lived experiences. It is the responsibility of the LeDeR Reviewer to contact the family/carers at the beginning of the process.

4) What happens after a notification to the LeDeR is done? Will there be a review of the GP notes?

On receipt of notification the Leder Programme alerts the Local Area Contact. A Reviewer is then identified to carry out the review. There is an expectation that the review would include relevant GP records as the primary record holder.

5) Who would review the GP notes or would GPs be asked to fill in a form?

The LeDeR Reviewer would review the notes for relevant information. Ideally a conversation with the GP would also take place. In the case of a Rapid Review (deaths that are over 60 working days) a form would be sent to the Practice that would be followed by a conversation with the practice.

6) Again there would be consent issues around accessing the deceased person's notes - who would give consent for this and who would ask for it?

The Learning Disabilities Mortality Review (LeDeR) Programme has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. In order for the LeDeR programme to fully understand the circumstances of the deaths of people with learning disabilities, we require access to the medical and/or other records of each person who comes within the remit of the LeDeR programme.

The LeDeR programme has Section 251 approval from the National Information Governance Board for Health and Social Care (NIGB). The lawful basis for processing personal data about people who have died, and their key contacts is CAG Section 251. The lawful basis for processing personal data about people in contact with the programme is that person's explicit consent. Section 251 allows data to be stored for the purpose of the programme for 10 years.

7) Although the purpose of the LeDeR is not "a formal investigation, a complaints process, an avenue to apportion blame", who would have access to the outcomes? Are the family entitled to have access to the outcome? Would it be made very clear to the family what the process is for? There would be concern that this could be looked at by families as a way to apportion blame and therefore seek to take further action.

The purpose of the LeDeR reviews is not to hold any individual or organisation to account. Other processes exist for that, including criminal proceedings, disciplinary procedures, employment law and systems of service and professional regulation. It is vital, if individuals and organisations are to be able to learn lessons from the past, that reviews are trusted and safe experiences that encourage honesty, transparency and sharing of information to obtain maximum benefit from them.

The Reviewer would speak to family members, friends, professionals and anyone else involved in supporting the person who has died to find out more about their life and the circumstances leading to their death. Therefore the review would be shared with them on conclusion as appropriate. The aim of the programme is to drive improvement in the quality of service delivery for people with learning disabilities and help to reduce premature mortality and health inequalities in this population. It is not an investigation.

8) There was concern that this may actually be a very time consuming activity for practices who are already drowning in immense workloads.

The Review is the responsibility of the LeDeR Reviewer with appropriate involvement with anybody who provided care. Often the time spent with GPs is a conversation either face to face or via the telephone.

For further information please contact:-

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