

Publications approval reference: PAR0028

To: All GP practices  
All chief executives of provider trusts

NHS England and NHS Improvement  
Skipton House  
80 London Road  
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27 July 2020

Dear colleagues,

People with a learning disability suffer profound health inequalities. As health professionals, we share a duty to reduce these and we need your assistance. The world leading Learning from Deaths Review (LeDeR) programme is the largest body of evidence in the world on the deaths of people with a learning disability reviewed at an individual level.

LeDeR reviews are about learning and not about blame; they enable improvements in the care and treatment provided by services locally and nationally.

NHS England and NHS Improvement invested £5 million last year to improve the timeliness of reviews completed and ensure learning is acted upon to reduce deaths which are potentially avoidable. During the COVID-19 pandemic we have seen a very significant rise in the number of people with a learning disability who have died compared to the same period last year. It is therefore particularly important now that we complete LeDeR reviews to ensure that we understand how to reduce mortality and morbidity for a future wave or similar epidemic.

To support in completing these reviews, we need colleagues in general practice and provider trusts to release case notes to reviewers as quickly as possible and ideally within a week of a request being made, using the secure LeDeR web-based portal. An alternative to uploading case notes might be to have a meaningful conversation with the reviewer in order to ensure they have as full a picture as possible of the person's life and circumstances leading up to their death.

Some of you have expressed professional concerns about releasing records. The [General Medical Council's Code of Confidentiality](#) (s137/138) provides guidance which supports the release of such case notes. You will know that your organisation

will still have access to the electronic patient record even after death and that you continue to remain legally responsible for the information they hold, even after the record has been shared with Primary Care Services England. NHS England and NHS Improvement have approval from the Secretary of State for Health under Section 251 of [the NHS Act 2006](#) to receive confidential patient information in order to undertake these reviews.

Thank you for your continued support to improve the lives of people with a learning disability.

Your sincerely,



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## **Extract GMC Code of Confidentiality**

### **s137**

*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 (see paragraphs 103 - 105)*
- *when disclosure is justified in the public interest to protect others from a risk of death or serious harm*
- *for public health surveillance, in which case the information should be anonymised, unless that would defeat the purpose*
- *when a parent asks for information about the circumstances and causes of a child's death*
- *when someone close to an adult patient asks for information about the circumstances of that patient's death, and you have no reason to believe the patient would have objected to such a disclosure*
- *when disclosure is necessary to meet a professional duty of candour (see paragraphs 100 - 101)*
- *when it is necessary to support the reporting or investigation of adverse incidents, or complaints, for local clinical audit, or for clinical outcome review programmes.<sup>60i</sup>*

### **s138**

*Archived records relating to deceased patients remain subject to a duty of confidentiality, although the potential for disclosing information about, or causing distress to, surviving relatives or damaging the public's trust will diminish over time.<sup>61</sup>*

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<sup>i</sup> <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/domain-2----safety-and-quality>