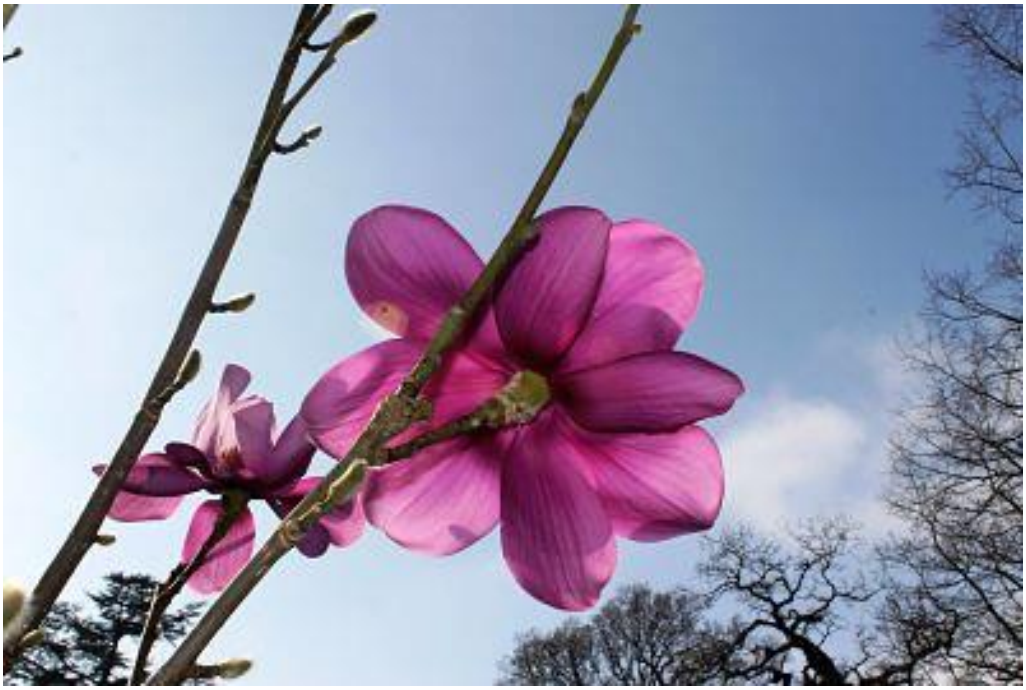
Learning Disabilities Mortality Review (LeDeR) Programme



Guidance for the conduct of local reviews of the deaths of people with learning disabilities

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Contents

Section 1: About the programme 3

Section2: The purpose, definitions used, and inclusion criteria for the LeDeR programme 4

- The purpose of the Learning Disabilities Mortality Review programme 4
- Definitions 4
  - Learning disabilities 4
  - Best practice 4
  - Potentially avoidable contributory factors to deaths 4
  - Potentially avoidable death 4
- Inclusion criteria for the LeDeR programme 4
  - Age of people with learning disabilities 4

Section 3: Establishing the LeDeR review process 5

- The LeDeR programme at local level 5
  - The local Steering Group 5
  - The local area contact 5
  - The local reviewer 6
- Data sharing and confidentiality 7
- How the LeDeR review process links with other mortality reviews 9

Section 4: Involving families in the review process 13

Section 5: Conducting a review of a death 14

- Notification of a death 14
- Initial review 14
- Multiagency review 17

Section 6: Quality assurance and dissemination of lessons learned 19

- Quality assurance 19
- Dissemination of lessons learned 19

Appendix 1: Initial review template 20

Appendix 2: How to prepare for multiagency review 44

Appendix 3: Final report following multiagency review 47

Appendix 4: Quality assurance checklist 52

Section 1: About the programme

1.1 The Learning Disabilities Mortality Review (LeDeR) programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is the first national programme of its kind in the world.

1.2 Its overall aims are:

- To support improvements in the quality of health and social care service delivery for people with learning disabilities.
- To help reduce premature mortality and health inequalities for people with learning disabilities.

1.3 The programme was established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)[1]. CIPOLD reported that for every person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so. More recently, analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with learning disabilities was 3.18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities[2].

1.4 The LeDeR Programme contributes to improvements in the quality of health and social care for people with learning disabilities in England by supporting local areas to carry out reviews of deaths of people with learning disabilities (aged 4 years and over) using a standardised review process. This enables them to identify good practice and what has worked well, as well as where improvements to the provision of care could be made. Recurrent themes and significant issues are identified and addressed at local, regional and national level.

1.5 The core principles and values of the programme are as follows:

- The LeDeR programme overall must effect change and make an identifiable difference to the lives of people with learning disabilities and their families.
- We value the on-going contribution of people with learning disabilities and their families to all aspects of our work and see this as central to the development and delivery of everything we do.
- We take a holistic perspective looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other.
- The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.
- The programme overall strives to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

[1] Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. (2013) *The Confidential Inquiry into premature deaths of people with learning disabilities. Final Report*. University of Bristol. Bristol. http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

[2] Glover G, Williams R, Heslop P, Oyinola J, Grey J. (2016) Mortality in people with intellectual disabilities in England. Journal of Intellectual Disabilities Research. Early view. Doi: 10.1111/jidr.12314

Section 2- Purpose of this guidance, definitions used, and inclusion criteria for the LeDeR programme

2.1 This guide provides advice about the process of conducting local reviews of deaths using the model of mortality reviews developed by the LeDeR programme.

Definitions

Learning disabilities

2.2 The LeDeR Programme has adopted the definition of learning disabilities that is used in the Learning Disabilities White Paper '*Valuing People'* (2001), which states that a person with learning disability has the following:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development[3]

Best practice

2.3 Best practice is defined as practice that is over and above the standard of care that is normally expected.

2.4 'Good' practice is that which should usually be delivered, following national and local policy and guidelines.

Potentially avoidable contributory factors to death

2.5 A 'potentially avoidable contributory factor' is any factor that has been identified as contributing to a person's death, and which could have possibly been avoidable with the provision of good quality health or social care. Potentially avoidable contributory factors could be in relation to:

- The person and/or their environment.
- The person's care and its provision.
- The way services are organised and accessed.

Potentially avoidable deaths

2.6 Potentially avoidable deaths are those where there are aspects of care and support that, had they been identified and addressed, may have changed the outcome, and on balance of probability the person may have lived for another year or more.

Inclusion criteria for the LeDeR programme

Age of people with learning disabilities

2.7 Initial reviews are undertaken of **all** deaths notified to the LeDeR programme of people with learning disabilities aged 4 years and older in England.

[3] Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Section 3: The LeDeR review process

The LeDeR programme at local level

3.1 The 'footprint' for the LeDeR Programme at local level is the NHS England regional structure of seven regions (North West; North East and Yorkshire; Midlands; East of England; London; South East; South West).

Local steering groups

3.2 All areas of England are covered by a local LeDeR steering group. Steering groups are responsible for the LeDeR programme in that area and ensuring that any learning, recommendation and actions arising from reviews of deaths are considered and taken forward, as appropriate, using locally agreed governance structures.

3.3 Purpose / role of the local steering group

- To receive regular updates from the Local Area Contact about the progress and findings of reviews.
- To ensure that any learning, recommendation and actions arising from reviews of deaths are considered and taken forward, as appropriate, using locally agreed governance structures.
- To work in partnership with the Local Area Contact(s)
    - To support the initial review of all deaths of people with learning disabilities (aged 4 years and over) in their area, and more detailed multiagency reviews of those for whom it is indicated.
    - To help interpret and analyse the data submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made.
    - To ensure that the data is appropriately handled to ensure security and confidentiality in line with the programme's CAG S251 approval.
    - To share anonymised case reports pertaining to deaths or significant adverse events relating to people with learning disabilities for publication in the LeDeR Programme repository in order to contribute to collective understanding of learning points and recommendations across cases.

Local area contacts (and their team as appropriate)

3.4 Local area contacts are the link between the local steering group and local reviewers. All local area contacts should be a member of their local LeDeR steering group which takes a strategic level oversight of the reviews of deaths of people with learning disabilities in that area.

3.5 Summary of responsibilities

- To receive notifications of deaths of people with learning disabilities from the central LeDeR team.
- Allocate deaths to be reviewed to local reviewers.
- Monitor the progress and completion of reviews to ensure that they are of a consistent standard, to the required quality, and completed in a timely and comprehensive way.
- Provide ongoing advice, support and training for local reviewers as necessary.

- Support the local reviewer to liaise with other investigatory processes if necessary.
- Monitor the quality of reviews of deaths and ensure that they are of an appropriate standard.
- Liaise with the local steering group about any issues that arise in relation to the reviews of deaths, as appropriate.
- Receive and sign off completed review documents.
- Present information to the local steering group.
- Work with the local steering group to take appropriate actions in relation to the findings from reviews of deaths.
- Build and maintain wider relationships to ensure knowledge and information is shared across internal and external stakeholders
- Encourage a culture that values openness, honesty, rigour and challenge.

3.6 Specific skills and experience

- A professional health or social care background with experience at a senior level.
- Knowledge of pertinent legislation and guidance relating to the care of people with learning disabilities, including the Mental Capacity Act (2007) and the Equality Act (2010).
- Experience of providing critical challenge.
- Experience of synthesising and analysing information to inform practice-based decisions.
- Excellent communication and interpersonal skills, both written and oral.
- Stakeholder engagement skills and ability to build relationships with people at all levels of seniority.
- IT literate.

3.7 Values

- Committed to reducing premature mortality of people with learning disabilities and their families.
- Committed to improving service provision for people with learning disabilities and their families.
- Committed to encouraging improvement through reflection and review of practice-related care.

Local reviewers

3.8 Local reviewers are responsible for undertaking robust and high-quality reviews of the deaths of people with learning disabilities.

In general, it is a reviewer in the area in which the person lived that will lead the review. If a person is in an 'out-of-area' placement, a reviewer from the area in which the person is registered with a GP will lead the review unless there are compelling reasons why this should not be the case (e.g. if the person has very recently moved and most information about them is held in a different area). In such circumstances, discussion is required between the sending and receiving areas to agree who should lead the review and how best to collaborate.

All reviews are undertaken using the secure web based LeDeR review system, with all review documents completed on-line and any additional case notes and supporting paperwork stored within the LeDeR review system.

3.9 Summary of responsibilities

- Receive information about a person who has died for whom a review is required from the local area contact.
- To update core data collected at notification of the death.
- To conduct an initial review of each death.
- To contact family members of people with learning disabilities who have recently died to involve them in the review as appropriate.
- To conduct a multiagency review of a death if appropriate, involving collation of case documentation, holding a multiagency meeting at which potentially contributory factors leading to death are discussed, learning points, recommendations and action plan agreed.
- Maintain communication with the local area contact as appropriate during the course of the review to update on progress and highlight any problems.
- Write an accurate and concise report of the review and complete the required documentation.
- Submit the completed documentation to the local area contact via the LeDeR review system.
- To encourage a culture that values openness, honesty, rigour and challenge.

3.10 Specific skills and experience

- A professional health or social care background with experience at a senior level.
- A thorough understanding of the needs of people with learning disabilities and their families.
- The ability to evaluate evidence and understand specialist terminology.
- Knowledge of pertinent legislation and guidance relating to the care of people with learning disabilities, including the Mental Capacity Act (2007) and the Equalities Act (2010).
- A questioning mind, able to probe further and challenge if necessary.
- Able to synthesise information, and to write reports based on robust evidence accurately and concisely.
- Excellent communication and interpersonal skills at all levels, including with recently bereaved family members.
- Stakeholder engagement skills and ability to build relationships with people at all levels of seniority.
- Enthusiastic and motivated to improve service provision for people with learning disabilities.
- IT literate.

3.11 Values

- Committed to reducing premature mortality of people with learning disabilities and their families.
- Committed to improving service provision for people with learning disabilities and their families.
- Committed to encouraging improvement through reflection and review of practice-related care.

Data sharing and confidentiality

3.11 It is important that information sharing is in line with expectations regarding confidentiality and the appropriate use of personal information.

3.12 Health records relating to deceased people do not carry a common law duty of confidentiality, but it is Department of Health and General Medical Council (GMC) policy that records relating to deceased people should be treated with the same level of confidentiality as those relating to living people. However, whilst confidentiality is an important duty, it is not absolute. Professionals can disclose personal information if:

- The patient consents. This is not applicable in the LeDeR programme as the person who is the subject of the review will have died without giving consent.
- It is required by law. This is not applicable in the LeDeR programme as there is no legal mandate for confidential patient-identifiable information to be shared for use by the programme.
- It is allowed by law. Some legislation falls short of creating a duty to share confidential information; instead it makes it possible for organisations to share confidential information. Such confidential information sharing must be necessary and proportionate to the purpose. Section 251 of the NHS Act 2006 provides the Secretary of State for Health with the authority to make regulations that set aside legal obligations of confidentiality to allow the disclosure of confidential patient information in situations where it is not possible to use anonymised information and where seeking consent is not practical. Further information about Section 251 can be found by following the link: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/.

3.13 The LeDeR programme has Section 251 approval (CAG reference: 16/CAG/0056) for the use of patient identifiable information in order for reviews to be undertaken of the deaths of people with learning disabilities. The specific aspects of the work that are subject to Section 251 approval are:

- The reporting of personal details about people with learning disabilities who have died from 1st April 2015 to 31 May 2020 to the LeDeR Programme.
- Collection of detailed case information and review of health or social care case notes in order for a local reviewer to conduct a review of the death.
- To share NHS numbers (or other key identifiers) with NHS Digital in order to obtain the Office for National Statistics ICD10 codes for each person's causes of death.

Access is agreed in relation to the following personal data:

- Relating to people with learning disabilities: name of deceased person, date of birth, date of death, gender, NHS number, first 2 digits of postcode, ethnicity, gender, information about the circumstances leading to the death of the individual, including the person's medical history, details of diagnoses and treatments, contacts with services, the care and support that they have received prior to death, and their cause of death.
- Relating to the person's next of kin/family: name of relative/next of kin, address, and relationship to the deceased.

3.14 In practice, what Section 251 approval means is that you may disclose identifiable information without consent for the notification of deaths of people with learning disabilities, and for contributing to reviews of their deaths. This means that those responsible for information about people with learning disabilities who have died can disclose the information to the LeDeR programme team and local reviewers without being in breach of the common law duty of confidentiality.

3.15 Information sharing protocols set out a common set of rules to be adopted by the various organisations involved in data sharing e.g. for the purposes of a safeguarding board. These are

likely to be in place as part of an existing contract between organisations; they could however, be supplemented by Individual Data Sharing Agreements for specific data sharing arrangements (e.g. reviews of deaths of people with learning disabilities) between stakeholders.

3.16 An individual data sharing agreement is not likely to be required whilst the LeDeR programme has Section 251 approval. However, local agencies may wish to formalize their own individual data sharing agreements to supplement Section 251 approval.

3.17 Existing national NHS guidance regarding good information governance standards, data protection and confidentiality guidance should be adhered to.

How the LeDeR review process links with other mortality reviews

3.18 A key part of the Learning Disabilities Mortality Review (LeDeR) programme is to support local areas to review the deaths of people with learning disabilities. 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.

3.19 In order to do this in a timely manner and to avoid duplication, reviewers need to be clear where and how the LeDeR process links with other review or investigation processes. Other investigations or reviews may include, for example: Serious Case Reviews, Safeguarding Adult Reviews, Safeguarding Adults Enquiries (Section 42 Care Act) Domestic Homicide Reviews, Serious Incident Reviews, Coroners' investigations and Child Death Reviews.

3.20 Key principles

In all cases, the key principles of communication, cooperation and independence should be adhered to.

Communication

Where another review or investigation is indicated or underway, the reviewer should, in the first instance, discuss this with the Local Area Contact. It is important that clear lines of communication between the LeDeR reviewer or Local Area Contact and the lead/key contact of the other investigation or review process are established. On a case by case basis, the extent of each investigation or review, and a plan for the collection of core data for each review process, will need to be developed.

Cooperation

Cooperation is vital between relevant parties where there is more than one review taking place; each review team is likely to benefit from the experience and expertise of each other.

Independence

Although the different review processes should conduct their work in a cooperative manner, each review will have its own remit and focus of attention, and the independence of each party is of importance. Those involved in the LeDeR process should not be involved in the direct care of those

patients involved and if possible not work directly with those involved in the delivery of the person's care.

When acting as a reviewer they should act with impartiality – challenging the 'status quo' to identify system weaknesses and opportunities for learning while making decisions based on objective criteria. The Local Area Contact should inform the LeDeR Steering Group covering their area about each LeDeR review that significantly impacts on or is affected by another investigation or review, sharing the agreed plan for data collection and providing the Steering Group with reports on progress and completion of the review.

The needs of the family and carers should receive careful consideration so as to avoid duplication of questioning and unnecessary upset.

3.21 Specific review or investigation processes

3.22 Structured Judgement Review (SJR)

The national guidance on Learning from Deaths requires acute, mental health and community NHS Trusts and Foundation Trusts to use an evidence-based methodology (such as the Structured Judgement Review (SJR) methodology) for reviewing the quality of care provided to patients who die. The national Learning from Deaths Implementation Guidance specifies that Trusts should conduct an initial case note review of all deaths of people with learning disabilities using SJR and should also adopt the LeDeR method for reviewing the deaths of people with learning disabilities.

All deaths of people with learning disabilities in acute hospitals should therefore receive a SJR into their last episode of care. The LeDeR review should discuss the findings of the SJR with the Trust reviewer so that they can feed into the broader LeDeR review. When the LeDeR review is completed, the Trust should be sent a redacted copy of the completed review.

3.23 Child death review process

It is a statutory requirement to review all deaths of children. 'Working Together to Safeguard Children' (2018) sets out the high-level principles for child death review. The processes that should be followed by all those involved when responding to, investigating, and reviewing all child deaths are set out in the Child Death Review Statutory Guidance issued in 2017.

Deaths of children aged 4-17 (inclusive) will therefore be reviewed by the child death review process. It would not be necessary, nor appropriate, to review the death again but the local reviewer and/or Local Area Contact for the LeDeR programme will need to liaise with the Child Death Review Co-ordinator for their area to ensure the collection of core data for the LeDeR programme and to offer expertise about learning disabilities as appropriate.

3.24 Serious Case Reviews

A serious case review takes place after a child dies or is seriously injured and abuse or neglect is thought to be involved. It looks at lessons than can help prevent similar incidents from happening in the future. Local Safeguarding Children Boards follow statutory guidance for conducting a serious case review.

The Child Death Review Co-ordinator is likely to be aware if a Serious Case Review is being conducted. As with deaths of all children, it would not be necessary, nor appropriate, to review the case again but the local reviewer and/or Local Area Contact for the LeDeR programme will need to liaise with the Child Death Review Co-ordinator to ensure the collection of core data for the LeDeR programme and to offer expertise about learning disabilities as appropriate.

3.25 Safeguarding Adult Reviews

The Care Act 2014 introduces statutory Safeguarding Adults Reviews, mandates when they must be arranged and gives Safeguarding Adult Boards flexibility to choose a proportionate methodology. A Safeguarding Adults Review (SAR) must be carried out when someone with care and support needs dies as a result of neglect or abuse and there is reasonable cause for concern about how professionals worked together to safeguard the adult. The focus of the review is to identify any lessons to be learnt and apply those lessons to future cases. Safeguarding Adults Boards are required to publish an annual report which includes the findings of any Safeguarding Adults Reviews conducted during that year and what it has done to implement the findings.

If the death of a person with learning disabilities is subject to a Safeguarding Adult Review, the local reviewer and/or Local Area Contact for the LeDeR programme will need to liaise with the Chair of the Safeguarding Adult Board to ensure the collection of core data for the LeDeR programme and to offer expertise about learning disabilities as appropriate.

3.26 Serious Incident Reviews

The revised Serious Incident Framework (2015) (to be replaced by the Patient Safety Incident Response Framework in Autumn 2019) builds on previous guidance that introduced a systematic process for responding to serious incidents in NHS-funded care. Serious Incidents in health care are defined as 'adverse events, where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is so great, that a heightened level of response is justified.' There are three levels of Serious Incident reviews:

a) concise investigations -suited to less complex incidents which can be managed by individuals or a small group of individuals at a local level
b) comprehensive investigations - suited to complex issues which should be managed by a multidisciplinary team involving experts and/or specialist investigators
c) independent investigations

The level of investigation should be proportionate to the individual incident and is agreed at an initial review (sometimes called a 72-hour review). Concise and comprehensive investigations should be completed within 60 days and independent investigations should be completed within 6 months of being commissioned.

If the death of a person with learning disabilities is subject to a Serious Incident Review, there is usually no problem in continuing with the LeDeR review which is generally broader in perspective. This should be discussed with the healthcare service provider's safeguarding lead.

3.27 Police Investigations

The police will be involved in investigating a death if there is a suspicion that a crime has occurred. Generally, deaths should be reported to the police if:

- It is possible that assault or violence caused or contributed to the death.
- It is possible that intentional or accidental poisoning (but not food poisoning) could have contributed to the death.
- Neglect may have caused or contributed to the death.
- A road traffic collision may have caused or contributed to the death.
- The deceased's own actions may have caused or contributed to the death (e.g. by drug use, self-harm or self-neglect).
- The deceased's employment have caused or contributed to the death.
- The death occurred in police custody, or shortly after police contact, or if it is thought that police action or inaction may have caused or contributed to the death.

Criminal investigation by the police takes priority over other enquiries, and the LeDeR review will need to be put on hold, as it may potentially prejudice a criminal investigation and subsequent proceedings (if any). Where this is the case, the LeDeR reviewer or the Local Area Contact and the police should agree a date for the LeDeR review to recommence.

3.28 Domestic Homicide Reviews

Domestic Homicide Reviews were established on a statutory basis under Section 9 of the Domestic Violence, Crime and Victims Act (2004) and came into force in April 2011. Domestic Homicide Reviews are locally conducted, multi-agency reviews of the circumstances in which the death of a person aged 16 or over, has or appears to have resulted from violence, abuse or neglect by:

- A person whom he/she was related or had been in an intimate personal relationship, or
- A member of the same household.

Local Community Safety Partnerships are informed of a suspected domestic homicide by the relevant police force and it is their responsibility to set up a Domestic Homicide Review. The purpose of the review is to identify what lessons are to be learned from the domestic homicide, particularly the way in which local professionals and organisations work individually and together to safeguard victims; and how the lessons will be acted on.

Where domestic homicide is suspected in a person with learning disabilities, the LeDeR reviewer should contact the Chairperson of the local Community Safety Partnership Board to agree a plan for the collection of core data for the LeDeR programme and to offer expertise about learning disabilities as appropriate.

3.29 Deaths referred to the Coroner

A coroner is an independent judicial office holder, appointed by a local council. Coroners usually have a legal background but will also be familiar with medical terminology.

Coroners investigate deaths that have been reported to them if it appears that

- The death was violent or unnatural.
- The cause of death is unknown.
- The person died in prison, police custody, or another type of state detention, including having a Deprivation of Liberty order.

The role of the coroner is to determine who the deceased person was and how, when and where they came by their death. When the death is suspected to have been either sudden with unknown cause, violent, or unnatural, the coroner decides whether to hold a post-mortem examination and, if necessary, an inquest.

A post-mortem examination of the body will usually establish the cause of death, but if it is unable to do so, or the death is found to be unnatural, the coroner has to hold an inquest. An inquest is a public court hearing held by the coroner in order to establish who died and how, when and where the death occurred.

Where a death has been referred to the Coroner for investigation, the LeDeR reviewer or the Local Area Contact should contact the local Coroner's Officer and agree a plan for the LeDeR review. In the majority of cases, the LeDeR review process can go ahead, and would be informed by the results of the post-mortem examination. Separate investigations into a death usually take place before an inquest so that the coroner can draw on the information for the inquest, but this would need to be agreed with the relevant coroner's officer.

Section 4: Involving families in the review process

4.1 Involving families in the review process is an important part of the work of the local reviewer. Families should be encouraged and supported to be involved throughout the entire review process or as much as the family feel able or want to be involved.

4.2 There are substantial benefits to involving families in the review of a person's death as they will often have the greatest knowledge about the person who has died. This knowledge is often vital to understanding the sequence of events leading to their relative's death. The family may also be able to contribute towards the identification of best practice and making any recommendations about how services could be improved.

4.3 Contacting and involving families needs to be undertaken in a timely, sensitive and respectful way, as it may be a very difficult time for those who have recently been bereaved.

4.4 Reviewers need to be clear to families about the purpose of the review and should reinforce the point that the review of their relative's death is part of a national process of reviews and not an indicator that there are any concerns about the treatment or care of their family member.

4.5 Reviewers should provide information about local bereavement resources and support groups to which people can be signposted, should they need information or support or want to make a complaint.

4.6 Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 pertains to the Duty of Candour[4]. The Duty of Candour regulations clearly state that NHS bodies (or those acting on their behalf) have a duty to promptly notify and offer an explanation and apology for incidents that have caused people harm. Reviewers need to be aware of Duty of Candour protocols and procedures in their local areas.

[4] http://www.legislation.gov.uk/uksi/2014/2936/regulation/20/made

Section 5: Conducting a review of a death

Notification of a death

5.1 Deaths of people with learning disabilities are notified to a single point of contact by anyone (family member, advocate, GP, residential care worker or other) who is aware of the death. Reporting a death of someone with learning disabilities can be done via 0300 7774 774 directly to a member of the LeDeR team, or via the Programme's secure web-based portal, which can be accessed through the LeDeR website.

5.2 The person reporting the death is asked to provide as much key information as possible. They are asked for details of the person with a learning disability who has died, the contact details of a person who knew them well, known health conditions and cause of death if known.

5.3 The person's death is allocated a programme ID number. The information is then transferred to the appropriate local area contact for allocation to a reviewer.

Reviews of deaths

5.4 Local reviews of deaths consist of:
An initial review of each death.
A fuller multiagency review of deaths that meet the criteria for this.

Initial review

5.5 For each death there is an initial review. The purpose of this is to provide sufficient information to be able to determine if there are any areas of concern in relation to the care of the person who has died, or if any further learning could be gained from a multiagency review of the death that would contribute to improving practice.

5.6 The initial review involves inviting those who knew the person well (e.g. a family member, paid carer) to contribute their views about the sequence of events leading to death, limited case note review and the completion of a standard review form. As part of the standard review form the local reviewer writes a 'pen portrait' about the person who has died and completes a timeline of events leading to their death.

5.7 All information is accessed, edited and completed via the secure web based LeDeR Review System. Local reviewers are responsible for requesting relevant case notes with the support of the local area contact where necessary. Local data sharing protocols for accessing case records and keeping the content confidential and secure should be followed at all times.

5.8 The initial review process involves:

- Checking and completing the information received in the notification of the death.

- Contacting a family member and/or other people who knew the deceased person well and discussing with them the circumstances leading up to the person's death (see 5.9 below).
- Scrutinising at least one set of relevant case notes and extracting core information about the circumstances leading up the persons death, for example from GP, social care, Community Learning Disability Team, or hospital records. The choice of case notes is likely to be determined by which professionals had the closest involvement with the person prior to their death (see 5.10 below).
- Developing a pen portrait of the person who had died (see 5.11 below) and a timeline of the circumstances leading to their death (see 5.12 below) following discussions with family members and appropriate professionals.
- Making a decision, in conjunction with others if necessary, about whether a multiagency review is indicated and what further actions are required (see 5.13 below). Actions should explain how each of the recommendations and learning points will be addressed. They should be written clearly and succinctly and using SMART objectives:
    - Specific - outlines a specific area for improvement and what needs to be achieved, the more specific the action the easier it is to set a realistic target date.
    - Measurable - outlines how the reviewer will know that the action has been achieved or at least an indicator of progress.
    - Achievable - actions that are realistic and could be accomplished.
    - Realistic - state what results should realistically be achieved, given available resources.
    - Time-related - specifying when the result(s) can be achieved.
- Completing the LeDeR programme review documentation.
- Submitting the completed documentation to the local area contact for quality assurance checks and 'sign off'. Once agreed that the review is complete, it is submitted to the central LeDeR team via the LeDeR Review system.
- The central LeDeR team redacts the report and returns it to the local area contact who collates learning points and actions and presents the information to the local steering group for action and implementation.

5.9 The purpose of discussing the circumstances leading to the death of the person who has died with someone who knew them well, is to develop an understanding about the person, identify any possible factors that may have contributed to their death and any best practice and reasonable adjustments that had been made for the person.
These conversations can take place with someone who knew the person very well. In most cases, we anticipate that this would be a family member. When this is not appropriate (e.g. the person has had little contact with their family over the years), the person who knew the person with learning disabilities best may be a friend, member of the care team where they lived, GP, Psychiatrist or Community Learning Disabilities Team member.
Any discussions need to be undertaken carefully and sensitively as they may be with family members who are recently bereaved or with care and support staff who are themselves experiencing feelings of shock and grief at the loss of the person. We would expect the local reviewer to hold such conversations in person, rather than over the phone.

5.10 The reviewer needs to make a decision about the most relevant case records to review, based upon information received at the notification stage and on their discussions with the person who knew the deceased person well.

This might be the care home records if the person with a learning disability died in a care home or the hospital records if the person had been in hospital for some time leading up to their death.

Local reviewers are responsible for requesting relevant case notes, with support from Local Area Contacts or others as appropriate. Case notes should be uploaded or scanned into the LeDeR Review system, but there may be some circumstances where it is easier and timelier to review the case notes in-situ.

It is essential that the local reviewer follows agreed data sharing protocols for accessing case records and keeping the content confidential and secure.

5.11 The purpose of the pen portrait is to present a clear, concise and factual picture of the person as they were, their health and wider support needs, and the extent to which those needs have been met by health or other services. It should be a short summary of the key information that has been gathered from the discussion with the informant who knew the person well, the case notes and the initial review documentation.

The pen portrait should be written using the following headings:

- The person and their needs (e.g. their personality, how they communicated their needs or how they were feeling, their likes and dislikes, and their behaviour).
- The persons social history and activities (e.g. significant life events, their lifestyle, social activities, sense of belonging to the local community, family and other contacts).
- Any additional information about the person that may be relevant but has not been covered elsewhere.

5.12 The purpose of a timeline is to present a chronological picture of a person's life and the relevant circumstances that led up to their death. Timelines need to include details of significant events and their dates, and who the information was gathered from. Significant events should include:

- Changes to a person's personal circumstances, accommodation, daily routine or activities.
- Health consultations.
- Investigations.
- Diagnoses.
- Significant decisions made about a person's care and treatment.
- Treatments provided.

5.13 One way of deciding whether a multiagency review is indicated, is by grading the care that that the person received. Grading is undertaken at the completion of the initial review, based on the information the reviewer has.

Grading the care received by the person is on a scale of 1-6 as follows:

1. This was excellent care (it exceeded expected good practice).
2. This was good care (it met expected good practice).
3. This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing).
4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.
5. Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.

6. Care fell far short of expected good practice and this contributed to the cause of death.

For grades 1-2: reviewers are asked what features made the care good or excellent, and how current practice could learn from this. For grades 3-4: reviewers are asked their reason for this grading, and to address areas where care fell short of good practice in their recommendations for service improvement. For grades 5-6: reviewers are expected to hold a multiagency review of the care provided for the person.

Multiagency review

5.14 There are a number of circumstances that would indicate that a multiagency review is required. These may be identified very early in on the initial review process or may emerge as the review progresses. If there is any doubt whether a multiagency review is indicated, the reviewer should discuss the circumstances with their local area contact.

5.15 A multiagency review is always required where the assessment of the care received by the person is graded 5 or 6. It should be considered:

- If the local reviewer thinks that a multiagency review would be appropriate, even though their initial assessment does not include any 'red flag' responses. It should be borne in mind that the purpose of the multiagency review is to gain further learning which will contribute to improving practice.
- When any red flag alerts are indicated in the initial review.
- If there have been any concerns raised about the care of the person who has died.

5.16 The purpose of the multiagency review is to include the views of a broader range of people and agencies who have been involved in supporting the person who has died, where it is felt that further learning could be obtained from a more in-depth analysis of the circumstances leading up to the person's death.

5.17 Preparation for the multiagency review process includes:

- Contacting families, individuals and any agencies that have been involved in supporting the person to inform them about the review and to ask them to add any additional insights to the pen portrait, timeline, and description of the circumstances leading to death.
- Requesting a copy of any relevant notes and documents relating to the person who has died.
- Arranging the meeting and sending the agenda and anonymised papers to participants in good time.
- Where a family member wants to attend the multiagency meeting, support arrangements need to be discussed with them prior to meeting to ensure their maximum involvement.

5.18 The reviewer, local area contact, or another appropriate person should chair and facilitate the multiagency meeting to ensure that all attending understand the purpose and process of the review and feel able to contribute to the discussions.

5.19 The multiagency review meeting provides an opportunity for those involved in the life and care of the person who has died to gather and discuss the circumstances that led to the person's death.

5.20 It is the role of the reviewer to chair and facilitate the multiagency meeting to ensure that all attending understand the purpose and process of the review and feel able to contribute to the discussions.

5.21 The focus of the multiagency meeting is to:

- Agree the content of the timeline and pen portrait including any new information to be added.
- Discuss any potentially avoidable contributory factors that have been identified relating to:
    - the person
    - the environment
    - their care and its provision
    - the way services are organised and accessed
- Discuss whether the meeting members are surprised that the person has died at this time and from this cause, and if so why.
- Note any best practice in relation to the care and support of the person prior to their death.
- Agree whether the person's death at that time was potentially avoidable (*Potentially avoidable deaths are those where there are aspects of care and support that, had they been identified and addressed, may have changed the outcome and on balance of probability the person may have lived for another year or more*).
- Identify any lessons learned.
- Consider any wider recommendations.
- Recommend changes to local practices as a result of the findings of the review.
- Agree the content of any action plan based upon the discussions.
- The meeting may not be able to reach agreement on issues such as whether a person's death was avoidable. If this is the case, then the discussions should be noted in the relevant section of the form and reasons given.

5.22 The review meeting is an opportunity for shared learning by all, and participants should be encouraged to be as open and honest as possible. The meetings are not a place for recrimination and blame. If poor or unsafe practice is identified it should be investigated through the relevant processes.

5.23 Following the multiagency review meeting the reviewer updates the timeline and pen portrait if necessary and completes the LeDeR programme documentation.

5.24 If a family member has been involved in the review process but not attended the meeting, the local reviewer will need to provide feedback to them in the agreed manner.

5.25 Once completed, the multiagency review documentation is sent via the LeDeR Review system to the Local Area Contact for quality assurance checks and 'sign off'. Once agreed that the review is complete, it is submitted to the central LeDeR team via the LeDeR Review system.

5.26 The central LeDeR team redacts the report and returns it to the local area contact who collates learning points and actions and presents the information to the local steering group for action and implementation.

Section 6: Quality Assurance and dissemination of lessons learned

Quality Assurance

6.1 The local area contact is responsible for quality-assuring each initial and multiagency review that is undertaken in their local area. When the local area contact is satisfied that the review meets the required standard i.e. that the review is comprehensive, has scrutinised sufficient and appropriate evidence, and has focused on recommendations and actions, the review is closed.

6.2 Where the review is not deemed to be adequate, additional work needs to be undertaken by the local reviewer to meet the required standards, based on recommendations for change from the local area contact.

6.3 It is important that local groups monitor the number of deaths reported and reviewed against the expected number of deaths for that area. This enables some monitoring of the effectiveness of reporting activity at a local level using a locally determined denominator. The LeDeR programme will greatly improve the knowledge of mortality rates pertaining to people with learning disabilities in a local area and therefore more accurate forecasting will become possible over time.

Dissemination of lessons learned

6.4 Reviews of the deaths of people with learning disabilities are a vital source of information to inform national and local policy and practices. All agencies involved in the review of an individual person have a responsibility to act on any lessons identified to improve practice.

6.5 The local area contact is responsible for the presentation of themes, best practice, recommendations and actions that have been identified within the review process to the local steering group for discussion and action.

Appendix 1: Initial review template (IR10)

Initial Review

Template Version: IR10

Person ID: Click here to enter text.

Region of England: Click here to enter text.

Date of notification: Click here to enter text.

Reviewer name:

File upload link: Click or tap here to enter text.

How to carry out an Initial Review

Questions 1 – 22 below take information from the death notification.

Please review these and then answer the remaining questions.

Thank you.

Death notification information

Details about the person who died

1. FIRST (GIVEN) NAME of the person who died

Name: Click here to enter text.

2. LAST NAME (i.e. family name or surname) of the person who died

Name: Click here to enter text.

3. Was the person known by any other name? If so, what was it?

Name: Click here to enter text.

4. Usual address and postcode of the person who died

Address: Click here to enter text.

Postcode: (It is very helpful if you can provide this.) Click here to enter text.

5. Date of BIRTH (This should be in the format dd/mm/yyyy)

Date: Click here to enter text.

6. Date of DEATH (This should be in the format dd/mm/yyyy)

Date: Click here to enter text.

7. Age at death

Age: Click here to enter text.

Information about the person's death

8. What was the place of death?

☐ Hospital

☐ Usual place of residence

☐ Hospice / palliative care unit

☐ Home of relative or friend

☐ Residential / nursing home that was not usual address

☐ I don't know

☐ Other: Click here to enter text.

9. Has this death been reported by a hospital trust under their Learning from Deaths policy?

☐ Yes ☐ No ☐ I don't know

If 'Yes', please record the contact details of the mortality lead at the Trust to whom the completed LeDeR review should be sent:

Click here to enter text.

10. What did reporter think the cause of death was?

The response to this question cannot be changed as part of the review, as it reflects the opinion of the person who reported the death.

Perceived cause:

11. Has anyone else been notified about the death?

☐ Yes ☐ No ☐ I don't know

If Yes, who has been notified? (Please tick all that apply)

☐ To the reporter's knowledge, no one else has been notified

☐ Coroner ☐ Safeguarding Team

☐ Child Death Review ☐ Police

☐ Care Quality Commission ☐ Someone else

If someone else has been notified about the death, please provide their contact details if you have them.

Contact details: Click here to enter text.

12. Did the reporter have any concerns about the death? If so, describe below:

The response to this question cannot be changed as part of the review, as it reflects the opinion of the person who reported the death.

Details:

13. Does the reporter have any additional information about the death that might help the reviewer?

The response to this question cannot be changed as part of the review, as it reflects the opinion of the person who reported the death.

Details:

Further information about the person and their death that might help the review, if it is available

14. Gender

☐ Male ☐ Female ☐ Other

If 'Other', please describe: Click here to enter text.

15. Deceased person's ethnic group

☐ **White**

☐ British

☐ Irish

☐ Gypsy or Irish Traveller

☐ Any other White background (please give details in box below)

☐ **Mixed / multiple ethnic groups**

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other Mixed / multiple ethnic background (please give details in box below)

☐ **Asian / Asian British**

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background (please give details in box below)

☐ **Black / African / Caribbean / Black British**

☐ African

☐ Caribbean

☐ Any other Black / African / Caribbean background (please give details in box below)

☐ **Other ethnic group**

☐ Arab

☐ Any other ethnic group (please give details in box below)

Details of person's ethnic group: Click here to enter text.

16. Marital Status of the person who died

☐ Single (never married)

☐ Married / civil partnership ☐ Stable / long-term partner

☐ Separated (but still legally married / in a civil partnership)

☐ Divorced

☐ Widowed

☐ I don't know

17. Name of and contact details of the person's GP surgery.

GP name: Click here to enter text.

Surgery contact details: (It is extremely helpful if you can provide the surgery postcode.)

Click here to enter text.

18. Name and contact details of next of kin / someone who knew the person well

Person 1:

Name: Click here to enter text.

Contact Details: Click here to enter text.

Relationship: Click here to enter text.

Person 2:

Name: Click here to enter text.

Contact Details: Click here to enter text.

Relationship: Click here to enter text.

19. NHS Number (This should be in the following standard format: 000 000 0000)

NHS number: Click here to enter text.

Reporter's contact details

If any clarification of the notification information is required, please use these to contact the reporter.

20. Name of the person notifying the death

Name: Click and type your name here.

21. Job and employing organisation of person notifying the death (if relevant)

Details: Click here to enter text.

22. How the reporter knew the person who has died

Relationship: Click here to enter text.

23. Reporter's contact details (if they are happy to be contacted)

Telephone number: Click here to enter text.

Mobile: Click here to enter text.

Email address: Click here to enter text.

Postal address and postcode: Click here to enter text.

END OF DEATH NOTIFICATION

Additional information about the person who has died

In preparation for the initial review of the person's death, please:

- Check and complete the information received at notification.
- Contact the notifier/s to ensure their views are included in this review.
- Identify someone who knew the person well (e.g. close family member) and speak to them about the person themselves and the circumstances leading to their death. Ask them to help you complete a pen portrait of the person who has died, and a timeline of the circumstances leading to their death.
- Review at least one set of relevant case notes (e.g. hospital record, electronic GP summary record, social care record).

In order to upload case review notes from agencies, please contact the individuals involved and ask them to use the following link. When they click on this link they will be able to upload files which you can access from the LeDeR dashboard.

File upload link: Click or tap here to enter text.

Section 1: Information relating to the person's health

24. What were the known medical conditions or health problems of the person who died, the dates of diagnoses, how the health conditions were managed, and the effectiveness of treatments?

Details: Click here to enter text.

Condition	Did the person have this condition? (Yes/No) *Please answer for ALL conditions before submitting the review.*	If yes, describe treatment / management	If yes, describe effectiveness of, or difficulties with treatment / management
Epilepsy/seizures			
Respiratory conditions/problems			
High blood pressure (hypertension)			
Diabetes			
Dementia			
Falls			
Obesity			
Gastric reflux			
Osteoporosis			
Constipation			
Skin conditions			
Dental problems			
Incontinence			
Sensory impairment e.g. hearing or visual problems			
Impaired mobility			
Impaired hand use (e.g. unable to move hands to feed self or push away something)			
Mental health needs			
Other conditions (please add below)			

25. What level of learning disability did the person who died have?

Please enter a response to this question before submitting the review.

☐ Mild ☐ Moderate

☐ Severe ☐ Profound / multiple

☐ I don't know

26. What prescribed medications did the person usually take?

☐ None

If 'None' is unselected, please enter at least the first row into this table before submitting the review.

Usual medications			
Medication name	Dose	Frequency	Purpose

27. Were there any additional prescribed medications given prior to the person's death?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ Not known

If 'Yes', please give details:

Medications at the time of death			
Medication name	Dose	Frequency	Purpose

28. Was this person prescribed an antipsychotic drug (either in the past or at the time of their death)?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ Not known

If 'Yes', please answer the following questions:

a. Please estimate the number of years of exposure to regular antipsychotic drugs

☐ None

☐ Less than 5 years

☐ Between 5-10 years

☐ In excess of 10 years

☐ Unable to answer question

b. What was the antipsychotic prescribed for?

☐ A psychotic or bipolar mental illness

☐ Challenging behaviour

☐ Other (please describe): Click here to enter text.

☐ Unsure of reason for antipsychotic

c. Have there been active attempts to stop the antipsychotic?

☐ None appear in the records

☐ A number of attempts to withdraw the antipsychotic appear in the records

☐ The antipsychotic was successfully withdrawn

---

29. Was the person in the past prescribed an antidepressant drug?

☐ Yes ☐ No ☐ Not known

If 'Yes', please answer the following questions:

a. Please estimate the number of years of exposure to regular antidepressant drugs

☐ None

☐ Less than 5 years

☐ Between 5-10 years

☐ In excess of 10 years

☐ Unable to answer question

b. What was the antidepressant prescribed for?

☐ Depression

☐ Anxiety

☐ Challenging behaviour

☐ Autism

☐ Other (please describe): Click here to enter text.

☐ Unsure of reason for antidepressant

c. Have there been active attempts to stop the antidepressant?

☐ None appear in the records

☐ A number of attempts to withdraw the antidepressant appear in the records

☐ The antidepressant was successfully withdrawn

---

30. Is there evidence of active review of the medication occurring in the past year?

Please enter a response to all parts of this question before submitting the review.

- By the GP actively reviewing the continuing need for the medicines on an annual basis

☐ Yes ☐ No ☐ Not known

- If specialist care involved, the specialist actively reviewing the continued need for the medicines on an annual basis

☐ Yes ☐ No

☐ Specialist not involved ☐ Not known

---

31. Did the person have a Learning Disabilities Annual Health Check in the last 12 months?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ Not known

If 'Yes', please answer the following questions:

Date of last Annual Health Check: Click here to enter text.

Please comment on the content and effectiveness of the Annual Health Check and any resulting Health Action Plan.

Click here to enter text.

If 'No' or 'Not known', please explain why not:

Click here to enter text.

32. Had the person received age and gender appropriate health screening? (e.g. breast cancer screening, bowel cancer screening)

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ Some but not all ☐ Not known

If 'Yes', please give more details:

Click here to enter text.

If 'No' or 'Not known', please explain why not:

Click here to enter text.

If 'Some but not all', please explain:

Click here to enter text.

33. Was the person underweight or obese, or had any significant changes in their weight over the past year?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ Not known

If 'Yes' or 'No', please give more details, including the person's last known weight or BMI:

If 'Yes' or 'No' are selected, please enter a response to this question before submitting the review.

Click here to enter text.

34. Was the person on an end of life pathway?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', please give more details, including whether there was an end of life plan, and how this was followed:

If 'Yes' is selected, please enter a response to this question before submitting the review.

Click here to enter text.

35. Please provide a summary of the person's health in general, their healthcare usage, and any gaps in their healthcare.

Please enter a response to this question before submitting the review.

Click here to enter text.

Section 2: Information about the person's social and care arrangements

36. What were the person's living arrangements?

Please enter a response to this question before submitting the review.

☐ Own or family home ☐ Supported living

☐ Residential home ☐ Nursing home

☐ Other (please describe): Click here to enter text.

37. Was the person who died placed out-of-area, either in a residential / nursing placement or in a supported living tenancy?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ I don't know

If yes, please state which area was their original 'home':

If 'Yes' is selected, please enter a response to this question before submitting the review.

Click here to enter text.

38. Was the person subject to any restrictive legislation?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ I don't know

If 'Yes', please give details:

If 'Yes' is selected, please enter a response to all parts of this question before submitting the review.

☐ Deprivation of Liberty Safeguards (DOLS) - approved

☐ Deprivation of Liberty Safeguards (DOLS) – applied for

☐ Section of the Mental Health Act

☐ Detention in police custody/imprisonment

☐ Other: Click here to enter text.

If the person was subject to any restrictive legislation, please describe more fully (e.g. dates, reason for restriction)

Click here to enter text.

39. Who did the person usually receive their main support from?

Please enter a response to this question before submitting the review.

☐ Family member or informal carer ☐ Paid carer ☐ None

If 'Family member or informal carer', was a carer's assessment completed? Please provide details:

Click here to enter text.

If 'Paid carer', please answer the following questions:

a. How was the person's care funded? (Please tick all that apply)

☐ Local Authority (directly commissioned)

☐ Local Authority via direct payment / personal budget

☐ NHS (directly commissioned)

☐ NHS via personal health budget

☐ CHC (Continuing healthcare) funding

☐ Joint-funding (NHS and local authority)

☐ Section 117 aftercare arrangements

☐ The person, or their family, themselves

☐ Other: Click here to enter text.

Please add any comments about their paid care here:

Click here to enter text.

b. How many hours of funded support did the person receive each week?

Click here to enter text.

c. Did the person experience any changes in service provision in the past year?

☐ Yes ☐ No

If 'Yes', please select one of the following options:

If 'Yes' is selected, please enter a response to all parts of this question before submitting the review.

☐ Yes, change in service PROVISION (e.g. hours of support)

☐ Yes, change in service PROVIDER

☐ Yes, change in PLACE of provision

☐ Yes, leaving the care of the local authority

Please provide additional details (e.g. what the changes were and why, and the impact of changes):

Click here to enter text.

40. Please identify and describe the services provided for the person during the last six months of their life (tick all that apply)

☐ Paid support work

☐ Voluntary support worker

☐ Occupational Therapy

☐ Psychology

☐ Speech and Language Therapy

☐ Physiotherapy

☐ Psychiatry

☐ Community Learning Disability Team Nurse

☐ Health Facilitator

☐ Acute Learning Disability Liaison Nurse

☐ Hospice / Palliative Care team

☐ Primary Care Learning Disability Liaison Nurse

☐ Specialist Nurse (e.g. PEG, continence, epilepsy, diabetic etc)

☐ Other: Click here to enter text.

☐ None

Please describe the services provided to the person in the last six months of their life:

Click here to enter text.

41. Please describe the availability and effectiveness of services to support the individual, and any outstanding gaps in services:

Click here to enter text.

42. Were any reasonable adjustments provided for the person?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', please describe any reasonable adjustments that were provided for the person:

(Please use a separate line for each one)

Reasonable Adjustments Provided	Comments

In your opinion, should any reasonable adjustments have been provided for the person (but were not)?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', please describe what reasonable adjustments should have been provided but were not.

Reasonable Adjustments that were required	Comments

Please add any comments about the provision of reasonable adjustments here:

Click here to enter text.

43. Pen portrait of the individual

Please provide a short summary about the person who has died, using the following headings:

Please write a short paragraph about the person and their needs (e.g. their personality, how they communicated their needs or how they were feeling, their likes and dislikes, and their behaviour).

Click here to enter text.

Please write a short paragraph about the persons social history and activities (e.g. significant life events, their lifestyle, social activities, sense of belonging to the local community, family and other contacts).

Click here to enter text.

Please add any additional information about the person that may be relevant but has not been covered elsewhere.

Click here to enter text.

Section 3: Information about the person's death

44. What was the cause of death as described on the Cause of Death Certificate? (If you do not know, please leave blank)

Please enter a response to this question before submitting the review.

I	(a) Disease or condition leading directly to death	Click here to enter text.
I	(b) Other disease or condition, if any, leading to I(a)	Click here to enter text.
I	(c) Other disease or condition, if any, leading to I(b)	Click here to enter text.
II	Other significant conditions contributing to death but not related to the disease or condition causing it	Click here to enter text.

If you do not have the information above, please describe the cause of death as you understand it:

Click here to enter text.

45. Timeline for circumstances leading to death

Please enter at least the first row into this table before submitting the review.

Please include information in the table below that may be relevant to the cause of death following the prompts below:

- Date of diagnoses and associated assessments/treatments/interventions
- Similar episodes of illness
- Sequence of events leading to death

N.B. The person's death should be the last line in the timeline.

Date (from earliest to latest)	**Reported by / where evidence obtained from**	**Circumstances**

46. Has a Structured Judgement Review (or equivalent) of this death taken place by an NHS Trust?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ I don't know

If 'Yes':

If 'Yes' is selected, please enter a response to all parts of this question before submitting the review.

☐ Please confirm that you have read a copy of the review report.

Please record the contact details of the mortality lead at the Trust to whom the completed LeDeR review should be sent.

Details: Click here to enter text.

If 'No' or 'I don't know', and place of death was a Hospital (see Q8):

All deaths of people with learning disabilities who die in hospital should have a structured judgement review (or equivalent) into their last episode of care. Please ensure that you have seen this and included its findings in your review.

47. Has there been any other review or investigations into this death? (tick all that apply)

Please enter a response to this question before submitting the review.

☐ Post mortem

☐ Coroner's inquest

☐ Serious Incident Review

☐ Safeguarding Investigation

☐ Police investigation

☐ Child death review

☐ Any other review or investigation

☐ None

Please provide additional details and confirm that you have included the findings of other investigations in your review:

Click here to enter text.

Section 4: Assessment of the care provided to the person and the circumstances leading to their death

Reminder: any answers shown in red indicate that a full multi-agency review might be required.

48. Has anyone expressed any concern about this death?

Please enter a response to this question before submitting the review.

☐ Yes ☐ Not to my knowledge

If 'Yes', please add any comments about this here:

If 'Yes' is selected, please enter a response to this question before submitting the review.

Click here to enter text.

49. Did the person have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place at the time of their death?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', was the documentation correctly completed and followed? (Please tick only one option)

If 'Yes' is selected, please enter a response to this question before submitting the review.

☐ The DNACPR documentation was correctly completed and followed

☐ The DNACPR documentation was correctly completed but was not followed

☐ The DNACPR documentation was neither completed nor followed correctly

☐ I don't know

Please add any comments about this here:

Click here to enter text.

50. Please describe any decisions where there is evidence that a mental capacity assessment took place and, if indicated, a best interests decision-making process was followed:

(Please use a separate line for each decision)

Decisions	Evidence	Outcome
e.g. DNACPR order	*e.g. MCA assessment undertaken 12/1/2018*	*e.g. Best interest decision meeting held as the person was assessed as not having capacity*

Please describe any decisions around which you think a mental capacity assessment and best interests decision-making process should have taken place but did not.

Decisions	Evidence	Outcome
e.g. DNACPR order	*e.g. No assessment of capacity evidenced*	*e.g. DNACPR order instigated. Challenged by family.*

Please add any comments about the use of the Mental Capacity Act here:

Click here to enter text.

51. From the evidence you have, do you think that the care package provided met the needs of the individual?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

Please add any comments about this here: Click here to enter text.

52. From the evidence you have, do you think that there were delays in the person's care or treatment that adversely affected their health?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

Please add any comments about this here: Click here to enter text.

53. From the evidence you have, do you think that problems with organisational systems and processes (including the coordination of care) led to a poor standard of care?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

Please add any comments about this here: Click here to enter text.

54. From the evidence you have, do there appear to be any gaps in service provision that might have contributed to the person's death?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

Please add any comments about this here: Click here to enter text.

55. From the evidence you have, do you think that this death might be attributable to abuse?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', have you made a safeguarding referral?

If 'Yes' is selected, please enter a response to this question before submitting the review.

☐ Yes ☐ No

Details: Click here to enter text.

56. From the evidence you have, do you think that this death might be attributable to acts of omission or neglect in any setting?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', have you made a safeguarding referral?

If 'Yes' is selected, please enter a response to this question before submitting the review.

☐ Yes ☐ No

Details: Click here to enter text.

57. To your knowledge, in the 12 months prior to death, had there been any significant and / or continuing safeguarding concerns raised in relation to the person?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', please add any comments about this here:

Click here to enter text.

Was the person subject to a safeguarding plan?

☐ Yes ☐ No

Please add any comments about this here:

Click here to enter text.

58. After reviewing this death, have you identified any best practice?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No

Please add any comments about this here: Click here to enter text.

59. Grading of care

Please enter a response to all parts of this question before submitting the review.

From the information you have gathered and analysed, please grade the quality of care the person received. Please base this on their overall experience of services, not on solely one organisation's input.

☐ 1. This was excellent care (it exceeded expected good practice). Please identify in Q62 what features of care made it excellent and consider how current practice could learn from this.

☐ 2. This was good care (it met expected good practice). Please identify in Q62 any features of care that current practice could learn from.

☐ 3. This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing). Please address these issues in your recommendations for service improvement in Q61, and identify in Q62 any features of care that current practice could learn from.

☐ 4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death. Please address these issues in your recommendations for service improvement in Q61, and identify in Q62 any features of care that current practice could learn from.

☐ 5. Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.

☐ 6. Care fell far short of expected good practice and this contributed to the cause of death.

Please comment on the reason for grading care as you have done: Click here to enter text.

---

60. After reviewing this death, will you be undertaking a Multi-Agency Review?

Please enter a response to this question before submitting the review.

☐ Yes: Care has been graded as 5 or 6 (to be automatically filled in if care has been graded 5 or 6 in Q58)

☐ Yes: Meets Priority Themed Review Criteria (aged 18-24 years or from Black or Minority Ethnic Community)

☐ Yes: Potential problems with care have been identified and additional learning could come from a multi-agency review

☐ No

Please add any comments about this here: Click here to enter text.

Section 5: Learning and Recommendations because of this review

61. Following your review, please now consider what you have learned from this individual's death that could lead to service improvements that could benefit others.

Please ensure that any issues, concerns or potential problems with care that have been identified in the review are addressed by a recommendation for service improvement.

Identified Issue	Learning	Recommendation to address issue
e.g. Zack was discharged from hospital without the care home staff being trained in catheter care which led to him having a UTI.	*e.g. Nursing staff do not routinely assess specific skills of care home staff before discharge.*	*e.g. Hospital staff must be responsible for ensuring that the skills and capabilities of care home staff are such that they can provide appropriate care before the patient is discharged.*

62. Please identify any positive practice that could benefit other people if the same was available to them, and any recommendations for service improvements as a result of this.

Positive practice identified	Recommendations from this

Section 6: The process of conducting your review

63. Please add any additional comments you might have in relation to this review (e.g. any particular difficulties you have had in completing this review)

Additional Comments: Click here to enter text.

64. It is an integral part of the LeDeR methodology that family are given the opportunity to share their experiences and any learning they would like to pass on. Have involved family member/s been given the opportunity to contribute to this review?

Please enter a response to this question before submitting the review.

☐ Yes ☐ No ☐ N/A (There are no involved family members)

If 'No', please explain why not:

Click here to enter text.

If 'Yes':

Please add any comments about how the family were involved in the review process and the contributions they have made:

Click here to enter text.

Please add any additional comments that the family would like to make that are not otherwise included in this report:

Click here to enter text.

Has the family given consent for identifiable information, in an anonymised format, about their relative's death to be shared widely in order to improve service provision if appropriate? (e.g. as a case study or a training resource)

If 'Yes' is selected above, please enter a response to this question before submitting the review.

☐ Yes ☐ No

If 'Yes', please upload the consent form to the LeDeR web-based platform, or post to the LeDeR team, before submitting this review.

65. Please list who has provided information (name and role) about the person and the circumstances leading to their death, and the sources of information you have used.

Name of person providing information	Role of person providing information	Date information was provided

Source of information (e.g. hospital record, community nurse notes etc.)	Date information was accessed

BEFORE SUBMITTING YOUR COMPLETED REVIEW

Please check the answers to ALL questions in the notification section, and questions 23-64 of the initial review, and complete/amend where necessary.

Please enter a response to this question before submitting the review.

☐ Please tick to confirm that all questions are complete and correct

Appendix 2: Preparing for multiagency review

Preparing for Multi-Agency Review

Person ID: Click or tap here to enter text.

Region of England: Click here to enter text.

In preparation for the multi-agency review, please can you:

1. Contact all agencies involved

- Identify individuals and agencies that have been involved in supporting the person who has died.
- Send them a draft copy of the pen portrait, timeline, and description of the circumstances leading to death and ask them to add any additional comments.

They should consider:

A. Initial diagnosis of the condition.
B. On-going management of the condition from initial diagnosis to critical illness.
C. Management and care received during final illness (including details and dates of any investigations, their results and any actions subsequently taken).

2. Contact family members

If family members have been involved in the initial review, we recommend that you check the draft information (pen portrait, timeline, and description of the circumstances leading to death) with them.

As part of this multi-agency review, it may be helpful for you to ask the family some additional questions if they have not already been covered, such as:

- Was there any particularly good practice in relation to this person's death?
- Were there any contributory factors to the death that could have been avoided?
- Is there anything about the person's death that has concerned them?

You should confirm whether the family would like to attend the multi-agency review panel meeting, and how you could help them to prepare for this.

3. Request documents

Request a copy of any relevant notes and documents pertaining to the person, for example

- Acute Trusts – summary record of past attendances, notes from most recent hospital attendance, copy of DNACPR order, copy of most recent medication record, any advance directives.
- GPs – summary copy of GP records, copy of any correspondence, copy of DNACPR order, copy of most recent medication record, any advance directives.
- Other services – records from final year of person's life, summary of care/ support plans and most recent medication records.

- In order to upload case review notes, please contact the individuals involved and ask them to use the following link. When they click on this link they will be asked to identify themselves, and will then be able to upload files. These files will appear inside the case review window.

  File upload link: Click or tap here to enter text.

4. Arrange a multi-agency review meeting

- Arrange a date, time and venue for the multi-agency review meeting and invite all individuals and agencies involved.

5. Prepare for the meeting

- Collate the information from the relevant case notes and responses.

1. Have you identified all relevant individuals and agencies that have been involved in supporting the person who has died?

Tick to confirm ☐

Please note the agencies involved here:

Details: Click here to enter text.

2. Have you sent all relevant agencies and individuals a draft copy of the pen portrait, timeline, and description of the circumstances leading to death and asked them to add any additional comments?

Tick to confirm ☐

Please note the agencies contacted here:

Details: Click here to enter text.

3. Have you received replies from all relevant agencies and individuals with their additions/amendments to the pen portrait, timeline, and description of the circumstances leading to death?

Tick to confirm ☐

Please note the agencies that have responded here:

Details: Click here to enter text.

4. Have you requested a copy of case notes from all relevant agencies and individuals?

Tick to confirm ☐

Please note the agencies contacted for case notes here:

Details: Click here to enter text.

5. Have you received a copy of case notes from all relevant agencies and individuals?

Tick to confirm ☐

Please note the agencies that have responded here:

Details: Click here to enter text.

6. Have you arranged a date, time and venue for the multi-agency review meeting and invited all individuals, agencies and the family?

Tick to confirm ☐

Please note the arrangements for the review meeting below:

Details: Click here to enter text.

7. Have you collated the information from the relevant case notes and responses to prepare for the review meeting?

Tick to confirm ☐

8. Have you moved all submitted material to the case folder in the LeDeR web-based platform?

Tick to confirm ☐

Appendix 3: Final report following multiagency review

Final Report Following Multi-Agency Review

Person ID: Click or tap here to enter text.

Region of England: Click here to enter text.

Please use the outcomes of the Multi-Agency Review meeting to complete this form.

---

1. Please list below the name and role of those contributing to this Multi-Agency Review

To add rows click into the last row of the table, right click, and select Insert – Insert Rows Below.

Name	Role	Method of contributing to review (in person / by phone / video conference / written submission / other)	Date

---

2. Pen portrait

Please provide a short summary about the person who has died, drawing on the contributions of all individuals and agencies submitting information for the review, using the following headings:

Please write a short paragraph about the person and their needs (e.g. their personality, how they communicated their needs or how they were feeling, their likes and dislikes, and their behaviour). Click here to enter text.

Please write a short paragraph about the persons social history and activities (e.g. significant life events, their lifestyle, social activities, sense of belonging to the local community, family and other contacts).

Click here to enter text.

Please add any additional information about the person that may be relevant but has not been covered elsewhere.

Click here to enter text.

3. Timeline

Please provide a timeline of the circumstances leading to the person's death, drawing on the contributions of all individuals and agencies submitting information for the review. You can find guidance about completing the timeline in the 'Help' section.

To add rows click into the last row of the table, right click, and select Insert – Insert Rows Below.

N.B. The person's death should be the last line in the timeline.

Date **(from earliest to latest)**	**Reported by / where evidence obtained from**	**Circumstances**

4. Best practice

Has any particularly good practice been identified in relation to the person's death? N.B. 'Best' practice here refers to that which is over and above the standard of care that should be usually be expected.

☐ Yes

☐ No

If yes, please describe: Click here to enter text.

5. Surprise at death?

Is the Panel surprised that the person died at this time from this cause?

☐ Yes

☐ No

If yes, please describe: Click here to enter text.

6. Potentially avoidable contributory factors in relation to the person and their environment

Have any potentially avoidable contributory factors relating to the person and /or their environment been identified? (e.g. overriding fear of medical interventions; family members don't feel listened to; housing inadequate for needs).

☐ Yes

☐ No

If yes, please describe: Click here to enter text.

7. Potentially avoidable contributory factors in relation to care

Have any potentially avoidable contributory factors relating to the person's care and its provision been identified? (e.g. the quality of pain relief, nutritional support, provision of reasonable adjustments).

☐ Yes

☐ No

If yes, please describe: Click here to enter text.

8. Potentially avoidable contributory factors in relation to services

Have any potentially avoidable contributory factors relating to the way services were organised and accessed been identified? (e.g. assessment processes, eligibility criteria, protocols between agencies).

☐ Yes

☐ No

If yes, please describe: Click here to enter text.

9. Was the death, on balance, potentially avoidable?

Potentially avoidable deaths are those where there are aspects of care and support that, had they been identified and addressed, may have avoided the person dying at this time from this cause.

☐ Yes

☐ No

☐ Panel cannot reach a unanimous decision

Please describe the reasons given for this response: Click here to enter text.

---

10. As a result of this review, have any lessons been learned in respect of this person's death?

☐ Yes

☐ No

If yes, please describe lessons learned: Click here to enter text.

---

11. Changes to local practices

Should there be any changes made to local practices following this review?

☐ Yes

☐ No

If yes, please describe what changes should be made: Click here to enter text.

---

12. Are there any wider recommendations that should be considered?

☐ Yes

☐ No

If yes, please describe what recommendations should be considered:

Click here to enter text.

13. Additional comments

Please use this space to add any additional comments that you feel are relevant about the process or content of the multi-agency review.

Click here to enter text.

14. Comments about the LeDeR Review process and IT System

Please add any comments that you might have about your experience of the LeDeR Review process or IT System.

Click here to enter text.

15. Learning and Recommendations

Following your review, please now consider what you have learned from this individual's death that could lead to service improvements that could benefit others.

Please ensure that any issues, concerns or potential problems with care that have been identified in the review are addressed by a recommendation for service improvement.

Identified Issue	**Learning**	**Recommendation to address issue**
e.g. Zack was discharged from hospital without the care home staff being trained in catheter care which led to him having a UTI.	*e.g. Nursing staff do not routinely assess specific skills of care home staff before discharge.*	*e.g. Hospital staff must be responsible for ensuring that the skills and capabilities of care home staff are such that they can provide appropriate care before the patient is discharged.*

16. Positive Practice

Please identify any positive practice that could benefit other people if the same was available to them, and any recommendations for service improvements as a result of this.

Positive practice identified	**Recommendations from this**

Appendix 4: Quality assurance checklist

Quality Assurance Panel Feedback Form	
Case ID	
Review quality assurance panel members	
Local Reviewer name	
Local Area Contact name	
Date reviewed	
Structure	**QA Panel comments**
Accurate and concise, and written in a way that is clear, jargon free and not repetitive.	
Where used, complex medical and organisational terms are explained simply.	
Fact based timeline describing the events leading up to the death of the person.	
Comprehensive and proportionate pen portrait.	
Highlighted relevant issues which are supported by evidence.	
Clear reasons for any missing information, or information not made available to the reviewer.	
Logical progression in the reasoning, and conclusions supported by facts.	
Gathering and analysing information	
Evidence of appropriate involvement of families at the relevant stages of the review process, or an explanation of why family has not been involved.	
Appropriate evidence available and used e.g. case records from agencies involved.	
Relevant parties involved in the review process.	
Appropriate focus upon identifying potential contributory facts and learning from the circumstances leading to the person's death.	
Observations on care and treatment are valid and supported by evidence.	
Focus is upon improvements and actions for implementation.	
Outcome and next steps	
Recommendations are clear and SMART.	