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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NHS England

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

Contents

Section 1: Introduction

1.1 The Learning Disabilities Mortality Review (LeDeR) Programme has been established in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)[1]. It has been commissioned by NHS England and is managed by the Healthcare Quality Improvement Partnership (HQIP).

1.2 Since the 1990s there have been a number of reports and case studies that have consistently highlighted that in England people with learning disabilities die younger than people without learning disabilities. CIPOLD reported that for every one 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].

1.3 The LeDeR Programme has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It will do so by supporting local areas to carry out local reviews of deaths of people with learning disabilities. Through an agreed local review process, it aims to firmly embed the responsibility for conducting the reviews and implementing any recommendations and plans of action, into the hands of regional and local services.

1.4 In addition to supporting the programme of local reviews of deaths of people with learning disabilities, the LeDeR Programme is also undertaking four additional projects. The focus of these is to:

- Support data linkage techniques to provide national data about the mortality of people with learning disabilities
- Map the provision of reasonable adjustments for people with learning disabilities across England
- Improve the consistency of death certification in relation to people with learning disabilities
- Establish a repository for anonymised reports pertaining to people with learning disabilities, e.g. Serious Case Reviews, Ombudsman Reports

[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

The policy context in which the LeDeR programme is operating

1.5 The LeDeR programme is operating at a time when national legislation, policy and guidance all clarify what people with learning disabilities should expect in terms of care provision.

1.5.1 The Mental Capacity Act 2005 protects and empowers people who may lack the mental capacity to make their own decisions, including decisions about their care and treatment.

1.5.2 The Equality Act 2010 legally protects disabled people from discrimination

1.5.3 The Care Act 2014 outlines the way in which local authorities are required to carry out assessments of need, including an assessment of carers' needs; how local authorities determine who is eligible for funded support; and how local authorities charge for both residential care and community care. It includes a new duty to provide advocacy for those who have 'substantial difficulty' in being involved in assessments and who do not have suitable friends or relatives to represent them.

1.5.4 The learning disabilities Direct Enhanced Service (DES) provides payment to GPs to offer an annual health check and health action plan to people with learning disabilities, and to maintain a learning disabilities register.

1.5.5 The Care Quality Commission (CQC) introduced a new regulation and inspection process for health and social care services in England in 2014 which assesses whether services are safe, effective, caring, responsive and well-led. Inspectors now also ask more specific questions related to people with learning disabilities in acute hospitals.

1.5.6 In 2015, NHS England committed to a programme of closing inappropriate and outmoded specialist inpatient facilities for people with learning disabilities and establishing stronger support in the community. The *Transforming Care Programme* is now working to roll out care and treatment reviews across England, reduce unnecessary hospital admissions and lengthy hospital stays, and test a new competency framework for staff to ensure that the right skills are in the right place.

1.5.7 The NHS England '*Commitment to Carers*' (2014) guidance echoes the requirements of the Care Act to place carers centrally in any consideration of a person's care. In addition, it set out the need to review existing processes to gather bereaved carers' views on the quality of care provided to their relative in the last three months of life.

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.

The purpose of the Learning Disability Mortality Review programme

2.2 The main purpose of the LeDeR review of a death of a person with learning disabilities is to:

- Identify any potentially avoidable factors that may have contributed to the person's death and
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

Definitions

Learning disabilities

2.3 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

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

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

Potentially avoidable contributory factors to death

2.6 A potentially avoidable contributory factor refers to 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

[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

- The person's care and its provision
- The way services are organised and accessed

Potentially avoidable deaths

2.7 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

2.8 Initial reviews are undertaken of **all** deaths notified to the LeDeR programme of people with learning disabilities aged 4-74 who are registered with a GP in England.

2.9 Deaths of children younger than 4 years of age are not be subject to review beyond the collection of core data. Their deaths are reviewed as part of the statutory Child Death Review Process.

2.10 Deaths of adults with learning disabilities aged 75 and over are not subject to review beyond the collection of core data. However, if concerns are raised about any such deaths, a referral is made to an appropriate body if required, for example the Local Safeguarding Adults Board or the Coroner.

Deaths subject to Priority Themed Reviews

2.11 All deaths of people with learning disabilities who fit the criteria for the current priority themed review are subject to a full multi-agency review. The anonymised reports and action plans are reviewed externally by an independent multi-agency review panel.

2.12 From 2016-2017, and possibly longer, deaths of young people aged 18-24, and of people from Black and Minority Ethnic communities are subject to priority themed review. The subset of deaths subject to priority themed review in subsequent years will be nominated through a consultation process and decided upon by NHS England.

Leading the review

2.13 In general, it is the area in which the person is registered with a GP that will lead the review. If a person is in an 'out-of-area' placement, 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 which would lead the review and how best to collaborate.

Section 3: Establishing 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 structure. This is of four regions (North, South, Midlands, and London) within which are 13 local areas.

The Local Steering Group

3.2 It is expected that each of the 13 local areas will establish a Local Steering Group which will be responsible for the implementation of the LeDeR Programme in that area and ensuring that any learning, recommendation and actions are reviewed and taken forward using locally agreed governance structures.

3.3 The role of the Local Steering Group is to:

- Guide the implementation of the programme of local reviews of deaths of people with learning disabilities
- Receive regular updates from the local area contact (see below) about the local reviews of deaths of people with learning disabilities
- Monitor action plans resulting from local reviews of deaths
- Take appropriate action as a result of information obtained from local reviews of deaths
- Resolve any interagency disputes that arise in relation to the local reviews of deaths of people with learning disabilities.

The Local Area Contact

3.4 Local area contacts are the link between the central LeDeR programme team, the Local Steering Group and local reviewers. The role of the Local Area Contact is to:

- Work in partnership with the LeDeR team in organising the delivery of training for local reviewers, and more general awareness raising about the programme
- Receive notifications of deaths of people with learning disabilities from the central LeDeR programme team
- Help allocate cases to appropriate local reviewers
- Monitor the progress and completion of reviews to ensure that they are of a consistent standard and completed in a timely and comprehensive way
- Provide ongoing advice, support and training for local reviewers as necessary
- 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 and action plans
- Anonymise and collate learning points and actions, and present the information to the Local Steering Group for action and implementation
- Work with the Local Steering Group to take appropriate action

The Local Reviewer

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

3.6 The reviews should be 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.

3.7 The role of the local reviewer is to:

- Receive notification of a death of a person with learning disabilities from either the central LeDeR programme team of the local area contact
- Complete an initial review of each death
- Lead and complete a multi-agency review of those deaths where this is indicated.
- Maintain communication with the local area contact and LeDeR programme team 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 any associated action plan
- Submit the completed paperwork of the review to the local area contact and the LeDeR programme

Data sharing and confidentiality

3.8 Due to the complex and multi-agency nature of the reviews it is important that information sharing is in line with expectations regarding confidentiality and the appropriate use of received information. Stakeholders across all care sectors need to work together positively to enable open information sharing for the purpose of achieving good quality reviews.

3.9 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/.

3.10 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 2018 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 the Office for National Statistics to obtain the 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.

3.11 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.

3.12 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.

3.13 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. The LeDeR Programme has developed a template for local data sharing agreements; if this would be helpful for you, please ask the LeDeR team for a copy.

3.14 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

3.15 It is important that the death of a person with learning disabilities is reviewed following the LeDeR mortality review process in order to capture any learning from deaths at individual and collective levels. In order to do this in a timely manner and to avoid duplication, reviewers need to be clear how, and in what ways, the LeDeR mortality review process links with other mortality reviews or investigations.

3.16 Other investigations or reviews may include, for example: Serious Case Reviews (SCRs), Safeguarding Adult Reviews (SARs), Safeguarding Adults Enquiries (Section 42 Care Act), Domestic Homicide Reviews (DHRs), Serious Incident Reviews, Coroners' investigations and Child Death Reviews.

3.17 Although the different review processes should conduct their investigation in a cooperative manner, each review will have its own remit and focus of attention, and the independence of each party is of importance.

3.18 The local area contact will inform the Local 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 Local Steering Group with reports on progress and completion of the review.

Police Investigation

3.19 The police are involved in investigating a death if there is a suspicion that a crime has occurred. Criminal investigation by the police takes priority over other enquiries, and the LeDeR mortality review may need to be put on hold so that it does not 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.

Domestic Homicide

3.20 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.

Deaths referred to the Coroner

3.21 When a death has been referred to the coroner for investigation, the LeDeR reviewer or the local area contact should contact the local coroner's office 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 a 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.

Serious Incident Review (SIR)

3.22 If the death of a person with learning disabilities is subject to a SIR, 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.

Safeguarding Adult Review (SAR)

3.23 If the death of a person with learning disabilities is subject to a SAR, the local reviewer and/or local area contact for the LeDeR programme will liaise with the Chair of the Safeguarding Adults Board to ensure the collection of core data for the LeDeR programme and to offer expertise about learning disabilities as appropriate.

Section 4: Involving families within 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 of 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 Reporting a death of a person with learning disabilities can be done in a number of ways and by anyone:

a. via **0300 7774 774** directly to a member of the central LeDeR programme team, or
b. via the Programme's secure web-based portal, which can be accessed through the LeDeR website or via the following link: http://www.bristol.ac.uk/sps/leder/notify-a-death/

5.2 The person reporting the death is asked to provide as much of the core information required to notify a death as possible. The information provided is checked by the LeDeR team to ensure that the death meets the inclusion criteria for the LeDeR programme. Once confirmed the death is allocated to a reviewer under the guidance of the local area contact.

Initial review

5.3 An initial review is completed for all deaths of people with learning disabilities in England that meet the inclusion criteria for the LeDeR programme, i.e: that the person is aged between 4-74 years, has learning disabilities and is registered with a GP in England.

5.4 It is the job of the local reviewer to conduct an initial review of each death. All information is accessed, edited and completed via the secure web based portal of the LeDeR Review System.

5.5 A good quality review ensures that sufficient and relevant information has been considered during the whole review process, delays and duplication are avoided, and any risk of omitting key information is mitigated.

5.6 The initial review process involves:

- Checking and completing the information received at the notification stage
- Contacting a family member or another person who knew the deceased person well and discussing with them the circumstances leading up to the person's death
- 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 professional had the closest involvement with the person prior to their death
- Developing a pen portrait of the person who has died and a timeline of the circumstances leading to their death
- Making a decision, in conjunction with others if necessary, about whether a multi-agency review is indicated
- Completing the LeDeR programme online documentation and an action plan, which will be reviewed by the local area contact and Local Steering Group, and as part of the national LeDeR process.

5.7 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 purpose of discussing the circumstances leading to the death of the person with someone who knew them well, is for the reviewer to develop an understanding about the person with learning disabilities, identify any possible factors that may have contributed to their death, and recognise any best practice and reasonable adjustments that had been made for the person. The resulting information contributes to populating a pen portrait of the person who has died, and a timeline of the sequence of events leading to their death.

5.9 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. A list of headings and prompts of things to include in a pen portrait can be found in Appendix 1 and on the LeDeR web based platform.

5.10 The purpose of a timeline is to present a chronological picture of a person's life and in particular the relevant circumstances that led up to their death. It should contain dates of significant events such as: changes to a person's personal circumstances, accommodation, daily routine or activities, health consultations, investigations, diagnoses and significant decisions made about a person's care, support and treatment.

5.11 There are a number of circumstances that would indicate that a multi-agency 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 multi-agency review is indicated, the reviewer should discuss the circumstances with their local area contact, a member of the LeDeR programme team, or another senior level practitioner.

5.12 A multi-agency review **is always required**:

- If the person fits the criteria for a current themed priority review. From 2016-2017 this is that they were from a Black and Minority Ethnic background or that they were aged 18-24
- Where the assessment of the care received by the person is graded 5 or 6 within the following scale

1. This was excellent care and met current standard practice.
2. This was good care, which fell short of current best practice in only one minor area.
3. This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death.
4. Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning would result from a fuller review of the death.

5. Care fell short of current best practice in one or more significant areas; although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.

6. Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.

5.13 A multi-agency review **should be considered**:

- If the local reviewer thinks that a multi-agency 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 multi- agency 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

5.14 If, at the completion of the initial review, there is no indication that a multi-agency review is required, the reviewer completes the initial review documentation and an action plan.

5.15 The action plan is intended to document how any recommendations and learning points identified during the review process should be taken forward. These are reviewed by the Local Steering Group who will be responsible for taking forward the agreed recommendations and actions. An action plan template and guidance can be found in Appendix 2

Multi-agency review

5.16 The purpose of the multi-agency 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 multi-agency 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 a multi-agency review meeting, and sending the agenda and anonymised papers to participants in good time
- Where a family member wants to attend the multi-agency meeting, support arrangements need to be discussed with them prior to meeting to ensure their maximum involvement

5.18 It is the role of the reviewer to chair and facilitate the multi-agency 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 multi-agency review meeting provides an opportunity for those involved in the life and care of the person who has died to discuss the circumstances that led to the person's death, identify any potentially avoidable contributory factors, note any best practice in relation to the person's care, agree whether the person's death at that time was potentially avoidable, make any necessary recommendations and agree a provisional action plan.

5.20 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 reported to the local area contact and investigated through the relevant processes.

5.21 Following the multi-agency review meeting the reviewer updates the timeline and pen portrait if necessary, and completes the LeDeR programme online summary report and action plan. These are then reviewed and agreed by the local area contact, and presented on a quarterly basis to the Local Steering Group and local governance structures.

Priority Themed Review

5.22 All deaths of people with learning disabilities who fit the criteria for priority themed review are subject to a full multi-agency review, and the anonymised reports and action plans reviewed externally by an independent, multi-agency review panel. Two panels are in existence: one is a multi-agency panel of professionals and family members. The second panel is of people with learning disabilities.

5.23 Any additional learning points or recommendations identified by the priority themed review panel members are presented to the local area contacts on a quarterly basis for scrutiny and action.

Timescales for conducting reviews

5.24 The initial review should be completed within four weeks unless there are exceptional circumstances.

5.25 The multi-agency review should be completed within four weeks unless there are exceptional circumstances.

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 multi-agency 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 can be closed.

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

6.3 The LeDeR team undertakes regular sampling of initial and multi-agency reviews in order to provide an external quality assurance process. The sampling criteria includes reviews completed by region, sector, agency and role. The quality of each individual report into the review of a death is assessed using the framework presented in Appendix 2.

6.4 The LeDeR team provides written feedback making recommendations for change to local area contacts where quality issues have been identified.

6.5 Those deaths that meet the criteria for priority themed review are subject to an additional level of scrutiny by an independent, expert, multi-agency review panel.

6.6 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 ongoing delivery of 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

6.7 Ongoing 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.

6.8 The local area contact is responsible for the collation of the themes, best practice, recommendations and actions that have been identified within the review process. These are presented to the local Steering Group for discussion and action.

6.9 The Steering Group is responsible for producing regular quality assurance reports. As the LeDeR programme pilot sites develop their approach, the content and construction of quality assurance reports will be finalised as a model template. Currently pilot sites are advised to include the following information in their reporting to central LeDeR programme team at the University of Bristol, Quality Surveillance Groups, Safeguarding Adults Boards and other locally agreed governance meetings.

- Local Activity data – referrals received, initial reviews, multi -agency reviews and action plans published
- Analysis of emergent themes from reviews i.e. frequency, common themes, issues of specific interest or exception
- Good practice areas or approaches noted for sharing within the network
- Information about issues escalated for further review via safeguarding or other investigative processes – e.g. NHS Serious Incident Framework
- Information about interfaces with other related groups and processes – i.e. Child Death Overview Panel, Safeguarding Adults Reviews, Coroner investigations
- Narrative information on the work being delivered via action plans post review
- Other related development work triggered in the local area as a result of a mortality review.

6.10 Information about notifications of death, and the reports of the reviews of deaths, are submitted to the central LeDeR programme team at the University of Bristol on an ongoing basis. The central LeDeR programme team provides each Steering Group with an annual report summarising the data that has been collated and analysed from the review processes pertaining to their area.

Section 7: Governance arrangements

7.1 The delivery of the work is ultimately the responsibility of NHS England, working with health and social care partners.

7.2 System-level governance process and approaches that are required to enable the delivery of the LeDeR programme are subject to some local variation in order to efficiently and safely integrate the work into existing systems and structures. Due to the multi-agency nature of the review process, it is clear that governance linkages are required with a range of bodies. Additionally there is work underway by CQC and NHS Improvement to explore mortality review processes in relation to people with learning disabilities from a regulatory and inspectoral perspective; it is important for providers and those responsible for oversight to ensure that local implementation of the LeDeR programme is in line with this developing work.

7.3 The outputs from the LeDeR programme need governance and oversight at local, regional and national level, to ensure any appropriate management action is taken as required, and that themes and lessons are fed into service improvements. It is important that the appropriate governance functions within the NHS England quality and service improvement hierarchy are in receipt of reporting from this programme.

Governance at national level

7.4 NHS England has established a National LeDeR Operational Steering Group to provide leadership, guidance and oversight to the local implementation of learning disability mortality reviews. This group has engaged with key partners to identify appropriate governance mechanisms and to support the delivery of the LeDeR programme. The group has a named lead for the programme from each of the four NHS England regions, along with representation from social care and the central LeDeR programme team at University of Bristol.

7.5 The National Operational Steering Group meets bi-monthly and can be utilised for governance-related issues from regional steering groups or other stakeholders. The group reviews and reports on progress. It does not require direct reports from local groups; however it receives progress updates from each of the named leads for the programme from the four NHS England regions, and carries out assurance and audit activities to assist in quality development of governance processes. The national LeDeR Operational Steering Group provides a key link between the delivery of the programme across regions and the Independent Advisory Group convened by HQIP which meets with the central LeDeR team based at the University of Bristol bi-annually.

7.6 As part of the programme methodology, completed reviews of deaths of people with learning disabilities are sent to the central programme team based at the University of Bristol. The anonymised reports will be collated and evaluated by the programme team to ensure consistency of reviews at national level and an annual report published highlighting learning

and recommendations being made as a result of local reviews of deaths. The annual report is disseminated to regulators, policy makers, commissioners, service providers, practitioners and patient and family networks with the aim of supporting changes that improve the quality and safety of care for people with learning disabilities.

Governance at local level

7.7 All areas should have a local steering group established. The preferred geography would be utilising existing Transforming Care Partnership footprints or other learning disability-focussed commissioning networks. The local steering group provides oversight, support and governance to the local delivery of the programme, and oversees how the programme is administered and delivered in a given area.

7.8 The local steering group should provide updates and assurance to:

- The central LeDeR team at the University of Bristol
- The named lead for the programme in their respective NHS England region (North, South, Midlands, London)
- The national Operational Steering Group.

7.9 There are obvious and strong linkages between detecting and reducing premature mortality in people with learning disabilities and safeguarding – particularly in relation to the preventative element of the role of Safeguarding Adults and Children's Boards. The Care Act clearly lays out responsibilities in relation to safeguarding adults as not being only about abuse or neglect, but also about the risk of abuse or neglect. The emphasis is on behaviours rather than the consequence of the behaviours.

7.10 The LeDeR programme and approach offers a process of learning from a death which can enable Safeguarding Adults and Children's Boards and local structures to focus on how to protect people with care and support needs from the behaviours and systems that pose a risk of abuse or neglect. Such learning may usefully inform where such boundaries (or tipping points) are, and should be, between poor quality, neglect or abuse, and organisational (previously referred to as institutional) neglect or abuse.

7.11 The initial pilot for the programme of reviews of deaths of people with learning disabilities, along with further exploratory work, has identified the benefits of a close relationship to, and embedding within, existing local safeguarding structures.

7.12 From a practical perspective the LeDeR programme, where seeking to address childhood mortality, recommends integration of this function into local arrangements for Child Death Overview Panel processes.

7.13 It is recommended that a good working relationship is developed between the LeDeR programme in each local area and the relevant Safeguarding Adults Board. Whilst recognising

the flexibility required for local delivery, it is recommended that partners in each area consider whether the local LeDeR steering group should adopt the function of a sub-group of the Safeguarding Adults Board, as part of their approach to Safeguarding Adult Reviews. This function would give the following assurances to Safeguarding Adults Boards:

- Assurance that all known deaths of people with learning disabilities receive a review of the full range of circumstances leading to death (bio – psycho, social) as indicated in line with LeDeR methodology
- An effective route of escalation to the Safeguarding Adults Board if a wider safeguarding issue is detected that would require consideration by the Board under its safeguarding adults review duties
- An effective mechanism for Safeguarding Adults Boards to share information and direction to services for people with learning disabilities within the local system.

7.14 An advantage of utilising Safeguarding Adults Board structures to assist in the delivery of the LeDeR programme is the existing duty to supply information as requested by Board under S45 of the Care Act (2014). Where this is relevant to a case, existing information sharing agreements can be utilised to facilitate the timely sharing of information to complete investigations. This is, however, only relevant in the execution of Safeguarding Adults Boards duties, (and not if no abuse or neglect is suspected). It is therefore suggested that local mortality steering groups utilise local Memorandums of Understanding (MoU) between stakeholders to facilitate the sharing of information in the geographical area, although these are not mandatorily required given Section 251 approval for the programme (see Section 3.8-3.13 above).

7.15 It is recommended that an annual report be provided to the Safeguarding Adults and Children's Boards of all contributory factors leading to the deaths of people with learning disabilities in its area, and that a summary of all review reports, including those where a death does not involve abuse or neglect, should be reported to the Director of Adult Social Services, so that any relevant learning can be disseminated with the health and social care workforce. It is advised that the annual report is also shared with the local Quality Surveillance Group.

7.16 Quality Surveillance Groups will form a key part of the governance and reporting structure. They bring together regulators, NHS England and Local Authorities locally, and provide a direct reporting and monitoring route for local mortality review Steering Groups through the named lead for the programme from each of the four NHS England regions. Quality Surveillance Groups should be monitoring excess mortality rates of people with learning disabilities and ensuring that there are appropriate Serious Incident Reviews undertaken wherever indicated. They need to be formally assured from localities, via the named lead for the programme from each of the four NHS England regions that actions are being implemented and actively support resolution of barriers and challenges.

Appendix 1: Initial review template

How to carry out an Initial Review

Questions 1 – 35 below take information from the death notification. This information has been automatically posted into this document.

Please can you:

- Review the answers to Questions 1 – 35 whilst completing the Initial Review and then answer the remaining questions.

Thank you.

Death notification information

1. Name of the person notifying the death
2. Role and agency of person notifying the death
3. How the reporter knew the person who has died
4. Reporter's contact details (if they are happy to be contacted), Telephone number, email address, postal address and postcode,
5. Reporter's preferred method for contact
6. Reporter's comments about the death
7. Who else has been notified about the death? (Tick all that apply)

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

☐ Coroner ☐ Safeguarding Board

☐ Child Death Review ☐ Police

☐ Care Quality Commission ☐ Anyone else

☐ I don't know

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

Details about the person who died

8. FIRST NAME of the person who died
9. SURNAME of the person who died
10. Was the person known by any other name? If so, what was it?
11. Date of BIRTH
12. Date of DEATH
13. Age at Death
14. Gender
15. How does the reporter believe the deceased person identified their ethnic group? (Tick One)

☐ White ☐ Mixed / Multiple ethnic groups

☐ Asian / Asian British ☐ Black / African / Caribbean / Black British

☐ I don't know ☐ Other: Click here to enter text.

16. Marital Status of the person who died

☐ Single ☐ Married / Partner
☐ Divorced / Separated ☐ Widowed
☐ I don't know ☐ Other: Click here to enter text.

17. In which area of England was the person registered with a GP?

☐ North: Yorkshire & the Humber ☐ North: Lancashire & Greater Manchester
☐ North: Cumbria & the North East ☐ North: Cheshire & Merseyside
☐ Midlands & East: North Midlands ☐ Midlands & East: Central Midlands
☐ Midlands & East: West Midlands ☐ Midlands & East: East Midlands
☐ South: South West ☐ South: South East
☐ South: Wessex ☐ South: South Central
☐ London Region ☐ Unknown

18. NHS Number
19. Did they have any known conditions or health problems?
20. Usual address and postcode of the person who died
21. Did the person who died usually live alone?
22. Was the person who died in an out-of-area placement? If yes, please state which area was their 'home' area
23. Was the person subject to any restrictive legislation?

☐ None ☐ Deprivation of Liberty Safeguards (DOLS)
☐ Section of the Mental Health Act ☐ Detention in police custody/imprisonment
☐ Other: Click here to enter text. ☐ I don't know

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

Those who knew the person who died

24. Please can you provide the contact details of someone who knew the person well, which may or may not be yourself (e.g. address, email, telephone number)
25. How did they know the person who died
26. Name of person's GP and contact details of GP surgery (e.g. postal address, email, telephone number)

Details of the Death

27. 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

Please provide the name and address of the place where the person died

28. What was the cause of death (as described on the Cause of Death Certificate 1a/1b/1c/2)
29. What did reporter think the cause of death was?
30. Will there be a post mortem?
31. Will there be a Coroner's inquest?

32. Will there be any other investigation into the death? If YES please describe
33. Was the reporter surprised that this person died from this cause at this time? Give an explanation of response

Initial Review Of Death – additional questions

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

- 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, summary record from GP, social care record).
- Check and complete the information received at notification.

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 asked to identify themselves, and will then be able to upload files. These files will appear inside that case review process.

34. Optional space for you (the reviewer) to write any notes, comments or thoughts of your own about this review. You are welcome to delete these prior to submitting your completed review if you so wish.
35. Information provided at notification stage has been checked and completed.
    ☐ Please tick to confirm
36. Someone who knew this person well has provided information to the reviewer about the person themselves and the circumstances leading to their death.
    ☐ Yes ☐ No
37. Please explain who has provided information and in what capacity. If no one who knew the person well has provided information, please explain why.
38. Please describe what relevant case notes you have reviewed
39. Please confirm that at least one set of relevant case notes (e.g. summary GP record, hospital notes relating to most recent hospitalisation, social care records) has been reviewed.
    ☐ Please tick to confirm

40. **Pen portrait of the individual**

Pen portrait of the individual. Please include information about the person themselves, their health, the environment in which they were living, and a description of their service use. You can find guidance about writing a pen portrait of an individual in the 'help' section on your LeDeR dashboard area.

41. Name of Local Authority/Health Commissioner

42. Was the person who died in regular contact with any of the following people?
    ☐ Their family / relative ☐ An attorney under a Lasting Power of Attorney direction
    ☐ A Deputy agreed / appointed by the Court of Protection
    ☐ An advocate ☐ Other: Click here to enter text.
    Please add any further details: Click here to enter text.
43. Did the person who died usually receive statutory or voluntary sector support?
    ☐ Yes ☐ No
    If YES did they receive support:
    ☐ Daytime only ☐ Day and night (waking night) ☐ Day and night (sleeping night
    Please describe any services and supports that the person received
44. Did the person who died experience any of the following changes in service provision in the past year?
    ☐ Yes, change in service PROVISION (e.g. hours of support)
    ☐ Yes, change in service PROVIDER ☐ Yes, change in PLACE of provision
    ☐ No ☐ Not applicable as not in receipt of services
    If YES can you provide details (e.g. number of changes, what changes were made, impact of changes)
45. Please provide a short summary of the circumstances leading to the person's death and then enter the key events in the timeline framework below. You can find guidance about completing the timeline in the 'help' section on your LeDeR dashboard area.

Timeline for circumstances leading to death

You can add rows by clicking into the last row of the table, going to 'Table Tools - Layout' and choosing the 'Insert Below' option from the 'Rows & Columns' section. Alternatively, click into the last row of the table, right click, select Insert – Insert Rows Below.

Date	Reported by / where evidence obtained from	Circumstances

46. Has anyone expressed any concern about this death?
☐ Yes ☐ Not to my knowledge
If yes, please add any comments about this here

47. If the person had Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) documentation, had this been fully and correctly completed with a clear and appropriate rationale for the decision not to resuscitate?
    ☐ Yes, and documentation was correctly completed
    ☐ Yes, but the documentation was NOT correctly completed
    ☐ No DNACPR order
    Please add any comments about this here

48. Based on what you have found in conducting this review, would an assessment of mental capacity have been relevant for this person?
    ☐ Yes ☐ No
    If yes, is there any indication that mental capacity has been considered?
    ☐ Yes ☐ No
    Please add any comments about this here

49. From the evidence you have, do you think that the person was treated in a timely way without any delays in their care or treatment that adversely affected their health?
    ☐ Yes ☐ No
    Please add any comments about this here

50. From the evidence you have, do you think that this death might be attributable to abuse or neglect in any setting?
    ☐ Yes ☐ No
    Please add any comments about this here

51. From the evidence you have, do you think that the person experienced standards of care, including the coordination of their care, that might indicate organisational dysfunction, danger or inadequacy?
    ☐ Yes ☐ No
    Please add any comments about this here

52. Do there appear to be any gaps in service provision that might have contributed in any way to the person's death?
    ☐ Yes ☐ No
    Please add any comments about this here

53. To your knowledge, has the person ever been subject to safeguarding concerns, or is there a current Adult Protection Plan or Child Protection Plan in Place?
    ☐ Yes ☐ No
    Please add any comments about this here

54. After reviewing this death, are you surprised that the person died from this cause at this time?
    ☐ Yes ☐ No
    Please add any comments about this here

55. After reviewing this death, do you think that any further learning could be gained from a multiagency review of the death that would contribute to improving practice?
    ☐ Yes ☐ No
    Please add any comments about this here

56. From the information that you have, please grade your overall assessment of the care received by the person:
    ☐ 1. This was excellent care and met current best practice.
    ☐ 2. This was good care, which fell short of current best practice in only one minor area.

☐ 3. This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death.

☐ 4. Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning would result from a fuller review of the death.

☐ 5. Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.

☐ 6. Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.

Note: If you think that you have insufficient information and are unable to grade your overall assessment of the care received by the person, please seek further information until you can do so - for example, review further case notes or speak to those who knew the person well.

57. Please add any additional comments you might have in relation to this review (e.g. any examples of best practice that should be recognised; any particular difficulties you have had in completing this review).
    Additional Comments

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

Next Action

59. Please review the options below and select one to decide your next action.
    1. **If you have answered any questions with an answer that is coloured red**, a multiagency review of this death is recommended.
       ☐ Please tick box if this applies
    2. **If this person meets the criteria for the current priority themed review** deaths (the person was aged 18-24 (inclusive) when they died, or they came from a non-white ethnic background), a multiagency review of the death is required.
       ☐ Please tick box if this applies
    3. If your initial assessment of this death suggests that NO multiagency review is required, but you think that such a review might be appropriate, (i.e. further learning could be gained from a multiagency review of the death that would contribute to improving practice), please do conduct a multi-agency review.
       ☐ Please tick box if this applies
    4. If your initial assessment of this death suggests that NO multiagency review is required, and you consider that no further learning could be gained from a multiagency review of the death that would contribute to improving practice, please complete the Action Plan below and submit the Initial Review and Action Plan to your local area contact.
       ☐ Please tick box if this applies

YOUR NEXT ACTION:

Please now either START A MULTI-AGENCY REVIEW Or COMPLETE AN ACTION PLAN and submit the Initial Review and Action Plan to your local area contact.

Action plan Please detail any actions that you recommend following this review of a person's death				
Description of action	Date agreed	Date for review/ completion	Person responsible for action	Outcome/comments

Appendix 2: How to prepare for a multi-agency review

The initial review that you completed has suggested that a fuller multi-agency review into this death is required, either because the death comes within the remit of the Priority Themed Reviews, or because there is an indication that further learning could be gained that would contribute to improving practice.
In preparation for the multiagency review, please can you:

1. Contact other agencies involved

- Identify individuals/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 as appropriate.

They might want to focus on:

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

We recommend that you also contact family members in person to go through this information with them. Ask them:

- If they thought that there was any particularly good practice that should be shared in relation to this person's death.
- If they thought that there were any contributory factors to the death that could have been avoided.
- If there is anything about the person's death that has concerned or worried them.

3. Request a copy of any relevant notes and 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.

- Give them the link that allows them to upload their documents / case notes to the case review folder (details on how to do this are given below)

- 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 asked to identify themselves, and will then be able to upload files. These files will appear inside that case review process.
  File upload link:

3. Arrange multi-agency review meeting

- Arrange a date, time and venue for the multiagency review meeting and invite all individuals/agencies.

4. Prepare for the meeting

- Collate the information from the relevant case notes and responses to prepare for the review meeting.

1. Have you identified all relevant individuals/agencies that have been involved in supporting the person who has died?
   Tick to confirm ☐
   Please note the agencies involved here
2. Have you sent all relevant agencies/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 as appropriate?
   Tick to confirm ☐
   Please note the agencies contacted here
3. Have you requested a copy of case notes from all relevant agencies / individuals?
   Tick to confirm ☐
   Please note the agencies contacted for case notes here
4. Have you received replies from all relevant agencies/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
5. Have you received a copy of case notes from all relevant agencies / individuals?
   Tick to confirm ☐
   Please note the agencies that have responded here
6. Have you arranged a date, time and venue for the multiagency review meeting and invited all individuals/agencies?
   Tick to confirm ☐
   Please note the arrangements for the review meeting below:
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 relevant case folder?
   Tick to confirm ☐

Appendix 3: Final Report Following Multi-Agency Review

Case ID
Region of England
Please use the outcomes of the Multi-Agency Review meeting to complete this form.

1. Pen portrait

Please provide a pen portrait of the individual, drawing on the contributions of all individuals/agencies submitting information for the review.
Please include information about the person themselves, their health, the environment in which they were living, and a description of their service use. You can find guidance about writing a pen portrait of an individual in the 'help' section.

2. Timeline

Please provide a timeline of the circumstances leading to the person's death, drawing on the contributions of all individuals/agencies submitting information for the review. You can find guidance about completing the timeline in the 'help' section.
You can add rows by clicking into the last row of the table, going to 'Table Tools - Layout' and choosing the 'Insert Below' option from the 'Rows & Columns' section. Alternatively, click into the last row of the table, right click, select Insert – Insert Rows Below.

Date	Reported by / where evidence obtained from	Circumstances

3. Good practice

Has any particularly good practice been identified in relation to the person's death? NB 'Good' 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

4. Surprise at death?

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

☐ Yes ☐ No
If yes, please describe

5. Potentially avoidable factors

Have any potentially avoidable contributory factors relating to the person and /or their environment been identified? (e.g. overriding fear of medical interventions; life-limiting genetic syndrome; unable to anticipate danger, placed out-of-area and isolated from those who know the person well; family members don't feel listened to; housing inadequate for needs).

☐ Yes ☐ No
If yes, please describe

6. 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, mental stimulation, provision of reasonable adjustments for the person).

☐ Yes ☐ No

If yes, please describe

7. Potentially avoidable contributory factors in relation to services

Have any potentially avoidable contributory factors relating to the way services are organised and accessed been identified? (e.g. assessment processes, eligibity criteria, the levels of trained personnel, protocols between agencies etc).

☐ Yes ☐ No

If yes, please describe

8. 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 changed the outcome.

☐ Yes ☐ No

☐ Panel cannot reach a unanimous decision

Please describe the reasons given for this response

9. Have any lessons been learned as a result of this review?

☐ Yes ☐ No

If yes, please describe lessons learned

10. Changes to local practices

Should there be any changes made to local practices as a result of the findings of this review?

☐ Yes ☐ No

If yes, please describe what changes should be made

11. 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.

12. 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.

13. 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.

YOUR NEXT ACTION:

Please COMPLETE AN ACTION PLAN and submit the Multi-Agency Review and Action Plan to your local area contact.

Action plan Please detail any actions that you recommend following this review of a person's death				
Description of action	Date agreed	Date for review/ completion	Person responsible for action	Outcome/comments

Appendix 4: Action plan guidance

The action plan is completed by the local reviewer in conjunction with all of those involved in the review of the person's death.

The 'Description of the action' column should contain statements about how each of the recommendations and learning points will be addressed. Actions should be written clearly and succinctly and where possible it is useful to write using SMART objectives, i.e. those that are:

- 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.

The 'Date for review/completion' column should specify dates for when the actions proposed should be completed. It may be difficult for the reviewer to outline specific dates if the actions need to be undertaken by others but a rough date should be proposed which will then be reviewed by the local area contact and the local Steering Group.

The 'Person responsible for action' column will identify the person with responsibility for taking the action forward and ensuring that it has been taken. Again it may be difficult for the local reviewer to identify a named person, especially during the initial review process. However it should be possible to give an indication of a recommended role, team or organisation at this stage which can then be confirmed by the local area contact and/or the local Steering Group.

The 'Outcome/comments' column should state what improvement is expected once the action has been completed. When thinking about how to write an outcome, reviewers may wish to consider questions such as:

- What will be different as a result of this action?
- What will it look like?
- How will success be measured?

Appendix 5: Quality Assurance Checklist

Review quality assured by:	
Local Reviewer name:	
Date reviewed:	

	Structure	**QA Reviewer Comments**
1	Written accurately and concisely and in a language that is clear, jargon free and not repetitive.	
2	Where used, complex medical and organisational terms are explained simply.	
3	Fact based timeline describing the events leading up to the death of the person who has died.	
4	Comprehensive and proportionate pen portrait.	
5	Highlighted all possible relevant issues which are reliable and supported by evidence.	
6	Provides clear reasons for any missing information, or information not made available to the reviewer.	
7	Logical progression in the reasoning and conclusions supported by facts, and no unsupported facts documented.	
Gathering and analysing information		
8	Evidence of appropriate involvement of families at the relevant stages of the review process.	
9	Appropriate evidence available and used - eg: case records from all agencies involved.	
10	All relevant parties involved in the review process	
11	Appropriate focus upon identifying potential contributory facts and learning from the circumstances leading to the person's death.	
12	Observations on care and treatment are valid and supported by evidence.	
13	Focus is upon improvements and actions for implementation.	
Outcome and next steps		
14	Recommendations are clear and SMART	
15	Recommendations are drawn logically from the discussions and conclusions.	
16	Recommendations are sufficient to address the particular circumstances that have led up to the person's death.	
17	Clear plans of action to support the implementation of change and improvement.	