Tees, Esk and Wear Valleys
NHS Foundation Trust

Protocol for reporting Learning Disability deaths to the Learning Disabilities Mortality Review (LeDeR) Programme

Ref CLIN-0091-v1

Status: Approved
Document type: Protocol

Contents

1 Purpose

The Learning Disabilities Mortality Review (LeDeR) Programme is delivered by the University of Bristol. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Work on the LeDeR programme commenced in June 2015 for an initial three-year period, which is now embedded.

A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities. The Programme is developing and rolling out a review process (See Appendices) for the deaths of people with learning disabilities, helping to promote and implement the review process, and providing support to local areas to take forward the lessons learned in the reviews in order to make improvements to service provision.

The LeDeR Programme will also collate and share the anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

A further part of the LeDeR programme is to conduct a series of additional projects. These are:

- Finding out more about the age and cause of death of people with learning disabilities in England by linking different data sets
- Finding out more about the provision of 'reasonable adjustments' for people with learning disabilities
- Providing better guidance so that the cause of death written on death certificates of people with learning disabilities is recorded in a consistent manner
- Establishing a collection of reports about people with learning disabilities from which we can learn more about commonly occurring problems.

This internal TEWV protocol will ensure a consistent approach throughout the Trust for reporting the death of a patient (aged four years and older) with a Learning Disability to the LeDeR Programme.

2 Related documents

This procedure refers to:-

- ✓ Incident Reporting and Serious Incident Review Policy
- ✓ Learning Disabilities Mortality Review (LeDeR) Programme

3 Introduction

The Learning Disabilities Mortality Review (LeDeR) Programme was established as a result of one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that some people with learning disabilities were

dying sooner than they should and that some of the reasons for this were related to the standard of health and social care that they received.

This has led to the University of Bristol running the LeDeR programme, which is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The main aim of the programme is to make improvements to the quality of health and social care for people with learning disabilities and they aim to achieve this by reviewing the death of every patient with Learning Disabilities.

To assist with this programme we must notify the LeDeR team about the death of any patient, over the age of four, who has a learning disability and is receiving care and treatment from TEWV services. This protocol will explain the process that staff and teams must follow once informed about the death of a patient with learning disabilities.

Following the National Guidance on Learning from Deaths, the Trust also internally carry out a Mortality Review, which looks at every death where a patient is on Care Programme Approach (CPA) or has Learning Disabilities and is not subject to a Serious Incident or Head of Service review. A report on these deaths is taken to the Patient Safety Group monthly and reviewed. If it is agreed that a further review is required, a Structured Judgement Review will be completed by the Senior Nurse to see if there is anything the Trust can learn and this will be fed back into the Patient Safety Group.

Following this procedure will help all disciplines of TEWV Trust to:-

- Inform staff about the process for reporting the death of a patient with Learning Disabilities to LeDeR.
- Ensure there is a shared understanding of the need to do this.
- Ensure a consistent approach to reporting deaths of patients' with a Learning Disability.

3.1 Protocol for Reporting Learning Disability Deaths

3.1.1 Immediate steps for the service to complete

When a member of a team is informed about the death of a patient with a Learning Disability, over the age of four, who is receiving care and treatment from TEWV, they must follow the below steps as soon as practicable:

- Check whether the death has been reported to LeDeR, you should find this on PARIS, and if not, take responsibility of notifying LeDeR about the death. If in doubt, please report to LeDeR anyway (it's better to over report than under report).
- Report the death on DATIX. *For guidance on completing a Datix incident form, please follow the Incident Reporting and Serious Incident Review Policy or contact the Central Approval Team.*

- Make sure the administrator or relevant person from the team completes the PARIS death module.

To notify the LeDeR team about the death, complete an online form found on the following webpage: **https://www.bris.ac.uk/sps/leder/notification-system/.** If any assistance is needed while completing this form, the LeDeR team can be contacted on 0300 7774 774 or by e-mail: leder-team@bristol.ac.uk.

There is a flow chart for reporting LeDeR on page 16, Appendix 3.

3.1.2 The role of the Patient Safety Team

Once the Datix incident form is completed, this notifies the Central Approval Team of the death and they will then discuss the details of the form at the patient safety team's daily clinical huddle with the Head of Patient Safety. It will be agreed whether the death requires a review as part of the Trust's Mortality Review or as a Serious Incident.

The Central Approval Team will log the death of every patient with Learning Disabilities to a spreadsheet, to keep a record of all Learning Disability deaths. The Central Approval Team will contact the reporter of the Datix Incident form to confirm that LeDeR has been notified of the death, and this information will be added to the spreadsheet.

3.1.3 What Happens Next?

When the LeDeR team is informed that a patient has died who had Learning Disabilities, they will inform the LeDeR Local Area Coordinator, who will then make arrangements for a review to be carried out. TEWV staff may be asked to be involved with this process and it is important that they assist with this review and provide any information requested; the sharing of information in these cases is authorised under Section 251 of the Health Research Authorities Confidential Advisory Group. Support should be provided to staff by their line manager during this process.

Following the review, it will be agreed whether there are any contributory factors, lessons learned, good practice and recommendations. An action plan will be created and the completed report and action plan will be returned to the local area contact for sign off and sent to the LeDeR programme.

If any learning is identified through the LeDeR review this will be shared with the Head of Service and should be taken to their local QUAG for discussion.

4 Definitions

TEWV Definitions	
Term	**Definition**
Patient Safety Team	• This is the team that complete the review on Serious Incidents.
Patient Safety Group	• This is the devolved governance group from QUAG, in regard to all Patient Safety Incidents.
Trust's Mortality Review	• Following the National Guidance on Learning from Deaths, the Trust carries out a Mortality Review, which looks at every death where a patient is on Care Programme Approach (CPA) or has Learning Disabilities and is not subject to a Serious Incident or Head of Service review. A report on these deaths is taken to the Patient Safety Group monthly for review.
Structured Judgement Review	• When reviewing the mortality review report, if the Patient Safety Group identifies any deaths that need further review, they may ask for a Structured Judgement Review to be carried out by the Senior Nurse. This will look at the care and treatment the patient received and any lessons that can be learned.
LeDeR Definitions	
Local Area Coordinator	• A Local Area Coordinator is someone who is asked to complete a review into the death of a patient with Learning Disabilities by Bristol University. There will be different Local Area Coordinators for each area.
LeDeR	• Learning Disabilities Mortality Review Programme.

5 References

Bristol University Website
National Quality Board Learning from Deaths
Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

6 How this procedure will be implemented

• This procedure will be published on the Trust's intranet and external website.
• This protocol will be shared with the Learning Disability Development Group, the Durham Learning Disability Management Team, Forensic Service, Adult Learning Disability Service, Adult Mental Health Service, Mental Health Services for Older People and Children and Younger Persons Service.
• Line managers will disseminate this procedure to all Trust employees through a line management briefing.

7 How the implementation of this protocol will be monitored

Auditable Standard/Key Performance Indicators		**Frequency/Method/Person Responsible**	**Where results and any Associate Action Plan will be reported to, implemented and monitored; (this will usually be via the relevant Governance Group).**
1	The Integrated Information Centre (IIC) will be used to produce a report on LD deaths to check whether LeDeR has been notified.	Standard monthly report.	Local QUAG's.

8 Document control

Date of approval:	19 March 2018	
Next review date:	19 September 2021	
This document replaces:	N/A	
Lead:	Name	Title
	Jennifer Illingworth	Director of Quality Governance
Members of working party:	Name	Title
	Anne Lowery Charlotte Rowland Denise Colmer Mandy Barrett Pamela Ridings David Hamilton Karen Pearson Michaela Hopps	Head of Patient Safety, Legal and Claims Datix Review Manager Senior Nurse Service Manager Modern Matron Team Leader Team Manager Team Leader
This document has been agreed and accepted by: (Director)	Name	Title
	Jen Illingworth	Director Quality and Governance
This document was approved by:	Name of committee/group	Date
	Patient Safety Group	19 March 2018
This document was ratified by:	Name of committee/group	Date
	Patient Safety Group	19 March 2018
An equality analysis was completed on this document on:	16 March 2018	

Change record

Version	Date	Amendment details	Status
1	19 Mar 2018	New document	Published
1	Mar 2021	Review date extended to 19 September 2021	Published

Appendix 1 - Equality Analysis Screening Form

Please note; The Equality Analysis Policy and Equality Analysis Guidance can be found on InTouch on the policies page

Name of Service area, Directorate/Department i.e. substance misuse, corporate, finance etc.	Trust wide					
Name of responsible person and job title	Anne Lowery – Head of Patient Safety, Legal and Claims					
Name of working party, to include any other individuals, agencies or groups involved in this analysis	LeDeR Protocol Group Anne Lowery, Charlotte Rowland, Denise Colmer, Mandy Barrett, Pamela Ridings, David Hamilton, Karen Pearson, Michaela Hopps					
Policy (document/service) name	Protocol for reporting Learning Disability deaths to The Learning Disabilities Mortality Review (LeDeR) Programme					
Is the area being assessed a…	Policy/Strategy		Service/Business plan		Project	
	Procedure/Guidance			x	Code of practice	
	Other – Please state					
Geographical area covered	Trust wide					
Aims and objectives	To advise staff about the need for reporting deaths to LeDeR and how to do it.					
Start date of Equality Analysis Screening	22/01/2018					
End date of Equality Analysis Screening	13/03/2018					

You must contact the EDHR team if you identify a negative impact. Please ring Sarah Jay or Julie Barfoot on 0191 3336267/3046

1. Who does the Policy, Service, Function, Strategy, Code of practice, Guidance, Project or Business plan benefit?

This protocol will benefit all TEWV staff as it will inform them of how to report a death of a patient with a learning disability through the LeDeR process, which is a required action when someone with learning disability dies receiving care and treatment from TEWV.

2. Will the Policy, Service, Function, Strategy, Code of practice, Guidance, Project or Business plan impact negatively on any of the protected characteristic groups below?

Race (including Gypsy and Traveller)	No	**Disability** (includes physical, learning, mental health, sensory and medical disabilities)	No	**Gender** (Men, women and gender neutral etc.)	No
Gender reassignment (Transgender and gender identity)	No	**Sexual Orientation** (Lesbian, Gay, Bisexual and Heterosexual etc.)	No	**Age** (includes, young people, older people – people of all ages)	No
Religion or Belief (includes faith groups, atheism and philosophical belief's)	No	**Pregnancy and Maternity** (includes pregnancy, women who are breastfeeding and women on maternity leave)	No	**Marriage and Civil Partnership** (includes opposite and same sex couples who are married or civil partners)	No

Yes – Please describe anticipated negative impact/s

There should be no negative impacts as a result of this protocol being implemented as it ensures that staff involved in the care and treatment of people with learning disability know how to report any death that may occur into the LeDeR process.

No – Please describe any positive impacts/s

The positive impact is that all staff from any service will be aware of the LeDeR process delivered by University of Bristol's guidance commissioned by the HQIP on behalf of NHS E. To know that a key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities helping to promote and implement the review process, and provide support to local areas to take forward the lessons learned in the reviews in order to make improvements to service provision by:

- Finding out more about the age and cause of death of people with learning disabilities in England by linking different data sets
- Finding out more about the provision of 'reasonable adjustments' for people with learning disabilities
- Providing better guidance so that the cause of death written on death certificates of people with learning disabilities is recorded in a consistent manner
- Establishing a collection of reports about people with learning disabilities from which we can learn more about commonly occurring problems.

This internal TEWV protocol will ensure a consistent approach throughout the Trust for reporting the death of a patient (aged four years and older) with a Learning Disability to the LeDeR Programme.

3. Have you considered other sources of information such as; legislation, codes of practice, best practice, nice guidelines, CQC reports or feedback etc.? **If 'No', why not?**	**Yes**	**X**	**No**	

Sources of Information may include: • Feedback from equality bodies, Care Quality Commission, Equality and Human Rights Commission, etc. • Investigation findings • Trust Strategic Direction • Data collection/analysis • National Guidance/Reports	• Staff grievances • Media • Community Consultation/Consultation Groups • Internal Consultation • Research • Other (Please state below)

4. Have you engaged or consulted with service users, carers, staff and other stakeholders including people from the following protected groups?: Race, Disability, Gender, Gender reassignment (Trans), Sexual Orientation (LGB), Religion or Belief, Age, Pregnancy and Maternity or Marriage and Civil Partnership

Yes – Please describe the engagement and involvement that has taken place

We have sent a copy of this protocol to all localities within the Trust, to receive comments from a wide range of staff and have taken on board all comments received. We also asked staff members to take this Protocol to any groups that they think are relevant, such as Learning Disability Groups, so that we could get comments from a wide range of people. We have been advised that this will be taken to North Yorkshire's Speciality Development Group on 15th March 2018 for comments.

No – Please describe future plans that you may have to engage and involve people from different groups

5. As part of this equality analysis have any training needs/service needs been identified?					
No	Please describe the identified training needs/service needs below There are no training needs required.				
A training need has been identified for;					
Trust staff	No	Service users	No	Contractors or other outside agencies	No
Make sure that you have checked the information and that you are comfortable that additional evidence can provided if you are required to do so					
The completed EA has been signed off by: You the Policy owner/manager: Type name: Jen Illingworth				Date: 13/03/2018	
Your reporting (line) manager: Type name: Anne Lowery				Date:16/03/2018	
If you need further advice or information on equality analysis, the EDHR team host surgeries to support you in this process, to book on and find out more please call: 0191 3336267/3046					

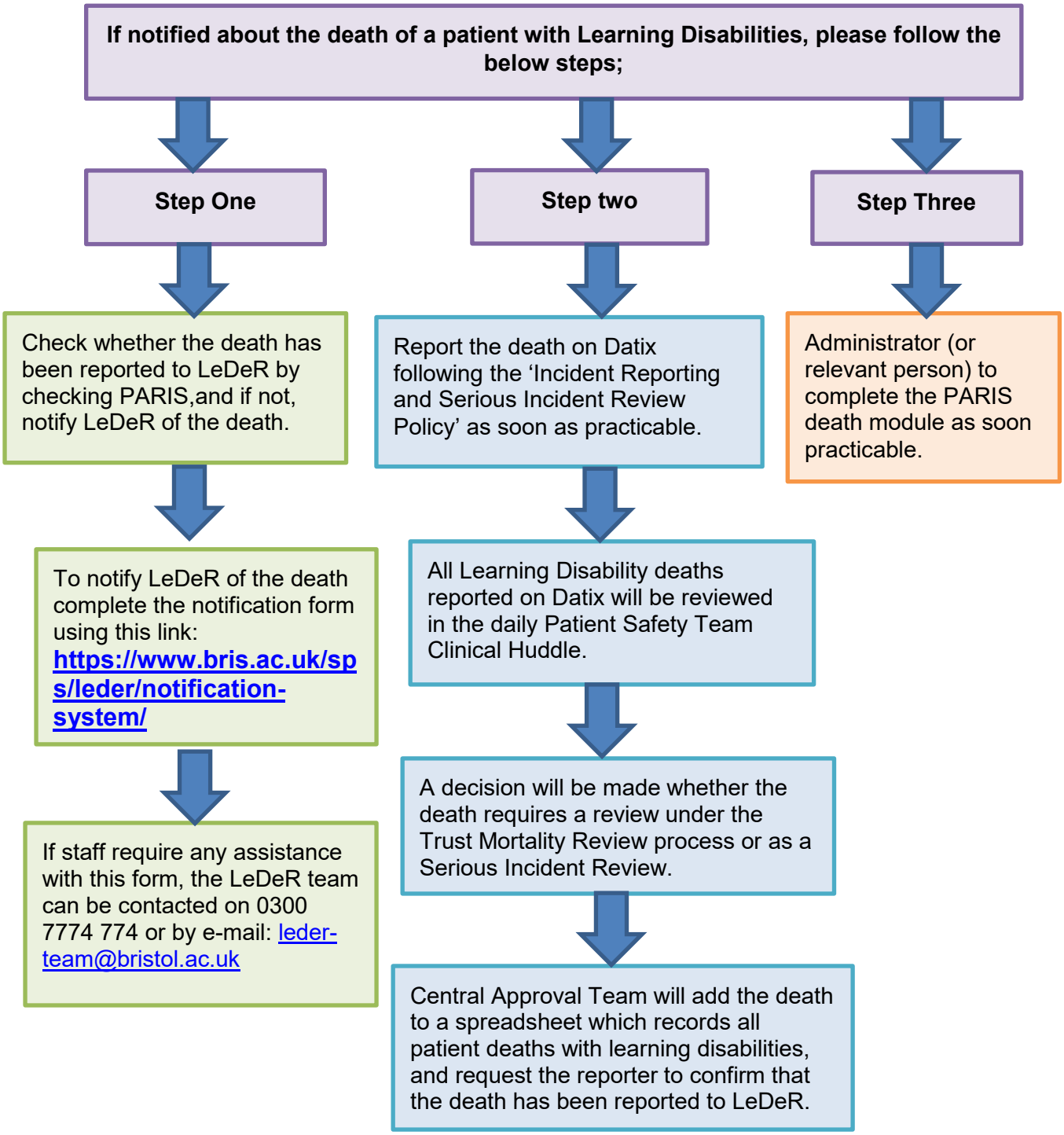
Appendix 2 – Approval checklist

To be completed by lead and attached to any document which guides practice when submitted to the appropriate committee/group for consideration and approval.

	Title of document being reviewed:	Yes/No/ Unsure	Comments
1.	**Title**		
	Is the title clear and unambiguous?	Yes	
	Is it clear whether the document is a guideline, policy, protocol or standard?	Yes	
2.	**Rationale**		
	Are reasons for development of the document stated?	Yes	
3.	**Development Process**		
	Are people involved in the development identified?	Yes	
	Has relevant expertise has been sought/used?	Yes	
	Is there evidence of consultation with stakeholders and users?	Yes	
	Have any related documents or documents that are impacted by this change been identified and updated?	Yes	
4.	**Content**		
	Is the objective of the document clear?	Yes	
	Is the target population clear and unambiguous?	Yes	
	Are the intended outcomes described?	Yes	
	Are the statements clear and unambiguous?	Yes	
5.	**Evidence Base**		
	Is the type of evidence to support the document identified explicitly?	Yes	
	Are key references cited?	Yes	
	Are supporting documents referenced?	Yes	
6.	**Training**		
	Have training needs been considered?	Yes	
	Are training needs included in the document?	No	No training is required
7.	**Implementation and monitoring**		
	Does the document identify how it will be	Yes	

	Title of document being reviewed:	Yes/No/ Unsure	Comments
	implemented and monitored?		
8.	**Equality analysis**		
	Has an equality analysis been completed for the document?	Yes	
	Have Equality and Diversity reviewed and approved the equality analysis?		
9.	**Approval**		
	Does the document identify which committee/group will approve it?	Yes	
Signature:			

Appendix 3 – Process for TEWV staff to follow



Appendix 4 - What will LeDeR local reviews of deaths consist of?

- An **initial review** of each death
- A **fuller multiagency review** of deaths that meet the criteria for this
- Expert panel scrutiny of the fuller multiagency review of deaths that are subject to **priority themed review**. Initially, this will be deaths of young people aged 18-24 years and people from Black and Minority Ethnic Communities.
- An **action planning process** that picks up on learning and recommendations identified during the review process and translates these into improvements in the delivery of health and social care for people with learning disabilities.

LeDeR process flowchart (PDF, 179kB)

You can find more detailed information on our website about reviewing a death of a person with learning disabilities.

For reassurance about our permission to share confidential information about people who have died, see the approval letter from the Confidentiality Advisory Group confirming S251 approval and the most recent amendment to the approval letter:

Confidentiality Advisory Group approval (PDF, 144kB)

CAG Amendment Outcome (PDF, 210kB)

Initial Review of a death

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.

The initial review involves inviting somebody 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 questionnaire. The local reviewer will write a ‘pen portrait’ about the person who has died and complete a timeline of events leading to their death.

At the completion of the initial review the local reviewer will decide if a full multi agency review is required or not. If not, the local reviewer will complete an action plan detailing any learning points or recommendations that should be considered. 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, the death will be subject to multiagency review

Multiagency Review of a death

If there are any areas of concern identified at the initial assessment, or if it is felt that a fuller review could lead to improved practice, a multiagency review takes place. Some other deaths will

automatically have a multiagency review, irrespective of the initial assessment of the death; these are deaths that are subject to priority themed review.

A multiagency review of a death involves the range of agencies that had been supporting the individual who had died, and considers three phases of care:

a) Initial diagnosis and management of the condition

b) Ongoing management of the condition from initial diagnosis to critical illness

c) Management and care received during final illness

Agencies are requested to contribute to the 'pen portrait' and timeline established at the initial assessment, then to return these documents to the local reviewer with a copy of any relevant notes. Once the information has been collated, a multiagency meeting is held to identify and discuss a number of issues:

- Any good practice that has been identified in relation to the person's death
- If any potentially avoidable contributory factors to the death have been identified
- If, on balance, there were any aspects of care and support that, had they been identified and addressed, may have changed the outcome
- If there have been any lessons learned as a result of the review of the death
- If there should be any changes made to local practices as a result of the findings of the review
- If there are any wider recommendations that should be made.

At the completion of the multiagency review, the local reviewer will complete a multiagency review report and an action plan detailing any learning points or recommendations that should be considered. The action plan will be reviewed to ensure that it is translated into improvements in the delivery of health and social care for people with learning disabilities.

Action planning Process

At the completion of each initial assessment or multiagency review, an action plan will be completed by the local reviewer. This will detail any actions to be taken that may improve the provision of care for people with learning disabilities or others. The purpose of the plan is to clarify the actions to be taken, by whom, and to identify a clear line of responsibility and timeframe for the actions. Action plans will be reviewed by each local area contact, and at regional level, anonymised action plans will be reviewed by the steering group. Recurrent themes and significant issues will be identified and addressed at local and regional levels.

The LeDeR Programme will monitor completed action plans to ensure that practice improvements take place as a result of the local reviews of deaths of people with learning disabilities.

Appendix 5 - LeDeR Process Flowchart

Link in with other process
Establish the nominated contact for the other review process and liaise with them.
Where possible collect core data required for the LeDeR review. Provide learning disabilities expertise to other review process if appropriate and required.

Further Action: Prepare for Multi-agency Review
Contact other agencies involved.
Contact family members/someone who knew person well.
Request notes and documents arrange and prepare for multi- agency meeting, update case documentation.

Notifications
LeDeR Team receive notification. Identify those meeting criteria for review.

Share with Steering Group
Local Area Contact shares anonymised learning points and actions with their relevant Steering Group to ensure learning is embedded and action plans are taken forward.

Summary and Close
The completed report and action plan is returned to the Local Area Contact for sign off and then sent to the LeDeR Programme.

Agree with the other review process
Complete initial review. Agree comprehensive pen portrait and timeline.
Agree potentially avoidable contributory factors.
Identify lessons learned, agree on good practice and any recommendations, complete action plan.

Multi-agency Meeting
Agree comprehensive pen portrait and timeline.
Agree potentially avoidable contributory factors to death.
Identify lessons learned, agree on good practice and any recommendations, complete action plan.

Decide whether further action is required
Further action is required if:
Additional learning could come from a fuller review; it is a Priority Themed Review, if red flags indicate this.

No Further Action
The completed report and action plan is returned to the Local Area Contact for sign off and then sent to the LeDeR Programme

Initial Review
Conversation with someone who knew the person well.
Review of relevant case notes, complete pen portrait, timeline and action plan.

Local reviewer: pre-initial review information gathering
Is this individual subject to any other existing review process.
Inform and assign cases for review

LeDeR Team informs Local Area Contact of a new case, LAC identifies suitable reviewers and informs LeDeR. Who informs reviewer of the case allocation.