NHS
Bristol, North Somerset and South Gloucestershire
Integrated Care Board

Learning Disabilities Mortality Review (LeDeR) Policy Framework

Please complete the table below: *To be added by corporate team once policy approved and before placing on website*	
Policy ref no:	44
Responsible Executive Director:	Rosi Shepherd – Chief Nursing Officer
Author and Job Title:	Lesley Le-Pine – Associate Learning Disability Projects
Date Approved:	January 2023
Approved by:	LeDeR Governance
Date of next review:	November 2025

Policy Review Checklist

	Yes/ No/NA	Supporting information
Has an Equality Impact Assessment Screening been completed?	Yes	Appendix 4
Has the review taken account of latest guidance/ Legislation?	Yes	
Has legal advice been sought?	N/A	
Has HR been consulted?	N/A	
Have training issues been addressed?	Yes	Training is provided nationally on the LeDeR platform
Are there other HR related issues that need to be considered?	N/A	
Has the policy been reviewed by Staff Partnership Forum?	N/A	
Are there financial issues and have they been addressed?	N/A	
What engagement has there been with patients/members of the public in preparing this policy?	N/A	
Are there linked policies and procedures?	Yes	linked in the document
Has the lead Executive Director approved the policy?	Yes	
Which committees have assured the policy?	Yes	Quality Performance and Outcome Committee
Has an implementation plan been provided?	Yes	to update the policy on ICB
How will the policy be shared with staff, patients and the public?	Staff will be able to access the policy via the BNSSG staff intranet and patients/public via our website.	
Will an audit trail demonstrating receipt of policy by staff be required; how will this be done?	N/A	

Table of Contents

Learning Disabilities Mortality Review (LeDeR) Framework

1 Introduction

1.1 The LeDeR programme was first established in 2015 by Bristol University as a response to the recommendations from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013). CIPOLD reported that people with learning disabilities are three times more likely to die from causes of death that could have been avoided with good quality healthcare. It is not a statutory process.

1.2 Subsequently established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

- improve care for people with a learning disability and autistic people
- reduce health inequalities for people with a learning disability and autistic people
- prevent people with a learning disability and autistic people from early deaths

1.3 The LeDeR programme collates and shares 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.

1.4 A diagram illustrating how the LeDeR process links with the Child Death Overview Process (CDOP) and the individual mortality review processes within individual organisations can be viewed in Appendix 1. The local BNSSG review process is set out in Appendix 2. More information about the programme and the review process can be found at: https://leder.nhs.uk/about

2 Purpose

2.1 The purpose of this policy framework is to detail how the Learning Disabilities Mortality Review (LeDeR) programme is managed within BNSSG area.

2.2 The LeDeR programme ensures that the deaths of people with learning disabilities aged four years and over are reviewed, irrespective of whether the death was expected, the cause of death or the place of death.

2.3 The LeDeR programme has been established to support local areas to review deaths of people with learning disabilities, and to use the lessons learned to make improvements to service provision. The LeDeR programme is not an investigation. If, during or after a review of a death, the Local Area Contact has concerns which have not or cannot be addressed within the scope of the LeDeR review process, the Local Area Contact or the local reviewer will recommend to the appropriate organisations/bodies the need for a fuller investigation (e.g. Adult Safeguarding Review).

2.4 The LeDeR programme works closely with other existing mortality review processes. More details regarding can be found in Section 7.

2.5 This Framework does not seek to duplicate this information, but to:
- detail the governance and operational arrangements specific to BNSSG;
- provide 'signposting' to existing LeDeR information.

2.6 To assist in achieving this aim, this framework also outlines the governance structures that BNSSG links with, including adult and child safeguarding arrangements and Child Death Overview Panels (Section 6).

3 Roles and responsibilities

Chief Nursing Officer

3.1 The responsibility for oversight of ongoing structures that facilitate the review of deaths in BNSSG, sits with the Chief Nursing Officer. The CNO assigns the day-to-day operational management of the programme to the Local Area Contact.

Local Area Contact

3.2 The Local Area Contact is the link between the LeDeR programme team (in BNSSG), the regional Steering Group and the locally delivered programme. Their role is to work with the LeDeR administrator and to:

- receiving notifications of deaths of people with learning disabilities and/or autism
- organising training of local reviewers
- allocating cases to local reviewers
- monitoring the progress and completion of reviews to ensure that they are of a consistent standard, completed in a timely and comprehensive way
- providing advice and support for local reviewers as necessary
- attending the bi-monthly BNSSG LeDeR Governance Group
- organising and chairing a six monthly BNSSG Local Reviewers Group and discussing any issues as appropriate
- chairing a monthly (or as required) LeDeR Quality Assurance Review Panel, receiving, signing off completed reviews and recommendations in agreement with the Panel members
- anonymising and collating learning points/recommendations and sharing these with the Governance Group and health and social care providers as appropriate.

Local Reviewers

3.4 Local Reviewers are responsible for undertaking robust and high-quality reviews of the deaths of people with learning disabilities and are integral to the success of the BNSSG programme. It is the responsibility of the reviewer to declare a conflict of interest in regard to a case to the LeDeR administrator.

4 BNSSG Governance Structure

4.1 Regional Steering Group

The Regional Steering Group for BNSSG is the Southwest LeDeR Steering Group. The Regional Steering Group meets monthly and attendance by the BNSSG LeDeR LAC is required.

4.2 BNSSG LeDeR Governance Group

The group meets bi-monthly and is chaired by the Chief Nursing Officer (CNO) It is attended by representatives from all NHS Provider and Social Care organisations in BNSSG.

The role of the Governance Group is to monitor and develop the effectiveness of review processes across health providers in BNSSG, by bringing together representations from provider organisations and those with specific area of interest to share best practice, with the ultimate outcome to reduce avoidable deaths.

4.3 Local Reviewers Peer Support Forum

All local reviewers will be invited to meet twice a year in an informal, supportive and educational environment.

4.4 BNSSG LeDeR Quality Assurance Panel

The Quality Assurance panel meets monthly or when there are enough cases to review and sign off completed reviews and provide assurance on the quality of the review process.

The panel can also request further investigation into certain aspects of reviews and/or further clarification prior to sign off.

4.5 The panel members are as follows:

- Local Area Contact/LeDeR Programme Manager
- Safeguarding Team representative
- Clinical Lead GP for learning disabilities,
- Local Authority representative Bristol
- Local Authority representative South Gloucestershire
- Local Authority representative North Somerset

4.6 During the review closure process, the Local Area Contact and the administrator:

- notify the reviewer that the review has been closed and thank them for their contribution to the LeDeR process **OR** feedback is given regarding the review and asked to add/amend any recommendations added during the Quality Assurance Panel, or further information to be gathered
- ask the reviewer who they will share the findings from the review with, for example the family/relatives/carers, and others they spoke to whilst undertaking the review
- share the learning with the individuals identified by the reviewer (as above)
- share themes and learning with GP practice(s) where the individual was registered to share learning as appropriate

4.7 BNSSG recognises that in some cases an independent investigation (commissioned and delivered separately from the organisation(s) involved in caring for the patient) may be required in some circumstances. Any concerns about a case should be escalated by the LAC to the Chief Nursing Officer, to agree the approach and potential commissioning of an Independent Review as outlined in the Serious Incident Framework

4.8 BNSSG will implement a local protocol for the triage, escalation and commissioning of independent reviews in line with the Serious Incident Framework to ensure the most appropriate level of investigation and governance is identified.

5 Links with other mortality review processes

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

5.2 In order to do this in a timely manner, to avoid duplication and to ensure there is no additional distress to the relatives of the individual, reviewers need to be clear where and how the LeDeR process links with other reviews or investigation processes.

5.3 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)
- Mental Health Homicide Reviews (MHRs)
- Serious Incident Reviews
- Coroners' investigations
- Child Death Reviews
- An organisation's internal Root Cause Analysis investigations

5.4 A diagram illustrating how the LeDeR process links with the Child Death Overview Process (CDOP) and the individual mortality review processes within individual organisations can be viewed in Appendix 1.

6

Notifying LeDeR of a death

6.1 Anyone can notify LeDeR of a death, including people with learning disabilities themselves, family members, friends and paid staff. Notifications can be made online via this link https://leder.nhs.uk/report

Information for families and carers

6.2 Key to the review process is the involvement of family members and/or carers to find out more about the life and the circumstances leading up to the death of their relative or friend. The information available to family and carers can be viewed via this link; https://leder.nhs.uk/about/working-with-families

7. Learning

7.1 **Identifying learning**

As part of the assurance and sign off process, it is the responsibility of the BNSSG LeDeR Quality Assurance Panel to ensure that identified learning from each review helps to achieve these aims. (example below from LeDeR review form)

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

7.2 **Sharing local learning**

The Local Area Contact collates and reports the recommendations of the reviews by 'theme' via the quarterly report to NHS England regional team. These themes report will be shared as appropriate with the Health Providers Network and a range of mortality/learning from deaths, end of life, safeguarding and risk meetings across BNSSG.

7.4 Assurance and oversight of local learning is provided by the BNSSG LeDeR Governance Group. This group also provides support to the Local Area Contact and Reviewers Group to affect wider-scale change. This will also link to the Strategic Transformation Plan for wider local learning.

8. Reporting

Reporting to NHS England

8.1 The Local Area Contact is required to submit a quarterly report to NHS England South West detailing the progress against Key Performance Indicators.

Reporting within BNSSG

8.2 The Local Area Contact will produce a quarterly report for the Quality Performance and Outcome Committee, detailing the progress of the programme and key learning. The Quality Performance and Outcome Committee which reports to ICB Board.

8.3 Progress reports, learning themes etc, Members of the Governance group are able to use this report for their own assurance and for the organisations they represent.

8.4 BNSSG LeDeR produces an annual report each year. These reports can be viewed via this link; https://bnssg.icb.nhs.uk/health-services/leder-programme/

9. Training

9.1 The Local Area Contact must complete on-line training from NHS England on the requirements and responsibilities of their role.

9.2 To undertake LeDeR reviews and become a 'Local Reviewer', specific online training must be completed. Once this training has been completed, the individual will be given access to the LeDeR programme database through which reviews are managed. The LeDeR administrator will notify the NHSE platform of reviewers who requires access to training modules.

10 Recommendation and Approval Process

10.1 The approval process for this updated BNSSG LeDeR Policy and Framework is via submission and subsequent approval by the Quality Performance and Outcome Committee.

11 Implementation

11.1 This is an updated Policy and Framework which has already been implemented, this procedural document summarises the current arrangements for the management of the LeDeR programme within BNSSG ICB.

12 Monitoring compliance and effectiveness

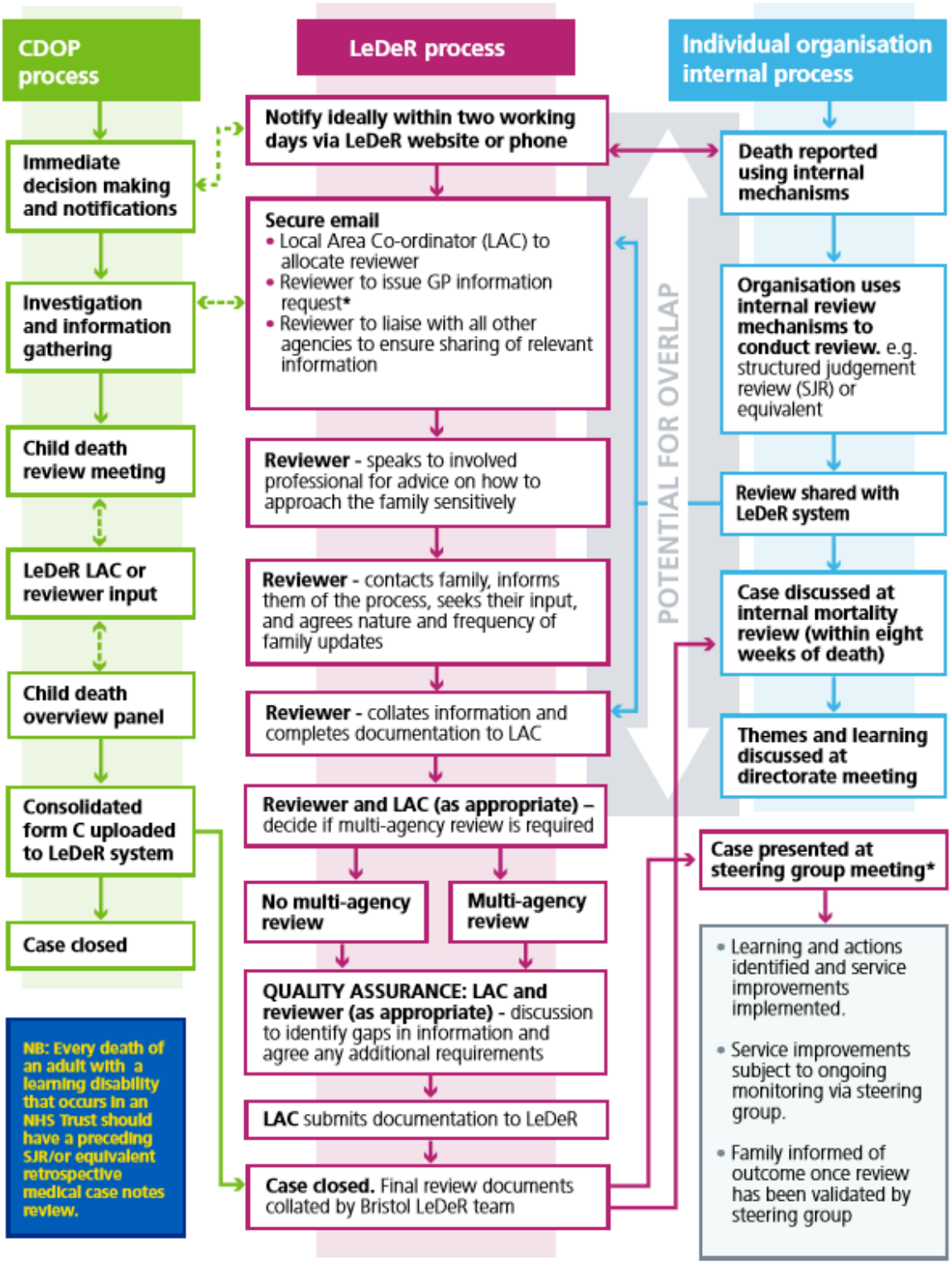
12.1 The assurance and oversight of the effectiveness of the LeDeR programme within BNSSG in achieving these objectives is provided by the BNSSG Quality Performance and Outcome Committee which has responsibility to;

- ensure case reviews and investigations are carried out to a high quality, acknowledging the primary role of system factors within or beyond the organisation rather than individual errors in the problems that generally occur.
- ensure that mortality reporting in relation to LeDeR reviews, investigations and learning is provided to the ICB Board in order that the executives remain aware and non-executives can provide appropriate challenge. The reporting will be discussed at the public section of the meetings with data suitably anonymised;
- ensures that learning from reviews and investigations is acted on to sustainably change clinical and organisational practice and improve care in commissioned services;

Appendix 1

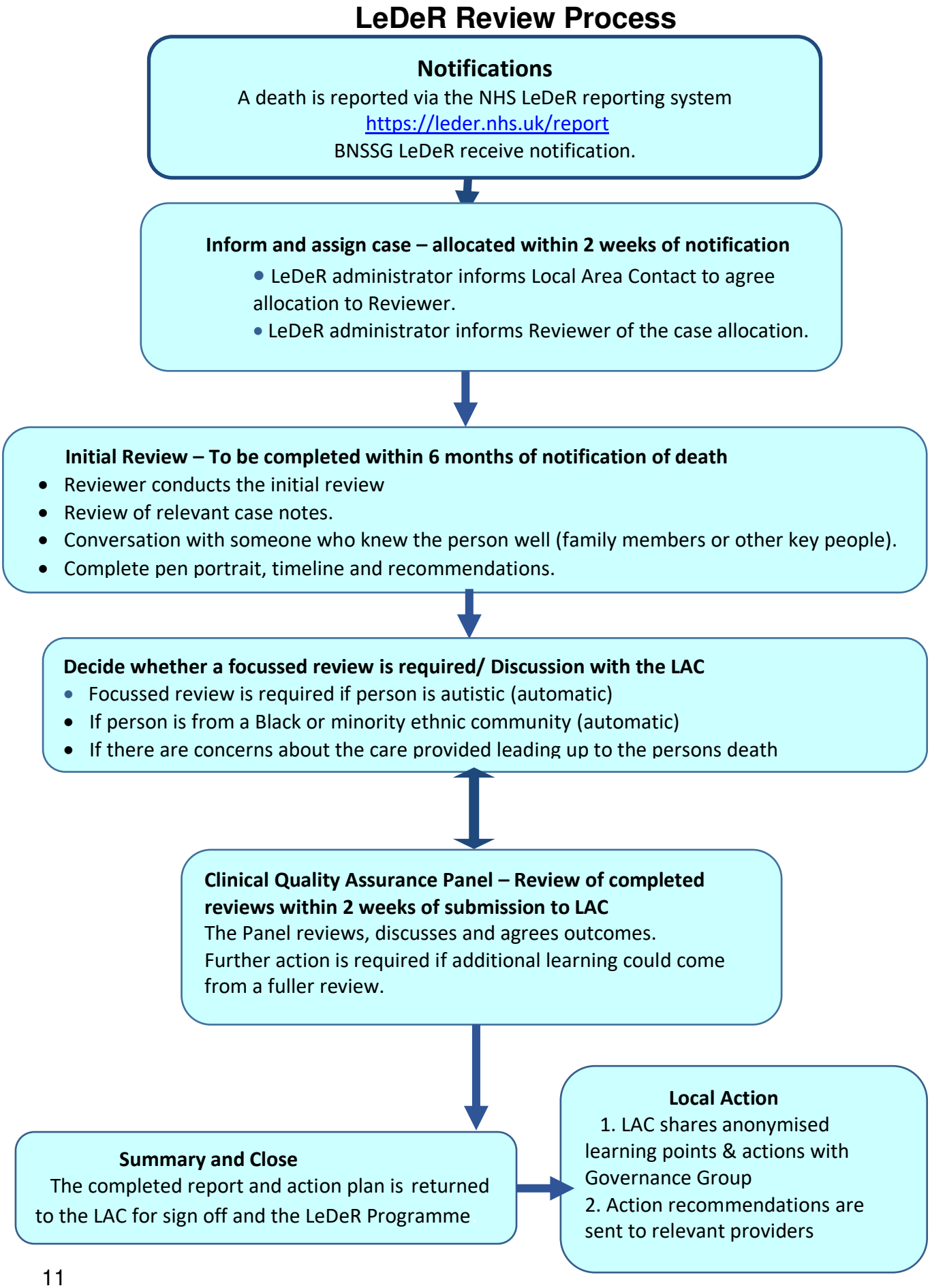
Notification and review of a death of an adult (18+) or child (age 4+) with a learning disability

NHS England



Please note: Parts of a process marked with an * may be subject to regional variation. If in doubt consult your regional co-ordinator

Appendix 2 – BNSSG Data Flow and Process Chart



Appendix 3

Equality Impact Assessment

Name of policy being assessed**: Learning Disabilities Mortality Review (LeDeR) policy framework)**

Does this Proposal relate to a new or existing programme, project, policy or service? **New Policy**

Lead Officer completing EIA	Lesley Le-Pine
Job Title	LeDeR Programme Manager
Department/Service	Nursing Directorate
E-mail address	Lesley.le-pine@nhs.net
Lead Equality Officer	Sharon Woma
Key decision which this EIA will inform and the decision-maker(s)	Approval of LeDeR policy

Step 1: Equality Impact Assessment Screening

1. Does the policy affect service users, employees and/or the wider community?

The policy sets out how, as a commissioning organisation, Bristol, North Somerset and South Gloucestershire ICB will fulfil its statutory duties and responsibilities for Learning Disabilities Mortality Review (LeDeR). The Policy operates in the context of all commissioned services for the population of Bristol, North Somerset and South Gloucestershire both within its own organisation and across the local health economy via its commissioning arrangements.

2. Could the proposal impact differently in relation to different characteristics protected by the Equality Act 2010?

This Equality Impact Assessment screening is undertaken to ensure that the Bristol, North Somerset and South Gloucestershire ICB LeDeR policy framework meets statutory obligations under programmes previously known as confidential enquiries. It has approval from the Secretary of State under section 251 of the NHS Act 2006 to process patient identifiable information without the patient's consent. It will not impact differently in relation to protected characteristics.

Assessment of impact of policy on Protected Characteristics with analysis positive + /neutral N / or negative -		
Protected characteristic	Analysis;	Reasons for answer and any mitigation required
Age* [eg: young adults, working age adults; Older People 60+]	N	The policy applies to all people and therefore is consistent in its approach regardless of age.

Disability Physical Impairment; Sensory Impairment; Mental Health;	+	The overall aim of the Learning Disabilities Mortality Review (LeDeR) programme is to drive improvement in the quality of health and social care service

Learning Difficulty/ Disability; Long-Term Condition		delivery and to help reduce premature mortality and health inequalities.
Gender Reassignment [Trans people]	N	This policy is consistent in its approach regardless of gender reassignment.
Race [including nationality and ethnicity]	N	This policy is consistent in its approach regardless of race, nationality or ethnicity
Religion or Belief	N	This policy is consistent in its approach regardless of religion and belief.
Sex [Male or Female]	N	This policy is consistent in its approach regardless of sex.
Sexual Orientation	N	This policy is consistent in its approach regardless of sexual orientation.
Pregnancy and Maternity	N	This policy is consistent in its approach regardless of pregnancy and maternity.
Marriage and Civil Partnership	N	This policy is consistent in its approach regardless of marriage or civil partnership status.

3 Relevance to the Public Sector Equality Duty:

The positive impact of the policy is that it has been developed to provide a clear process, and policy framework for the ICB, to fulfil LeDeR policy framework statutory obligations under programmes previously known as confidential enquiries.

4. Health Inequalities:

Does the proposal relate to an area with known Health Inequalities? **Yes**

The overall aim of the Learning Disabilities Mortality Review (LeDeR) programme is to drive improvement in the quality of health and social care service delivery and to help reduce premature mortality and health inequalities.

On the basis of this screening assessment do you consider this proposal to be relevant to the General Duty or to any particular protected characteristic? Disability **-** Health Inequalities.

5. Conclusion:

I am satisfied that this service/policy/function has been successfully equality impact analysed. There is no requirement to proceed to the Full Equality Impact Assessment.

Proceed to full EIA:	No
Quality Assured by:	Quality and Patient Safety Team
Date of Screening	29th September 2022
Action Plan	N/A
Signed	Lesley Le-Pine
Date	19th October 2022