Learning from the lives and deaths - people who have a learning disability and/or autistic people (LeDeR) Policy Framework

Complete the blank cells in the table below. The rest will be added by the corporate team once the policy approved and before it is added to the website.	
Policy ref no:	44
Responsible Executive Director:	Rosi Shepherd
Author and Job Title:	Vicki Cooper, LeDeR Local Area Coordinator
Date Approved:	03 July 2025
Approved by:	ICB Board
Date of next review:	July 2028

Policy Review Checklist

	Yes/No/NA	Supporting information
Has an Equality Impact Assessment Screening been completed?	Yes	Completed and included in the appendices
Has the review taken account of latest Guidance/Legislation?	Yes	Latest guidance is mentioned in the framework and reviewed by LeDeR Local Area Contact
Has legal advice been sought?	N/A	
Has HR been consulted?	N/A	
Have training issues been addressed?	Yes	Detailed in framework, training provided by NHSE.
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?	Yes	LeDeR budget reviewed regularly.
What engagement has there been with patients/members of the public in preparing this policy?	N/A	
Are there linked policies and procedures?	Yes	Policies links included in framework
Has the lead Executive Director approved the policy?	Yes	LeDeR Governance Group
Which Committees have assured the policy?		Outcomes, Performance and Quality
Has an implementation plan been provided?	N/A	Framework has been reviewed, amendments highlighted in this section
How will the policy be shared with staff		Uploaded onto BNSSG public facing internet page
Will an audit trail demonstrating receipt of policy by staff be required; how will this be done?	N/A	
Has a DPIA been considered in regard to this policy?	Yes	National DPIA issued. DPIA to ensure LeDeR data storage has been completed.

	Yes/No/NA	Supporting information
Have Data Protection implications have been considered?	Yes	Detailed in framework and through IG input to Corporate Policy Review Group

Version	Date	Consultation

Table of contents

LeDeR Policy Framework

1 Introduction

Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) is a service improvement programme. LeDeR aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and/or autistic people. The LeDeR programme reviews information regarding the support from health and social care people receive prior to their death. Everyone with a learning disability and/or diagnosis of autism aged 18 and over is eligible for a LeDeR review.

The LeDeR service improvement programme is managed and commissioned by NHS England. LeDeR supports local areas to review the deaths of people with learning disabilities and people who are autistic, identify learning from those deaths, and take forward the learning into service improvement initiatives. The programmes overall aims are:

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

Responsibility for ensuring the delivery of LeDeR reviews currently lies with local Integrated Care Systems (ICSs). Integrated Care Board's (ICBs) are responsible for ensuring that LeDeR reviews are completed for their local area – this ICB policy governs the arrangements. Actions following reviews must be implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequities and premature mortality.

1.1 BNSSG ICB Values

This policy supports the ICB's health inequalities programme which directly contributes to embracing diversity. The LeDeR programme drives an ICS approach to ensure people who have a learning disability and/or autistic individuals have priority access to health and social care provisions.

2 Purpose and scope

The purpose of this policy framework is to detail how the LeDeR programme is managed within BNSSG ICS.

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people. LeDeR, reviews the health and social care interactions people received up until their death.

LeDeR reviews are not investigations but intended to support health and social care professionals and policy makers to clarify:

- the learning from various causes of death.
- understand overall health inequalities.
- understand the reasons for premature mortality for people with learning disabilities and autistic people.
- identify variation and best practice.
- identify key recommendations for improvement.

There are two types of LeDeR review an initial review or a more detailed review called a focused review. The criteria for a focused review includes:

- All autistic people who do not have a learning disability aged 18 and above.
- People from ethnic groups other than white British.
- People who have been in a detained setting in the criminal justice system/ or have been under a Mental Health Act restriction within five years of death.
- Where there is likely to be learning from the life of the person to inform service improvements.
- Where the family have requested a focused review.
- Where there are any concerns about the care the person received.

If a LeDeR review identifies lapses of care, a focused review will be completed, other teams may be drawn in for example BNSSG's Safeguarding or patient safety teams may be liaised with to ensure compliance with relevant statutory frameworks.

2.1 Scope of LeDeR

- This is a national programme in England and provides a structured, consistent approach to review deaths of people who have a learning disability and/or autistic people.
- The reviews include everyone with a learning disability and autistic individual over the age of 18 years of age.
- Those individuals with a learning disability and/or autistic individual aged under 18 will be reviewed via Child Death Overview Panel.

This policy sets out the ICBs statement of intent to systematically act upon findings in LeDeR reviews and improve the care provided by all services (not just learning disability and autistic specific services) to stop people dying prematurely and provide better quality services.

3 Duties – legal framework for this policy

To ensure deaths can be reviewed NHS England hold approval from the Confidentiality Advisory Group (CAG) of the Health Research Authority under Section 251: 20/CAG/0067 (previously 16/CAG/0056 to be reviewed April 2025 CAG registers - Health Research Authority), for information to be shared for the purpose of the LeDeR programme. UK GDPR and Data Protection Act 2018 (Data Protection Act 2018) are applicable in relation to records of deceased patients next of kin/family members. LeDeR must be able to demonstrate compliance with the six data principles.

3.1 Information Sharing BNSSG adheres to the guidance provided in section 8.2 of the national policy B0428-LeDeR-policy-2021.pdf. BNSSG will ensure appropriate information sharing protocols are in place to facilitate effective data sharing for the purpose of LeDeR across the ICS. In all circumstances of information sharing, staff will ensure that:

- When information needs to be shared, sharing complies with the law, guidance, best practice is followed and an information sharing agreement is in place.
- Only the minimum information necessary for the purpose will be shared.
- Individuals' rights will be respected, particularly confidentiality, security and the rights established by the UK GDPR.
- Confidentiality will be adhered to unless there is a robust public interest or a legal justification in disclosure.

A Data Protection Impact Assessment (DPIA) for LeDeR is available if required. BNSSG LeDeR programme abides by the Records Management policy Records Management Policy - The Hub, the Information Governance policy Information-Governance-Policy-ICB.docx and the Confidentiality and Security of Information Policy.

NHS England will hold ICBs for the delivery of the actions identified in reviews as part of their assurance processes. ICSs should improve the ways that local health and social care services meet the needs of people with a learning disability and autistic people.

4 Responsibilities and Accountabilities

4.1 National LeDeR team: Employed by NHS England, the team support ICSs to complete LeDeR reviews. They ensure training is available that meets the needs of the system. The national team also commission the web platform that supports people to notify deaths and for reviewers to complete reviews.

4.2 Senior Responsible Officer (SRO): Is held by the Chief Nursing Officer (CNO) and the LeDeR programme has direct oversight from BNSSGs ICB Board via the Outcomes, Quality and Performance Committee. The chair of the LeDeR Governance Group is a delegated duty from the CNO to the Deputy Chief Nursing Officer. The CNO assigns operational management of the programme to the BNSSG ICB Local Area Contact. Key findings are also shared though the relevant

system groups to ensure learning is embedded into the relevant commissioning decisions. Primary groups for this will be the Mental Health and Learning Disability HCIG and ODGs.

4.3 Local Area Contact (LAC): The LAC is the link between the local system and the national LeDeR programme. The LACs role is to work in partnership with the LeDeR programme team and is responsible for:

I. Receiving notifications of deaths.
II. Identifying and organising the training of local reviewers.
III. Allocating cases to local reviewers whilst managing identified conflicts of interest.
IV. Monitoring the progress and completion of reviews to ensure that they are of a consistent standard and completed in a timely and comprehensive way.
V. Providing advice and support for local reviewers as necessary.
VI. Organising and chairing the monthly LeDeR Quality Assurance and Oversight Group.
VII. Collating themes and trends following LeDeR reviews and sharing these with the LeDeR Governance Group.
VIII. Organising and attending the LeDeR Governance Group
IX. Attending the LeDeR ICS Improvement Group.

4.4 Local Reviewers: Are responsible for undertaking robust and high-quality reviews of the deaths of people with a learning disability and/or autistic people and are integral to the success of the BNSSG LeDeR programme. It is the responsibility of the reviewer to declare a conflict of interest to the BNSSG ICB LAC in regard to the LeDeR case.

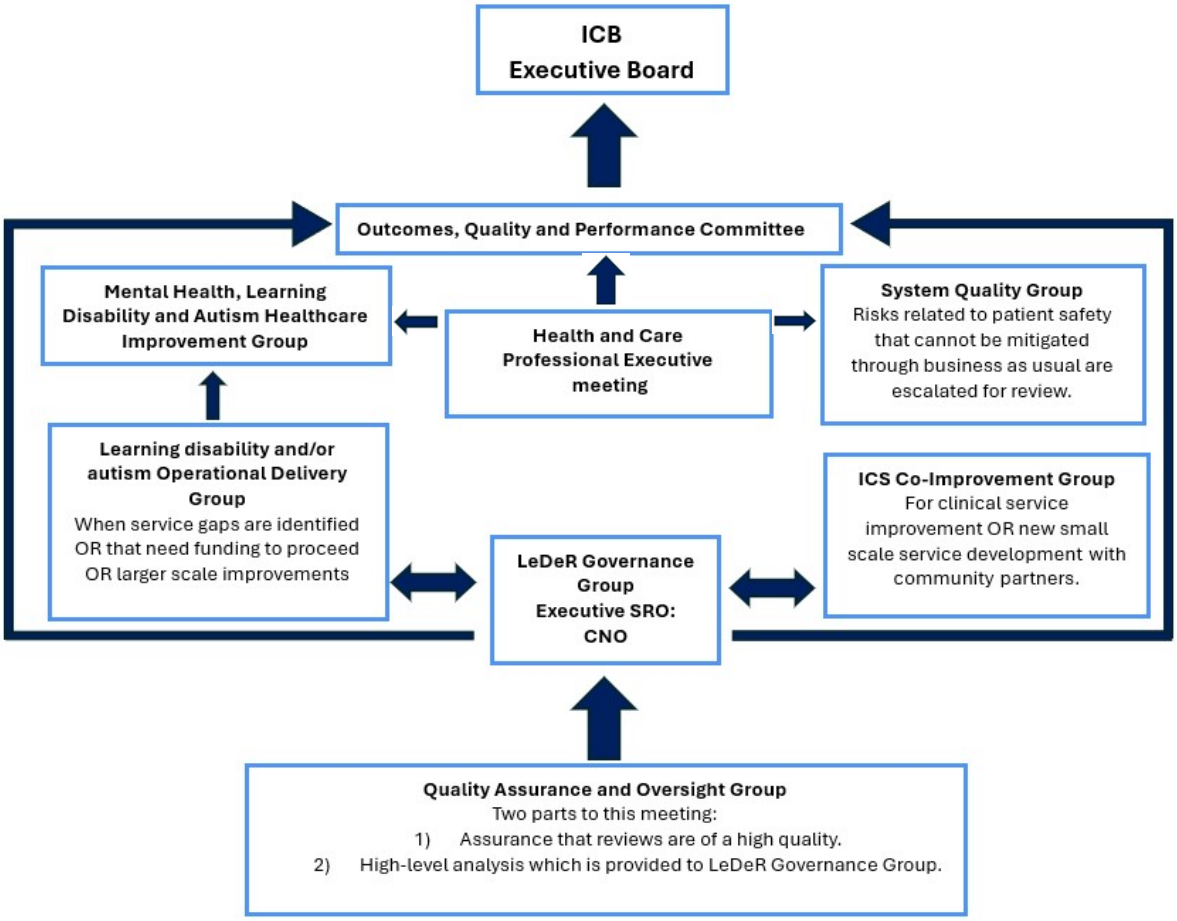
Further role descriptions for LeDeR roles can be found at B0428-LeDeR-policy-2021.pdf (england.nhs.uk)

5 Definitions/explanations of terms used

Term	Definition
ICB Bristol, North Somerset and South Gloucestershire Integrated Care Board	NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board is responsible for the day-to-day running of the NHS for our local area.

Term	Definition
ICS Bristol North Somerset and South Gloucestershire Integrated Care System	The Integrated Care System comprises of 10 partner organisations, including the three Local Authorities in our area, NHS Trusts, the new Integrated Care Board and community and General Practice providers.
BNSSG Bristol, North Somerset and South Gloucestershire	The geographical footprint that the Integrated Care System covers.
LAC Local Area Contact	Programme manager for LeDeR and facilitates the completion of reviews and drives service improvements across the health and social care system.

6 BNSSG LeDeR Governance Structure



6.1 LeDeR Governance Group

Bristol, North Somerset and South Gloucestershire ICB's Chief Nursing Officer chairs our LeDeR Governance Group which meets bi-monthly. Representatives attend the Governance Group from all Bristol, North Somerset and South Gloucestershire health providers, the three local authorities who commission adult social care, GPs, Independent Care Provider representatives, safeguarding colleagues, and the NHS England regional LeDeR lead. The principal objective of the LeDeR Governance Group is to adhere to the four pillars of an Integrated Care Board (ICB):

- Improving outcomes in population health and healthcare.
- Tackling inequalities in outcomes, experience and access.
- Enhancing productivity and value for money.
- Helping the NHS to support broader social and economic development.

This group takes strategic oversight of the reviews of deaths of people with a learning disability and/or autistic people, driving transformation to improve care in services. Health and social care partners support in addressing health inequalities, including outcomes, experience, and access. Assurance updates are reported to the ICB Outcomes Quality and Performance Committee via quarterly governance reports, with onward reporting through to the ICB Board. Key areas of escalation are also shared with the Mental Health and Learning Disability Health and Care Improvement Group and associated Operational Delivery Group, where learning from the LeDeR programme will support strategic decision making and ensure priorities set for the system reflect lessons learned from LeDeR.

6.2 ICS Co-Improvement Group

The aim of the newly formed ICS Co-Improvement Group is to drive small scale quality improvement initiatives. The group comprises of representatives from Bristol, North Somerset and South Gloucestershire health and social care providers.

The LeDeR Governance Group identifies specific areas of focus to the ICS Co-Improvement Group, which is accountable to the Governance Group. If larger pieces of improvement work are required, the LeDeR Governance Group allocate, ensuring the right capacity and skills are available to deliver in a timely way.

6.3 Quality Assurance and Oversight Group

The Quality Assurance and Oversight Group oversees completed review reports. Meeting monthly, the panel not only provides oversight of the quality of reviews but also produces an analysis of learning themes. Emerging new themes are reported into the LeDeR Governance Group, where appropriate next steps are agreed.

Membership of the Quality Assurance and Oversight Group includes the Local Area Contact (LAC), Clinical Learning Disability and/or autism GP Lead, Safeguarding representatives, Local Authority representatives and all Bristol, North Somerset and South Gloucestershire health provider representatives.

6.4 LeDeR Reviewer Peer Support

It is essential that strong supervision and support is in place for our reviewers to support the delivery of high-quality reviews. The LAC has developed a peer support model for reviewers, where a Senior reviewer provides peer supervision to reviewers. This will ensure reviewers are well supported and they are guided through the review process by an experienced colleague. Additionally, the LAC and LeDeR Administrator will meet with reviewers regularly to ensure the reviewers have all the appropriate notes to complete the review and provide an opportunity to debrief if the reviewer has had a challenging or upsetting review. Within this forum it is an opportunity for the LAC to share updates from the national team, overarching themes, and updates on quality improvement initiatives following learning from LeDeR reviews. In this space colleagues can discuss any areas of the LeDeR process where reviewers feel less confident. From these discussions, further improvement opportunities are discovered and actioned.

7 Links with other mortality review processes

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. Statutory processes supersede LeDeR reviews, however learning from these statutory processes can be incorporated into the LeDeR review. It is vital, if individuals and organisations are to be able to learn lessons from the past, that reviews are trusted and safe experiences that encourage honesty, transparency and sharing of information to obtain maximum benefit from them. The LeDeR review outcomes will also be linked through on a periodic basis to the BNSSG Mortality Group chaired by the ICB Chief Medical Officer and attended by a range of system partners including Directors of Public Health.

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.

8 Training requirements

8.1 The Local Area Contact has received on-line training from NHS England on the requirements and responsibilities of their role, this is updated annually.

8.2 The LAC is provided administrative support. On-line training is provided to administrative support colleagues from NHS England on the requirements and responsibilities of this role and is updated annually.

8.3 To undertake LeDeR reviews, reviewers complete specific online training. Once completed the reviewer will be given access to the LeDeR programme database through which reviews are managed. Training is updated annually.

8.4 No other LeDeR specific training requirements have been identified. Work continues to raise awareness of the LeDeR programme with BNSSG ICS organisations. It is the responsibility of BNSSG ICB LAC to address any emerging identified training.

9 Reporting

9.1 NHS England report on each ICBs key performance indictors monthly. This data is published on NHS Futures.

9.2 The LAC provides a bi-monthly LeDeR activity report to the LeDeR Governance Group, this data is also shared with the LD/A ODG.

9.3 The LAC with support of the ICS organisations submit a LeDeR annual report which is published onto the ICBs website. BNSSG LeDeR Annual Report 2023/24 (icb.nhs.uk)

9.4 To date, Kings College London have produced annual reports each year, detailing the national actions and learning. Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London (kcl.ac.uk)

10 Equality Impact Assessment

Confirmation required that EIA screening has been completed and reference it as an appendix.

11 Implementation and Monitoring Compliance and Effectiveness

11.1 As a Policy, this procedural document summarises the current arrangements for the management of the LeDeR programme within BNSSG ICB.

11.2 The aspects of the Policy that have already been implemented are: The LeDeR Governance meeting and the Quality Assurance and Oversight Meeting.

11.3 The aspects of the Policy that require implementation are: Bimonthly ICS Improvement Group.

12 Countering Fraud, Bribery and Corruption

The ICB is committed to reducing and preventing fraud, bribery and corruption in the NHS and ensuring that funds stolen by these means are put back into patient care. During the development of this policy document, we have given consideration to how fraud, bribery or corruption may occur in this area. We have ensured that our processes will assist in preventing, detecting and deterring fraud, bribery and corruption and considered what our responses to allegation of incidents of any such acts would be.

In the event that fraud, bribery or corruption is reasonably suspected, and in accordance with the Local Counter Fraud, Bribery and Corruption Policy, the Nursing & Quality Team will refer the matter to the ICB's Local Counter Fraud Specialist for investigation and reserve the right to prosecute where fraud, bribery or corruption is suspected to have taken place. In cases involving any type of loss (financial or other), the ICB will take action to recover those losses by working with law enforcement agencies and investigators in both criminal and/or civil courts.

13 References, acknowledgements and associated documents

13.1 LeDeR National Policy B0428-LeDeR-policy-2021.pdf (england.nhs.uk)

13.2 BNSSG ICB LeDeR page LeDeR programme - NHS BNSSG ICB

13.3 Kings College London LeDeR National Annual Report Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London (kcl.ac.uk)

13.4 BNSSG ICB Information and Data Quality Policy Information and Data Quality Policy - The Hub

13.5 BNSSG Records Management Policy Records Management Policy - The Hub

13.6 BNSSG Confidentiality and Security of Information Policy.

14 Appendices

Equality Impact Assessment

Implementation Plan

This framework includes the updated changes made by the National LeDeR programme. The major change of not reviewing deaths of children and young people under the age of 18 who live with a learning disability and the inclusion of deaths of autistic people. The framework also demonstrates BNSSG ICBs governance arrangement to ensure the LeDeR programme is robust and resilient to support BNSSGs learning disability and autistic population.

Target Group	Implementation or Training objective	Method	Lead	Target start date	Target End date	Resources Required