NHS
Kernow
Clinical Commissioning Group

# Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) programme policy and procedure

**Date approved:** 31 May 2022

This policy was adopted by NHS Cornwall and Isles of Scilly Integrated Care Board (ICB) on 1 July 2022.

We are working to change the branding on our policies and to make sure they are accessible.

We intend to complete this work by 1 April 2023. While this work is underway, all references to NHS Kernow, the CCG and related structures should be taken to relate to the ICB.

This policy may not be suitable for users of assistive technology. If you use assistive technology (such as a screen reader) and need a version of this document in a more accessible format, please email ciosicb.corporategovernance@nhs.net. Please tell us what format you need. It will help us if you say what assistive technology you use.

# Document control sheet

**Title of document**: Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) programme policy and procedure
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**Target audience**: LeDeR stakeholders
**Can this policy be released under FOI**? Yes
**Give reasons for exemption if no**: Not applicable

# Version control

| Version number | Revision date | Revision by | Nature of revisions |
|---|---|---|---|
| V1.0 | 11 May 2022 | Lisa Nightingale, head of clinical quality | Updated panel membership, reporting and governance |
| V2.0 | 31 May 2022 | Lisa Nightingale, head of clinical quality | Ratified by the quality committee |
| V2.1 | June 2022 | Quality team | Final accessibility checks |
| V3.0 | June 2022 | Governance team | Governance checks |

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# 1. Introduction

This policy describes the aims of the LeDeR programme. The programme aims to improve care, reduce health inequalities and prevent premature death of people with a learning disability, and autistic people. It looks at information about the health and social care they received so that lessons can be learnt, and changes made.

# 2. Responsibilities

NHS Kernow Clinical Commissioning Group (NHS Kernow) is responsible for delivering these reviews and for making sure that actions are taken to improve services. These responsibilities will transfer to the NHS Cornwall and Isles of Scilly Integrated Care Board.

## Reviewers

Reviewers will be independent from the service which provided care to the person. They will carry out initial and focussed reviews.

## Senior review officer

The senior review officer (SenRO) will manage the review team and lead monthly support groups. They will help identify those initial reviews which should move on to more focussed reviews.

## Administrator

The administrator will arrange LeDeR quality panel meetings and administer the LeDeR web platform. They will make sure that anonymised reviews are shared with those who were involved in the care of the individual.

## Local area coordinator

The local area coordinator (LAC) will act as the point of contact for the NHS England and NHS Improvement (NHSEI) regional coordinator. They will assign reviews to the SenRO. They will promote LeDeR at local level across health and social care. They will also work with commissioning teams to develop a 3 year strategic plan which addresses the themes from reviews. The LAC will produce reports showing review activity, the identification of issues and general themes and the actions that are taking place to improve services. They will monitor and report local performance to NHSEI. They will make sure that appropriate governance arrangements are in place so that local organisations work together to achieve service improvements.

## Assistant local area coordinator

The assistant local area coordinator will act as a point of contact in the absence of the LAC and support them in their duties.

### Clinical lead

The clinical lead (NHS Kernow programme manager and clinical lead for learning disability) will give specialist advice to reviewers and the LeDeR quality panel. They will work with the LAC to develop a strategic plan which addresses the themes from reviews. They will be responsible for monitoring and evaluating that strategic plan in line with the established commissioning cycle.

### Senior responsible officer

This executive lead is responsible for the delivery and assurance of the LeDeR programme. They will ensure that the challenges faced by people from black, Asian and minority ethnic communities are considered and addressed as part of the programme.

### LeDeR quality panel

The panel will consider all focussed reviews, particularly their quality, the learning gained from them, and good practice. The panel will agree on actions to be taken as a result of focussed reviews.

### Monthly reviewer support group

This group will support reviewers, who in the course of their work will be exposed to distressing information.

### Assurance groups

The NHS Kernow quality assurance meeting will keep an overview of actions to be completed by providers. Unresolved concerns about actions which are not completed can be escalated to the NHS Kernow quality committee.

## 3. Policy

LeDeR aims to improve local services for people with a learning disability (aged 4 years and over), and autistic people (adults). The programme values the contribution of people with lived experience, and this will be reflected in our procedures.

Reviews will be conducted by independent reviewers with appropriate supervision and administrative support. All reviews should be completed within 6 months of them being notified on the LeDeR web platform unless statutory processes prevent that being possible. This means that good practice or problems can be shared and addressed as soon as possible.

A LeDeR review is not a mortality review. It does not restrict itself to the last episode of care before the person's death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. LeDeR reviews take account of any mortality review that may have taken place following a person's death.

LeDeR reviews are not investigations or part of a complaints process. Any serious concerns about the quality of care should be raised with the provider of that service directly or with the Care Quality Commission (CQC).

The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.

This policy should also be read alongside the NHSEI policy.

# 4. Procedure

## Notifications to the programme

Anyone can notify a death to the LeDeR programme via the website.

## Assigning a review

After NHS Kernow is notified, the SenRO will allocate each case to a reviewer.

## Initial review

The reviewer will carry out an initial review using the standard assessment to guide them through the process. This initial review will include:

1. If possible, a guided conversation with or contribution from a family member or someone close to the person who died.
2. A detailed conversation with the GP or a review of the GP records.
3. A conversation with at least 1 other person involved in the care of the individual who died. For example, this might be with the person who carried out the mortality review in the hospital, or another family member who wants to speak to the reviewer about the care their loved one received.

## Outcome of the initial review

The reviewer decides whether a focused review is required. The SenRO will review the justification for this and confirm whether it should remain as an initial review or move to a focused review. They will seek specialist advice where appropriate, including that of a general practitioner.

In some cases, even though a focused review is not required, there may be immediate actions for a specific individual or team within the health and care system which need to be put in place. These will be forwarded to the NHS Kernow quality assurance meeting for implementation by providers. The SenRO will record decisions on the LeDeR web platform and action log. Redacted reviews will be shared with all those who were involved in the care of the individual. This will include family or carers unless they prefer not.

## Focused review

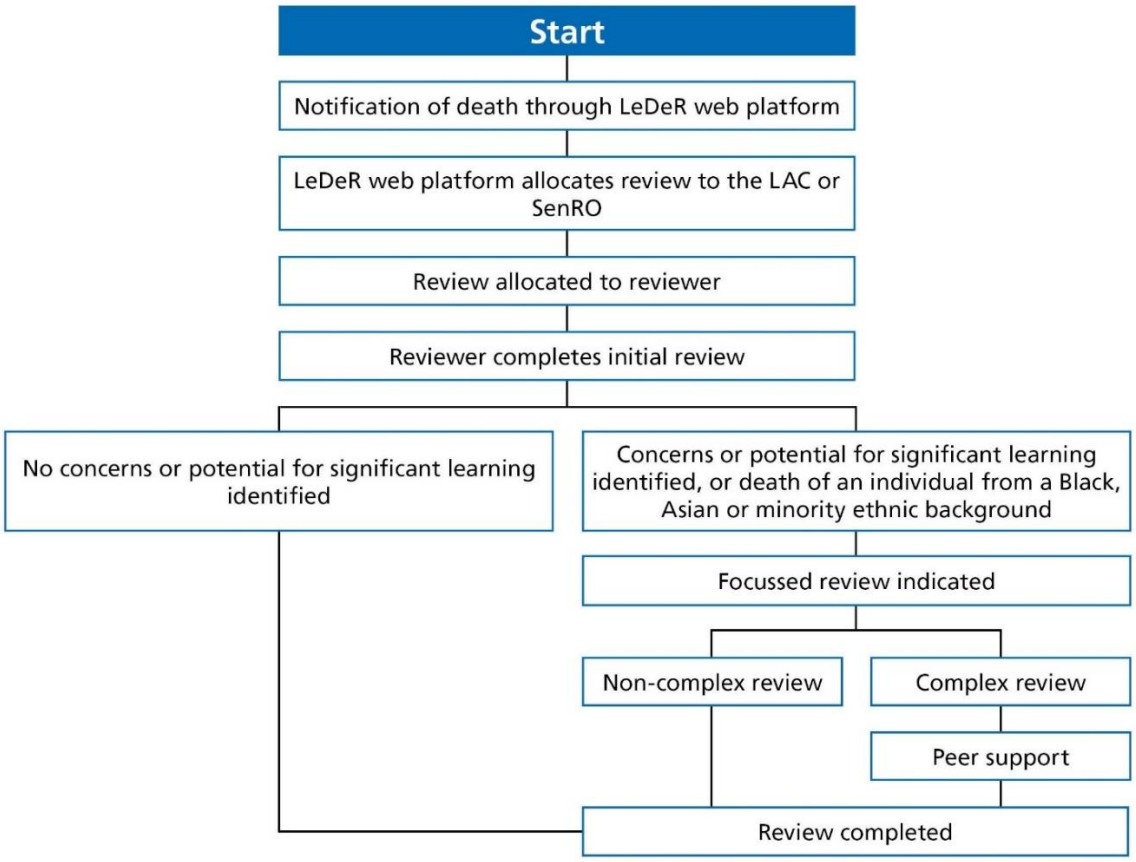
A focused review will be carried out:

1. If the person is from a black, Asian or minority ethnic background.
2. If there is significant learning to be gained.
3. If there are concerns about the quality of care provided to the person by 1 or more providers, or there is evidence of a lack of integrated or coordinated care.
4. If a family member asks for a focused review to be completed.
5. In the years 2021 to 2023, all deaths of adults who have a diagnosis of autism but who do not have a learning disability.

A focused review will be completed using the standard assessment process. Reviewers may work with the SenRO and the wider team of reviewers for additional expertise and support. The SenRO may carry out particularly complex reviews.

Reviewers will need to consider whether any other process, such as referral to safeguarding, provider complaints process or a serious incident investigation, should be conducted alongside or in place of a LeDeR review. LeDeR is a service improvement programme rather than a formal investigation process. This should be made clear to family members.

# LeDeR review process




## Consideration by the LeDeR quality and governance panel

Once completed and agreed by the SenRO, the focussed review will be considered by the LeDeR quality panel. Membership will include the following, with a minimum of the LAC, SenRO, and one clinical lead for quoracy:

- local area contact
- senior review officer
- reviewer and LeDeR administrator
- representatives of people with lived experience, their families or carers
- NHS Kernow, clinical lead
- Royal Cornwall Hospitals NHS Trust clinical lead
- Cornwall Partnership NHS Foundation Trust clinical lead
- NHS Kernow, strategic lead nurse for general practice nursing
- representative from Cornwall Council social care and from public health
- a named lead with responsibility for black, Asian and minority ethnic inequalities

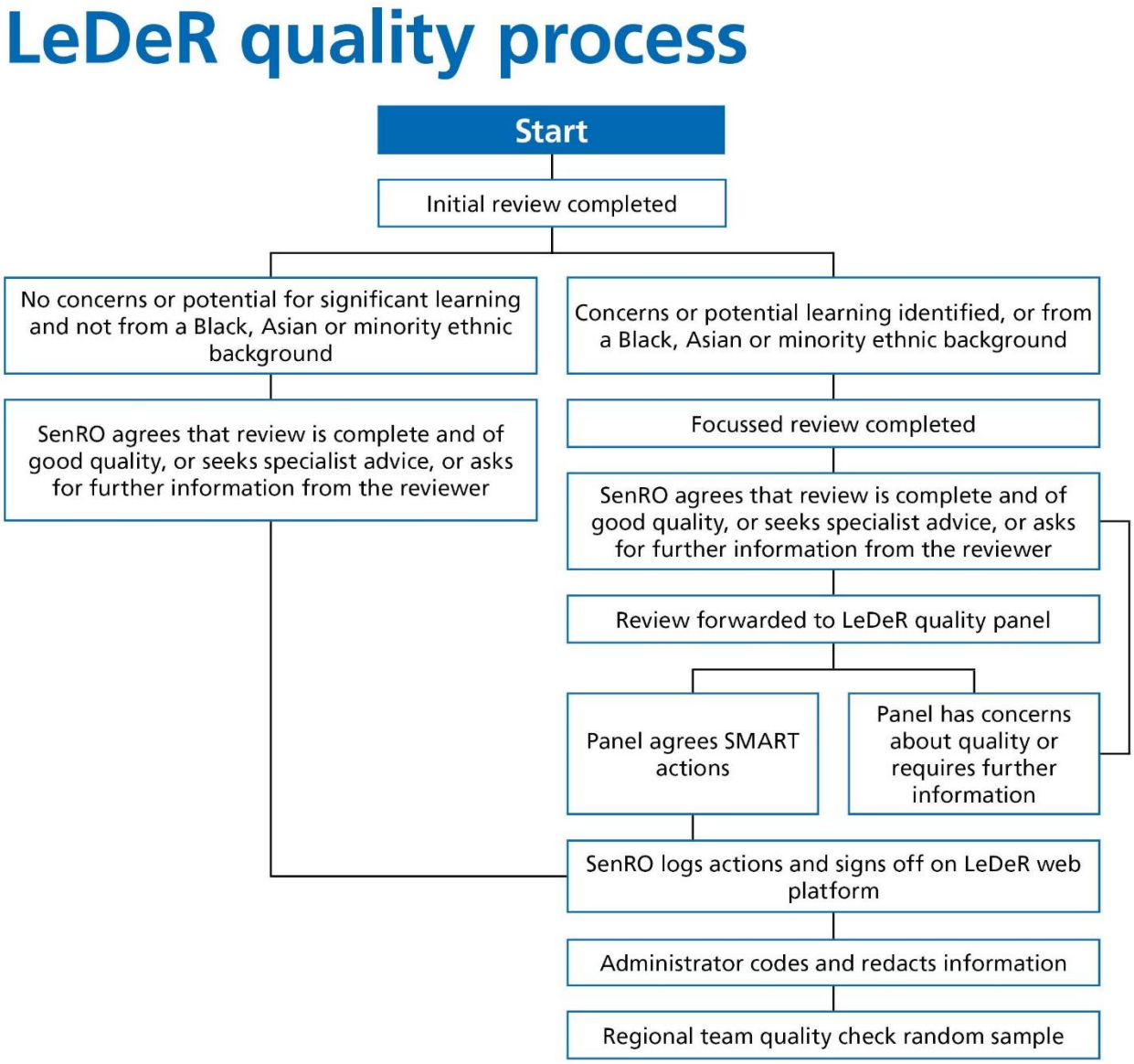
The panel will consider the:

- quality of the review
- learning gained from the review
- good practice
- any actions to be taken forward

Actions agreed at the panel will be forwarded to the NHS Kernow quality assurance meeting for provider implementation and entered onto the action log and LeDeR web platform.

The panel will meet every month, although this may vary according to demand.

Any conflict of interest will be declared before consideration of a case and recorded on the LeDeR web platform.



## 5. Governance

We will know that the LeDeR programme is effective when we identify:

- reduced recurrent themes found in LeDeR reviews
- reduced levels of concern and areas for improvement in reviews
- reduced frequency of deaths that were potentially avoidable
- evidence of service improvements

We expect the LeDeR programme to deliver:

- a positive experience of the LeDeR process for bereaved families
- decreasing numbers of preventable deaths
- greater use of reasonable adjustments in health and care services
- better outcomes for people as a result of local service improvement projects
- increased awareness of the main causes of death
- improved data about the lives and deaths of autistic people

The LeDeR quality panel reports to the NHS Kernow quality assurance meeting (QAM), which itself reports into the quality committee (QC). In addition, reports are also made to NHSEI. The schedule of reporting is as follows:

- monthly report against key performance indicators to the quality and governance panel and to QAM
- quarterly report on progress against service improvement actions report to the quality and governance panel QAM, QC (by exception), the learning disabilities programme board and NHSEI
- quarterly report on key milestones to the quality and governance panel QAM, QC (by exception), the learning disabilities programme board and NHSEI
- annual report to the quality and governance panel QAM, QC, the learning disabilities programme board and NHSEI

## Appendix 1: Equality impact assessment

An equality impact assessment is used to establish how a policy or similar document may impact on individuals, communities, or equality groups to identify and minimise or remove any disproportionate impact. A full impact assessment should be undertaken for policies, strategies, procedures, or projects which are anticipated to have an impact on members of the public. Read guidance on how to complete this document.

**Name of policy or service to be assessed:** Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) programme policy and procedure
**Department or section:** Nursing and quality
**Date of assessment:** 23 December 2021
**Person(s) responsible for the assessment:** Drew Wallbank
**Is this a new or existing policy?** New

### Aims, objectives and purpose of the policy

**Describe the aims, objectives, and purpose of the policy.**

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 by reviewing information about the health and social care support people received.

**Who is intended to benefit from this policy, and in what way?**

People with a learning disability and autistic people, through service improvements. Staff and members of the LeDeR quality panel, through clear procedures.

**What outcomes are wanted from this policy?**

- a positive experience of the LeDeR process for bereaved families
- decreasing numbers of preventable deaths
- greater use of reasonable adjustments in health and care services
- better outcomes for people as a result of local service improvement projects

- increased awareness of the main causes of death
- improved data about the lives and deaths of autistic people

**What factors or forces could contribute or detract from the outcomes?**

Failure to complete service improvements as identified in reviews.

**Who are the main stakeholders in relation to the policy?**

Those involved in the LeDeR programme, through clear procedure.

**Who implements the policy, and who is responsible for the policy?**

The LeDeR local area contact (LAC)

## Differential impacts

**Does this have a positive or negative impact on people who have a black, Asian and minority ethnic (BAME) background? How will any negative impact be mitigated?**

The policy and procedure makes positive impact on those groups shown to have poorer health outcomes. It focusses on people with learning disability and autism, also making specific provision for black and minority ethnic groups, including Romany gypsy, Irish traveller, and Jewish communities.

**Does this have a positive or negative impact on people who identify as male, female or intersex? How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of gender identity.

**What is the positive or negative differential impact on people from the perspective of disability? How will any negative impact be mitigated?**

The policy and procedure makes positive impact on with learning disability and autism.  It aims to improve service and health outcomes.

**Does this have a positive or negative impact on people who identify as heterosexual, lesbian, gay, bisexual, pansexual or asexual? How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of sexuality.

**What is the positive or negative differential impact on people from the perspective of age? How will any negative impact be mitigated?**

Neutral

**What is the positive or negative differential impact on people from the perspective of religion or belief? How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of religion or belief.

**What is the positive or negative differential impact on people from the perspective of marriage and civil partnership? This is particularly relevant for employment policies. How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of relationship status.

**Does this have a positive or negative impact on people who identify as trans or transgender, non-binary, or gender fluid? How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of gender identity.

**Does this have a positive or negative impact on people who are pregnant, breast feeding mothers, or those on maternity leave? How will any negative impact be mitigated?**

Neutral: it targets people with learning disability and autism irrespective of this.

**Are they any other identified groups? How will any negative impact be mitigated?**

No. not applicable

## Human rights values

**How have the core human rights values of fairness, respect, equality, dignity, and autonomy been considered in the formulation of this policy, service, or strategy?**

Through improvement of health outcomes which impact on these values.

**Which of the human rights articles does this document impact?**

☒ To life
☒ Not to be tortured or treated in an inhuman or degrading way
☒ To liberty and security
☐ To a fair trial
☒ To respect for home and family life, and correspondence
☐ To freedom of thought, conscience, and religion
☐ To freedom of expression
☐ To freedom of assembly and association
☐ To marry and found a family
☒ Not to be discriminated against in relation to the enjoyment of any of the rights contained in the European Convention
☐ To peaceful enjoyment of possessions

**What existing evidence (either presumed or otherwise) do you have for this?**

The improvement of health outcomes supports these articles.

**How will you ensure that those responsible for implementing the policy are aware of the human rights implications and equipped to deal with them?**

They will follow the procedures.

## Public Sector Value Act 2020

NHS Kernow is committed and obliged to fulfil the requirements of the Public Sector Social Value Act 2012. This Act requires the organisations to consider how services commissioned or procured might improve the economic, social, and environmental wellbeing of an area.

**Please describe how this will support and contribute to the local system, wider system, and community.**

This is a service improvement programme.

**Describe how the policy contributes towards eliminating discrimination, harassment, and victimisation.**

This is a service improvement programme.

**Describe how the policy contributes towards advancing equality of opportunity.**

Through positive action towards this group of people.

**Describe how the policy contributes towards promoting good relations between people with protected characteristics.**

**If the differential impacts identified are positive, explain how this policy is legitimate positive action and will improve outcomes, services and or the working environment for that group of people.**

The service improvement programme makes positive impact on those groups shown to have poorer health outcomes. It focusses on people with learning disability and autism, also making specific provision for black and minority ethnic groups, including Romany gypsy, Irish traveller, and Jewish communities.

**Explain what amendments have been made to the policy or mitigating actions have been taken, and when they were made.**

Not applicable.

**If the negative impacts identified have been unable to be mitigated through amendment to the policy or other mitigating actions, explain what your next steps are using the following equality impact assessment action plan.**

Not applicable.

## Equality impact assessment action plan

| Issue to be addressed | Action required | Responsible person | Timescale for completion | Action taken |
|---|---|---|---|---|
| Not applicable | Not applicable | Not applicable | Not applicable | Not applicable |

**Comments on action plan**:

Not applicable

**Signed (completing officer)**:



**Date**: 23 December 2021

**Signed (head of department or section)**: Lisa Nightingale

**Date**: 11 May 2022

Please ensure that a signed copy of this form is sent to both the corporate governance team with the policy and the equality and diversity lead.