



APPENDIX 1

Cumbria and the North East Learning Disability Mortality Steering Group Steering Group Terms of Reference

Terms of reference

This document sets out the standard terms and background that will apply to all meetings.

Background

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

The aim of the programme is to drive improvement in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities in this population, through mortality case review. These reviews are intended to support health and social care professionals, and policy makers to clarify the contribution of various causes of death to the overall burden of excess premature mortality for people with learning disabilities; identify variation and best practice; and identify key recommendations for improvement.

The programme will complement and contribute to the work of other agencies such as the Learning Disability Public Health Observatory, academic research studies, NICE, the CQC inspection programme, Local Government Associations, The Transforming Care Programme, and Third sector and voluntary agencies.

The scope of the local reviews of deaths

The LeDeR Programme will support reviews of deaths of people with learning disabilities aged 4 years and over.

The Programme will support reviews of all deaths, irrespective of the cause of death or place of death.

Name of group

Cumbria and the North East Learning Disability Mortality Steering Group

Purpose / role of the group

- To work in partnership with the Regional lead for the work.



- In partnership with stakeholders to ensure that at least one appropriate person (Local Area Contact) is recruited for each local area. The Local Area Contact will have oversight of the programme activities in the local area.
- To guide the implementation of the programme of local reviews of deaths of people with learning disabilities.
- To support the proportionate review of all deaths of people with learning disabilities in their area, and more detailed reviews of those for whom it is indicated, and those subject to a rolling programme of priority themed review.
- To receive regular updates from the Local Area Contact about the progress and findings of reviews.
- To help interpret and analyse the data submitted from local reviews, including areas of good practice in preventing premature mortality, and areas where improvements in practice could be made.
- To monitor the action plans that are developed as a result of the reviews of deaths, and take or guide appropriate action as a result of such information.
- To ensure agreed protocols are in place for information sharing, accessing case records and keeping content confidential and secure.
- To ensure that the data is appropriately handled to ensure security and confidentiality in line with the programme's CAG S251 approval.
- To share anonymised case reports pertaining to deaths or significant adverse events relating to people with learning disabilities for publication in the LeDeR Programme repository in order to contribute to collective understanding of learning points and recommendations across cases.

Membership

The CNE Learning Disability Mortality Steering Group membership will include the following:

- North East & Cumbria Learning Disability Network manager
- North East & Cumbria Learning Disability Network chair
- Directors of Nursing & Quality, CCGs
- North Region LeDeR Co-ordinator, NHS England
- Deputy Director of Quality, CNE, NHS England
- Learning Disability ADASS lead representative
- Coroner's office representative
- Independent chair of Safeguarding Board (children and adults) representative
- Regional Safeguarding Designated Clinicians Forum representative
- Inspection Manager, Care Quality Commission
- LeDeR Confirm & Challenge representatives
- Advocacy organisations representative
- Community & specialist learning disability providers NHS FT Trusts

Role of Members

Members review programme direction and make decisions to make sure that:

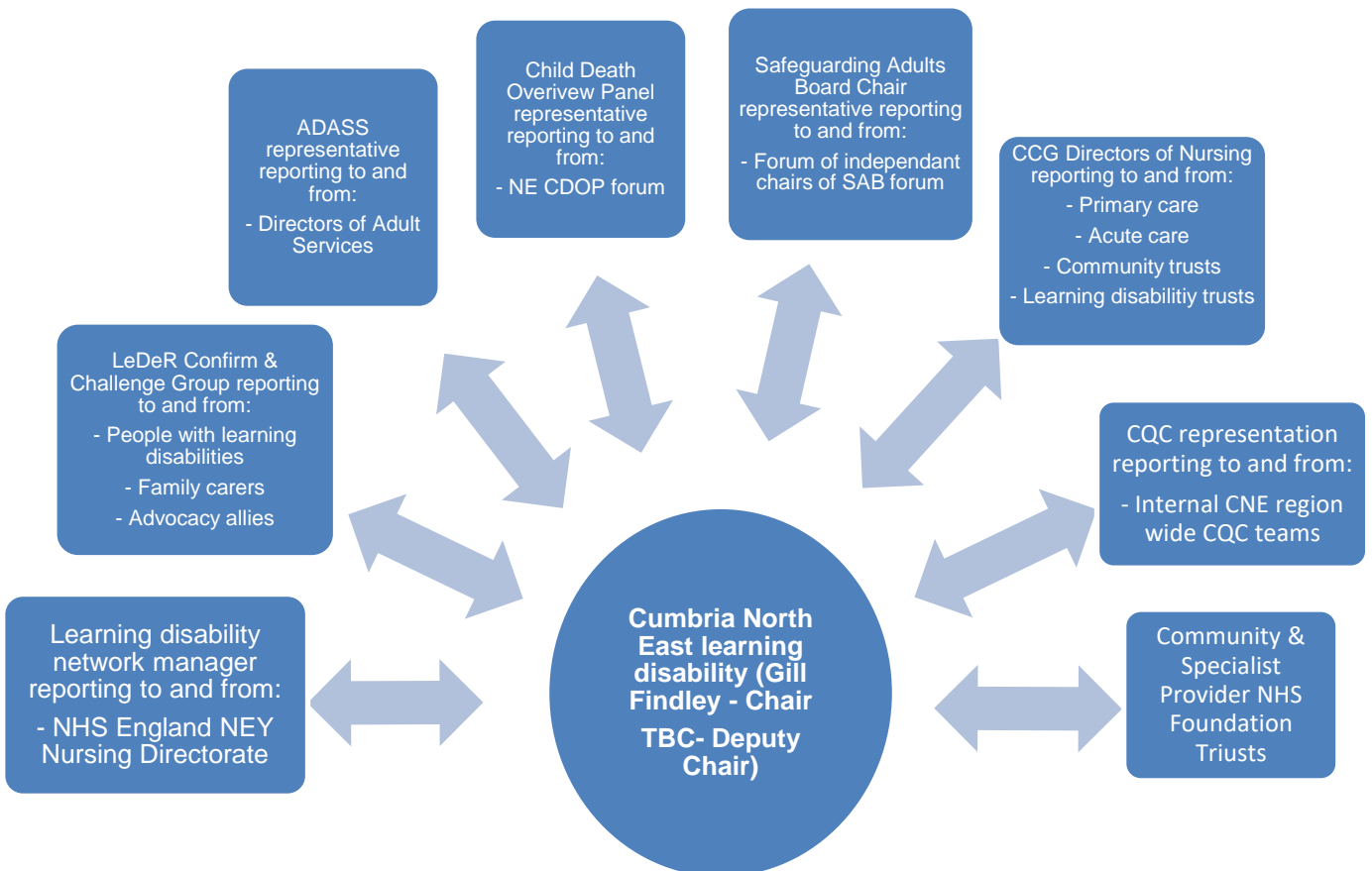
- Members will ensure there are robust local arrangements in place with primary and secondary care (acute trusts, community trusts and specialist learning



disability/mental health trusts) where engagement and communication regarding LeDeR implementation with this sector will be directed.

- Members will ensure these local arrangements are effective.
- Partners work together to support the success of the programme and make sure that no single interest will undermine the programme.
- All risks are assessed and managed well, putting in place actions and contingency plans for all high impact risks.
- The time and resources needed for the programme objectives are available.
- Recording of programme information is accurate and coherent.
- Support is available for the Local Area Contact from the North Region LeDeR Co-ordinator
- The progress of the overall programme is monitored and any remediable action is undertaken.

Governance





Meeting frequency

- Meetings to be held bi-monthly with plans to move to quarterly when programme operating as business as usual
- Meeting organised by the Learning Disability Network and chaired by Gill Findley, Director of Nursing – NHS North Durham & HAST CCGs. The deputy chair is Brian Cranna, Inspection Manager, CQC.
- Among other matters, the meetings may establish time specific working groups to focus on specific issues, which may be delegated to resolve / approve specific actions.



LEARNING DISABILITIES SERVICE IMPROVEMENT GROUP County Durham

Terms of Reference

1. Purpose/Aims

The primary purpose of the Learning Disabilities Service Improvement Group (LD SIG) is to

1. Come together to share good practice and discuss service improvement based on national and local intelligence and learning from LeDer reviews.
2. Make our voice as strong as possible to influence people who are involved in making the changes happen.
3. Work in partnership with all stakeholders to improve the lives of people with a learning disabilities living in County Durham.
4. Share experiences, knowledge and soft intelligence as part of the learning.
5. Participate in the quality assurance process of LeDer reviews, identifying the learning and making appropriate recommendations.
6. Support key policy drivers, and share evidence base and good practice and how it can be implemented in services.
7. Ensure agreed actions and points to consider are fed into:
 - Strategic plans within respective multiagency teams
 - Regional and local public health forums and plans
 - Cumbria & the North East Learning Disability Network
 - Local Safeguarding Adults Board
8. Devise a clear thematic action plan to influence change in accordance with regional directives across health and social care service delivery.

2. Aim

Based on identified trends and themes from Leder reviews, local intelligence, knowledge and experience of group members, the group will share good practice and identify where improvements need to be made.



3. Accountability and Governance

The group will be accountable to the Commissioning Group of the Mental Health and Learning Disabilities Partnership, chaired by Director of Commissioning, Strategy and Delivery for County Durham CCG. Concerns and recommendations will be escalated and shared accordingly in relation to completed Leder reviews and service improvement.

Concerns and recommendations will also be escalated to the local safeguarding adult board (SAB) via annual reports and referral into Serious Adult Review panel as necessary.

4. Objectives

1. To progress areas of work as specified within thematic action plan (but not limited to) which include:
 - Improving uptake and quality of annual health checks for people with a learning disability
 - Improving uptake of national cancer screening programmes
 - Improving uptake of the Flu Immunisation Programme
 - Developing recommendations that have emerged through the LeDeR programme
 - Encouraging people to adopt healthier lifestyles
2. To ensure people with learning disability and their families get good information about health services and what they should expect.
3. To share good ideas and ways of working on making Valuing People Now happen.
4. To offer ideas and advice to regional groups, i.e. the learning disabilities health network.
5. To help member and external groups develop peer support and peer review, by working together to help solve problems and share ideas.
6. To disseminate information out to the wider system and sharing information through networking with groups such as Access to Acute Services, Good Access to Primary Care and Clinical Leads groups.
7. To be knowledgeable of other local and regional plans and establish how members can contribute towards their success.
8. To examine national, regional and local data, from sources such as Public Health England, NHS England, NEC Business Intelligence team and reports from independent organisations.



9. To use data, in conjunction with local softer intelligence, to identify needs and required actions.
 - To discuss completed Leder reviews against Bristol University standards and methodology to ensure consistency in the quality of Leder reviews.
 - To identify themes and trends within completed Leder reviews and submit reports biannually to the Commissioning Group of the Mental Health and Learning Disabilities Partnership for further analysis and discussion in order to agree future planning and actions around the learning.
 - To ensure that lessons learnt and good practice are shared throughout various learning disability forums throughout the local area.
 - To network and foster closer working relationships with practitioners from all areas of healthcare and social care.
 - To link with national and regional learning disability networks and discuss their application to local services.

5. Members roles and responsibilities

- Membership is open to all health and social care professionals who either act as a health and social care facilitator to a person or to people with learning disabilities or has a role in commissioning service for people with a learning disability.
- Each member will attend, or send a senior appropriate delegate to each of the meetings to ensure that the agenda and programmes of work move forward within agreed timescale.
- Each member will read nominated LeDer reviews in advance of the meeting and be prepared for discussion and decisions on individual reviews.
- Each member will ensure that there is a system in place to share information from their respective organisation and/or professional group and cascade information within their organisation/professional group.
- Each member will actively seek to improve outcomes for people with learning disabilities by using their expertise and influence to design and deliver actions/ programmes of work, and update the group on progress.

6. Membership

- Director of Nursing and Local Area Contact for LeDer (Chair)
- CCG Quality and Development Manager (Deputy Chair)



- Local Area Contact for Leder CCG
- Adult Safeguarding representative
- Lay Representation People’s Parliament
- Lay Representative Durham Carers
- Local Authority LD team representative
- LD Acute Liaison Services representative
- LD Health Facilitation representative
- LeDer reviewers
- Nominated Primary Care Macmillan Nurse representative
- Primary Care LD Lead representative

7. Frequency

The meetings will be held bimonthly.

8. Administration

Arrangements for administrative support will be provided by **Karen Kennedy** Personal Assistant for CCG Quality Team Support kkennedy2@nhs.net

6. Conflicts of interest

Members should comply with the CCG’s Standards of Business Conduct and Declarations of Interest Policy and complete a declaration of interest form on an annual basis which can be updated at any time but which will be formally reviewed on a six monthly basis. If a member feels compromised by any agenda item they should declare a conflict of interest as soon as they are aware of it, ideally before the meeting. The conflict will then be considered by the Chair either prior to the meeting or at the meeting. The Chair would then determine whether the person who declared the interest should leave the meeting for the discussion and decision making, take part in the discussion but not the decision making or take part in both the discussion and the decision making of that particular agenda item. A detailed record of any declarations of interest made in relation to the items on the agenda will be recorded in the minutes of the meeting and on the declaration of interest form which will be signed by the Chair. Terms of reference will be reviewed on an annual basis.

10. Quoracy

The quoracy will consist of four members of the core Group being present, with at least one member from CCG, local authority, CDDFT and TEWV

Version control

	Date reviewed / updated	Updated by	Record of update	Next update due
Version 1 Draft	4 th October 2019	Claire Kerr NECs	Minutes Reviewer’s meeting	
Version 2	15 th November 2019	SIG members	Minutes SIG	November 2020



LEARNING DISABILITIES SERVICE IMPROVEMENT GROUP Teesside DRAFT Terms of Reference

2. Introduction

The primary purpose of the Learning Disabilities Service Improvement Group (LD SIG) is to learn from Learning Disabilities Mortality Reviews (LeDeR) and share experiences, knowledge and information in order to improve the health and wellbeing of people with learning disabilities.

The group is responsible for the quality assurance of completed LeDer reviews, identifying the learning and making appropriate recommendations as necessary to improve the quality of health and social care provision across Teesside. The group is also responsible for sharing and evidencing good practice from the day to work within learning disability teams.

2. Aim

Based on identified trends/ themes from LeDeR reviews, local intelligence and the knowledge and experience of group members, the aim of the group is to share good practice and identify where improvements need to be made.

The aim of the group is to also devise a clear action plan to influence change in accordance with regional directives across health and social care service delivery.

3. Accountability

The group will be accountable to **TBC**. Concerns will be escalated accordingly in relation to outstanding actions and/or quality of completed LeDeR reviews.

4. Objectives

- To discuss completed LeDeR reviews against Bristol University standards and methodology to ensure consistency in the quality of Leder reviews.
- To ensure that the level of investigation undertaken by the LeDeR reviewer is appropriate, identifies lessons learned and makes appropriate recommendations according to findings.
- To seek further advice and support from clinicians and partners in the local area as necessary, if outcomes or grading of review is uncertain.



- To identify themes and trends within completed LeDeR reviews and submit reports biannually to the **TBC** for further analysis and discussion in order to agree future planning and actions around the learning.
- To ensure that lessons learnt and good practice are shared throughout various learning disability forums throughout the local area.
- To network and foster closer working relationships with practitioners from all areas of healthcare and social care.
- To link with national and regional learning disability networks and discuss their application to local services.
- To support the analysis themes and trends from local data, including Learning Disability registers, Annual Health Checks and screening update.

5. Members roles and responsibilities

Membership is open to all health and social care professionals who act as a health and social care facilitator to a person or to people with learning disabilities.

- Each member will attend, or send a senior appropriate delegate to each of the meetings to ensure that the agenda and programmes of work move forward within agreed timescale.
- Each member will read nominated LeDeR reviews in advance of the meeting and be prepared for discussion and decisions on individual reviews.
- Each member will ensure that there is a system in place to share information from their respective organisation and/or professional group and cascade information within their organisation/professional group.
- Each member will actively seek to improve outcomes for people with learning disabilities by using their expertise and influence to design and deliver actions/ programmes of work, and update the group on progress.

9. Membership (requires an identified deputy chair)

- Head of quality and adult safeguarding - representing the CCG's (Chair)
- Local Area Contact for LeDeR representative
- Local Authority Safeguarding Practice representative
- ?? Local Authority Learning Disability team
- Representative from Learning Disability Acute Liaison Services
- Representation from Learning Disability Health Facilitation team
- Nominated Primary Care Macmillan Nurse representative
- ?? Primary Care Learning Disability Champion



10. Frequency

The meetings will be held bi-monthly.

11. Administration

Arrangements for secretarial support will be provided by TBC

12. Conflicts of interest

Members should comply with the CCG's Standards of Business Conduct and Declarations of Interest Policy and complete a declaration of interest form on an annual basis which can be updated at any time but which will be formally reviewed on a six monthly basis. If a member feels compromised by any agenda item they should declare a conflict of interest as soon as they are aware of it, ideally before the meeting. The conflict will then be considered by the Chair either prior to the meeting or at the meeting. The Chair would then determine whether the person who declared the interest should leave the meeting for the discussion and decision making, take part in the discussion but not the decision making or take part in both the discussion and the decision making of that particular agenda item. A detailed record of any declarations of interest made in relation to the items on the agenda will be recorded in the minutes of the meeting and on the declaration of interest form which will be signed by the Chair.

Terms of reference for the LeDeR Reviewer's Service Improvement Group will be reviewed on an annual basis and submitted to the local learning disability improvement group for approval.

10. Quoracy

The quoracy will consist of four members of the core Group being present, with at least one member from CCG, local authority, NTHFT, STHFT and TEWV.

Version control

	Date reviewed / updated	Updated by	Record of update	Next update due
Version 1 Draft	20.01.2020	Alison Peevor		
Version 2 Final draft	04.03.2020	All group members		