

Title of Meeting:	NY CCG Governing Body	Agenda Item: 5.2										
Date of Meeting:	24 June 2021	<table border="1"> <thead> <tr> <th colspan="2">Session (Tick)</th> </tr> </thead> <tbody> <tr> <td>Public</td> <td>X</td> </tr> <tr> <td>Private</td> <td></td> </tr> <tr> <td>Development Session</td> <td></td> </tr> </tbody> </table>			Session (Tick)		Public	X	Private		Development Session	
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Development Session												
Paper Title:	Learning Disability Mortality Review Annual Report 2020/21											
Responsible Governing Body Member Lead Sue Peckitt, Chief Nurse		Report Author and Job Title Sue Peckitt, Chief Nurse										
Purpose – this paper is for:	<table border="1"> <thead> <tr> <th>Decision</th> <th>Discussion</th> <th>Assurance</th> <th>Information</th> </tr> </thead> <tbody> <tr> <td>X</td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Decision	Discussion	Assurance	Information	X						
Decision	Discussion	Assurance	Information									
X												
<p>Has the report (or variation of it) been presented to another Committee / Meeting? If yes, state the Committee / Meeting: No.</p>												
<p>Executive Summary The Learning Disability Mortality Review (LeDeR) programme was established in 2015 to drive improvements in the quality of health and social care for people with a learning disability and to help reduce premature mortality and health inequalities. Now, in 2021, the programme nationally provides the largest body of evidence on deaths of people with a learning disability at an individual level anywhere in the world.</p> <p>This is the second Annual Report for the Learning Disability Mortality Review (LeDeR) programme compiled on behalf of North Yorkshire and York CCGs.</p> <p>The report describes the national update from NHS England / NHS Improvement (NHSE/I) and the local delivery of the programme across the North Yorkshire and York area.</p> <p>Notably the report includes the findings and learning from completed reviews; the key achievements; and the challenges and opportunities for the programme in 2021/22.</p>												
<p>Recommendations</p> <p>The Governing Body is asked to: Approve the publication of the Learning Disability Mortality Review Annual Report 2020/21</p>												
<p>Monitoring Not applicable.</p>												

CCG Strategic Objectives Supported by this Paper

CCG Strategic Objectives		X
1	Strategic Commissioning: <ul style="list-style-type: none"> To take the lead in planning and commissioning care for the population of North Yorkshire by providing a whole system approach and to support the development of general practice. To make the best use of resources by bringing together other NHS organisations, local authorities and the third sector to work in partnership on improving health and care. To develop alliances of NHS providers that work together to deliver care through collaboration rather than competition. 	
2	Acute Commissioning: We will ensure access to high quality hospital-based care when needed.	
3	Engagement with Patients and Stakeholders: We will build strong and effective relationships with all our communities and partners.	
4	Financial Sustainability: We will work with partners to transform models of care to deliver affordable, quality and sustainable services.	
5	Integrated / Community Care: With our partners and people living in North Yorkshire we will enable healthy communities through integrated models of care.	
6	Vulnerable People: <ul style="list-style-type: none"> We will support everyone to thrive [in the community]. We will promote the safety and welfare of vulnerable individuals. 	X
7	Well-Governed and Adaptable Organisation: In supporting our objectives we will be a well-governed and transparent organisation that promotes a supportive learning environment.	X

CCG Values underpinned in this paper

CCG Values		X
1	Collaboration	X
2	Compassion	X
3	Empowerment	X
4	Inclusivity	X
5	Quality	X
6	Respect	X

Does this paper provide evidence of assurance against the Governing Body Assurance Framework?

YES		NO	X
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Any statutory / regulatory / legal / NHS Constitution implications	CCG's are required to publish an annual LeDeR Annual Report. The Governing Body has delegated authority to approve arrangements for discharging the groups statutory duties associated with its commissioning functions to support safeguarding and promoting the welfare of adults and children.
Management of Conflicts of Interest	No conflicts of interest have been identified prior to the meeting.
Communication / Public & Patient Engagement	The Learning Disability Mortality Review Annual Report 2020/21 is published on the CCG website.
Financial / resource implications	No financial or resource implications identified.
Outcome of Impact Assessments completed	No assessment applicable, however the LeDeR Programme will support the delivery of responsibilities under the Equalities Act by identifying and addressing the health inequalities that people with a learning disability experience.

Sue Peckitt, Chief Nurse, NHS North Yorkshire CCG

North Yorkshire and Vale of York CCG Annual Learning Disability Mortality Review (LeDeR)

Contents Page

Section	Description	Page No
1		
	Executive Summary	3
	1.1 Introduction	3
	1.2. National Context	4
	1.2.1 New LeDeR Policy and implications	5
	1.2.2 Definition of Learning Disabilities	6
	1.2.3 Scope of the LeDeR Programme	7
	1.2.4 Notification of a Death	7
	1.2.5 Confidentiality and Data Sharing	7
	1.3 Local Context	7
	1.3.1 Covid-19 Impact	8
2	LeDeR Process in North Yorkshire and Vale of York CCG	9
	2.1 Purpose of the LeDeR Review	9
	2.2 Initial Review	9
	2.3 Multi-agency Review as part of the LeDeR Process	9
3	Accountability & Governance	10
	3.1 Accountability	10
	3.2 LeDeR Steering Group	10
	3.3 Quality Assurance (QA) Panel	11
	3.4 Local Reviewers/Conducting Reviews	11
4	Findings from Deaths in North Yorkshire and Vale of York CCG	12
	4.1 Deaths Notified to the LeDeR Programme	12
	4.2 Deaths Notified	12
	4.3 People's death by Age Group	12
	4.4 People's deaths by Gender	13
	4.5 People's death by Age	13
	4.6 People's deaths by Ethnicity	13
	4.7 Place and Time of Death	14
	4.8 Cause of Death	14
	4.9 The Use of Antipsychotic Medication	15
	4.10 Annual Health Checks	17
	4.11 Safeguarding Concerns	18
	4.12 Medication Reviews	18
	4.13 Generic Screening	19
	4.14 Family Involvement in the Review	19
	4.15 End of Life Pathway	20
	4.16 Reasonable Adjustments	21
5.	Quality of Care Provided	22

Section		Description	Page No
	5.1	Quality of Care	21
	5.2	Grading/Quality of Care	22
6.		Deaths of Children	23
	6.1	Child Deaths Overview Panel	23
7.		Learning into Action	23
8.		Future Priorities	28
9		Acknowledgements	28
10.		References	28
11.		Appendices	29
	1	LeDeR Process Flowchart	29
	2	LeDeR Steering Group Terms of Reference	30

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Executive Summary

This is North Yorkshire and Vale of York CCGs CCG's Annual Report of the Learning Disabilities Mortality Review (LeDeR) programme. It presents information about the deaths of people with learning disabilities who were reported into the programme. The purpose of the 2020/21 Annual Report is to evaluate and summarise the key themes and trends from the LeDeR reviews reported between 1st April 2020 and 31st March 2021 and will focus on factors including:

- 50% of cases were males – this is lower than nationally at 58%.
- 100% of adults with learning disabilities whose deaths were reviewed were White British – this is higher than nationally at 90%.
- 76% of deaths occurred in hospital which is an increase from last year's figures and reflects the number of Covid 19 deaths which occurred in hospitals.
- The most common confirmed cause of death was Covid 19 (38.1%).
- 50% of completed Reviews concluded that individuals received care that met or exceeded good practice (Grade 1 or 2) – compared to 56% nationally.
- The average age of death for females was 65.7 years and 66.7 for males. The latest national figure was 59 years for females and 61 for males.

Themes and trends linked to best practice, learning and recommendations are also summarised. Some of the themes from the local data have been compared to the national 2019 LeDeR Annual Report data for comparison. This report is available to read at <http://www.bristol.ac.uk/sps/LeDeR/resources/annual-reports/>

The North Yorkshire and Vale of York CCG Annual LeDeR Report (this document) will be shared with key local stakeholders.

1.1 Introduction

The Learning Disabilities Mortality Review (LeDeR) Programme is a world-first programme of its kind aimed at making improvements to the lives of people with learning disabilities, through a national review into their deaths, to improve the standard and quality of care for this group of people.

The programme, implemented across England, is aimed at identifying learning and was delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Nationally, work on the LeDeR programme commenced in June 2015 for an initial three-year period. In North Yorkshire and Vale of York CCG, implementation commenced in November 2016, and by the end of 2017, the LeDeR programme was fully rolled out across England.

People with learning disabilities, their families and carers have been central to developing and delivering the programme nationally.

Under the LeDeR programme all Clinical Commissioning Groups (CCGs) areas must deliver a local procedure for reviewing deaths of people with a Learning Disability as part of this national review.

The 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 many people with learning disabilities were dying earlier of preventable health conditions younger than they should, and up to 30 years earlier than the rest of the population. Some of the reasons related to the standard of health and social care that they received, but also related to other wider social determinants of ill health, such as poverty and social exclusion.

The overall aim of the LeDeR programme is to help reduce premature mortality and health inequalities in this population, through driving improvement in their lives and in the care that they receive.

The LeDeR programme collates and shares anonymised information about the deaths of people with learning disabilities nationally, so that common themes, learning points and recommendations can be identified and taken forward into Policy and practice improvements.

Values and Principles

The core principles and values of the programme are:

- valuing the contribution of people with learning disabilities and their families to all aspects of our work
- taking a holistic perspective, looking at the circumstances leading to deaths of people with learning disabilities, and not prioritising one source of information over another
- aiming to ensure that reviews of deaths lead to reflective learning, which will result in improved health and social care service delivery
- to embed reviews of deaths of people with learning disabilities into local structures to ensure the continuation of the learning taken from the reviews.

The issues and causes of death identified within the national LeDeR Annual Report (published 16 July 2020), alongside the findings from locally completed reviews reflect the many challenges that people with a learning disability face in living their lives.

Whilst there is much work already underway nationally and locally to improve access to healthcare to address inequality, there is more work to be done. Through the development of new tools to support Practitioners and Providers and new resources to develop skills and awareness, we aim to improve access to the right care and support, through developing a culture of improved information, knowledge, vigilance, and interventions for people with a learning disability.

1.2. National Context

People with a learning disability experience significant health inequality when compared to the rest of the general population. To put this into context the life expectancy for people with learning disabilities in 2020 can be equated to what the rest of the general population could have expected in the 1940's.

The 2018 Learning Disabilities Mortality Review (LeDeR) found the median age at death was 60 for men and 59 for women, for those (aged 4 and over) who died April 2017 to December 2018. This is significantly less than the median age of death of 83 for men and 86 for women in the general population. This means the difference in median age of death between people with a learning disability (aged 4 and over) and the general population is 23 years for men and 27 years for women.

However, these health inequalities should not be inevitable and can be mitigated by improved education, prevention, early intervention, and timely access to healthcare throughout their lives.

1.2.1 LeDeR Policy and Implications

On 23rd March 2021, NHSE/I published their first LeDeR Policy setting out for the first time for the NHS, the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme from June 2021. From 1st June, the LeDeR programme will transfer to a new web-based IT system from the University of Bristol web-based platform. The Policy also introduces the inclusion of Autism into the programme from the Autumn of 2021.

In response to the change and following stakeholder engagement, the new name for the LeDeR programme is 'Learning from Life and Death Reviews – people with a learning disability and autistic people'. However, it will continue to be called LeDeR.

The changes include a new IT system run within the NHS, a two-stage review process and later in the year, we will begin reviewing the deaths of people with a diagnosis of Autism.

The fundamental push of the Policy is to drive change and service improvement further, by focusing in on deaths where there is concern about the care of the person and/or significant learning to be gathered.

As part of the Policy, ICSs will have a central role going forward and be responsible for ensuring all aspects of LeDeR continue to be carried out, including new governance arrangements and a strategy to reduce Health Inequalities and premature deaths at a local level and very importantly, that actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality. This enables the ICS to identify good practice and what has worked well, as well as where improvements in the provision of care could be made. Local actions are taken to address the issues identified in reviews. Recurrent themes and significant issues are identified and addressed at a more systematic level, regionally and nationally.

CCGs will initially take this work forward until ICS come fully online. It is likely the workforce model will not be fully agreed or in place until next April, this is due to the significant changes ahead regarding CCGs and ICSs across England, which impacts on these decisions.

By 1st April 2022, all changes within the Policy must be implemented by ICSs, subject to legislative changes relating to ICSs being passed in coming months. Changes to the LeDeR reporting system.

Guidance has been circulated to CCGs detailing the changes ahead and key dates which will impact on completion of reviews. This will indicate key actions and decisions needed by Local Area Contacts (LACs), to minimise disruption and delay in completing reviews and guard against any loss or replication of information and data.

As of the 31st of April, all current allocated local reviews have been completed and approved. The new local LeDeR Quality Assurance Panel, managed by the CCG, had continued to meet weekly ensuring that all cases were approved in an efficient and timely manner.

This marks a significant achievement and is testimony to the hard work and commitment by reviewers, the local LeDeR team and the CCGs internal mechanisms that have resulted in swifter allocation, as well as robust quality and assurances processes that are now embedded.

LeDeR Bristol Annual Report 2021

Bristol will produce one final Annual Report analysing the death that occurred from the 1st of April 2020 to the 31st of March 2021. Date for publication is to be confirmed.

LeDeR Policy CCG key actions for 2021/22

- Must have a robust plan to ensure that reviews are allocated within 3 months and completed within 6 months of the notification of death.
- Ensure that local governance for LeDeR is robust to demonstrate that action is being taken from local review findings to improve services, reduce health inequalities and address premature mortality.
- Ensure that the issues found in local reviews are raised with Senior ICS Care System leaders, including local authority partners, supporting joined-up action to improve services, reduce health inequalities and reduce premature mortality.
- Every CCG is a member of a 'Learning from LeDeR' Steering Group and have a named person with lead responsibility including a BAME lead.
- Produce an Annual Report. Annual Reports will be expected to be published by 30th June every year going forward a following its presentation at a public meeting of the CCG Board.
- Analysis of all regional learning and actions taken from last year's CCG reports will be shared, along with several good practice examples of CCG templates by the end of February 21.
- Very few CCG reports were published with an easy read version. CCG are asked to consider this in planning of this year's reports, given one of their key stakeholders are people with a learning disability. The Accessible Information Standard would provide the basis of good practice around this area.
- LeDeR to be included in the 3-year strategy (Phase 4 planning) demonstrating action taken in response to the issues identified in LeDeR reviews and national findings, including how the local system will reduce the health inequalities faced by people including those from BAME communities who have a learning disability.

It is expected this will be at ICS level.

1.2.2 Definition of Learning Disabilities

The LeDeR programme follows the definition outlined in 2001 by the white paper 'Valuing People'.

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.

1.2.3 Scope of the LeDeR Programme

Initial reviews are undertaken of **all** deaths notified to the LeDeR programme of people with learning disabilities aged 4 years and older in England.

The following reviews will take precedence over local reviews:

- Serious Case Reviews (SCRs)
- Safeguarding Adult Reviews (SARs)
- Safeguarding Adults Enquiries (Section 42 Care Act)
- Domestic Homicide Reviews (DHRs)
- Serious Incident Reviews
- Coroners' investigations
- Child Death Overview Panel (CDOP)
- Mothers and Babies Reducing Risk through Adults and Confidential Enquiries (MBRRACE).

1.2.4 Notification of a Death

The person reporting the death is asked to provide as much of the core information required to notify a death as possible. The information provided is checked by the National LeDeR team to ensure that the death meets the inclusion criteria for the LeDeR programme. Once confirmed, the death is transferred to the LeDeR LAC who in turn will carry out their own local eligibility checks prior to allocation to a reviewer.

1.2.5 Confidentiality and Data Sharing

The National LeDeR programme applied to the national Confidential Advisory Group (CAG) for Section 251 (of the NHS Act 2006) approval for the use of patient identifiable information, in order that reviews can be undertaken of the deaths of people with learning disabilities.

The programme has been given full approval to process patient identifiable information without consent. Specifically, this provides assurance for health and social care staff that the work of the LeDeR programme has been scrutinised by the national CAG. The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved.

The key purpose of the CAG is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. More information about Section 251 approval is available at: www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/

1.3 Local Context

This Report is the published report on the learning from deaths of those people with learning disabilities within North Yorkshire and Vale of York CCG. The report covers the period of **1st April 2020 until 31st March 2021**.

The aim of this report is to bring information together to understand and to reflect on themes that can inform and improve practice across the health and social care community in North Yorkshire and Vale of York CCG.

It's important to remember that the people whose deaths are reported were known and loved by many and their loss will have had a profound impact on those around them.

1.3.1 Covid-19 Impact

Covid-19 has presented a new set of challenges that are expected to emerge over a period of time. Rapid learning from Covid-19 related deaths is a National priority which will also be supported in the local region. The Covid-19 pandemic has demonstrated nationally and locally that there is a disproportionate impact on people with learning disabilities. People with learning disabilities were seen to be more likely to have other physical health problems such as obesity and diabetes and certain kinds of learning disability, such as Down's syndrome, can make people more vulnerable to respiratory infections, which can increase their risk of dying from Covid-19.

A rapid learning review (see reference 1) of the deaths of people identified as having learning disabilities with Covid-19 across England (1) found 451 per 100,000 people registered as having a learning disability, died with Covid 19 between 21st March 2020 and 5th June 2020, a death rate 4.1 times higher than the general population after adjusting for other factors such as age and sex.

The report also states among people with learning disabilities, the rate of Covid-19 deaths for adults in residential care was higher than the rates of Covid-19 deaths of adults with learning disabilities generally. This difference is likely in part to reflect the greater age and disability in people in residential care. It was found that people with learning disabilities are likely to have had difficulty recognising symptoms of Covid-19, or following government advice about getting tested, self-isolation, social distancing and infection prevention and control, the report says. It may also be more difficult for people caring for them to recognise the onset of symptoms if these cannot be communicated.

On the 12th of November 2020, the University of Bristol published its report into the deaths of 206 people with a learning disability at the start of the Covid-19 pandemic. Two of the CCGs reviews were included in the report.

Local Covid-19 deaths

	Death notifications/Covid 19 cases
Deaths notified in Q1	9 Covid-19 related deaths
Deaths notified in Q2	1 Covid-19 related deaths
Deaths notified in Q3	4 Covid-19 related deaths
Deaths notified in Q4	4 Covid-19 related deaths (1 case cause of death unknown at present)

Locally deaths in Quarter 1 showed an increase in the average notifications of over 60%, 24 deaths were reported and of these 9 deaths were attributed to Covid-19. The previous year the average number of deaths per quarter was 10. Quarter 1 figures show a reflection of the sharp increase in Covid-19 deaths during the first wave of the Pandemic. In quarters 2, 3 and 4 deaths reverted back to previous average figures however, in Quarter 3 and Quarter 4, 40% of deaths were attributed to Covid-19 mirroring the second wave of the Pandemic.

SECTION 2 - LeDeR Process in North Yorkshire and Vale of York CCG

2.1 Purpose of the LeDeR Review

The purpose of the LeDeR Review is to:

- Identify any potentially avoidable factors that may have contributed to the person's death.
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.
- Identify good practice

2.2 Initial Review

Drawing on the wider learning from work on reviewing deaths in NHS Trusts, the LeDeR methodology places the person with learning disabilities at the centre of the review. The 'pen portrait', is a strength based focused recording of the person's likes, abilities, character and communication and is at the heart of the review.

Sadly, for some individuals it is not possible to complete more than a basic pen portrait due to a lack of family involvement and with so little of their life having been documented. Some care settings are better at being able to describe who the person was, their likes and dislikes, whilst others are not.

A chronology is completed detailing at least the last year of the person's life. From the information collated reviewers are required to analyse information and formulate recommendations based on issues and learning identified. These smart, measurable, achievable, realistic and timely (SMART) recommendations identify where quality can be improved and good practice shared, through the identification of recurrent themes

2.3 Multi-agency Review as part of the LeDeR Process

The purpose of the Multi-agency Review is to include the views of a broader range of people and agencies who have been involved in supporting the person who has died, where it is felt that further learning could be obtained from a more in-depth analysis of the circumstances leading up to the person's death.

There are several circumstances that would indicate that a Multi-agency Review is required. These may be identified very early on in the initial review process or may emerge as the review progresses. A Multi-agency Review is always required:

- Where the assessment of the care received by the person is graded high at a score of 5 or 6 within the 1-6 rating scale.
- When any red flag alerts are indicated in the Initial Review.
- If there have been any concerns raised about the care of the person who has died.

The table below details the number of Multi-agency Reviews held in North Yorkshire and Vale of York CCG.

No of Multi-Agency Review Meetings	Relating to No of Deaths
1	1

SECTION 3 - Accountability & Governance

3.1 Accountability

Whilst the programme is managed by Bristol University on behalf of NHS England, NHSE/I have aligned LeDeR to the national Transforming Care Programme (TCP). The on-going development and progress of LeDeR locally is therefore monitored through North Yorkshire and Yorkshire Transforming Care Partnership Board and the North Yorkshire Mental Health and Learning Disability Partnership Board.

3.2 LeDeR Steering Group

The North Yorkshire and York LeDeR Steering Group has continued to strengthen its membership from across the North Yorkshire TCP footprint. The group provides oversight, support and governance for the local delivery of the programme, operating within the CCG

Constitution and aligning with relevant CCG policies and procedures. The group is an established pathway for exchange of information with the North Yorkshire and Yorkshire Transforming Care Partnership Board and the North Yorkshire Mental Health and Learning Disability Partnership Board.

The group met quarterly. Members include: -

- Director of Quality and Governance North Yorkshire CCG (or representative).
- Commissioning Lead for Mental Health and Learning Disability NY CCG.
- CCG Designated Professional's for Safeguarding Adults representative.
- NHS Provider organisations representatives.
- Director for Public Health, North Yorkshire County Council (or appropriate representative).
- Director for Public Health, City of York Council (or appropriate representative).
- CCG Designated Doctor for the Child Death Overview Panel (corresponding member).
- Child Death Overview Panel representative (corresponding member).
- North Yorkshire Safeguarding Adult Board representative.
- City of York Safeguarding Adult Board representative.
- North Yorkshire Safeguarding Children Partnership representative.
- City of York Safeguarding Children Partnership representative.
- North Yorkshire County Council Assistant Director, Care and Support.
- Service user representative (to be confirmed).
- GP Lead for Learning Disabilities (corresponding member).
- NHS England and Improvement, Health Inequalities Senior Manager -North East Yorkshire and LeDeR Regional Coordinator.
- LeDeR Reviewers may attend with the agreement of the Chair.
- Specialist Practitioner/Local Area Contact.

Terms of reference are agreed and a local information sharing agreement is also in place. (Appendix 1).

- The group continues to review the Government guidance and national directives in relation to Covid-19 and people with a learning disability basis and share out relevant information through already established networks.
- The first local LeDeR Bulletin was presented to the local Steering Group in December 2020 and a further LeDeR Bulletin, published in easy read format, was circulated in February 2021. This is disseminated via the LeDeR Communication Network which includes the Adult Partnership Boards, local Health Providers and the North Yorkshire Health Action Group.
- Data collection captures more information from reviews, steered by the themes and learning found both locally, regionally and nationally. Learning into action continues to be monitored by the local LeDeR Steering Group.
- A quarterly Position Statement setting out the local delivery of the LeDeR program is produced and presented at the LeDeR Steering Group and subsequently submitted to the North Yorkshire and Vale of York's CCGs Quality Assurance Committee, provided to the Learning Disability Integrated Care System (ICS) Transforming Care Partnership Group and Board and the local Safeguarding Boards.

Local Updates

- The Local LeDeR Team still sit in the CCGs Quality structure, however, is now led by the Programme Director of Transformation which has been devolved by the CCGs Chief Nurse.
- Due to an increase in funding from NHS England the post of Specialist Advisor/Local Area Contact continued for a further 2 years which commenced at the beginning of November 2020.

3.3 Quality Assurance (QA) Panel

The system of quality assurance for completed reviews by the weekly CCG LeDeR Quality Assurance Panel has proven to be successful. The process ensures appropriate scrutiny of reviews by the LeDeR Local Area Contact and Director for Transformation. Specialists, including the LeDeR Regional Coordinator are co-opted onto the Panel, as necessary. This enables learning and actions to be agreed and formally recorded. The lessons and actions are then presented to the LeDeR Steering Group.

3.4 Local Reviewers/Conducting Reviews

The Local Area Contact is informed of a new death by the National LeDeR review system. They identify a suitable reviewer(s) to allocate the person for a LeDeR review (Appendix 2).

Recruitment and retention of reviewers has continued to be a challenge and Covid-19 capacity issues has compounded the challenge. As the programme has evolved over the last three years, funding opportunities have arisen through NHSE/I and the Transforming Care Programme and North Yorkshire and Vale of York CCG have been successful in securing funds to employ Reviewers in 2020/21.

The funding has also made it possible for 36 LeDeR reviews to be outsourced. These reviews have been completed to a high standard with quality assurance being provided from both NHSE/I regionally and latterly the Local LeDeR Quality Assurance Panel. This has enabled the targets for reviews to be completed within the NHSE/I timeframe (i.e., allocated within three months of notification and completed within six months of being notified).

SECTION 4 – Findings from Deaths in North Yorkshire and Vale of York CCG

4.1 Deaths Notified to the LeDeR Programme

For the purposes of comparison, any national figures referenced relate to the national LeDeR Annual Report 2019/2020, published in 2020.

In total 55 death notifications were received and 100% of the allocated reviews were completed.

The improvement has been made possible in part due to additional funding awarded by NHSE/I, which has allowed the CCG's to contract with a third party to complete reviews. There has also been a concerted effort by NHS reviewers and the wider team to achieve these targets, this has been an exceptional accomplishment given the existing volume of outstanding reviews coupled with the increased volume of referrals due to the impact of Covid-19.

4.2 Deaths Notified

	Death notifications
Deaths notified in Q1	24 deaths.
Deaths notified in Q2	10 deaths
Deaths notified in Q3	10 deaths
Deaths notified in Q4	11 deaths (1 case cause of death unknown at present)

Of the current active and completed cases, 5 were child deaths (aged 18 or below).

4.3 People's death by Age Group

Information regarding the age of death is of significance to the LeDeR Programme, given that this is a key marker of health inequality. The age range of deaths reported was 4 years – 92 years.

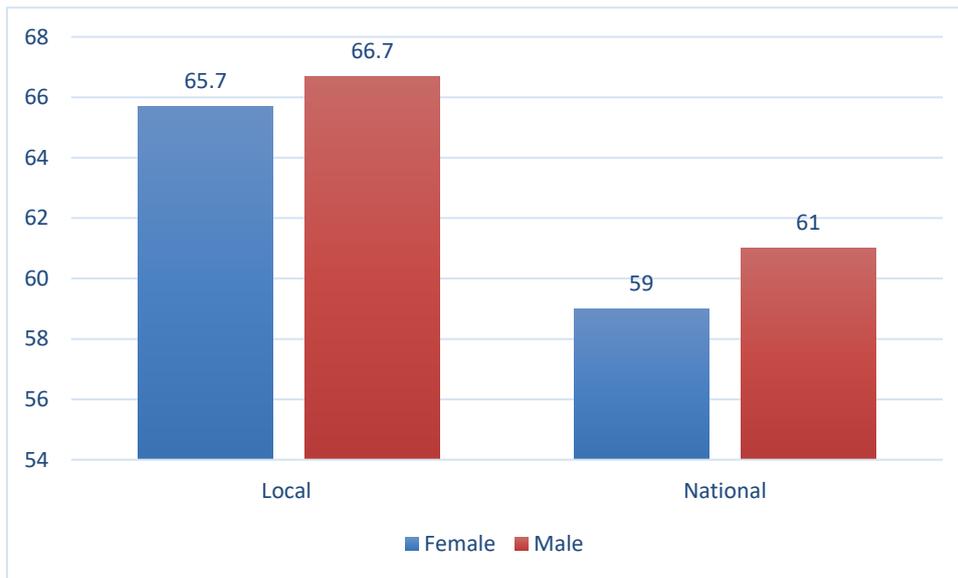
Age at death	2019/2020	2020/2021
4 - 40	16%	6.5%
41 - 60	22%	37%
61 - 95	62%	56.5%

The increase of deaths in the 41- 60 age group was a direct impact of Covid-19.

4.4 People's death by Gender

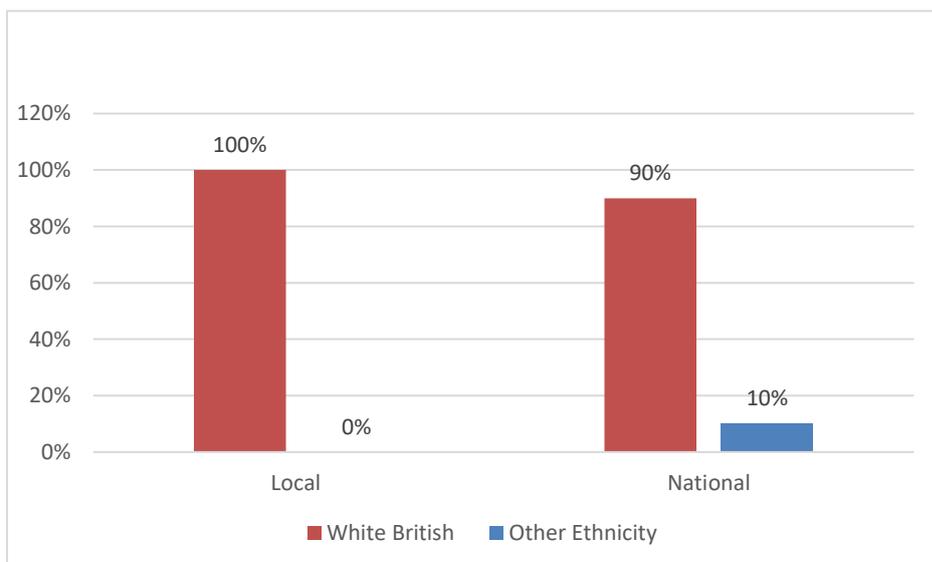
Of the completed reviews, the numbers of male and female deaths were equal. This was a change from last year's figures where male deaths outnumbered female deaths. Nationally, 58% were males.

4.5 People's death by Age



Locally the average age of death for females was 65.7 years and 66.7 for males. The latest national figure was 59 years for females and 61 for males.

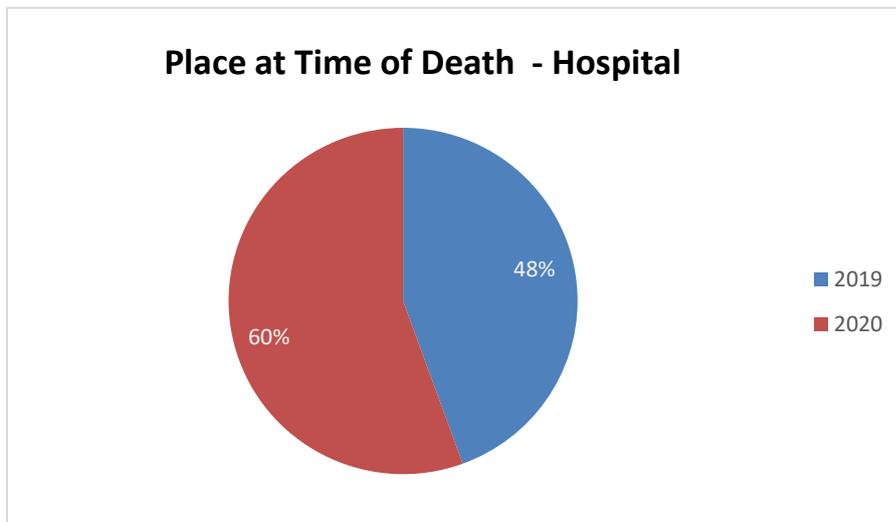
4.6 People's deaths by Ethnicity



The 2019/2020 National Annual LeDeR Report reported that the majority of people who died, 90%, were of White British ethnicity, 10% were from other ethnic groups.

Locally 100% of people were reported as being White British ethnicity.

4.7 Place at Time of Death



In 60% of cases locally, the place of death was in a hospital which compares exactly with the findings from the 2019 National LeDeR Annual Report. Locally this demonstrates an increase of 12% from last year's figure of 48%. Most of the Covid-19 deaths occurred within a hospital setting.

Note: From this point onwards graphs data relates to completed cases only (adults)

4.8 Cause of Death

The cause of death is reported using a completed Medical Certificate of Cause of Death (MCCD).

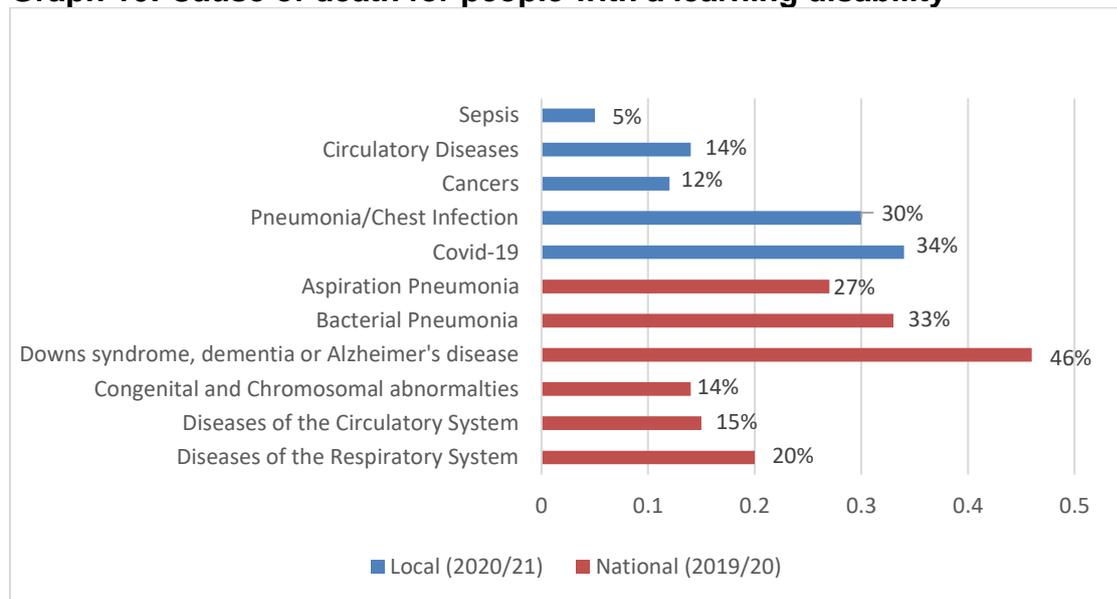
The national figures for 2020/2021 are not yet available to compare. However, in 2019/2020 national figures for people with learning disabilities reported the most frequent causes of death by ICD-10 chapter were diseases of the respiratory system (20%), diseases of the circulatory system (15%) and congenital and chromosomal abnormalities (14%). Other causes of death mentioned in Part 1 of the MCCD for people whose underlying cause of death was attributed to Down's Syndrome, Dementia or Alzheimer's Disease (46%), Bacterial Pneumonia (33%) and Aspiration Pneumonia (27%) (Bristol University 2019).

NB these figures are pre Covid-19 which will have a great bearing on causes of death.

Local causes of death for people with a learning disability (2020/2021)

- 34% of known causes of deaths were attributed to Covid-19
- 30% of known causes of deaths were attributed to Pneumonia/chest infections
- 12% of known causes of deaths were attributed to cancers
- 14% of known causes of deaths were attributed to circulatory diseases
- 5% of known causes of deaths were attributed to Sepsis.
- Other causes of death certified included epilepsy, peritonitis, perforation of the bowel, Alzheimer's Disease and choking.

Graph 10: Cause of death for people with a learning disability



4.9 The use of Antipsychotic Medication

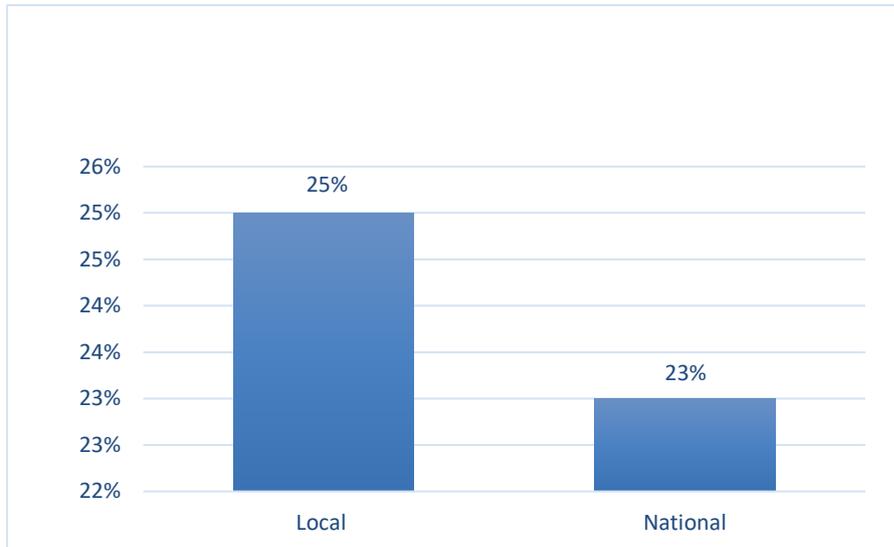
Stopping over medication of people with a learning disability, autism or both (STOMP) is a national project to prevent the overprescribing of psychotropic medicines.

Psychotropic medicines are used to treat psychosis, depression, anxiety, sleep problems and epilepsy. However, they can also be used in people whose behaviour is seen as challenging and presenting a risk to themselves or others. People with a learning disability, autism or both are more likely to be given these medicines than others.

Public Health England reports that every day about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, without a diagnosis of the above specific health conditions. Children and young people are also reported to have been prescribed these medications. Psychotropic medicines can cause a number of side effects and have a negative impact on long-term health. <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp>

There have been several local initiatives to reduce the prescribing of antipsychotic medications under the STOMP/STAMP agenda. These include Webinars for practitioners, connectivity with the Annual Health Check; ensuring medications and alternative therapy/support is available to individuals. Resources for professionals/carers and Advocates in an Easy Read format is available on the CCGS website.

Graph 11: Was the person prescribed an antipsychotic drug?

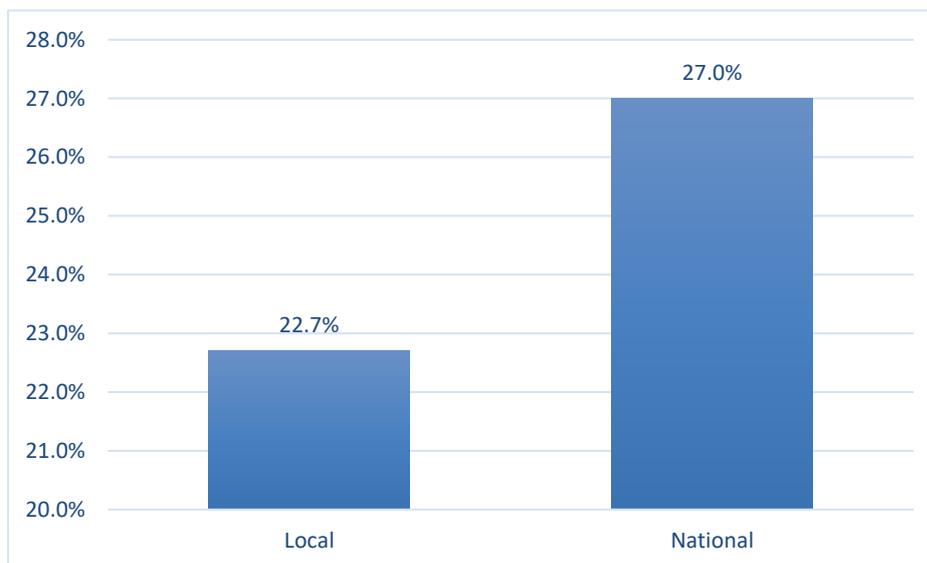


The latest national figure indicated that 23% of cases reviewed were receiving antipsychotics.

Locally the figure was 25%, indicating 2% more than the national figure.

However, this is still a reduction of 7% from last year's local figures.

Graph 12: Was the person prescribed anti-depressants?

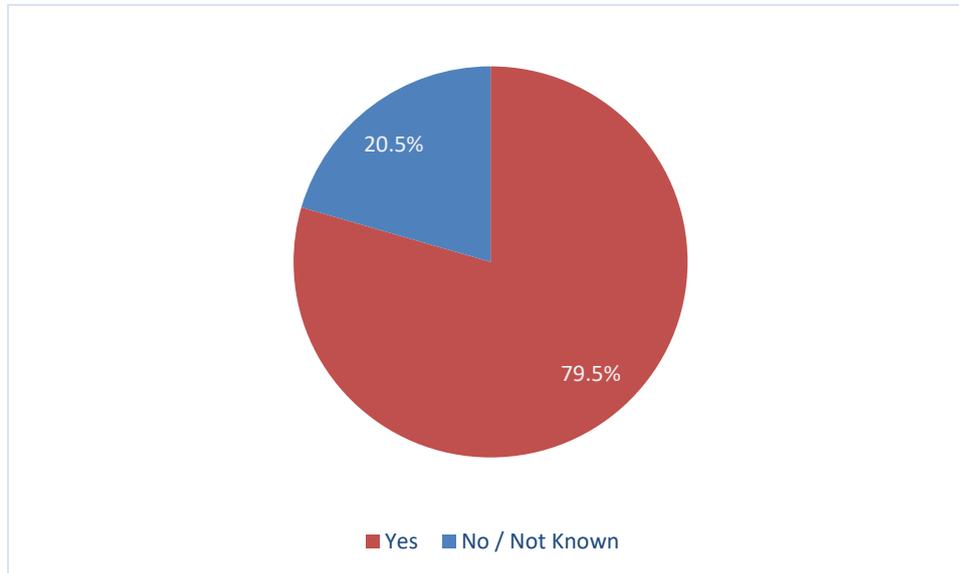


22.7% of the reviews identified the use of antidepressants; in all cases they were judged to have been used appropriately.

The latest national figure was 27%.

4.10 Annual Health Checks

Graph 13: Did the person receive an Annual Health Assessment within the last 12 months?



Of people known to be on GP learning disability registers, 79.5% had received an Annual Health Assessment in the year before their death.

The National Trajectory is set at 60% of people with a learning disability should have a comprehensive physical health check and be offered relevant interventions at least once a year. NHSE/I has published a variety of resources to increase AHC uptake and can be found via <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

Locally work to increase the uptake of Annual Health checks to reach the National Trajectory includes: -

- Use of Care Coordinators and Social Prescribers to target harder to reach groups.
- Increased Health Care Assistant resource.
- Longer appointments and increased administration time.
- Help with attendance including the application of reasonable adjustments.
- Combination of AHC with Covid-19 vaccination.
- Proposed `People First` Roadshows funded by LeDeR to include Annual Health Checks.

Possible digital innovations in the community to be considered include: -

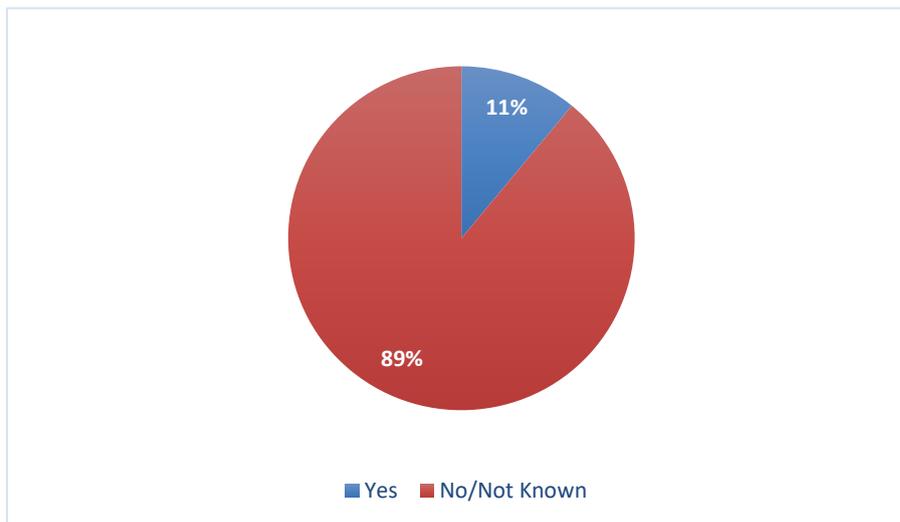
- ✓ To deliver checks in locations where patients are likely to be already such as existing appointments e.g., psychiatrists, clozapine clinics.
- ✓ To gather 'straight forward' data over phone/text/zoom.
- ✓ To investigate remote technology/provide portable equipment so checks can be conducted outside of clinics.
- ✓ To build flex into the system (no strict Did not Attend policies) so patients are catered for who do not feel able to attend on the day of an appointment.

The NHSE/I Learning Disability and Autism Programme DNA/CPR Task and Finish Group members are considering a series of training webinars/roadshows for professionals and people with lived experience delivered by professionals and people with lived experience to explain Annual Health Checks.

4.11 Safeguarding Concerns

It must be acknowledged that people with a Learning Disability are more vulnerable and far less likely to self-report abuse or neglect.

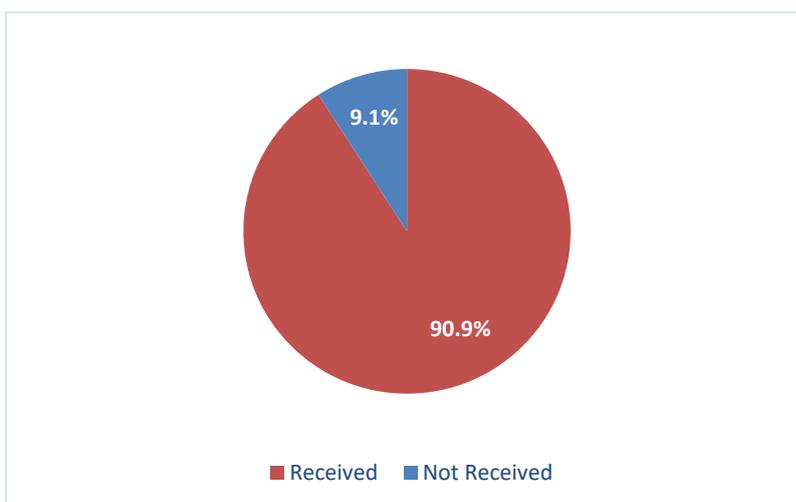
Graph 14: Was the person subject to Significant and/or Continuing Safeguarding Concerns in the Last 12 Months?



11% of the reviews identified that safeguarding concerns had previously been raised.

All Safeguarding enquiries had been reviewed by the Local Authority with appropriate actions being taken.

4.12 Medication reviews - Graph 15: Did the person receive a Medication Review within the last 12 Months?



90.9% of people had received a medication review within the last 12 months prior to their death. This data is interesting in comparison to the completion of Annual Health Checks (79.5%).

It is reasonable to think that these may be completed at the same appointment. Medication Reviews may not have been carried out face-to-face with the patient.

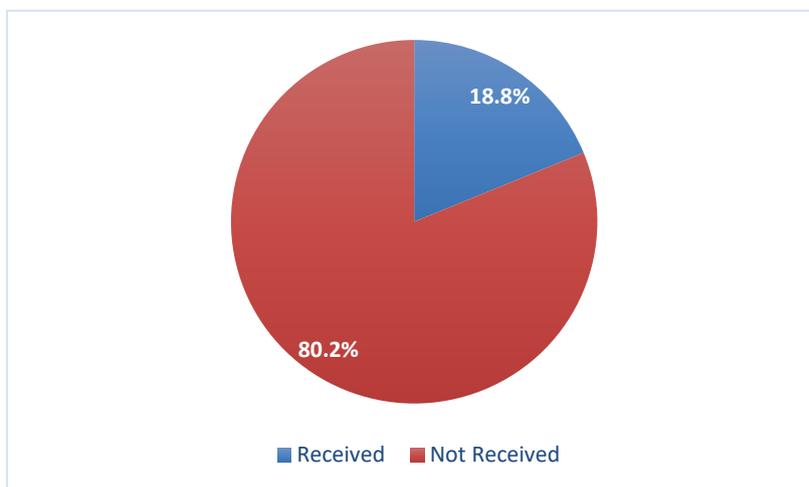
4.13 Generic Screening

People with learning disabilities have poorer health and are more likely to die at a younger age than people in the general population, in part because of poor access to health services. People with learning disabilities are also reported to have a poorer uptake of cancer screenings compared to the general population. The Equality Act 2010 states that you must make reasonable adjustments for people with a learning disability to have equal access to healthcare.

For example, some reviews found that there was a lack of reasonable adjustments on the use of standard invitation letters as well as recording of non-attendances, without consideration of the need for people to be supported to attend appointments.

Concerningly many reviews found a lack of reasoning as to why a person had not participated in the National Bowel Screening Programme.

Graph 16: Did the person receive generic screening in the last 12 months?



18.8% of people eligible had received generic cancer screening. In some cases, for example breast and cervical cytology, there was some evidence in the patients records that a decision was taken that it was not in the patient's best interests to perform the screening. However, in some cases the correct documentation regarding this was lacking.

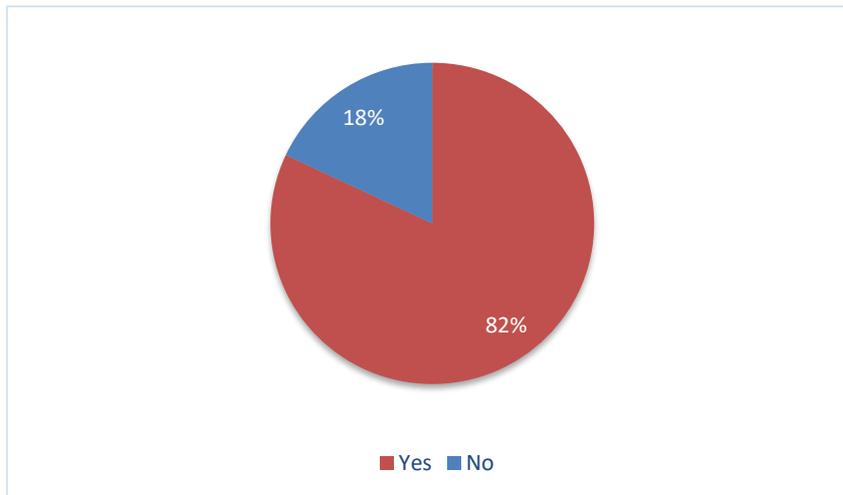
A guidance and resource pack has been developed by partners for care providers to support people to access health screening http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf

4.14 Family Involvement in the Review

Involving families in the review process is an important part of the work of the local reviewer. Families (or in the event of no family involvement, someone who knew the person well) are encouraged and supported to be involved in the review process as much as they feel able or want to be involved.

Contacting and involving families is undertaken in a timely, sensitive and respectful way, however, being sensitive to their needs may result in reviews commencing later when they feel better able to engage in the process.

Graph 17: Was there Family Involvement in the Review?



There was family involvement in 82% of reviews, 18% declined to take part in the process.

4.15 End of Life Pathway

In accordance with NHS England's End of Life Programme persons receiving end of life care are afforded the opportunity of having choice, with more supported planning around the place where they are looked after at the end of their life.

Within the LeDeR review there is a requirement to understand if end of life care planning was in place for those where death was expected. This was the case for 54.5 % of local reviews. To put this figure in context, some deaths were unexpected, therefore the chance to plan for end of life was not appropriate. Reviews found examples of timely involvement of the Palliative Care Teams.

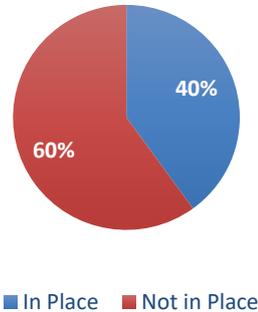
One local initiative by the Learning Disabilities service has implemented 'My future wishes' list that helps professionals and carers discuss with someone with a learning disability what they wish to happen at the end of their lives in appropriate situations.

Graph 16: Did the person have a Do Not Attempt Cardio Resuscitation (DNACPR) in place at time of death?

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life. <https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/>

Therefore, there is not an expectation that 100% of reviews should identify DNACPRs.

Did the person have a DNACPR in place at time of death?



The review identifies if a Do Not Attempt Cardiopulmonary Resuscitation order was in place or not. 40% (22) had completed DNACPRs.

Reviewers felt that the majority of these were appropriate, correctly completed and followed following the ReSPECT Agenda (2).

It was concerning that one review revealed that Downs Syndrome was indicated as a reason for a DNACPR decision. In May 2019 Professor Stephen Powis, National Medical Director sent a letter to Senior Clinicians reminding them that terms such as Learning Disability and Downs Syndrome should never be used as a reason for issuing a DNACPR (3). As per LeDeR process this learning was shared with the individual as well as locally via the local Steering Group.

4.16 Reasonable Adjustments

Under the requirements of the Equality Act 2010, organisations have a duty to make reasonable adjustments if someone is at a disadvantage due to their disability. This means by law healthcare providers must make reasonable adjustments to ensure that people with a learning disability have equal access to health services.

Reviews identified many examples of reasonable adjustments including:

- ✓ End of clinic appointments when departments were less busy.
- ✓ Double appointments, enabling clinicians to spend more time with the patient.
- ✓ Relatives or carers attending appointments with patient.
- ✓ Nursed in a side ward whilst in hospital by carers that they knew.
- ✓ Easy Read health information.
- ✓ 1 to 1 continuous care whilst in hospital.

5. SECTION – QUALITY OF CARE PROVIDED

5.1 Quality of Care

At the end of a review, having considered all the information available to them, reviewers are asked to provide an overall assessment of the care provided to the individual and provide a grade. The table below shows the grading of care and the LeDeR reviewers' overall assessment of the care received:

Not all reviews generate learning, with a significant number of reviews demonstrating good care throughout the life, and end of life, of the individual.

Table 5.2: Grading/Quality of Care

Grading/Quality of Care (completed cases)			
Grading of Care in Adult Cases		Number of Reviews	%
1 =	This was excellent care (it exceeded expected good practice)	6	13.6
2 =	This was good care (it met expected good practice)	16	36.3
3 =	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the persons wellbeing)	16	36.3
4 =	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to cause of death	2	4.5
5 =	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death	3	6.8
6 =	Care fell short of expected good practice and this contributed to the cause of death	0	0

NB Child deaths do not receive a grading of care.

Everyone should expect to receive care that meets good practice, this was the case for 86.2% of local Reviews.

However, it is important to note that 6.8 % fell short of satisfactory practice. Where the care fell short of satisfactory practice 14% were deemed to have an adverse effect on the individual, although care did not directly contribute to the cause of death. The lessons learned from this feedback have formed part of the Action Plan for 2020/21.

The LeDeR Quality Review Panel noted areas of good practice including:

- ✓ Flagging of hospital records.
- ✓ Support whilst an inpatient from the Hospital Learning Disability Nurse.
- ✓ Relatives or carers attending appointments with patient.
- ✓ Easy Read health information.
- ✓ Nursed in a side ward whilst in hospital by carers that they knew.
- ✓ Early referral to the Palliative Care Team.
- ✓ Smooth transition from assisted living to a nursing home by the Community Learning Disability Team.
- ✓ End of clinic appointments. Double appointments.
- ✓ Emergency Admission to Hospital packs.
- ✓ Hospital Passport.
- ✓ 1 to 1 continuous care whilst in hospital.

The LeDeR Quality Review Panel noted areas where practice fell short of expected good practice including:

- Failure to identify Covid 19 infections early enough to prevent spread amongst residents and staff (very early in first Pandemic wave).
- Lack of provision of healthy living management /advice including weight management in clinically obese patients.
- Poor discharge planning in complex cases.
- Lack of early identification of the deteriorating patient.
- Lack of Annual Health Checks (AHC).
- Lack of Person-Centred Care.
- Lack of application and documentation of the Mental Capacity Act (MCA).
- Routine cancer screening not offered or followed up when not attended.

6. SECTION – DEATHS OF CHILDREN

6.1 Child Deaths Overview Panel (CDOP)

Local Safeguarding Children Partnerships are required to review the deaths of all children who normally reside in their area. The regulations are outlined in Working Together to Safeguard Children and the CDOP statutory and operational guidance. Closer working relationships between local LeDeR processes and the CDOP have been established. Any learning is shared through the LeDeR programme network in the usual way

The purpose of the Child Death Review Process is to collect and analyse information about the death of each child who normally resides in North Yorkshire and Vale of York CCG with a view to identifying any matters of concern or risk factors affecting the health, safety or welfare of children, or any wider public health concerns. There are a number of national programmes which centre on the review of deaths or particular types of child death including the LeDeR process. As such, CDOPs are advised to complete the child death review process rather than the LeDeR review.

Where the child had a learning disability and comes under the remit of the LeDeR programme the completed child death report is then uploaded to the LeDeR system and effectively forms the LeDeR review.

During the review period 5 cases were notified to the LeDeR platform, which related to the death of a child with learning disabilities. Due to the small number of cases, specific demographic data has been withheld to prevent inadvertent identification of the individuals.

7. LEARNING INTO ACTION

Undertaking a review of a death, in itself, is helpful, but it is the lessons learned from a review that are vital in sharing best practice and making recommendations as to how services could improve to prevent health inequalities.

Local learning themes are shared with the Steering Group members and also contribute to the NHS Long-Term Plan, through the prevention and health inequalities agenda. Individual Steering Group partners will take relevant learning back into their organisations to address recommendations and is responsible for ensuring learning identified is acted upon in its area. The CCG records all evidence of learning into action from reviews.

A summary of common themes is detailed below:

LEARNING INTO ACTION

Learning theme
Lack of Annual Health Checks (AHC)
Summary
<p>Annual Physical Health Checks (including the resulting interventions and follow up activity) are a key way to manage comorbidities, reduce unnecessary hospitalisations, promote health positively and reduce premature mortality. The NHS Long Term Plan includes priorities to increase the number of people receiving physical health checks for people living with severe mental illness and learning disability, and for across the NHS, to do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives, and that physical health checks will also be introduced for autistic people.</p> <p>GP Surgeries have been advised by NHSE/I that there is a national expectation that Learning Disability and Severe Mental Illness annual physical health checks should still be completed during this time of COVID-19. However, completing AHCs in primary care is undoubtedly a challenging ask due to current pressures.</p> <p>The better use of Health Passports will improve information exchange between services. This will ensure guidance on person centred care goes with the individual across their care pathways</p>
Recommendations from reviews
<ul style="list-style-type: none"> • CCG training sessions for Primary Care staff to improve the Annual Health Check uptake. • Prompts on systems to ask whether someone has had an Annual Health Check • AHCs along with Covid 19/Influenza vaccinations

Learning theme
Lack of Person-Centred Care
Summary
<p>It was clear from reviews that Hospital Passports are used when provided to wards. However, these were not always provided on admission and/or were not updated. (It should also be noted that a Hospital Passport is not compulsory and therefore has to be agreed with if possible, with the person involved).</p>

Recommendations from reviews

- The promotion of Hospital Passports shared through local partners and their respective bulletins.
- Hospital Passports to be provided on admission and/or were not updated.
- The use of social stories and more specific tailored information to support access to healthcare.
- Banks of easy read leaflets available for staff to access.
- The use of Pictocom communication books, also available electronically.
- Invites to carers to continue safely accompanying a person through hospital admission throughout the Covid-19 pandemic.
- Offering pre-op visits to meet staff and understand what will happen in theatre
- Prompts to offer a Hospital Passport included in the inpatient admission initial assessments.
- Hospital Passports which identify ‘most appropriate’ person to be consulted and an opportunity to provide two further key people.
- Prompt letters from services to GP Practices to add people to LD registers and offer Annual Health Checks.

Learning Theme

Lack of application and documentation of the Mental Capacity Act (MCA)

Summary

A common theme across all mainstream services is the need for increasing the confidence and competency in working with people and their families in relation to the application of the Mental Capacity Act (MCA). The MCA is not consistently being applied in a way that supports and protects the rights of individuals. There is not always evidence of how capacity is being assessed and how a “Best Interests” decision is being made. The phrase ‘Best Interests’ sometimes appears to be used as a clinical shorthand, possibly for an arbitrary decision, rather than indicating a specific process undertaken within the framework of the MCA with associated record of this in the care notes. In other instances, expressed wishes and feelings appear to be being equated with capacity.

There is room to make much better use of Independent Mental Capacity Advocates (IMCA) as an independent voice for people with learning disabilities, particularly when in hospital.

Several Reviews found instances where no evidence of Mental Capacity Assessments took place, particularly where there was poor concordance with health interventions.

Recommendations from reviews

- Local services strengthen their governance in relation to adherence to the MCA and provide training and audit of compliance on the ground so that professionals fully appreciate the requirements of the Act in relation to their own role.
- Development of electronic Capacity Assessment and Best Interest forms in Acute Trusts.
- Development of electronic Best Interests forms which prompt consultation with key people, including Advocates.

Learning Theme

Lack of the early identification of the deteriorating patient

Summary

Several reviews have found problems with timely and appropriate responses related to changes in presentation and need. There is evidence of missed opportunities for escalation leading to poor outcomes in all settings including hospital; nursing and residential homes; and people's own homes. Contributory factors include the person being unable to communicate their discomfort due to communication impairment or opportunities to communicate; lack of consideration of capacity and best interests when the person has 'declined' interventions; and diagnostic overshadowing.

Recommendations from reviews

- The consistent application of NICE Guidance 51: Sepsis: recognition, diagnosis and early management by health professionals
- The promotion of the CCGs Simons Story presentation that raises the awareness of Sepsis for Advocates and Self Advocates

Learning Theme

Lack of provision of healthy living strategies/advice including weight management.

Summary from reviews

Several reviews identified that although a high Body Mass Index (BMI) had been identified, particularly within Primary Care, there was no interventions discussed or recommended.

Recommendations
<ul style="list-style-type: none"> • NICE Guidance 53: Weight management: lifestyle services for overweight or obese adults should be followed on identification of a BMI of over 25. • Banks of easy read leaflets/aides available for staff to access.
Learning Theme
Routine cancer screening not offered or followed up when not attended.
Summary
<p>Routine cancer screening saves lives by detecting cancers at an early stage.</p> <p>Several reviews found that such screening was either not offered or not followed up when someone did not attend. As stated earlier, some reviews found that there was a lack of reasonable adjustments on the use of standard invitation letters as well as recording of non-attendances, without consideration of the need for people to be supported to attend appointments. However, bowel cancer screening in particular was found to be very poor in uptake, even though it is a non-invasive process often relying on a carer to acquire the stool specimen for testing. Reviews indicated that non-compliance was not followed up by the GP Practice.</p>
Recommendations from reviews
<ul style="list-style-type: none"> • The use, when appropriate of reasonable adjustments on the use of standard invitation letters; recording of non-attendances (e.g., did not attend) without consideration of the need for people to be supported to attend appointments. • Clear documentation of the use of the Mental Capacity Act if it is in the patient's best interests not to be offered cancer screening. • GPs to have/use an effective system in place to follow up non-compliance.

8. Future Priorities

Following the implementation of the new LeDeR Policy CCGS are required to produce a 3-year LeDeR Strategy that will demonstrate how the ICS Care System will act strategically to tackle those areas identified in aggregated and systematic analysis of LeDeR reviews and national findings. The Strategy will be shared with NHS England and NHS Improvement's Regional Team and updated annually in June each year. The document will be localised via the Local LeDeR Steering Group.

9. Acknowledgements

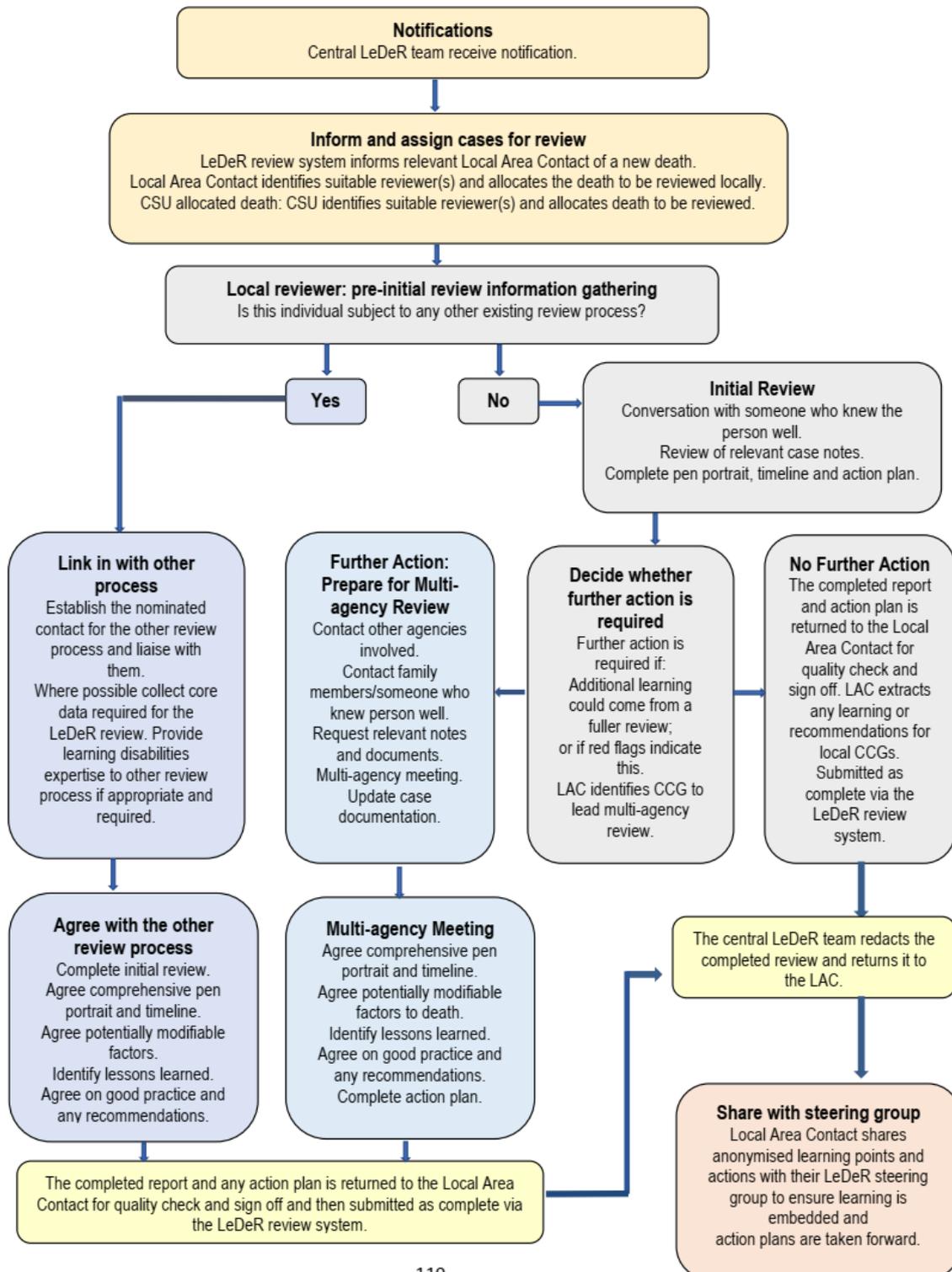
The data presented in this report represents individuals who were loved and supported by their families, friends and carers. On behalf of the CCGs, the local LeDeR team would like to pass on sincere condolences to those who are bereaved and also express grateful thanks for the contributions they have made to helping us make improvements in our services to support the lives of others.

10. References

1. Deaths of People identified as having learning disabilities with Covid 19 in England in the Spring of 2020. Public Health England.
2. <https://www.resus.org.uk/respect>
3. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/CO/60-letter-DNACPR.pdf>.

11. Appendices

Appendix 1: The LeDeR Review Process



NORTH YORKSHIRE AND YORK CCG'S
LEARNING DISABILITIES MORTALITY REVIEW STEERING GROUP
TERMS OF REFERENCE

The Steering Group has been formed to ensure the LeDeR process is implemented and embedded across the North Yorkshire and York Clinical Commissioning Groups (CCG's). The Steering Group adheres to the guidance provided by NHS England and Improvement.

The Steering Group will operate within the North Yorkshire and York CCGs Constitution and will at all times comply with the relevant CCGs policies and procedures. The Long-Term Plan sets out how the NHS will strengthen its contribution to prevention and health inequalities. This includes accelerating the Learning Disability Mortality Review (LeDeR) Programme to identify common themes and learning points and provide targeted support to local areas. The Long-Term Plan also states that the whole NHS will work together to improve the health and wellbeing of people with a learning disability.

The aim of the LeDeR programme is to drive improvement in the quality of health and social care service delivery for people with learning disabilities. It identifies the causes of premature mortality in this population, through case review. These findings support health and social care professionals and Policy makers to identify key recommendations for improvement. NHS England and Improvement publishes action from learning, in an annual report and via NHS Futures, to support local teams to make a difference to the health and wellbeing of people with a learning disability in their areas. Each CCG is a member of a LeDeR Steering Group, which is responsible for ensuring learning is identified and acted upon in its area.

MEMBERSHIP

Membership of the steering group is determined and approved by the Chairperson.

Membership will comprise of:

- Director of Quality and Governance North Yorkshire CCG (or representative)
- Commissioning Lead for Mental Health and Learning Disability NY CCG.
- CCG Designated Professional's for Safeguarding Adults representative.
- NHS Provider organisations representatives
- Director for Public Health, North Yorkshire County Council (or appropriate representative)
- Director for Public Health, City of York Council. (Or appropriate representative)
- CCG Designated Doctor for the Child Death Overview Panel (corresponding member)
- Child Death Overview Panel representative (corresponding member)
- North Yorkshire Safeguarding Adult Board representative.
- City of York Safeguarding Adult Board representative.
- North Yorkshire Safeguarding Children Partnership representative
- City of York Safeguarding Children Partnership representative.
- North Yorkshire County Council Assistant Director, Care and Support

- Service user representative (to be confirmed).
- GP lead for Learning Disabilities (Corresponding member).
- NHS England and Improvement, Health Inequalities Senior Manager -NEY & Leder Regional Coordinator)LeDeR Reviewers may attend with the agreement of the Chair.
- Yorkshire Ambulance Service representative
- Specialist Practitioner/Local Area Contact

Other members may be co-opted into the meeting as required.

Role of Members

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

- Partners work together to support the success of the programme and make sure that no single interest will undermine the programme.
- All members are equally valued and supported effectively to contribute. This includes compensating for their time and travel costs for participating in the work of the Steering Group, unless they decline such compensation.
- 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 Contacts.
- The progress of the overall programme is monitored, and any remediable action is undertaken.
- Representatives will be responsible for providing feedback via their respective organisational networks.
- 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.

- 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.

ATTENDANCE AND QUORACY

The meeting will be quorate if 3 members attend from separate agencies including the Chair. Members will demonstrate a commitment to attend meetings and ensure completion of allocated work within the agreed timescales. If a quorum has not been reached, then the meeting may proceed if those attending agree but any record of the meeting should be clearly indicated as notes rather than formal minutes, and no decisions may be taken by the non-quorate meeting of the steering group.

DECISION MAKING

The steering group is not a decision-making body. The Chair of the meeting has responsibility for deciding whether there is a conflict of interest and the appropriate course of corresponding action.

AIMS & OBJECTIVES

The main aims of the steering group are to:

- Ensure local learning is acknowledged, shared appropriately with key stakeholders, and acted upon if appropriate.
- Ensure local reporting of deaths to the LeDeR programme.
- Work with a multi-disciplinary approach in mind and communicate effectively across the health and social care economy.
- Ensure system wide learning by sharing good practice as well as supporting and implementing identified improvements.
- Ensure the effective steering of the LeDeR programme across North Yorkshire and York. Develop the LeDeR Programme across North Yorkshire and York.
- To receive regular updates from the Local Area Contact about the progress and findings of reviews.
- To ensure that any learning, recommendation and actions arising from reviews of deaths is acted upon, as appropriate, using locally agreed governance structures and in collaboration with local stakeholders and commissioners.

- To ensure plans for action from learning are applied using Annual Health Checks and consequential health action plans for each person, medication reviews for individuals, applying the Learning Disability Improvement Standards and ensuring reasonable adjustments are made to local pathways in line with the needs of individuals.
- To work in partnership with the CCG lead responsible for LeDeR (in most cases it will be the Local Area Contact):
 - To support the initial review of all deaths of people with learning disabilities (aged 4 years and over) in their area as per agreed process.
 - 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 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 to enhance local understanding of learning points and recommendations

CONFIDENTIALITY

Due to the complex and multi-agency nature of the reviews it is important that information sharing is in line with expectations regarding confidentiality and the appropriate use of received information. Stakeholders across all care sectors need to work together positively to enable open information sharing for the purpose of achieving good quality reviews, in accordance with the Information Sharing Agreement.

All reviews presented will be anonymised.

MANAGEMENT AND REPORTING

Assurance will be provided that all known deaths of people with learning disabilities receive a review of the circumstances leading to death as indicated by the LeDeR methodology.

Representation on the North Yorkshire and York LeDeR Steering Group from the Local Safeguarding Children's Board and Local Safeguarding Adult's Board ensures local and national learning regarding deaths where a person has a defined Learning Disability, is shared and acted upon within the multi-agency arena.

The Child Death Overview Panel will share their completed Form C review document with the LeDeR programme in North Yorkshire and York in place of a LeDeR review, and if safeguarding is a feature these will be escalated to the Local Safeguarding Children's Boards relevant sub groups;

Completed adult LeDeR Reviews where safeguarding is a feature will be shared with the relevant Local Safeguarding Adult's Board Review subgroups.

The North Yorkshire and York LeDeR Steering Group will provide the minutes of the meetings to a representative of the North Yorkshire Transforming Care Partnership to provide assurance; any outstanding issues will be escalated to the North Yorkshire Transforming Care Partnership by exception. The North Yorkshire Transforming Care Partnership will share

The minutes and papers from this meeting will not be routinely made available to the public and will not be included in the CCGs Publication Scheme. Any formal request for the minutes and papers from this meeting will, however be carefully considered under the Freedom of Information Act 2000.

- The Steering Group is accountable to the local Transforming Care Partnership Board.
- The Steering Group reports to the ICS Partnership Board
- The Steering group reports via the Local Area Contact to the local Health Task Group.
- The LeDeR Steering Group reports on a quarterly basis to the Yorkshire and Humber Executive Steering Group.
- The process for selecting members is transparent.
- Terms of Reference will be reviewed in 12 months.

ADMINISTRATION

Administration for meetings will be undertaken by a personal assistant from the CCG. The secretary of the steering group shall be a person approved by the group as having the requisite knowledge and experience, and will be responsible for:

- Supporting the Chair in the management of the Steering Group's business (including setting the Agenda, collation of papers and highlighting conflicts of interest);
- Maintaining a record of matters arising, issues to be carried forward and minutes of the meetings.
- Maintaining an attendance register.
- Electronic papers for the steering group will, where possible, will be issued one week ahead of the meeting.

FREQUENCY

The Steering Group will meet quarterly.

