**Learning from lives and deaths – ‘People with a learning disability and autistic people’ (LeDeR)**

**Annual Report**

**1st April 2024 to 31st March 2025**

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## Executive Summary

This report is the fourth "Learning from lives and deaths; people with a Learning Disability and Autistic people" (LeDeR) annual report written for NHS Humber and North Yorkshire Integrated Care Board (ICB), on behalf of the following 6 places

* North Yorkshire (NY)
* York (Y)
* North Lincolnshire (NL)
* Northeast Lincolnshire (NEL)
* Hull (Hu)
* East Riding (ER)

A total of **111** (learning disability) deaths were notified to the LeDeR programme from across the six Places within the Humber and North Yorkshire Health and Care Partnership between the 1st April 2024 and the 31st March 2025 (119 deaths reported within the 2023/2024 ICB annual report).

During the time-period of this report; 1st April 2024 – 31st March 2025, **110** LeDeR reviews were completed across the six Places. The completed reviews section in this report relate to people who died between 2022 and 2024. Some reviews can take some time to complete due to statutory processes.

Conditions and diseases of the respiratory system remain the most common cause of death across all places. Aspiration and aspiration pneumonia remain the most common conditions within this category. Cancer and conditions and diseases of the cardiac system are the next most common conditions linked to cause of death. These findings are consistent with the general population.

This report has explored the severity of a person's learning disability to consider if this is a factor in premature mortality with no significant health inequalities identified.

There have been some place variations linked to age and gender this year. Of note, North and Northeast Lincolnshire have shown a higher proportion of men dying and a lower average age of death in this area. However, caution must be made interpreting this data, both due to the lower number of notifications in this locality and the unknown number of people living with a learning disability in this area.

Learning and themes identified within the closed reviews include the following

* Mental capacity and best interest processes
* Experience at end of life
* Management of long-term conditions
* Annual Health Check
* Fundamentals of care in acute care.

**Five** reviews were referred on for a Safeguarding Adults Review.

A large proportion of reviews found elements of good care, above what would be expected practice. Of note, the report found many examples of individuals living in long term placements with carers who knew and supported them well and accessing a wide range of social interaction and activity was a feature.

Involvement from the learning disability teams in acute care made a positive impact in care, experience, and outcome.

Some of the recommendations for 2025/2026 will include:

* Discretionary locally agreed focused reviews where Aspiration and Aspiration Pneumonia feature anywhere on Part 1 of the death certificate
* Linking with medical examiners to ensure all notifications are received, specifically for those with a diagnosis of Autism only and those from minority ethnic groups.

Humber and North Yorkshire ICB Steering Group has developed a health improvement plan which has identified 6 initial priority areas. These are outlined in the Recommendations section of the report.

## The LeDeR Process; Introduction and Background

The Learning from lives and deaths - ‘People with a learning disability and autistic people’ (LeDeR), was established in 2016. The main aims are to reduce health inequalities and prevent premature mortality.

In March 2021, NHS England published their first LeDeR policy, "Learning from lives and deaths - People with a Learning Disability and Autistic people" (LeDeR). This policy set out, for the first time, the core aims, values and the expectations of different parts of the health and social care system in delivering the programme.

The policy introduced the inclusion of diagnosed Autism into the programme from January 2022.

The policy can be found at: [www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/](http://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/) .

The focus of this policy is a stronger emphasis on delivery of the actions from completed reviews and holding local systems to account for delivery, to ensure evidence of local service improvement. NHS England regional teams will hold Integrated Care Systems (ICS’s) to account, for the delivery of the actions identified from completed reviews with quarterly reports required on progress made.

LeDeR reviews continue to be cognisant of other review processes such as Safeguarding Adult Reviews (SARs) and the Patient Safety Incident Response Framework 2022 (formerly the NHSE Serious Incident Framework 2015) to avoid duplication wherever possible.

*To note: the death of an individual with a learning disability does not automatically trigger a safeguarding response. However, at any point through the LeDeR review process, if safeguarding concerns are identified, the local area safeguarding process is followed.*

The Child Death Review (CDR) process is now the primary review process for a child with a learning disability. From July 2023, child deaths were removed from the LeDeR process.

## Governance Arrangements

In 2024/2025 the Humber and North Yorkshire ICB implemented an organisational restructure, dedicating additional resource to support the LeDeR programme and a clearer governance structure. Despite changes in the organisation design the Director of Nursing continues as remains the Senior Responsible Officer for the Humber and North Yorkshire ICB LeDeR programme, with an identified Local Area Contact.

Quarterly returns, as required by NHS England, are submitted by the ICB. These returns identify the learning and progress against actions from completed reviews alongside updates on other areas of work.

## LeDeR Panel

Humber and North Yorkshire ICB continue to hold one LeDeR panel meeting for sharing of the learning from completed initial reviews and for discussion and approval of the completed Focused reviews across all 6 places within the ICB. This combined approach has demonstrated a commitment to shared learning and reduction of duplication.

The learning and good practice from the reviews is shared with system partners via a Quarterly Professionals newsletter.

An Easy Read version of this newsletter is also produced and disseminated.

## LeDeR Steering Group

The Humber and North Yorkshire ICB Steering Group provides oversight, support, and governance for the local delivery of the LeDeR programme, with membership from across the respective ICB footprint, reporting directly to the Humber and North Yorkshire Health and Care Partnership Learning Disability and Autism Programme Delivery and Oversight Board.

A workplan has been developed by the Steering Group, which will focus on key areas such as Healthy lifestyles, cancer, respiratory health and screening and immunisations. Collaborative working will be a keystone to improving health outcomes.

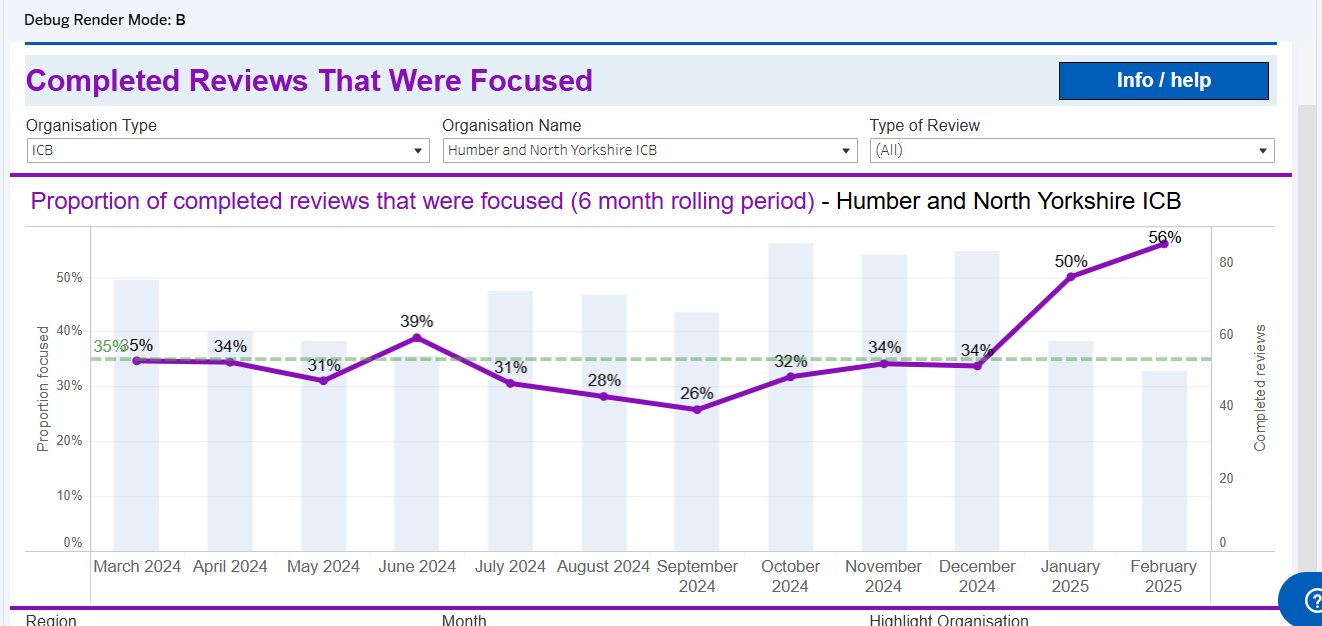
## Key Performance Indicators

In line with national policy and performance indicators, established by NHS England, Humber and North Yorkshire ICB is monitored by NHS England against two key indicators.

**NHSE Key Performance Indicator 1**:

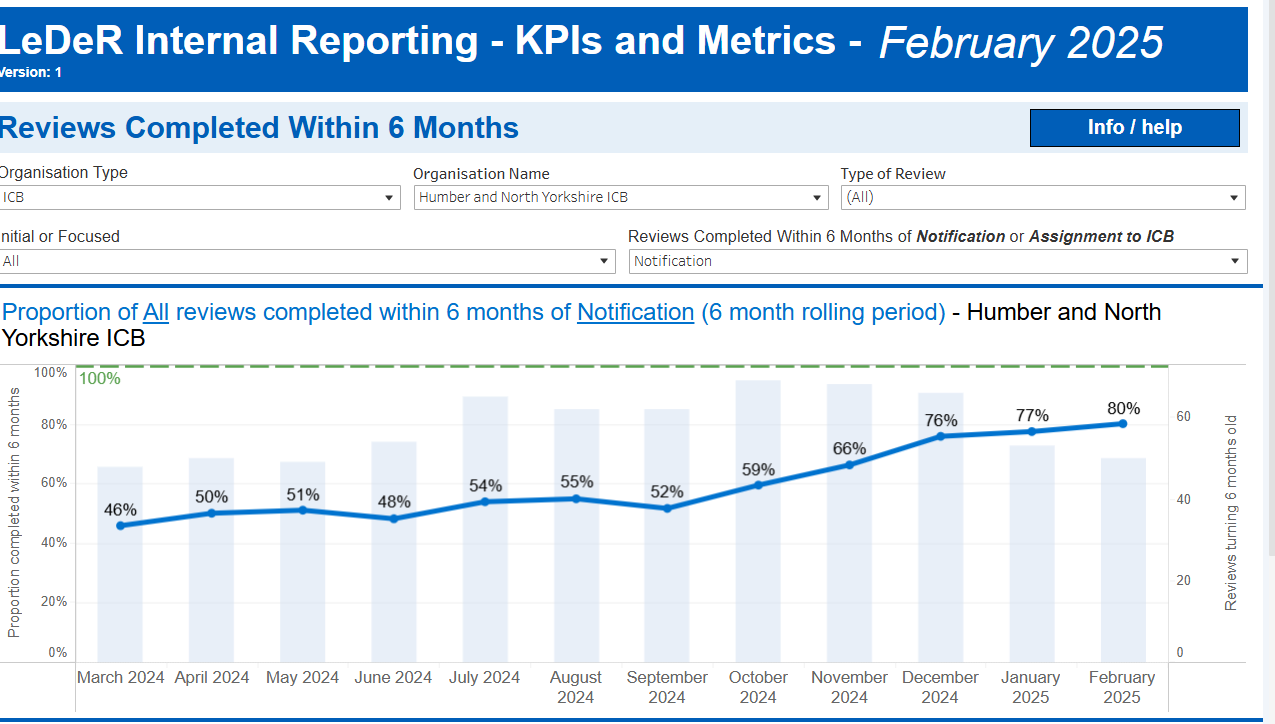
A minimum of 35% of all reviews should progress to a Focused Review. This is a more in-depth review and provides a grading of care and services.

A recommendation was made in 2024/25 for Humber and North Yorkshire to include all cardiac and cancer related deaths (as specified in Part 1a of the death certificate) for a locally agreed inclusion for Focused Review.



**Humber and North Yorkshire ICB are rated the 6th best performing ICB in England for progressing reviews to a Focused review. This is likely a result of including all cancer and cardiac deaths locally for an automatic Focused review.**

**NHSE Key Performance Indicator 2:** All reviews should be completed within a 6-month deadline from the date of notification. For reviews which are placed on hold, due to statutory processes, the duration of their hold time is not included in the six-month time frame from the date of notification enabling the review to be completed when all relevant information is available.



**Our performance demonstrates 80% of all reviews being completed within at 6-month timeframe.**

**This means Humber and North Yorkshire ICB are placed 9th in England.**

We finish Quarter 4 in an excellent position having cleared the backlog of overdue cases across the ICB footprint.

## SECTION 1 – NOTIFICATIONS TO LEDER

## 1.1 Number of notifications received 1st April 2024 to 31st March 2025

Notifications to the LeDeR platform provide minimal information only. This includes age at death, gender, date of death, place of death and ethnicity. At the point of notification, we do not yet have access to an individual's cause of death or where the person usually resided (e.g. care home versus supported living for example).

The following analysis is based on this basic demographic data and provides us with some initial steer for the following year and place specific information to inform locally agreed Focused criteria and workstreams for the next financial year.

There were **111** notifications into the LeDeR programme across Humber and North Yorkshire between 1st April 2024 and 31st March 2025. This figure does not include Autism only notifications – see Autism section of the report.

Noted last year, the numbers of notifications for the deaths of Autistic people remained very low. To protect anonymity and ensure statistical significance, this data is not included in the 24/25 Report analysis.

In the year 23/24 there were **116** notifications made indicating a slight reduction in the number of individuals reported into the programme.

The table below shows notifications made, by ICB place. North Yorkshire place continues to make the highest number of notifications. North Yorkshire has the largest population size of all 6 places within the ICB footprint.

It is important to note that there is the likelihood that notifications are missed following the death of a person with a learning disability or Autistic person. Most notifications come from hospitals where there are good processes in place to ensure a notification is made following the death of a person on the learning disability register. Work continues, to raise the profile of LeDeR to encourage all deaths to be notified.

Humber and North Yorkshire continue to have minimal numbers of notifications from ethnic minority populations. Analysis of ethnicity populations within the learning disability population has been attempted. However, coding of ethnicity in primary and secondary care remains variable and inconsistent.

**RECOMMENDATION:** **To develop a strategy to work with medical examiners to ensure all individuals with a learning disability and autistic people are included into the programme. Furthermore, to share findings from completed reviews with coronial teams.**

## 1.2 Age breakdown

The average age at death for notifications made into LeDeR between 1st April 2024 and 31st March 2025 was **60.4** years old.

The overall average age of death has remained consistent across the previous 3 years.

LeDeR report 2022/2023 – average age of death was **60.1** years old

LeDeR report 2023 / 2024 – average age of death was **61.5** years old

LeDeR report 2024 / 2025 – average age of death was **60.4** years old

**Average age at death per place**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Age range** | **NY** | **Y** | **Hu** | **NEL** | **NL** | **ER** |
| **20-29** | 3 | --- | --- | --- | 3 | 1 |
| **30-39** | 3 | 1 | --- | 1 | --- | --- |
| **40-49** | --- | --- | 1 | 1 | --- | 1 |
| **50-59** | 6 | 4 | 6 | 3 | 3 | 6 |
| **60-69** | 11 | 8 | 6 | 3 | 2 | 5 |
| **70-79** | 6 | 6 | 3 | 2 | 1 | 4 |
| **80+** | 2 | 2 | 1 | --- | --- | 5 |
| **Average age at death** | **58.4y** | **66.9y** | **62.8y** | **58.9** | **47.4y** | **66.4y** |

This year, there have been some variations across the 6 Places within the Humber and North Yorkshire ICB.

North Lincolnshire place was found to have the lowest average age at death at **47.4** years of age.

York and East Riding places were found to have the highest average age at death at **66.9**years and **66.4** years, respectively.

To note, the number of notifications in specific places may be low, resulting in potential complexities in the analysis of data to understand themes and accurate representations of populations.

**Median ages at death per place - notifications**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **NY** | **Y** | **Hu** | **NEL** | **NL** | **ER** |
| **2024/2025** | **61.5** | **67** | **61** | **59** | **52** | **64** |
| **2023/2024** | **63.5** | **61** | **65.5** | **58** | **67.5** | **68** |

There has been a reduction in the *median* age at death in North Yorkshire, Hull, North Lincolnshire, and East Riding. In North Lincolnshire, 4 out of 10 deaths were individuals aged under 40 years old.

## 1.3 Gender of notified individuals

For the notifications made in 2024/2025, **73 (65%)** were for males and **38 (34%)** for females. This is a change from previous years data indicating more males have died in 24/25 compared with the prior 2 years.

* 2022/2023: Males 55% Females 45%
* 2023/2024: Males 54% Females 46%
* 2024/2025: Males 65% Females 34%

The chart above shows the trends in gender for the previous 3 years.

To note - North Lincolnshire showed a higher percentage of males in this year's data compared to other places within the ICB. The numbers of notifications remain small.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **NY** | **Y** | **Hu** | **NEL** | **NL** | **ER** |
| **Male** | **24 (77%)** | **14 (67%)** | **10 (59%)** | **6 (60%)** | **8 (80%)** | **11 (50%)** |
| **Female** | **7 (33%)** | **7 (33%)** | **7 (41%)** | **4 (40%)** | **2 (20%)** | **11 (50%)** |

## 1.4 Place of death

The following data is based on what the notifier inputs as the place of death. "Own home" and "residential care home" can be used interchangeably and describe the same type of accommodation. The notification can not specify if the individual had care support or if care was not required or provided by family.

There are several providers for acute care that cover all 6 places are as follows. Each Trust has a system in place for ensuring deaths of people on the learning disability register are reported into LeDeR.

The chart above denotes where people died in notifications made within the period 1st April 2024 to 31st March 2025.

* Hospital settings continue to be the most common place of deaths for individuals with a learning disability overall with **54%** of all deaths occurring in an acute setting. However, compared to 2023/2024 there has been a slight decrease in the numbers of deaths in a hospital setting from 56% last year
* Deaths within hospice settings for the learning disability population remains low at **4.5%** this year compared with 4% in the previous year.
* "Care home" can be used to describe supported living, residential or nursing care establishments. "Own home" usually describes a care facility with few individuals living with family members. Two notifications specified own home - with family.
* **25%** of deaths occurred in a "care home" and **16%** in "own home" (41% combined). In 2023/2024 there were 38% of deaths in a community setting – care home or own home. No deaths in 2024/2025 occurred in a public place / other setting.

## SECTION 2 – CLOSED REVIEWS

This section of the report will explore the quantitative data findings from reviews that were closed in the period 1st April 2024 to 31st March 2025.

**A further 3 were out of scope (no formal diagnosis of learning disability or Autism) and therefore not included**

**6 reviews were for Autistic individuals (see autism section of the report)**

**116 reviews were closed in this period**

Closed cases data outlined in this report cover deaths that occurred between 2022 and 2024 – broken down as follows:

2022: 2 cases

2023: 34 cases

2024: 76 cases

To note, hold times linked to statutory processes can delay closures significantly

## 2.1. Age at death

**Average age at death for all closed cases is outlined below. There is further analysis according to other variables later in the report.**

**Median age at death**

**62 years**

**Average age at death**

**60.4 years**

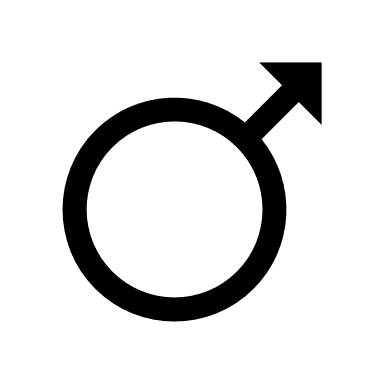
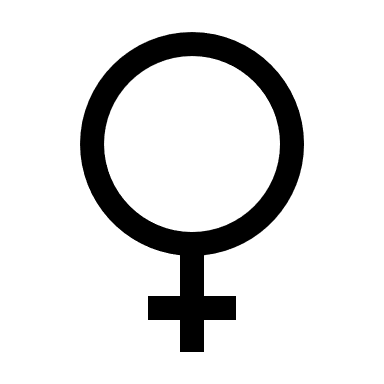
LeDeR report 2022/2023 – average age of death was **75** years old

LeDeR report 2023 / 2024 – average age of death was **63.2** years old

LeDeR report 2024 / 2025 – average age of death was **60.4** years old

***\*As a caveat – the closed cases data represents individuals who died over a 2-to-3-year period. Average age at notification shows a less variable picture.***

## 2.2. Gender of individuals in closed cases

** Male – 65 (59%)  Female – 45 (40.9%)**

In last year's LeDeR report (2023 / 2024) – **61%** of completed reviews were for males and **39%** were for females.

## 2.3 Cause of Death – Part 1a

The first part of this section will look at the categorisation of death as specified in Part 1a on the death certificate. The following table outlines the different parts of the death certificate and what that indicates.

**Cause of Death clarification on death certificate**

1a) CAUSE OR DISEASE THAT LED DIRECTLY TO DEATH

1b) INTERMEDIATE CAUSE OF DEATH

1c) UNDERLYING CAUSE OF DEATH

ii) USED WHEN ONE OR MORE CONDITION CONTRIBUTE TOWARDS DEATH BUT IS NOT PART OF THE SEQUENCE LEADING TO DEATH

**Part 1a analysis**

The following table relates to conditions as specified on **Part 1a** of the death certificate

**Respiratory**

Respiratory related deaths accounted for the highest diagnostic category. This continues to be the leading cause of death in people with a learning disability each year from LeDeR data both in our ICB locality and nationally. Within this category, **33** individuals had a respiratory related condition as Part 1a on their death certificate. Pneumonia (all types) accounted for the most deaths at 14 people. 11 reviews had cause of death as Aspiration pneumonia. Respiratory failure accounted for 4 deaths and 2 people had other respiratory conditions

**Cardiac**

**15** individuals died from a cardiac related disease or condition. Myocardial Infarction was the most common cause within this category with 7 deaths, followed by cardiac arrest (4 deaths) and congestive heart failure (3 deaths). Other cardiac causes were attributed to 2 deaths.

**Cancer**

Cancer deaths accounted for **14** deaths. To note – data analysis further on in this report outline that while cancer was Part 1a in 14 deaths, a further 6 people had cancer listed as Part 1b or 1c on the death certificate. While the second most common cause of death (according to Part 1a) would be cardiac related deaths, including cancer as a contributing factor, means cancer would move to the second most common cause of death for people with a learning disability across the date range in this report.

An analysis was done to consider the types of cancer people died from and if those individuals were eligible and received cancer screening. Types of cancer in this cohort covered a very wide range of types of cancer.

Including the cancers listed on Part 1b or 1c.

**Bowel related cancer**: There were **3** bowel related cancers (rectum, bowel, and colon). Individuals were aged 33, 64 and 44. Only one person would have met the age criteria for bowel cancer screening (FIT test).

There were no issues raised linked to the diagnostic process in these individual's care. End of Life learning will be outlined in the Learning and Themes section of the report.

**Other Cancers:** Other cancer types that are linked to screening programmes only appeared in singular cases and were therefore not included in the analysis of this report. There was no significant learning linked to availability or uptake of screening.

**Other conditions**

Of those who died from an epilepsy related condition, **2** individuals died from sudden and Unexpected Death in Epilepsy (SUDEP).

An Epilepsy Benchmarking exercise has been completed to understand and review epilepsy services for individuals with a learning disability and autistic people across all 6 places within the Humber and North Yorkshire Partnership. NHS England have commissioned support from a learning disability charity to include the voices of people with lived experience. Findings will be shared with key stakeholders and additionally will inform a Health Action Plan overseen by the ICB Steering Group.

To note, out of the **6** individuals who died from gastro-intestinal or bowel related conditions, 3 people died because of a bowel related obstruction. 2 of these individuals had a cancer listed as Part 1b.

|  |  |
| --- | --- |
| **Average age of death in the top 3 conditions** | |
| **Respiratory** | Average: 60.8 years |
| Median: 61 years |
| **Cardiac** | Average: 60.4 years |
| Median: 61 years |
| **Cancer** | Average: 59.7 years |
| Median: 64 years |

## 2.4. Cause of Death – Part 1b and 1c

As outlined above, there is additional learning when we consider other elements to conditions listed on the death certificate. This report will consider additional learning where the diagnostic categories of Part 1a and Part 1b and 1c are different.

**Conditions listed on Part 1b or 1c – where the condition linked to the cause of death is a different diagnostic category to Part 1a.**

*Examples 1.*

1a) Pulmonary embolism 1a) SUDEP

1b) Idiopathic DVT 1b) Epilepsy

These will **not** be included in the following analysis as the conditions are categorically the same.

*Examples 2.*

1a) perforated large bowel obstruction 1a) MI

1b) sigmoid adenocarcinoma 1b) Aspiration

Where there is an indication of a **different** category contributing to cause of death, but Part 1 b or c is relevant to the report findings, these **will** be included in the following analysis.

**There were 45 closed reviews which had different diagnostic categories in Part 1a to Part 1b or Part 1c.**

As indicated in section 2.3, cancer as a feature on Part 1b or 1c on the death certificate increases this diagnostic category by **6** deaths.

These were not cancers linked to any national screening programme and did not highlight any theme or prevalence of specific cancer type.

Aspiration and aspiration pneumonia plus other respiratory related deaths accounted for **11** diagnostic categories on this section of the death certificate. Dysphagia (difficulty swallowing) was indicated in a further **4** cases

When added to the 33 individuals who had a primary cause of death linked to a respiratory condition on Part 1a, this increases respiratory related conditions directly linked to the death of that individual to **48**.

**RECOMMENDATION: All deaths that feature Aspiration Pneumonia or choking anywhere on Part 1 (a, b, or c) of the death certificate will progress to a Focused review.**

**Reviewers will be asked to look specifically if there was any involvement from Speech and Language Teams, eligible vaccination uptake, repeated admissions for respiratory related conditions and risk management.**

## 2.5. Severity of Learning Disability analysis against age and cause of death

This year's report will consider a person's severity of learning disability against other variables.

The following table outlines how many closed reviews in each severity of learning disability.

|  |  |  |  |
| --- | --- | --- | --- |
| **mild** | **moderate** | **severe** | **Profound / multiple** |
| **55** | **25** | **24** | **6** |

Half of all closed reviews were for people who had a mild learning disability. Moderate and severe learning disabilities were almost equal after this, with profound and multiple learning disability accounting for a low percentage of all closed reviews.

**The following tables outline the top 3 causes of death (Part 1a) in each category of learning disability:**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **MILD** | **MODERATE** | **SEVERE** | **PROFOUND MULTIPLE** |
| **Respiratory** | 45.7% | 42.8% | 58.3% | 66.6% |
| **Cardiac** | 34.2% | 14.2% | 25% | 0% |
| **Cancer** | 20% | 42.8% | 16.6% | 33.3% |

*RED – highest percentage*

*ORANGE – second highest percentage*

*BLUE – third highest percentage*

**Mild learning disability** – **Respiratory** was the most common cause of death in closed reviews, followed by cardiac, then cancer.

**Moderate learning disability** – **Respiratory** and **Cancer** were the joint most common causes of death, followed by cardiac.

**Severe learning disability** – **Respiratory** was the most common cause of death, followed by cardiac then cancer.

**Profound and multiple learning disability** – **Respiratory** was the most common cause of death followed by cancer. No deaths were attributed to cardiac related illness in this cohort.

Learning from closed reviews does not suggest any significant findings linked to severity and access to preventative strategies.

**The following table outlines age at death according to severity of learning disability**

**Highest % age group at death**

* MILD – 60-69 years
* MODERATE – 50-59 and 70-79 years
* SEVERE – 50-59 years
* PROFOUND / MULTIPLE – 40-49 years

**AGE COMPARED WITH CAUSE OF DEATH (Part 1a) – ALL SEVERITY**

* For **respiratory** deaths, those in the age bracket 60-69 accounted for the highest % of deaths, followed closely by 50-59 group.
* For **cardiac** deaths, those in the age bracket 60-69 accounted for the highest % of deaths, followed equally by those aged 50-59 and 70-79.
* For **cancer** related deaths, those in the age bracket 60-69 accounted for the highest % of deaths, followed by 50-59.

## SECTION 3 – LEARNING FROM CLOSED REVIEWS AND POSITIVE PRACTICE

This section of the report will summarise the main learning from closed reviews. The following themes and areas of learning exclude what we consider expected practice.

Any positive practice identified pertains to care over and above what would be the expected standard.

**110** total closed reviews (Learning Disability). Closed reviews relate to people who died between 2022 and 2024.

## 3.1 Annual health checks

An Annual Health Check (AHC) should be completed for all individuals aged 14 and over who are on the GP Learning Disability Register.

This health check is provided by Primary Care and is offered to all people with a learning disability to manage long term conditions, ensure any problems are found early and support healthy transition to adulthood. The appointment will complete a physical health check, review medications and vaccinations and discuss lifestyle. Reasonable adjustments should be made to support individuals to attend and allow any referrals or future investigations that may be needed.

**79%** of all closed reviews showed an Annual Health Check had been completed in the last year of life. The table below shows completed Annual Health Checks per place.

Humber and North Yorkshire have a target, set by NHS England, for 75% of all people on the learning disability register to have an annual health check.

**North Yorkshire:** 81.8% of closed reviews showed an AHC completed in the last year of life. Data as of 28.2.2025 for the current Learning Disability population in this place showed compliance at 71.7%.

**York**: 87.5% of closed reviews showed an AHC completed in the last year of life. Data as of 28.2.2025 for the current Learning Disability population in this place showed compliance at 69.3%.

**Hull**: 82.3% of closed reviews showed an AHC completed in the last year of life. Data as of 31.3.2025 for the current Learning Disability population in this place showed compliance at 79%.

**North East Lincolnshire**: 77.7% of closed reviews showed an AHC completed in the last year of life. Data as of 31.3.2025 for the current Learning Disability population in this place showed compliance at 82.5%.

**North Lincolnshire**: 69.2% of closed reviews showed an AHC completed in the last year of life. Data as of 28.2.2025 for the current Learning Disability population in this place showed compliance at 73.7%.

**East Riding**: 68.1% of closed reviews showed an AHC completed in the last year of life. Data as of 31.3.2025 for the current Learning Disability population in this place showed compliance at 85%.

Overall, compliance is meeting or expected to meet target key performance indicators across each place. Learning from individual closed reviews mainly centred around the annual health check not being done where indicated, however in some cases it would not have been appropriate to complete (e.g. in the case of palliative care) or the individual may have been monitored regularly die to complex health. For those who did have an annual health check completed, the Quality of the check showed variable standards with some interventions demonstrating excellent input and others indicating some areas of improvement – an example is recording high Body Mass Index (BMI) with no referrals on to weight management or healthy eating follow up.

This chart shows the most common themes from closed LeDeR reviews over the last year. There were multiple other examples of individual learning. Any specific actions following a LeDeR review are monitored via the monthly Panel.

*\*MGT- management*

*\*\*BI/MCA – best interests / mental capacity act*

## 3.2 End of Life Care

**22** reviews highlighted learning related to end-of-life care. In most reviews this was specifically linked to:

* care and choice at the end of life
* management of pain
* lack of recognition at an earlier stage that the individual was palliative / ceilings of care

Other learning referenced family and carer support, both when caring for the unwell person and bereavement support after death.

**7** reviews highlighted **good** practice specifically linked to end-of-life care and processes. We would like this number to be higher.

Cancer Screening

Of note, **12** reviews highlighted learning specifically linked to lack of cancer screening in age-appropriate adults. This primarily outlined lack of support for completion of bowel cancer screening test or non-attendance with no follow up.

The LeDeR platform does not specifically request us to record compliance with cancer screening. Inclusion of this was initiated following last year's annual report. We will continue to monitor compliance and learning over the next year.

## 3.3 Mental Capacity and Best Interests

Learning related to Mental Capacity and Best Interests decision making remains the most common theme arising from LeDeR reviews, with **19** reviews highlighting learning in this category.

Almost all these cases centred around decision specific processes linked to care and treatment.

In Harrogate Hospital Trust, an automatic notification is in place, to alert the Acute Liaison Nurse of any ResPECT documentation or DNACPR status being added to a patient’s record of a patient with a learning disability flag. This supports prompt review of the documentation, decision, and decision-making process.

*\*ReSPECT –* ***Re****commended* ***S****ummary care* ***P****lan for* ***E****mergency* ***C****are and* ***T****reatment.*

*\*\*DNA CPR –* ***D****o* ***N****ot* ***A****ttempt* ***C****ardio-****P****ulmonary* ***R****esuscitation.*

## 3.4 Reasonable Adjustment

**7** reviews showed findings linked to the lack of reasonable adjustments which may have had a direct impact upon compliance or experience of care. There were no findings that linked severity of learning disability, place of residence and death or condition.

Four reviews highlighted incongruent documentation regarding the severity of an individual's Learning Disability.

A sensory room has opened in Scarborough urgent treatment centre providing sensory specific equipment and space.

## 3.5 Management of Long-Term Conditions

15 reviews highlighted learning linked to management of long-term conditions. This is broken down into some key common themes.

* Delays in secondary care appointments (specialist consultant, scans, or other investigations).
* Delays in surgery post covid.
* No follow up.

6 of the15 reviews were for North Yorkshire patients, 3 for Hull and York respectively, 3 for North Lincolnshire and East Riding.

There was no specific common condition.

Harrogate hospital has made key policy changes to automatically notify when a person with a learning disability does not attend an appointment, to enable follow up and support with reasonable adjustment. The Trust have also made key changes to policy to prioritise individuals with a learning disability who are on waiting lists.

In York and Scarborough hospital Trust the learning disability 8-week elective surgery pathway is now up and running, following a successful pilot. This ensures patients with a learning disability are notified to the hospital learning disability team who ensure reasonable adjustments are considered and person-centred care is facilitated.

Weight Management

Four reviews showed learning linked to the lack of weight management strategies in individuals with a high Body Mass Index.

***RECOMMENDATION:*** *Reviewers to record the Body Mass Index score, if documented within the last year of life. Analysis can then be explored in next year's report regarding weight, diet support and choice and referral to appropriate services.*

Medication Management

**7** reviews cited learning linked to management of medication. There were no specific patterns to the types of medication (e.g. acute or long-term medications). There was not a significant impact upon quality of care in any review.

## 3.6 Fundamentals of Care and Safeguarding

LeDeR has made **5** referrals for consideration of a Safeguarding Adults Review over the last year.

Sadly, **11** reviews highlighted learning linked to fundamentals of care, for example, hydration, nutrition and moving and handling in hospitals or care homes.

**10 of these patients died in a hospital setting.**

Any review that identifies learning linked to fundamentals of care automatically progresses to a Focused review.

***RECOMMENDATION****: Steering Group to explore raising awareness of nutrition and hydration via work to improve content and use of hospital passports.*

## 3.7 Positive Practice

**24 reviews showed no significant areas of learning.**

The annual report would like to highlight the **8** reviews that highlighted excellent support from GP. These highlighted the bespoke support and reasonable adjustments made, liaison with multi-disciplinary teams and consideration of diagnostic overshadowing.

Community Care and Support

**50** reviews showed good or excellent support from carers with many of these reviews highlighting individuals living in the same care home for many years with familiar and caring staff.

The use of multi-disciplinary working showed favourable outcomes in complex cases. Multiple reviews showed care staff sourcing additional training to be able to support the person to stay in their home and be cared for effectively and safely.

Learning Disability Nurses

Without exception, the involvement of the learning disability nurse at each Hospital Trust showed a significant improvement in care and experience during admissions or hospital-based care. The LeDeR annual report would like to extend its gratitude to the Hospital learning disability teams for their professionalism, support, and engagement with the LeDeR process and most of all to their positive and consistent attitude towards high quality patient and family care, support for colleagues and advocacy for our most vulnerable patients.

The vulnerabilities team on the South Bank have devised their own database to keep track of complex patients awaiting procedures to ensure the person is fully prepared and care plans in place. Furthermore, the learning disabilities nurses in Humber Health Partnership have been referring patients to the community learning disability team on discharge with an aim for a 48 hour follow up and have robust plans to avoid and reduce readmission. They have been working with community teams to provide training to carers about the risks of Aspiration Pneumonia and recognition of signs and symptoms.

## 3.8. Focused Reviews

Focused Reviews are completed (regardless of findings) where the following applies

* A diagnosis of Autism only (not where the individual may have had a learning disability and Autism)
* Where the individual is from a minority ethnic background.
* If the individual had been subject to restriction under the Mental Health Act in the 5 years preceding death
* If the person had ongoing criminal justice involvement
* Concerns about care or significant safeguarding concerns.
* Family can request a Focused review

A recommendation from the 2023/2024 LeDeR Annual Report was to include Cardiac or Cancer deaths (Part1a) for a locally agreed automatic Focused Review.

**32** reviews were completed as focused in 2024/2025

The following chart represents closed cases in 2024 / 2025

The majority, 20 reviews, were progressed to a Focused review due to locally agreed criteria of cause of death being cardiac or cancer related. 2 reviews were from prior years' locally agreed inclusion: (Sudden and unexpected death in epilepsy (SUDEP)).

The next most common reason to progress to Focused review.

* Where the initial review indicated care concerns
* A serious incident or safeguarding elements.

Two reviews were for automatic inclusion where the person was subject to mental health restrictions in the 5 years preceding death. To note, one of these was due to incorrect documentation at notification. The person had been under a deprivation of liberty rather than mental health act restrictions as specified under the inclusion criteria.

**Grading of Care**

Focused reviews are graded according to two areas - Quality of Care and Service delivery in the period leading to death.

|  |  |  |
| --- | --- | --- |
| **Grade** | **Quality of Care the Person Received Based on Experience** | **Thinking about the care they received in the period leading up to their death, to what extent did the person get the right support at the right time and in the right place?** |
| **1** | Care fell far short of expected good practice, and this contributed to the cause of death. | Responsiveness of ICS services to the person's needs fell far short of the expected standard and this contributed to the cause of death. |
| **2** | 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. | Responsiveness of ICS services to the person's needs fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death. |
| **3** | Care fell short of expected good practice, and this did impact on the person’s wellbeing but did not contribute to the cause of death. | Responsiveness of ICS services to the person's needs fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death. |
| **4** | Satisfactory care (fell short of expected good practice in some areas but this did not significantly impact on the person’s wellbeing). | Responsiveness of ICS services to the person’s needs fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing. |
| **5** | Good care (met expected good practice). | Responsiveness of ICS services to the person's needs was good and met the expected standard. |
| **6** | Excellent care (exceeded expected good practice). | Responsiveness of ICS services to the person's needs was excellent and exceeded the expected standard. |

Any review where the grading of care is 1 or 2 is submitted on a quarterly basis to NHS England.

**The following table outlines the number of reviews according to the grading of care and services.**

**65.6%** of reviews highlighted satisfactory to excellent care delivery.

**71.8%** of reviews highlighted satisfactory to excellent availability of services.

**No reviews received a grading of 1 in any category.**

## 3.9 LeDeR Steering Group Annual Statement

*The Humber and North Yorkshire Integrated Care Board (HNY ICB) LeDeR Steering Group has continued to meet bi-monthly throughout the past year.*

*The HNY ICB continues to collaborate with an external provider responsible for conducting all HNY ICB LeDeR reviews. The relationship with this provider has strengthened over the past year, with the ICB now one of the highest performing in the country for completing reviews within the specified timescale.*

*Further improvement work is needed to ensure that people with a learning disability and autistic people have the opportunity to both access and attend cancer screening appointments with individually tailored reasonable adjustments as common place.*

*Whilst annual health checks continue to be offered there is a need to standardise best practice across the ICB footprint to ensure a consistency of approach and quality. The annual health check needs to be integrated with the management of long-term conditions and efforts to promote healthy lifestyles.*

*It is recognised there is still a need for further work to be undertaken with regards to the application of the Mental Capacity Act and Best Interests decision making.*

*It is also acknowledged there is more work to be done to reduce health inequalities for people with a learning disability and autistic people, however we know that overall people in the HNY ICB receive good care.*

*The improvement plan for 2025-2026, includes six workstreams focused on addressing recommendations from this annual report and will ensure that existing system wide workstreams consider the needs of people with learning disabilities and autistic people.*

*I would like to conclude by extending my thanks to everyone who has contributed to the work of the ICB LeDeR Steering Group over the past year. The level of consistent attendance and participation is a reflection of the commitment from system partners in taking forward service improvements.*

*Finally, I would like to acknowledge the two Local Area Contact colleagues (LACs) for their work and dedication to the LeDeR programme over the past year.*

*Humber and North Yorkshire Integrated Care Board - LeDeR Steering Group Chair.*

## SECTION 4 – AUTISM

There were **6** individuals with a diagnosis of Autism notified into the LeDeR programme in the last year, despite efforts to raise the profile of LeDeR.

All 6 individuals were notified from either North Yorkshire, York, or East Riding Place.

There were **6** individuals with a diagnosis of Autism closed in the 2024/ 2025 period.

Due to the continued low numbers of notifications, we are unable to derive any statistically significant data from these reviews and have excluded them again from this year's report.

Some excellent work has been completed in York and Scarborough Teaching Hospital with the Autism liaison nurse. This is the only Trust in our ICB who employ to this role. In 2022, a seconded role was funded by the ICB for an Autism liaison nurse to perform a needs gap analysis on the Trust's position against legislation and guidance. The exercise highlighted a gap for Autistic patients, without a learning disability.

Following this a plan was developed to plan and implement an Autism liaison team. This was co-produced and launched in April 2025.

A group of people posing for a picture

AI-generated content may be incorrect.

*"The team now consists of 2 Autism liaison practitioners one based at York, and one based in Scarborough and our training facilitator who is driving the delivery of The Oliver McGowen mandatory training on learning disability and autism to all staff.*

*The Autism Liaison Team visibly work to promote staff understanding of autism, use and awareness of hospital passports, and reasonable adjustment requests.*

*They also provide support and specialised advice to patients, staff, and care partners with the goal of enabling Autistic patients to equitably access, and experience trust services. We have introduced a hospital passport upload to the electronic patient record and if consent is given, this can be added to our register within the patient database that alerts us to any admissions.*

*There is lots of work to do in the coming year!"*

**Named Nurse Complex Needs / Autism Liaison Service Lead**

**York and Scarborough Teaching Hospital**

The LeDeR programme has seen the positive impact the involvement of this team has had on experience and care within the Trust and notifications reflect an awareness of those who die in hospital with a diagnosis of Autism.

Humber Health Partnership have been making significant progress in identifying and supporting Autistic people.

***RECOMMENDATION:*** *Consideration of a Focused Review for individuals who have a dual diagnosis of Autism and Learning Disability on a case-by-case basis, where the reviewer has found examples of the impact of Autism in access, experience, and outcomes in health.*

## SECTION 5 - RECOMMENDATIONS

## 5.1 Review of Recommendations from 2023/2024

The following recommendations were made in last year's 2023/2024 report. An update is provided as to the progress made.

**23/24 Recommendation One**

*For a focused review to be undertaken for any individual whose death is notified to the LeDeR programme where the cause of death as recorded within part 1 of a completed Medical Certificate of Cause of Death (MCCD) is identified as:*

*- Cardiac*

*-Cancer*

*The above relate to the ICB health outcome priorities for 2024/2025 (cutting cardiovascular disease and reducing harm from cancer).*

*Based on the data within the reviews completed during 2023/2024, having the above as focused reviews would also support the ICB with achieving the required 35% of all reviews being a focused review in addition to those reviews already meeting this criterion as set by NHSE.*

All deaths where the person's death was linked to diseases of the respiratory or cardiac system (as featured on Part 1a of the death certificate) were progressed to a Focused review in 2024/2025. The person's experience of care at the end of life is an identified area of improvement. There were no significant common findings linked to cardiac related conditions.

**23/24 Recommendation Two**

*For the LeDeR Steering Group to have a focus on pneumonia and aspiration pneumonia with learning from completed reviews relating to these causes feeding into the steering group to identify any areas of concern/focused pieces of work which may be required such as education and training relating to feeding which may reduce the risk of aspiration pneumonia.*

These conditions continue to represent a high proportion of all respiratory related deaths. Any review where aspiration, choking or aspiration pneumonia features on Part One of the death certificate will progress to a Focused review with an emphasis on determining risk, admissions to hospital in the period preceding death and involvement from speech and language teams. Respiratory related deaths were completed as Initial reviews unless additional learning was raised. The discretionary inclusion for a locally agreed focussed reviews in the forthcoming year will allow a deeper analysis and understanding of themes and learning linked to these conditions.

**23/24 Recommendation Three**

*For the ICB to consider review of the current RESTORE2mini/deteriorating patient training on offer in order to provide uniformity in the training across the ICS with consideration of this being delivered centrally on a rolling programme to ensure all staff within care homes and domiciliary care are in receipt of the training.*

*For the ICS/ICB to also consider if this training could be offered to all staff providing care within individuals own homes.*

North Yorkshire and York Places use the “Stop and Watch” tool instead of the RESTORE 2 mini. This is embedded in all care homes with appropriate training provided.

Following a benchmarking exercise, a standardised training programme has been developed in North and Northeast Lincolnshire for care homes with no cost to providers. Consideration to the offer of support and training in other places will be progressed in the next year.

**23/24 Recommendation Four**

*For LeDeR reviewers to identify within all reviews (initial and focused) if the individual has been offered all age-appropriate screening and whether they have been supported to undertake the screening*

All reviews now include this information in free text supporting any learning to be easily identified linked to cancer screening and immunisation uptake. This will continue in the next year.

**23/24 Recommendation Five**

*For providers across health and social care to ensure staff receive training in relation to compliance with the Mental Capacity Act (2005), Deprivation of Liberty Safeguard (DoLs) documentation and the use of Best Interest meetings with robust documentation.*

Harrogate and District Foundation Trust have recruited to a Mental Capacity Lead who will form an integral part of the Safeguarding team. Key staff in the Trust are contributing to the formulation of an ICB wide hospital passport.

Across Humber Health Partnership, a project is underway across the North and South Bank areas to explore the quality of decisions and documentation linked to Mental capacity Act and best interests. Bitesize training is provided to all staff. The roll out of the reasonable adjustment flag is underway with digital teams in the Trust.

York and Scarborough Teaching hospitals Trust have Mental Capacity and deprivation of liberty educators in post. An audit of staff awareness of mental capacity has been completed with training reviewed and updated. Bespoke training is available to those who are unable to attend.

Good practice example – Harrogate Trust: Cataract surgery had been planned for a patient following best interest discussions involving family, IMCA (Independent Mental Capacity Advocate) and staff at her care home. The patient declined to attend on the day due to increased anxiety and initial discussions were for her anxiety to be managed with medication. The Acute Liaison Nurse visited the patient at home to explore reasonable adjustments that could be made to support this patient to have the surgery that she required. It became clear that her anxiety was around attending hospital rather than the actual procedure. She asked lots of questions about pets as she was hoping to get her own pet dog. It was agreed that the acute liaison nurse would visit the patient at home on the day before the procedure and that he would bring his dog on the visit. This gave the patient something positive to focus on, reduced anxiety without the need for medication and enabled the patient to have her surgery.

**23/24 Recommendation Six**

*Work to continue to fully understand the position across the ICS regarding our minority ethnic groups and diverse population, to ensure everyone with a learning disability who sadly passes away is offered the opportunity to be included in the LeDeR programme.*

Despite extensive attempts to understand this population size with the support of Business Intelligence, there remains challenges linked to data and coding. Recommendations made for 25/26 will explore the role of medical examiner in supporting notifications.

**23/24 Recommendation Seven**

*For everyone involved with the LeDeR programme across the ICS to continue to share the learning from completed reviews within their respective organisations (and wider). For all to also continue to raise awareness of LeDeR in order to ensure all individuals with a learning disability or who are autistic and sadly pass away within the Humber and North Yorkshire Integrated Care System have their death reviewed through notification to the programme.*

Newsletters have been adapted to ensure Easy Read content is appropriate and Professionals newsletters are being shared with colleagues. A link has been included to the newsletter, which provides the detail of how to make a notification.

**23/24 Recommendation Eight**

*For the LeDeR Steering Group to have greater scrutiny in relation to the learning from completed reviews as identified within the LeDeR panel meeting and in particular where the learning relates to the key themes as identified within this report.*

A strategic improvement workplan has been developed by the Steering Group, with priority areas. A deep dive schedule will be formulated across the coming year.

**23/24 Recommendation Nine**

*For consideration during quarter one 2024/2025 for the two LACs to work collaboratively to approve any review submitted regardless of Place area to reduce slippage in the approval process due to a LAC being on annual leave or absent.*

There has been a significant restructure and staffing changes in the ICB over the last year which includes the LeDeR Programme. Despite this, key performance indicators have been exceeded, and the Humber and North Yorkshire LeDeR Programme continues to deliver high quality reviews within the designated timescale.

## 5.2 Recommendations for 2025/2026

***RECOMMENDATION:*** ***To progress the LeDeR 2025/2026 proposed Steering Group Improvement plan.***

Alongside the specific recommendations set out in this year's report, the Steering Group has developed a proposed workplan centred around 6 main priorities.

* Cancer
* Respiratory
* Cardiovascular Disease
* Epilepsy
* Integrated Care
* Personalised Care and Support

A diagram of a health care system

AI-generated content may be incorrect.

For each workstream, there will be identified areas of improvements. Where these may interact with other workstreams a blended or matrix approach to delivery will be considered. It is anticipated that for each of these workstreams or improvement areas, that aims will be established, ensuring as a system we are focused on finding the right solution to address the LeDeR findings.

***RECOMMENDATION:*** ***To develop a strategy to work with medical examiners to ensure all individuals with a learning disability and autistic people are notified into the programme. Furthermore, to share findings from completed reviews with coronial teams.***

The annual report has again identified that notifications for Autistic people and individuals from minority ethnic groups are low.

A recommendation is therefore made that an agreed approach will be discussed to explore if the role of the Medical Examiner can support in this process.

Furthermore, training and awareness videos to be shared with all community mental health teams, learning disability and Autism teams and via care home bulletins to encourage staff to make a notification.

An annual report summary page (see appendix one) has been produced to provide front line staff with an "at a glance" summary of the annual report findings and how to notify.

A link with details of how to make a notification has been added to the professional's newsletter.

***RECOMMENDATION: To establish 100% compliance with notifications into LeDeR from Medical Examiner function. Explore options to develop awareness of learning disability registers, diagnostics, and practice level coding.***

This report has highlighted some key findings linked to specific place areas, in regard to key demographics (age and gender). The report emphasises the lower numbers of notifications in some areas and closed reviews in this place and care needs to be taken when interpreting data as we may be missing information if the individual has not been notified into the programme.

An emphasis on raising awareness of the LeDeR Programme in key areas will be prioritised.

***RECOMMENDATION:*** ***Reviewers to record the Body Mass Index score, if documented within the last year of life. Analysis can then be explored in next year's report regarding weight, diet support and choice and referral to appropriate services.***

Review teams have already established a practice of recording Body Mass Index within the LeDeR review – both Initial and Focused reviews. Over the next year, anyone with a Body Mass Index of 25 or over will have some dialogue around healthy lifestyles or diet advice and information. Anyone with a Body Mass Index of 30 or over and a diagnosis of diabetes will be considered on a case-by-case basis for a Focused Review.

It is important that individual choice regarding diet and lifestyle is respected.

***RECOMMENDATION:*** ***Deaths that feature Aspiration Pneumonia or choking anywhere on Part 1(a b or c) of the death certificate will progress to a Focused review.***

***Reviewers will be asked to look specifically if there was any involvement from Speech and Language Teams, eligible vaccination uptake, repeated admissions for respiratory related conditions and risk management.***

Respiratory related deaths remain the leading cause of death both locally and nationally (23/24 data). Due to the high percentage of Aspiration Pneumonia and aspiration related deaths and incidences, deaths attributed to these conditions (as specified on Part 1a, b or c of the death certificate) will be considered to progress to a Focused review in the next year.

Additionally, findings from the LeDeR report to be shared with hospital Trust's speech and language teams.

***RECOMMENDATION****:* ***Steering Group to explore raising awareness of nutrition and hydration via work to improve content and use of hospital passports.***

This recommendation is made linked to the findings regarding fundamentals of care in some reviews. The Steering Group Improvement plan will incorporate these findings, and the findings of future reviews to inform workstream priorities.

***RECOMMENDATION:******Consideration of a Focused Review for individuals who have a dual diagnosis of Autism and Learning Disability on a case-by-case basis.***

Consideration was given to the low numbers of Autism only notifications. Where an individual has both a diagnosed learning disability and Autism, if the review highlights examples of the impact of Autism specifically regarding access to services, treatment compliance, patient or family experience and outcomes in health then a Focused review will be considered.

***RECOMMENDATION:*** ***Explore "on Hold" reviews to consider if appropriate to progress***

A review of all cases that are on hold due to statutory processes (for example awaiting coronial Inquest) has already been commenced to consider if the LeDeR review can be completed as far as able and shared with the relevant professional. In some cases, reviews can stay on hold a considerable amount of time, which impacts upon relevance to current practice, identifying themes in real time, professional changes, and organisational memory.

Where it is considered appropriate to progress outside of coronial processes, NHS England will be contacted for approval to progress provided family members (where appropriate) agree with this recommendation.

***RECOMMENDATION: Increasing uptake of Oliver McGowan training***

The HNYICB remains committed to raising awareness of the real-life experience those with a Learning Disability and Autism experience, particularly through delivery of the Oliver McGowan training. The training continues to be part of our mandatory training offer, which includes those who work in the ICB and our provider organisations.

As an ICB 79% of our workforce having undergone the Oliver McGowan training, however, would recommend this be a key priority for 2025, ensuring all those working in our ICB and our system have completed this training package.

The LeDeR team at Humber and North Yorkshire Health and Care Partnership would like to conclude this report by thanking the family members, carers and professionals who have supported the review process and share their experiences in their time of grief.

At the heart of LeDeR are the individuals' **life** stories which provide an invaluable resource for us to understand the key factors in health inequality, care experience and treatment pathways.

We further thank our reviewer team at Xyla who always ensure a high standard of review which is completed to deadline and who provide presentation of the person's life and death to the panel.

## Appendix One: Summary sheet - An 'at a glance' synopsis of the main findings in this report

**LeDeR Annual Report 2024/2025 North Yorkshire and The Humber**

**Summary of Findings**

**Please note – these findings relate to people with a Learning Disability only. Individuals with an Autism only diagnosis were separated due to low numbers.**

**NOTIFICATIONS**

**111** Notifications were made into the LeDeR Programme. There were 119 in 2023/2024.

The average age of death across all places was **60.4** years.

To note, this year, we saw some variations in place, with North Lincolnshire having an average age of death at 47.4years. Interpretation needs to be made with care due to low numbers of notifications in this area.

This year **65%** of all notifications were male across all places. A significant shift from the two years prior where around 54% of males died across the year.

**54%** of individuals died within a hospital setting. 25% of individuals died in their care home and 16% died in their own home. To note, both these descriptions can signify the same setting.

**CLOSED CASES**

**110** reviews were closed. A further 6 reviews were closed for Autism only, but this data has been excluded from the report.

Respiratory related conditions continue to account for the highest numbers of deaths overall, followed by cardiac related then cancer.

When we include conditions as listed as Part 1b or 1c on the death certificate, this changes cancer to the second most common condition.

Respiratory related conditions were the most common cause of death in each severity. Those with a moderate learning disability had respiratory and cancer as the most common cause of death. There were no cardiac related deaths in those with a multiple or profound learning disability.

50% of the closed cases were for people with a mild learning disability

Those with a profound and multiple learning disabilities had the youngest age range at time of death (40-49years). Other severities correlated with the average age of death at notification.

There were minimal variations in age at death according to condition with the highest age bracket being 60-69 years old for respiratory, cardiac and cancer related deaths.

**LEARNING AND POSITIVE PRACTICE**

Annual Health Check compliance was generally meeting or expected to meet ICB targets. Learning from individual reviews highlighted learning linked to non-completion, quality, or lack of onward referral.

Learning linked to end-of-life care highlighted improvements needed in terms of experience and choice but generally, lack of screening was not found to be a factor in premature mortality.

Lack of reasonable adjustment and variations in documentation linked to diagnosis and severity of learning disability.

Learning linked to the management of long-term conditions included lack of follow up and key investigations, weight management and medications related learning.

Learning linked to fundamentals of care were a factor in hospital care.

5 referrals for a Safeguarding Adult Review were made.

Overwhelmingly, positive experiences of care centred around long term residential placements with well-known carers who went above and beyond to support individuals to lead full and active lives.

The involvement of the learning disability teams during acute care was a direct positive factor in experience and outcome.

GP care highlighted as excellent in several cases.

65.6% of Focused reviews were graded between satisfactory to excellent in relation to experience of care

71.8% of Focused reviews were graded between satisfactory to excellent in relation to availability of services

**RECOMMENDATIONS**

Implementation of the LeDeR 2025 proposed Steering Group Improvement plan.

To develop a strategy to work with medical examiners to ensure all individuals with a learning disability and autistic people are notified into the programme.

Monitor notifications per place on a quarterly basis with a priority to link in with medical examiners in North Lincolnshire. An emphasis on raising the awareness of LeDeR in lower notification areas will also be given attention.

Reviewers to record the body mass Index score, if documented within the last year of life.

All deaths that feature Aspiration or Aspiration Pneumonia anywhere on Part 1 to progress to an automatic Focused review.

Steering group to explore raising awareness of nutrition and hydration via work to improve content and use of hospital passports

Consideration of a Focused review for individuals who have a dual diagnosis of Autism and Learning Disability on a case-by-case basis.