Humber and North Yorkshire
Health and Care Partnership

NHS
Humber and North Yorkshire
Integrated Care Board (ICB)

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

Annual Report

1st April 2023 to 31st March 2024

Hazel Moore
Head of Nursing: North Lincolnshire Health and Care Partnership (NLH&CP) on behalf of the 6 Partnership areas within the Humber and North Yorkshire Health and Care Partnership

20th May 2024

Content **Page**

	Thank you to our experts by experience.	**3**
	Executive Summary	**4**
1.0	Introduction and Background	**6**
2.0	Governance Arrangements	**6**
3.0	Deaths of Individuals with Learning Disabilities in our Local Area 1st April 2023 - 31st March 2024	**7**
4.0	Overview of Completed Reviews 1st April 2023 - 31st March 2024	**8**
5.0	Themes and Trends	**13**
5.1	Gender of Individuals from Reported Deaths 1st April 2023 - 31st March 2024	**14**
5.2	Gender of Individuals from Completed Reviews 1st April 2023 - 31st March 2024	**16**
5.3	Ethnicity of Individuals	**19**
5.4	Age of Individuals at the time of Death: Reported deaths 1st April 2023 - 31st March 2024	**20**
5.5	Age of Individuals at the time of Death: Completed Reviews 1st April 2023- 31st March 2024	**23**
5.6	Place of Death Reported Deaths 1st April 2023 - 31st March 2024	**26**
5.7	Place of Death: Completed Reviews 1st April 2023 - 31st March 2024	**27**
6.0	Grading of Care from Completed Focused Reviews: 1st April 2023 - 31st March 2024	**29**
6.1	Quality of Care Person Received Based on Experience	**29**
6.2	Quality of Care Based on how Available and Effective Services were for the Person	**30**
7.0	Cause of Death: Completed Reviews Only; 1st April 2023 - 31st March 2024	**31**
8.0	Identified Good Practice from Completed Reviews 1st April 2023 - 31st March 2024	**34**
9.0	Identified Learning from Completed Reviews 1st April 2023 - 31st March 2024	**35**
10.0	Outcomes and Achievements Against the Recommendations within the ICB 2022/2023 Annual Report	**36**
11.0	Overview from the ICB LeDeR Steering Group	**47**
12.0	Key Themes from Completed Reviews 1st April 2023 - 31st March 2024	**48**
13.0	Recommendations for Actions to be Taken Forward for 2024 - 2025	**50**

We would like to take this opportunity to thank our experts by experience who are active members of the LeDeR Governance Panel meeting and the LeDeR Steering Group.
They have been passionate advocates in promoting the rights of people with learning disabilities and autistic people within both meetings throughout the year.
We appreciate their commitment to attending these meetings and the support they have provided and look forward to continuing to work with them as we strive to improve both the patient experience and local services within our ICS.

Executive Summary

This report, is the third Learning from lives and deaths; people with a learning disability and autistic people (LeDeR) annual report written on the Integrated Care System (ICS) footprint, known as NHS Humber and North Yorkshire Health and Care Partnership, and has been written by NHS North Lincolnshire Place, Humber and North Yorkshire Integrated Care Board (ICB), on behalf of the following Partnerships:

- NHS North Lincolnshire Health and Care Partnership.
- NHS North East Lincolnshire Health and Care Partnership.
- NHS East Riding of Yorkshire Health and Care Partnership.
- NHS Hull Heath and Care Partnership.
- NHS North Yorkshire Health and Care Partnership.
- NHS York Health and Care Partnership.

With effect from April 2023, the Integrated Care Board (ICB) moved to a single LeDeR Governance panel meeting as identified within the recommendations of the 2022/2023 ICB LeDeR annual report. Further to this, and again as a recommendation within the 2022/2023 annual report, the two LeDeR Steering groups merged to form an ICB LeDeR Steering group with effect from August 2023.

At the time of writing this report, there continues to be two separate Transforming Care Partnership (TCP) meetings within the ICB, however during 2024/2025, these will transition to one Transforming Care Partnership for the ICB.
A total of 116 deaths were sadly notified to the LeDeR programme from across the six Places within the Humber and North Yorkshire Health and Care Partnership between the 1st April 2023 - 31st March 2024 (119 deaths reported within the 2022/2023 ICB annual report).

- 54% of the people whose deaths were notified to the programme, identified as male (60% within the 2022/2023 ICB annual report); this is slightly lower than that of the national picture of 55% (as identified within the National LeDeR report 2022; published November 2023), (56% in the 2021 national report). For the Humber area, this was 57% (56% in the 2022/2023 ICB annual report) and 51% for North Yorkshire (64% in the 2022/2023 ICB annual report).

- Challenges remain with no/extremely low notifications from our non-white British communities across the ICS. Due to this, the data has been excluded from this annual report and it is noted further work is required during 2024/2025 to fully understand the number of individuals within this cohort for the ICS to be assured that no notifications are being missed for individuals within these cohorts. Within the national LeDeR report (2022) which relates to notifications and reviews completed during 2022, the ethnicity of people with a learning disability who had sadly died and denoted as white was 94%.

- 56% of people whose deaths were notified to the programme died within a hospital setting (45% within the 2022/2023 ICB annual report), this is marginally lower than the national picture of 57% as reported within the national LeDeR report (2022).

During the time-period of this report; 1st April 2023 - 31st March 2024, 126 LeDeR reviews were completed across the six Places (85 reviews completed within the 2022/2023 ICB annual report). It is to be noted that a large proportion of these reviews have been completed outside of the required NHS England timeframe of six months from the date of notification. The completed reviews relate to people who died between 2021 - 2023. Further detail relating to this can be found within page 9 of the report.

The most common confirmed cause of death identified within 37% of the reviews completed from 1st April 2023 - 31st March 2024, were diseases of the respiratory system (also identified within 32% of completed reviews within the 2022/2023 ICB annual report), with pneumonia accounting for 17% (10% within the 2022/2023 ICB annual report) and aspiration pneumonia accounting for 14% (11% within the 2022/2023 ICB annual report).

Diseases of the circulatory system (cardiac issues) remain as the second most common cause of death recorded within 21% of completed reviews (14% within the 2022/2023 ICB report), and cancers were the third most common cause of death recorded within 12% of completed reviews (6% within the 2022/2023 ICB report).

The three main key themes from the 126 completed reviews 1st April 2023 - 31st March 2024 remain as identified within the 2022 - 2023 ICB annual report, namely:

- Annual Health Checks (identified within 11% of the completed reviews).

Whilst it should be acknowledged that a proportion of the completed reviews were from 2022 and that 50% of Places met the NHSE trajectory of 75% of individuals to be offered and receive an Annual Health Check, the main themes identified were:

  - ➢ Individual not on the GP learning disability register.
  - ➢ No record of completion of the Annual Health Check (within information received from the practice to complete the review).
  - ➢ Standard of the completed Annual Health Check.

Further information relating to work undertaken on this area can be found within page 36 of this report.

- Mental Capacity Act: (identified within 16% of completed reviews) with further work required within the following areas:
  - ➢ Consistent use of the Mental Capacity Act.
  - ➢ Documentation of mental capacity assessments.
  - ➢ Best interest processes.

Further information relating to work undertaken on this area can be found within page 38 of this report.

- End of Life Care: (identified within 18% of completed reviews) with further work required within the following areas:
  - ➢ Recognition that someone is nearing the end of their life.
  - ➢ Earlier end-of-life discussion and advanced care planning, including commencement of end-of-life pathways.
  - ➢ Review of the ReSPECT document.

Further information relating to work undertaken on this area can be found within page 43 of this report.

It is to be noted that whilst the above key learning has been identified as areas of work required to improve the lives of individuals with a learning disability, reviewers also identified and highlighted areas of good practice of which some examples can be seen within page 34 of this report.

The NHS England LeDeR Learning from lives and deaths - People with a learning disability and autistic people Annual Report 2022 can be accessed at: www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities

1.0 Introduction and Background

The Learning from lives and deaths - 'People with a learning disability and autistic people' (LeDeR), was established in 2016 as a result of one of the key recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (2013). CIPOLD identified that many people with a learning disability were dying earlier than they should from preventable health conditions, and up to 30 years earlier than the remainder of the population.

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 for the NHS, the core aims and values and the expectations of different parts of the health and social care system in delivering the programme from June 2021. The policy also introduced the inclusion of 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/ . The name for the programme also changed to Learning from Life and Death Reviews – 'people with a learning disability and autistic people'. However, it continues to be called LeDeR. The focus of the new 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.

2.0 Governance Arrangements

Accountability

The Executive Lead for the LeDeR programme within the Humber and North Yorkshire Health and Care Partnership is the Executive Director of Nursing, with the delegated lead being the Director of Nursing (Hull and East Riding of Yorkshire Place).
The two Local Area Contacts (LACs) within the ICB allocate the reviews to the reviewers and undertake the quality assurance process.
The Quarterly returns as required by NHSE are submitted on the ICB footprint. These returns identify the learning and progress against actions from completed reviews alongside updates on other areas of work pertinent to the recommendations from the 2022/2023 H&NY ICB annual LeDeR report.

LeDeR Panels

Following the recommendation within the 2022/2023 H&NY annual LeDeR report, the ICB moved to one LeDeR panel meeting for sharing of the learning from completed initial reviews and for discussion and approval of the completed focused reviews. The joining of the panels has brought together system partners from across the ICS footprint, with the first joint meeting taking place in April 2023. The learning and good practice from the reviews is shared within the LeDeR learning newsletter which is completed each month following the review panel. Review of the panel membership will take place during quarter one 2024/2025 to ensure all system partners have representation.

LeDeR Steering Groups

As with the panel meeting, the recommendation within the 2022/2023 H&NY annual LeDeR report was to move to one ICB Steering Group meeting. This took effect from August 2023 with the Steering Group providing oversight, support and governance for the local delivery of the LeDeR programme, with membership from across the respective ICS footprint.

During quarter 1 2024/2025, work will be undertaken to strengthen the link between the panel and Steering group regarding the monitoring of actions identified within the panel as well as themes and trends from completed reviews.

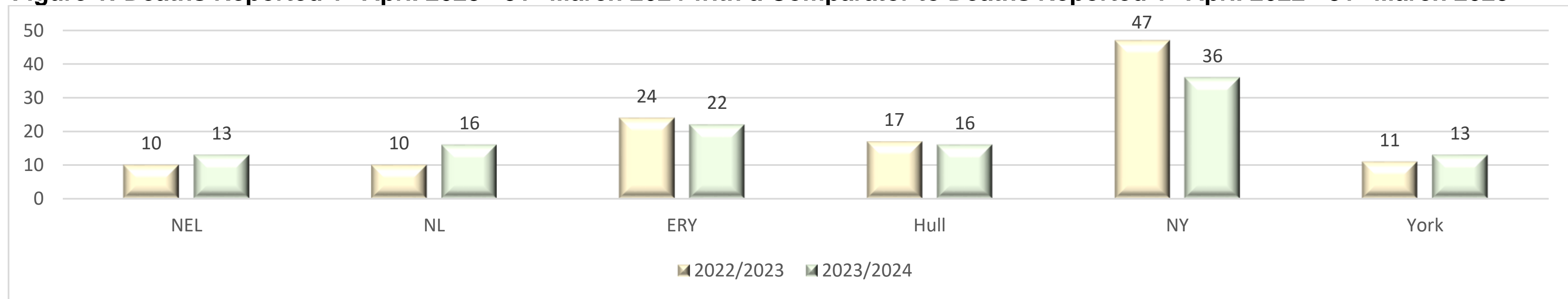
3.0 Deaths of Individuals with Learning Disabilities and Autistic People in our Local Area 1st April 2023 - 31st March 2024

Sadly, a total of 116 deaths of individuals with a learning disability were reported across the six Places within the Humber and North Yorkshire Health and Care Partnership during the time-period 1st April 2023 - 31st March 2024.

To note; due to the very small numbers of reported deaths for autistic people only, they have not been included within this report to ensure confidentiality is maintained. The data for the autistic people only reviews will be maintained and reported separately for purposes of learning within the ICS with a view to adding into future annual reports as the number of notifications and subsequent reviews increase and confidentiality of the individuals can be assured.

Figure 1 below identifies the number of deaths reported by each of the Places within the Humber and North Yorkshire Health and Care Partnership, with a comparator to the number of deaths reported 1st April 2022 - 31st March 2023.

Figure 1: Deaths Reported 1st April 2023 - 31st March 2024 with a Comparator to Deaths Reported 1st April 2022 - 31st March 2023



4.0 Overview of Completed Reviews 1st April 2023 – 31st March 2024

Changes to the programme in June 2021, saw a move to a new web platform and a change in the process for completion of reviews. All deaths notified to the programme, receive an initial review, which consists of the allocated reviewer speaking to; family, carers, and professionals involved in the persons' care. In some circumstances, a focused review, which looks in more detail at the life and death of the person is completed. NHS England have an expected trajectory that of all reviews completed, 35% are completed as focused reviews, with the LeDeR policy identifying that focused reviews should be completed in the following situations:

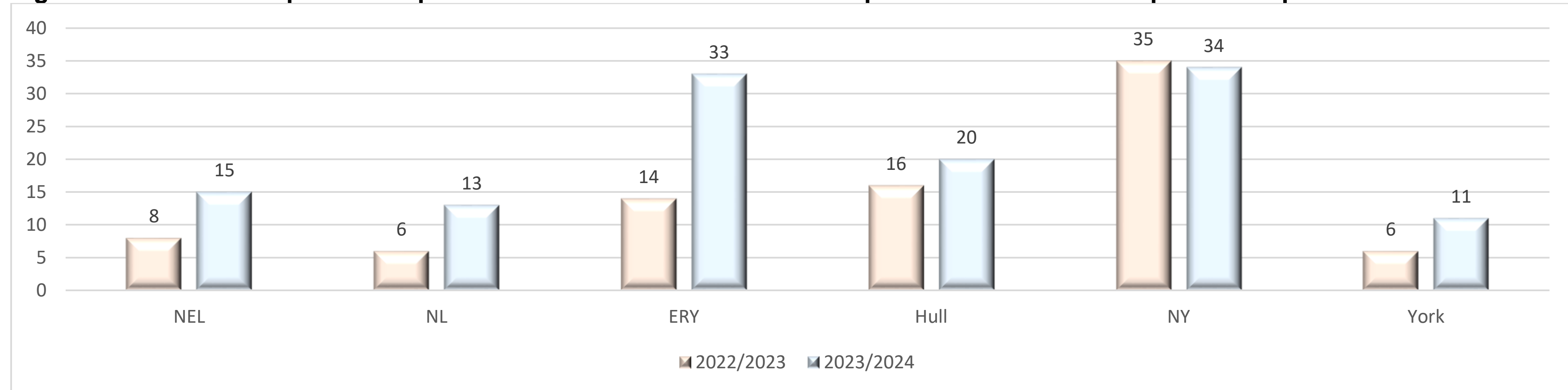
- Where a person is from a non-white British background.
- Where the reviewer or Local Area Contact (LAC) feels there may be greater learning from completing a focused review.
- Where the initial review has highlighted concerns in relation to the quality of care provided, or a lack of integrated or co-ordinated care.
- Where a family member requests a focused review.
- Where an individual has a formal diagnosis of autism and no learning disability.

Within the H&NY Annual LeDeR report 2022/2023, a recommendation was made for a local agreement to complete focused reviews where the cause of death was recorded as due to ischaemic heart disease or epilepsy for deaths notified for the time period 1st April 2023 - 31st March 2024.

Between 1st April 2023 - 31st March 2024, 126 initial LeDeR reviews were completed across the six Places (85 reviews had been completed during 2022/2023). These reviews were from notifications submitted to the programme between 2021 - 2023.

Figure 2 below, identifies the number of reviews completed by each Place 1st April 2023 - 31st March 2024, with a comparator of the number completed 1st April 2022 - 31st March 2023.

Figure 2: Reviews Completed 1st April 2023 - 31st March 2024 with a Comparator to Reviews Completed 1st April 2022 - 31st March 2023



To Note:

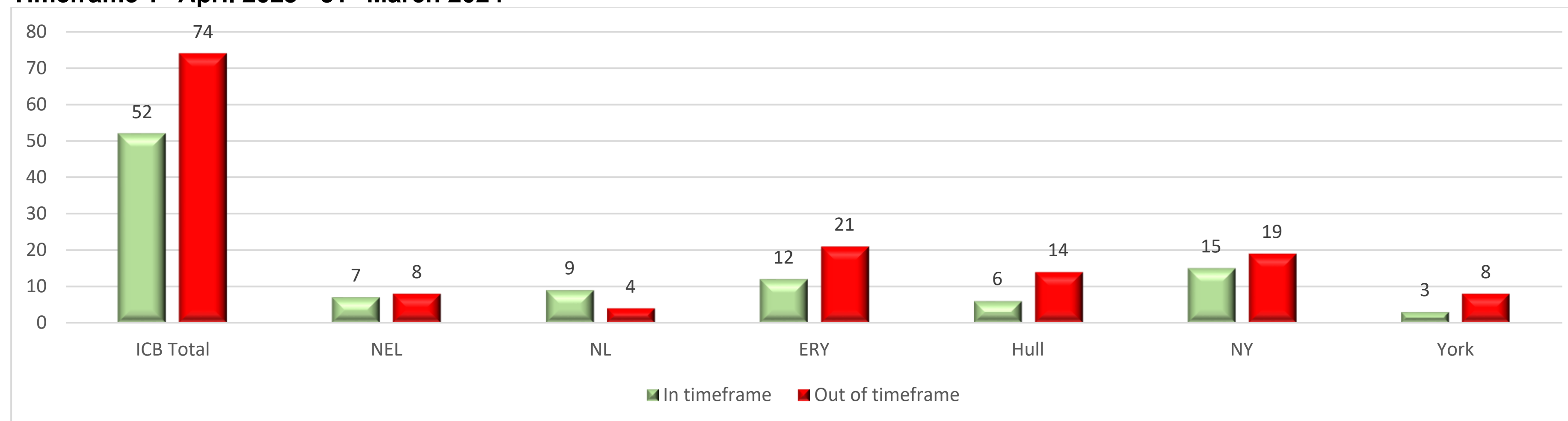
Deaths notified to the programme after 1st October 2023 would not be required to be completed within the timeframe of this report. Any reviews which meet this criterion will be included within the 2024/2025 Annual LeDeR Report.

Of these completed reviews, 52 were completed within the required timeframe across the Humber and North Yorkshire Health and Care Partnership (within six months from the date of notification to the system). Delays in completion of reviews within the required timeframe relate to:

- Reviewer capacity.
- Initial review completed within timeframe; however, the review indicated a focused review was required leading to delay in the completion of the focused review.
- The individual's death being subject to a statutory investigation such as coroner, safeguarding or serious incident investigation.
- Family wishing to be involved with the review.

Figure 3 below identifies the number of reviews completed within timeframe for each Place 1st April 2023 - 31st March 2024, with figure 4 showing the breakdown of completed reviews by year of notification to the programme.

Figure 3: Reviews Completed within Timeframe 1st April 2023 - 31st March 2024 with a Comparator to Reviews Completed Outside of Timeframe 1st April 2023 - 31st March 2024



To note:

Whilst the number of reviews completed outside of timeframe is greater than the number completed within timeframe, the Humber and North Yorkshire Health and Care Partnership entered the financial year 2023/2024 with an accumulated backlog of reviews requiring completion which were already out of timeframe.

Further to this, a large proportion of the reviews were approved on the LeDeR system just outside of the timeframe as set by NHSE. The NHSE timeframe is taken to the point in time the review is approved on the system and not the date of which the review was submitted to the LAC for quality assurance which could be within the 6-month time period. Delays in approving on the system by the LAC are due to:

- Panel meeting for presentation of focused review does not fit with the completion date of the review or panel members having queries/questions prior to approving which means the review is returned to the reviewer for additional information and requires re-submission to panel.
- LAC capacity or being on annual leave/absent when the review is submitted.

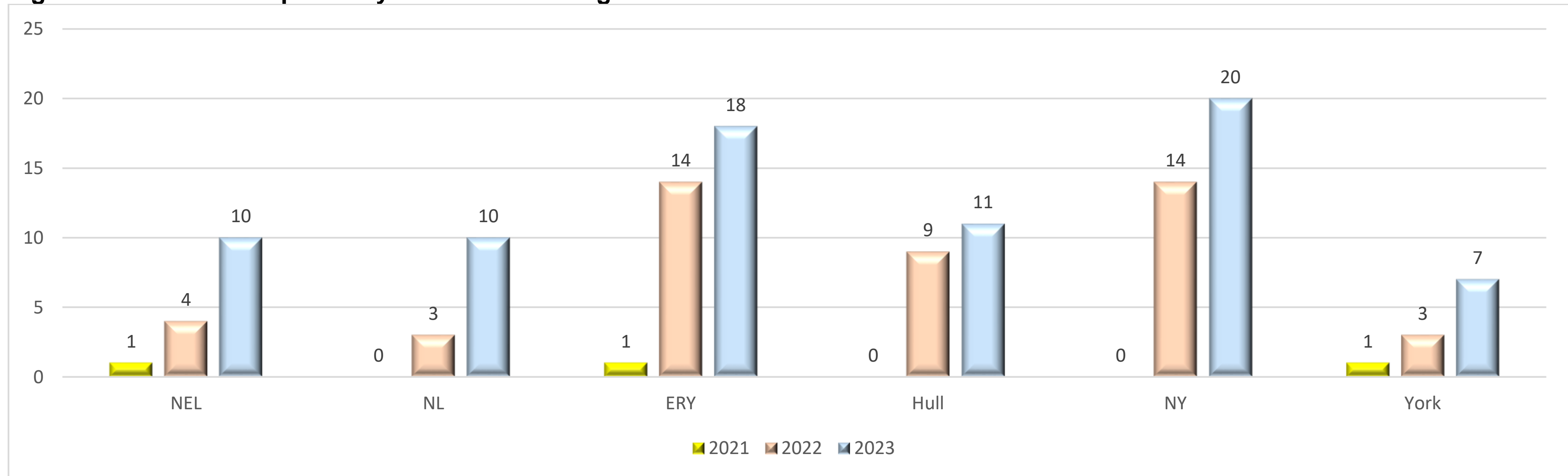
In order to improve the timeliness with approval of reviews a number of actions have been taken commencing in quarter 1 2024/2025:

- Reviewers provided with a deadline for completion of initial reviews which should allow time for those which require conversion to a focused review to still be completed within the required timeframe.
- Reviewers provided with a deadline for completion of focused reviews in order for them to be presented and approved at panel within the completed timeframe.

Further consideration during quarter 1, 2024/2025 is for the two LACs to work collaboratively to approve any review submitted regardless of Place area (currently x1 LAC has responsibility for the Humber review process and x1 LAC has responsibility for the NY and York review process). This should reduce any slippage in the approval process due to a LAC being on annual leave or absent.

Figure 4 below shows the number of reviews completed by each Place during 2023/2024 from year of notification.

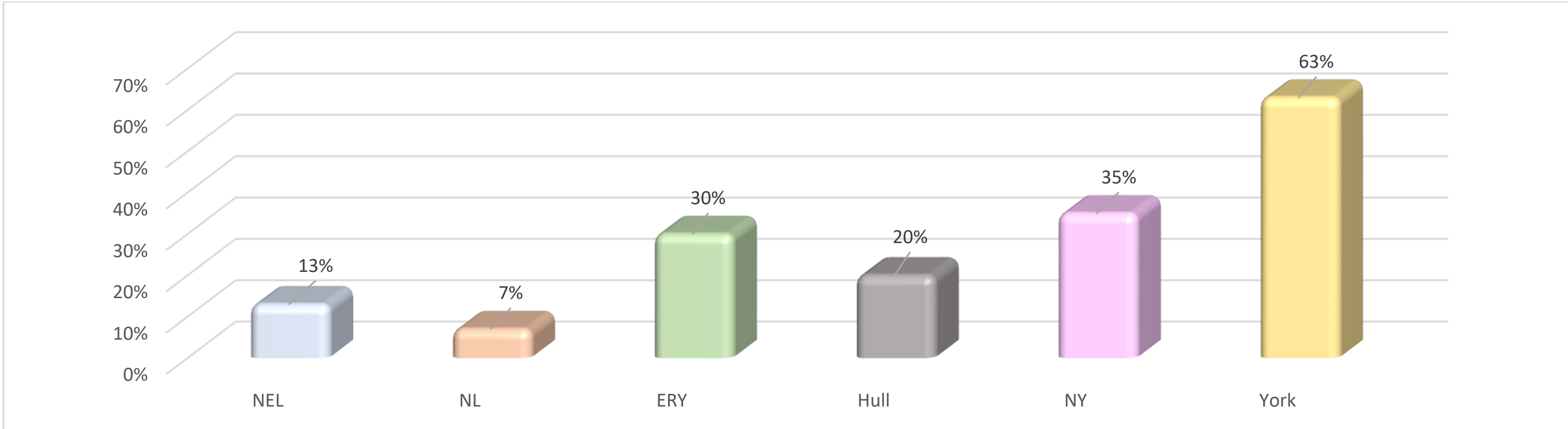
Figure 4: Reviews Completed by each Place During 2023 - 2024 from Year of Notification



Of the 126 initial reviews completed, 36 (28%) were identified as requiring a focused review to be completed (a more in depth look at the individual's life and death) (14 focused reviews (16.4%) completed during 2022/2023). Whilst an increase in the number of completed focused reviews is noted, this remains under the 35% expected by NHSE.

Figure 5 below shows the number of focused reviews completed as a percentage by each Place across the Humber and North Yorkshire Health and Care Partnership for the time period 1st April 2023 - 31st March 2024.

Figure 5: Focused Reviews Completed by Place 1st April 2023 – 31st March 2024

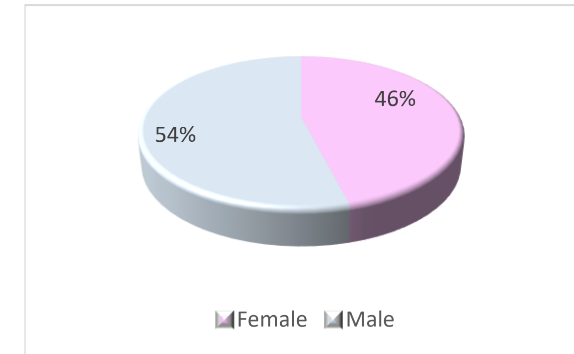


5.0 Themes and Trends

5.1 Gender of Individuals from Reported Deaths 1st April 2023 - 31st March 2024

	Gender	
	Female	Male
= 116	53	63
%	**46%**	**54%**

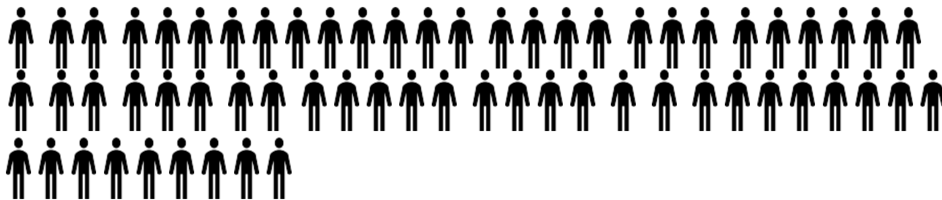
Gender Comparison



Of the 116 deaths sadly reported by the six Places 1st April 2023 - 31st March 2024:

- The individual's gender was reported within the notification in all deaths.
- 53 of the individuals identified as female (46%).

- 63 of the individuals identified as male (54%).



- The gender comparison of individuals whose deaths were notified within the Humber and North Yorkshire Health and Care Partnership 1st April 2023 - 31st March 2024, was very slightly higher for females and very slightly lower for males to that of the national picture as reported within the LeDeR Annual report 2022.

Within the Learning from lives and deaths – People with a learning disability and autistic people Annual Report 2022 (www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities) which covered deaths notified to the programme during 2022, the reported genders were:

- 55% identified as male.
- 45% identified as female.

5.1.2 Gender of Individuals from Reported Deaths Humber and North Yorkshire Places 1st April 2023 - 31st March 2024

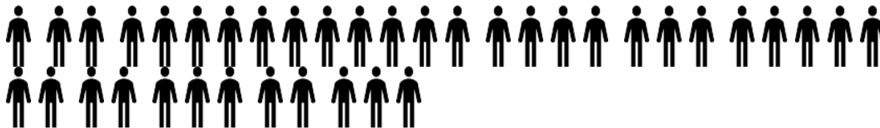
Humber Places

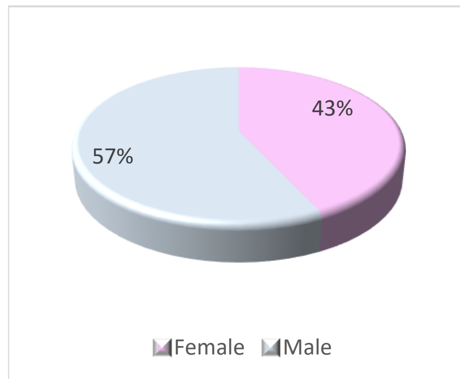
	Gender	
	Female	**Male**
N = 67	29	38
%	**43%**	**57%**

Of the 67 deaths reported by the four Places within the Humber:

- 29 of the individuals identified as female (43%).

- 38 of the individuals identified as male (57%).





The gender comparison of individuals whose deaths were notified within the Humber 1st April 2023 - 31st March 2024, was slightly higher for males and slightly loser for females to that of the national picture (as reported within the National LeDeR Annual report 2022).

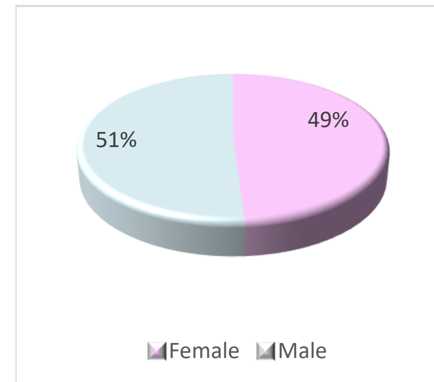
North Yorkshire Places

	Gender	
	Female	**Male**
N = 49	24	25
%	**49%**	**51%**

Of the 49 deaths reported by the two Places within North Yorkshire:

- 24 of the individuals identified as female (49%).

- 25 of the individuals identified as male (51%).

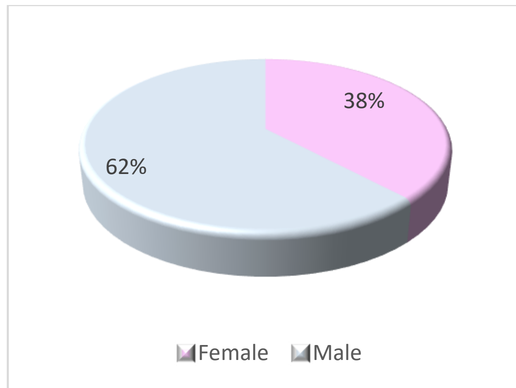


The gender comparison of individuals whose deaths were notified within North Yorkshire 1st April 2023 - 31st March 2024, was lower for males and higher for females to that of the national picture (as reported within the National LeDeR Annual report 2022).

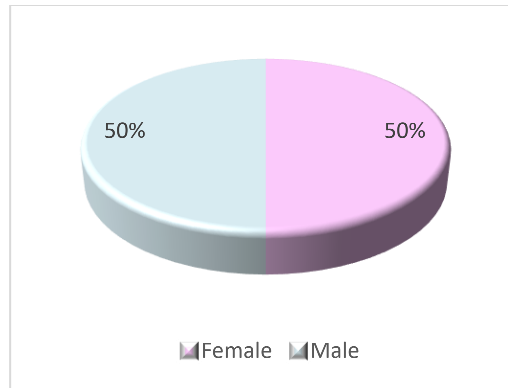
5.1.2 Gender of Individuals from Reported Deaths by Individual Place 1st April 2023 - 31st March 2024

The below charts show the gender comparison within each Place for reported deaths from 1st April 2023 - 31st March 2024.

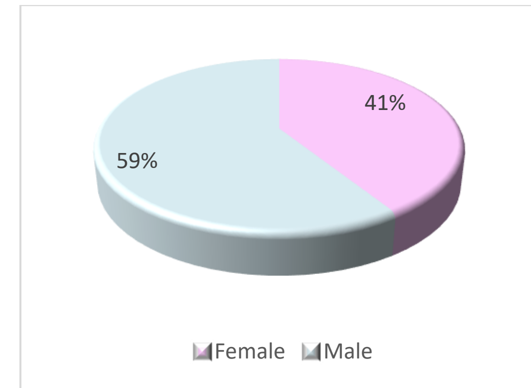
North East Lincolnshire Place



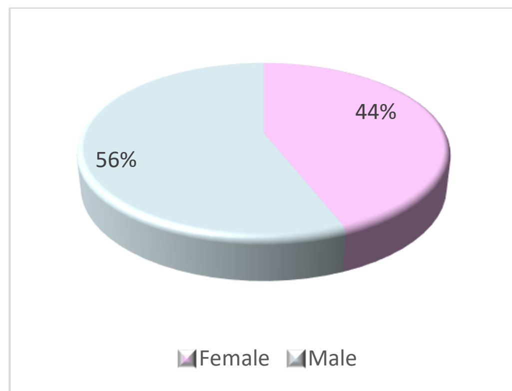
North Lincolnshire Place



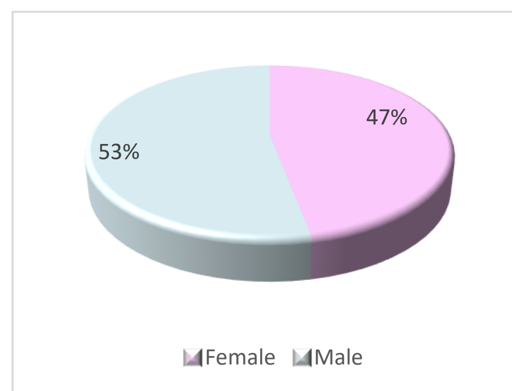
East Riding of Yorkshire Place



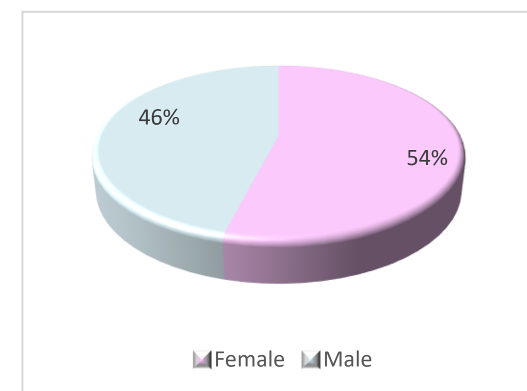
Hull Place



North Yorkshire Place



York Place



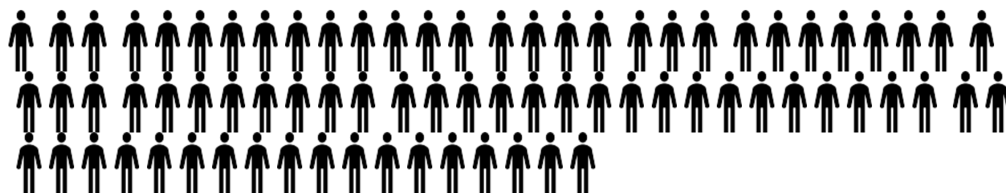
5.2 Gender of Individuals from Completed Reviews 1st April 2023 – 31st March 2024

	Gender	
	Female	Male
N = 126	49	77
%	**39%**	**61%**

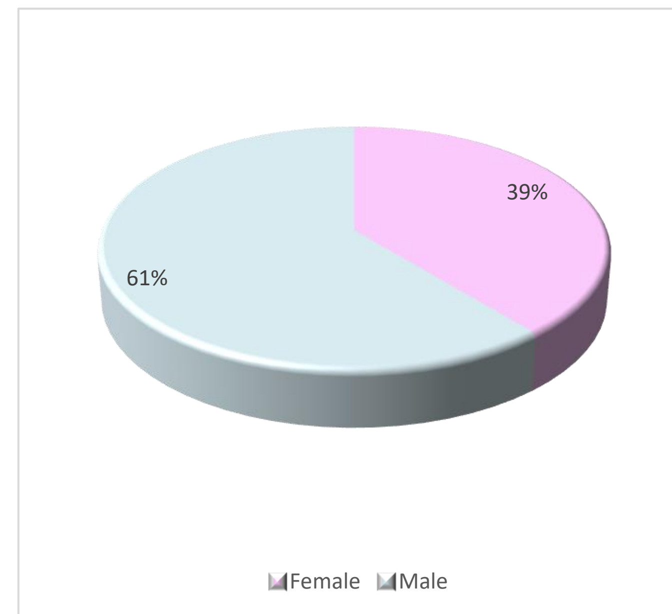
Of the 126 deaths reported by the six Places 1st April 2023 - 31st March 2024:

- 49 of the individuals identified as female (43%).

- 77 of the individuals identified as male (61%).



Gender Comparison



5.2.1 Gender of Individuals from Completed Reviews Humber and North Yorkshire Places 1st April 2023 - 31st March 2024

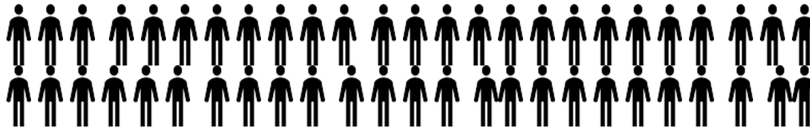
Humber Places

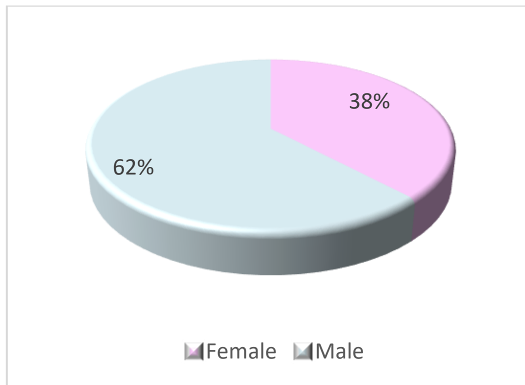
	Gender	
	Female	**Male**
N = 81	31	50
%	**38%**	**62%**

Of the 81 reviews completed by the four Places within the Humber:

- 31 of the individuals identified as female (52%).

- 50 of the individuals identified as male (48%).





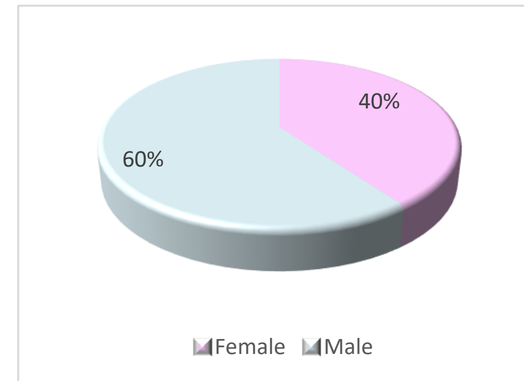
North Yorkshire Places

	Gender	
	Female	**Male**
N = 45	18	27
%	**40%**	**60%**

Of the 41 reviews completed by the two Places within North Yorkshire:

- 16 of the individuals identified as female (40%).

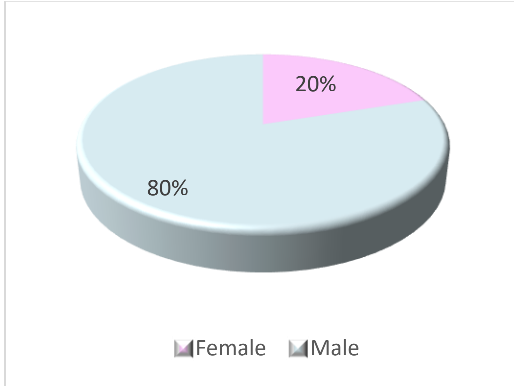
- 27 of the individuals identified as male (60%).



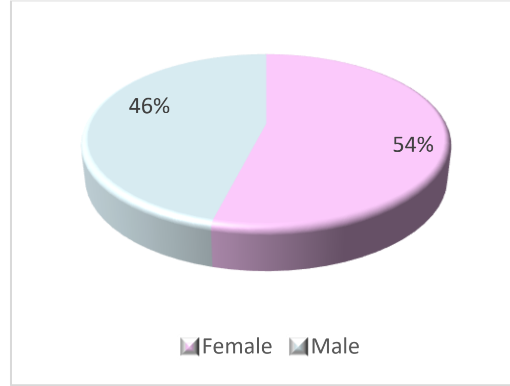
5.2.2 Gender of Individuals from Completed Reviews by Individual Place 1st April 2023 - 31st March 2024

The below charts show the gender comparison within each Place for completed reviews 1st April 2023 - 31st March 2024.

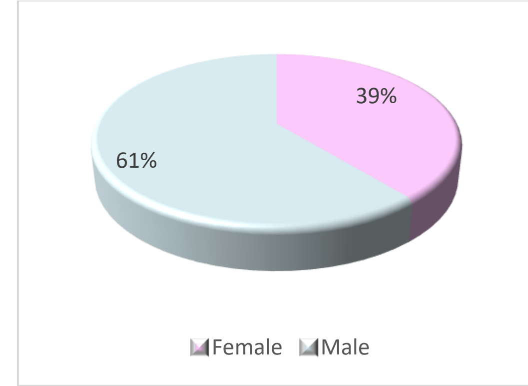
North East Lincolnshire Place



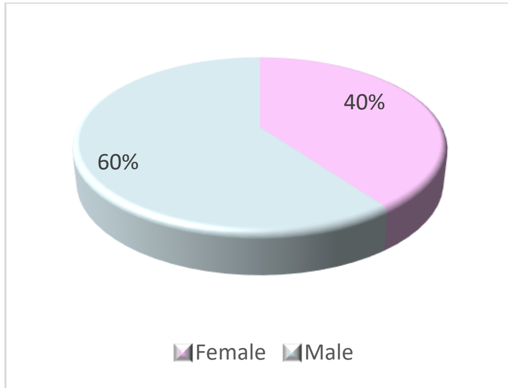
North Lincolnshire Place



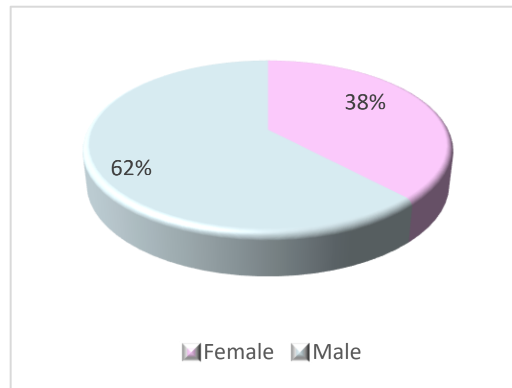
East Riding of Yorkshire Place



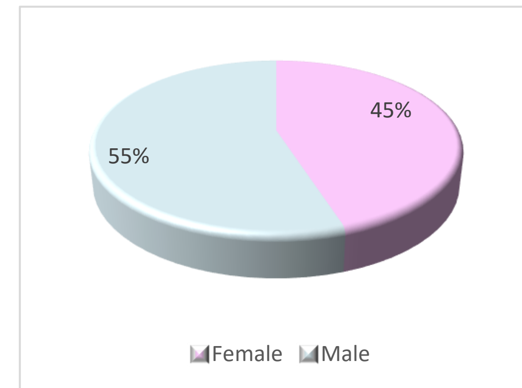
Hull Place



North Yorkshire Place



York Place



Themes and Trends

5.3 Ethnicity of Individuals

Historically, our ICS has received extremely small numbers of notifications to the LeDeR programme over the past three years for individuals who are from our non-white British communities, and subsequently extremely low numbers of completed reviews. Due to this and to ensure confidentiality is not breached, exact numbers have not been included within this year's annual report.
What we are aware of is:

- Notifications relating to our residents across the ICS who are within the cohorts of non-white British are lower than that of the national picture, which identified within the 2022 LeDeR annual report that 94% of people with a learning disability who died in 2022 were denoted as white.

- The 2021 census identifies that 95.3% of the population of the Humber and North Yorkshire ICS identify as white British, therefore whilst we would not expect large numbers of notifications from other cohorts, we cannot currently be fully assured that all individuals who sadly pass away from within our non-white British communities have their death notified to the LeDeR programme.

- Challenges have continued during 2023/2024 to be able to break down the data to be fully cited on the number of individuals of non-white British ethnicity/ minority groups who have a learning disability.

- This is also being looked at by NHS England regionally, with attempts to overlay ethnicity linked in with the learning disability registers.

- Further work is required during 2024/2025 in order to be able to better understand our populations ethnic backgrounds.

Themes and Trends

5.4 Age of Individuals at Time of Death: Reported Deaths 1st April 2023 - 31st March 2024

Of the 116 individuals whose deaths were reported 1st April 2023 - 31st March 2024:

- The age range was 21-91 years.
- The mean average age of death was 61.5 years (60.1 years within 2022-2023 ICB annual report).
- The median age of death was 63 years (62.5 years within 2022-2023 ICB annual report).

In relation to those individuals who were female:

- The age range was 21-84 years.
- The mean average age of death was 59 years (63.2 years within 2022/2023 ICB annual report).
- The median age of death was 63 years (62.5 years within 2022/2023 ICB annual report).

In relation to those individuals who were male:

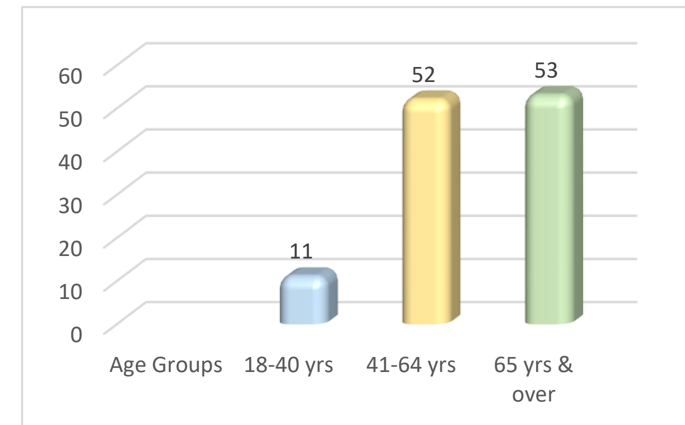
- The age range was 30-91 years.
- The mean average age of death was 64 years (58.7 years within 2022/2023 ICB annual report).
- The median age of death was 57.5 years (62 years within 2022/2023 ICB annual report).

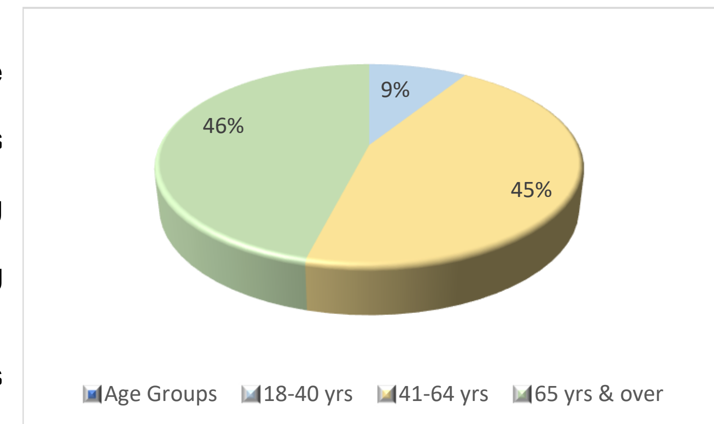
The median age at the time of death for individuals with a learning disability across the 6 Places, was slightly higher than within the 2022-2023 ICB annual report and as a comparator to the national picture was:

- Comparable with the national picture of 62.9 years for deaths reported during 2022 (as identified within the national report).
- Comparable with the national picture of 62.9 years for females for deaths reported during 2022 (as identified within the national report).
- Comparable with the national picture of 62.9 years for males for deaths reported during 2022 (as identified within the national report).

The median age at death in the general population was 86.1 years for females and 82.6 years for males in 2018-2020 (latest data available as reported within the national report).

Age at Death - Reported Death





Themes and Trends

5.4.1 Age of Individuals at Time of Death: Reported Deaths, Humber and North Yorkshire Places 1st April 2023-31st March 2024

Humber Places

Of the 67 individuals whose deaths were reported within the Humber Places 1st April 2023 -31st March 2024:

- The age range was 26-91 years.
- The mean average age of death was 64.5 years.
- The median age of death was 69.5 years.

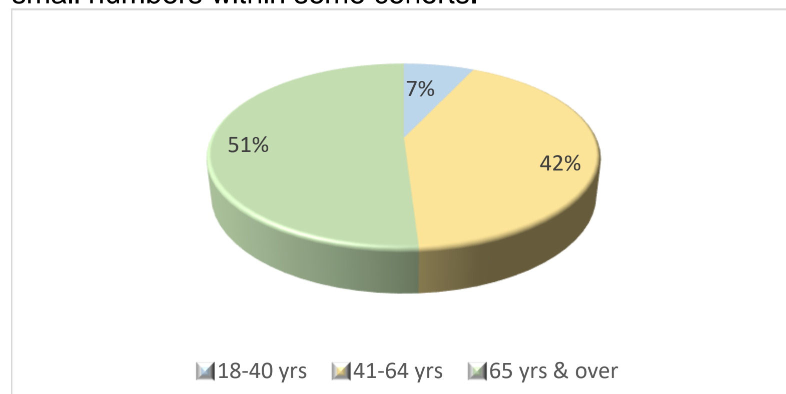
In relation to those individuals who were female:

- The age range was 26-84 years.
- The mean average age of death was 61.4 years.
- The median age of death was 64 years.

In relation to those individuals who were male:

- The age range was 30-91 years.
- The mean average age of death was 65.3 years.
- The median age of death was 69.5 years.

Chart below shows the age range as a percentage due to small numbers within some cohorts.



North Yorkshire Places

Of the 49 individuals whose deaths were reported within North Yorkshire Places 1st April 2023 -31st March 2024:

- The age range was 21-84 years.
- The mean average age of death was 60.6 years.
- The median age of death was 62 years.

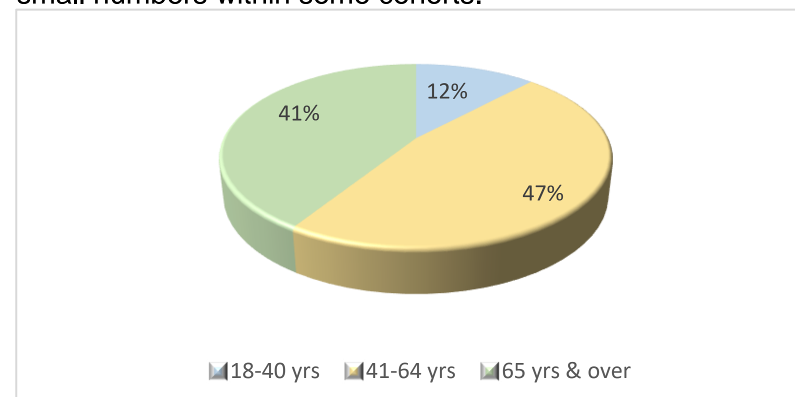
In relation to those individuals who were female:

- The age range was 24-77 years.
- The mean average age of death was 56.2 years.
- The median age of death was 61 years.

In relation to those individuals who were male:

- The age range was 35-84 years.
- The mean average age of death was 56.2 years.
- The median age of death was 62 years.

Chart below shows the age range as a percentage due to small numbers within some cohorts.

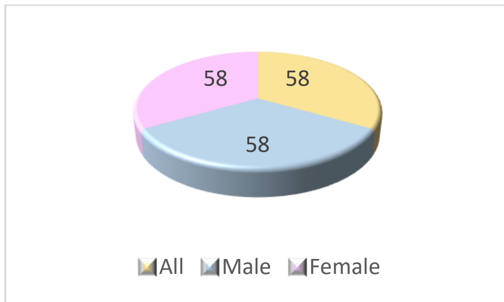


Themes and Trends

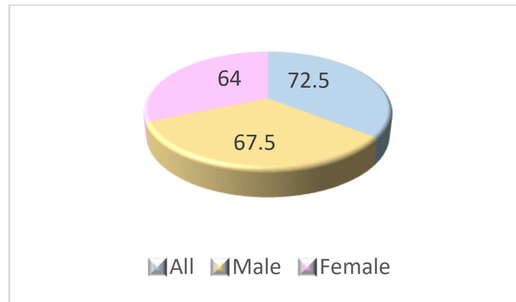
5.4.2 Median Age of Individuals at Time of Death: Reported Deaths: Individual Place 1st April 2023 - 31st March 2024

The below charts show the median age of individuals at the time of death for reported deaths within each Place 1st April 2023 - 31st March 2024.

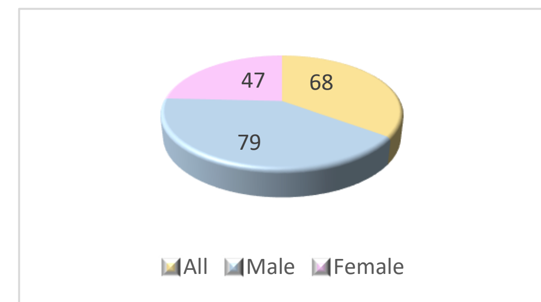
North East Lincolnshire Place



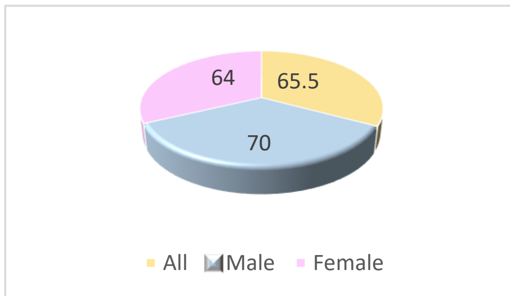
North Lincolnshire Place



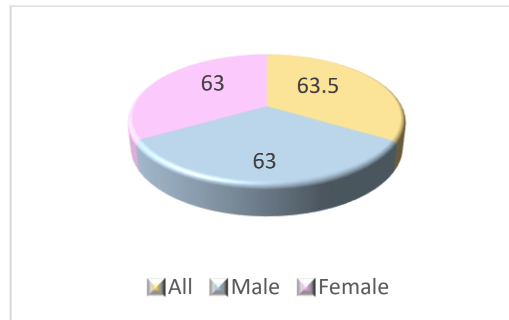
East Riding of Yorkshire Place



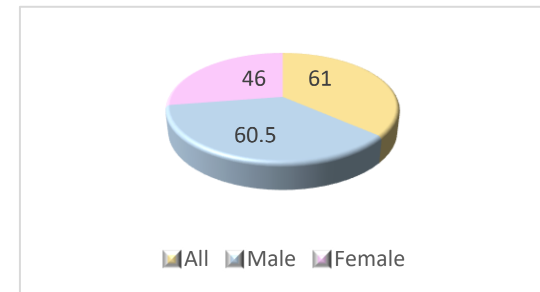
Hull Place



North Yorkshire Place



York Place



Themes and Trends

5.5 Age of Individuals at Time of Death: Completed Reviews 1st April 2023 - 31st March 2024

For the 126 completed reviews during the time period 1st April 2023 - 31st March 2024:

- The age range was 21-91 years.
- The mean average age of death was 63.2 years (75 years within the 2022/2023 ICB annual report).
- The median age of death was 76.5 years (61 years within the 2022/2023 ICB annual report).

In relation to those individuals who were female:

- The age range was 21 -88 years.
- The mean average age of death was 61.2 years (63.2 years within the 2022/2023 ICB annual report).
- The median age of death was 62 years (62.5 years within the 2022/2023 ICB annual report).

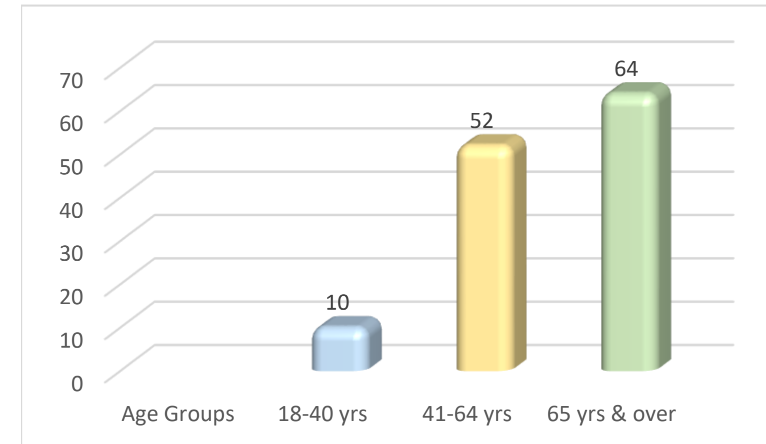
In relation to those individuals who were male:

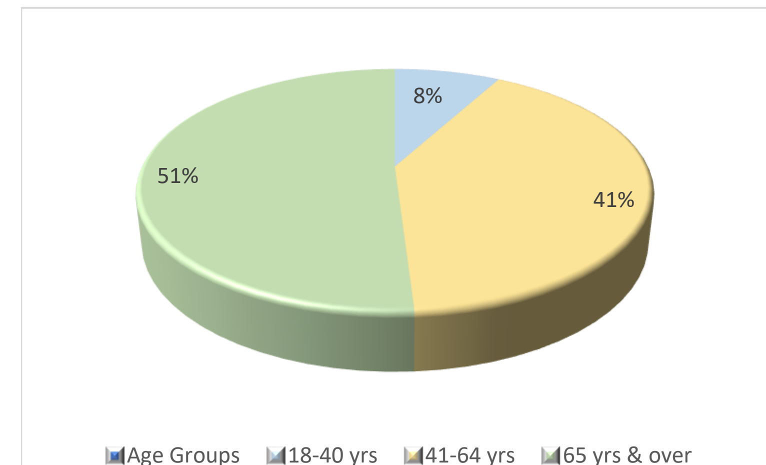
- The age range was 23-91years.
- The mean average age of death was 64.4 years (56.7 years within the 2022/2023 ICB annual report).
- The median age of death was 67 years (60.5 years within the 2022/2023 ICB annual report).

The average life expectancy in the Yorkshire and Humber region in England 2020-2022 (latest data available) was 81.9 years for females and 77.9 years for males: www.ons.gov.uk

The average life expectancy nationally in England 2020-2022 (latest data available) was 82.6 years for females and 78.6 years for males: www.ons.gov.uk

Age at Death – Completed Reviews





Themes and Trends

5.5.1 Age of Individuals at time of Death: Completed Reviews, Humber and North Yorkshire Areas 1st April 2023 - 31st March 2024

Humber Places

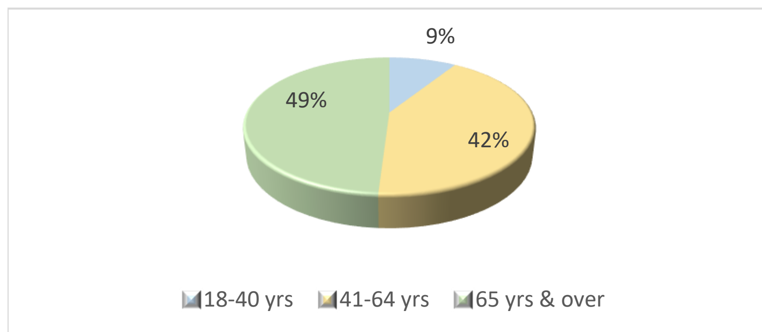
Of the 81 reviews completed for individuals who resided within the Places of the Humber:

- The age range was 23-91 years.
- The mean average age of death was 62.8 years.
- The median age of death was 64 years.

In relation to those individuals who were female:
- The age range was 23-91 years.
- The mean average age of death was 62.1 years.
- The median age of death was 62 years.

In relation to those individuals who were male:
- The age range was 23-82 years.
- The mean average age of death was 63.2 years.
- The median age of death was 67 years.

Chart below shows the ages ranges as percentages due to small numbers within some cohorts.



North Yorkshire Places

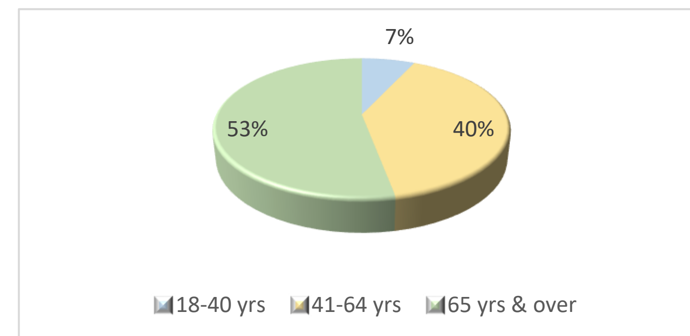
Of the 45 reviews completed for individuals who resided within the Places of North Yorkshire:

- The age range was 21-86 years.
- The mean average age of death was 63.9 years.
- The median age of death was 65 years.

In relation to those individuals who were female:
- The age range was 21-81 years.
- The mean average age of death was 59.6 years.
- The median age of death was 61.5 years.

In relation to those individuals who were male:
- The age range was 41-86 years.
- The mean average age of death was 66.7 years.
- The median age of death was 67 years.

Chart below shows the ages ranges as percentages due to small numbers within some cohorts.

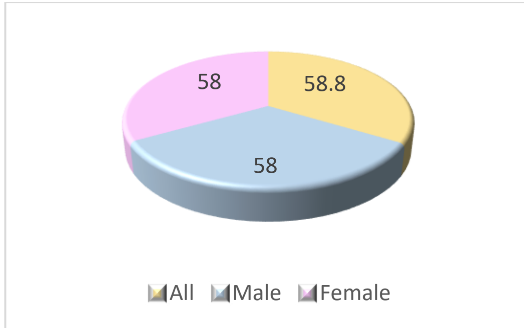


Themes and Trends

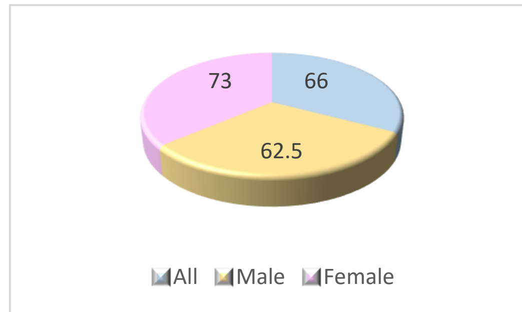
5.5.2 Median Age of Individuals at Time of Death: Completed Reviews, Individual Places 1st April 2023 - 31st March 2024

The below charts show the median age of individuals at time of death for completed reviews within each Place 1st April 2023 - 31st March 2024.

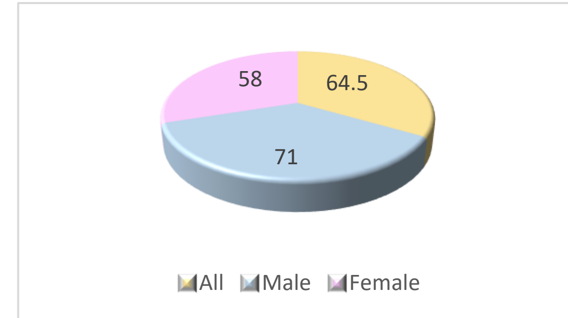
North East Lincolnshire Place



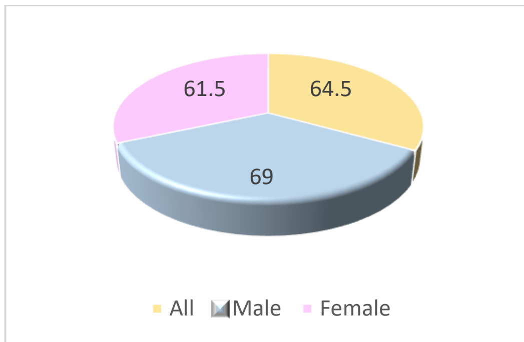
North Lincolnshire Place



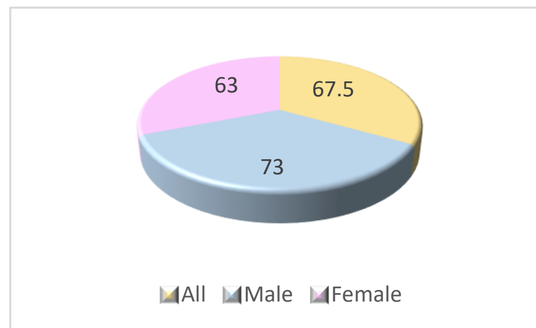
East Riding of Yorkshire Place



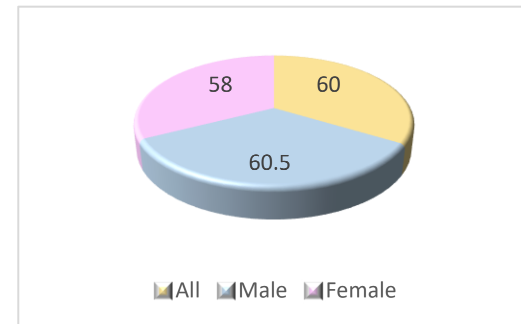
Hull Place



North Yorkshire Place



York Place

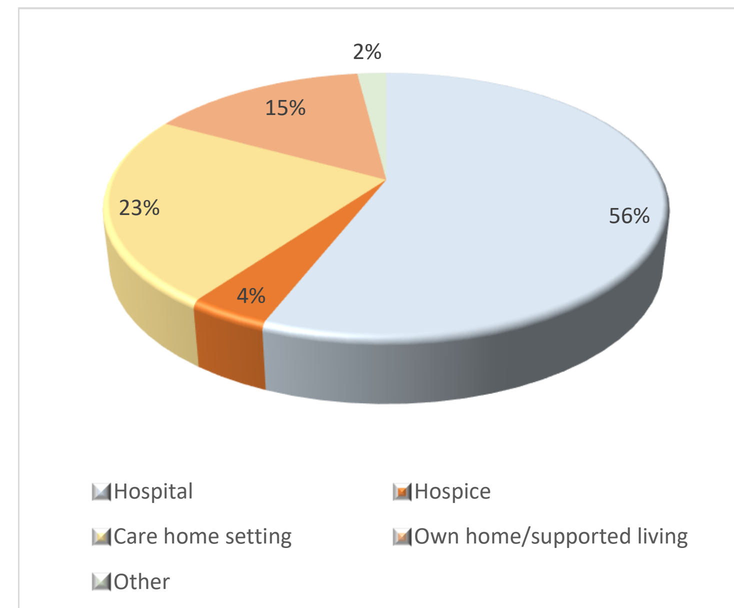


Themes and Trends

5.6 Place of Death: Reported Deaths 1st April 2023 – 31st March 2024

Place of Death		
N=116		**%**
Hospital	65	56%
Hospice	5	4%
Residential/Nursing home setting	27	23%
Own home/supported living	17	15%
Other	2	2%

Place of Death – Reported Deaths



Of the 116 deaths sadly reported during the time period 1st April 2023 - 31st March 2024:

- 65 (56%) individuals died within a hospital care setting, (45.5% within the 2022/2023 ICB annual report).
- 5 (4%) individuals died within a Hospice care setting; (5% within the 2022/2023 ICB annual report).
- 27 (23%) individuals died within a residential/nursing home setting (of which for the majority of individuals, this would be their usual place of residence), (30% within the 2022/2023 ICB annual report).
- 17 (15%) individuals died within their own home or supported living accommodation, (19.5% within the 2022/2023 ICB annual report).

The reported place of death as hospital for individuals whose death was reported 1st April 2023 - 31st March 2024, is higher at 56% than reported within the Humber and North Yorkshire 2022-2023 LeDeR Annual report of 45.5%, and comparable with the 57% as reported within the LeDeR National report for deaths which occurred during 2022.

Themes and Trends

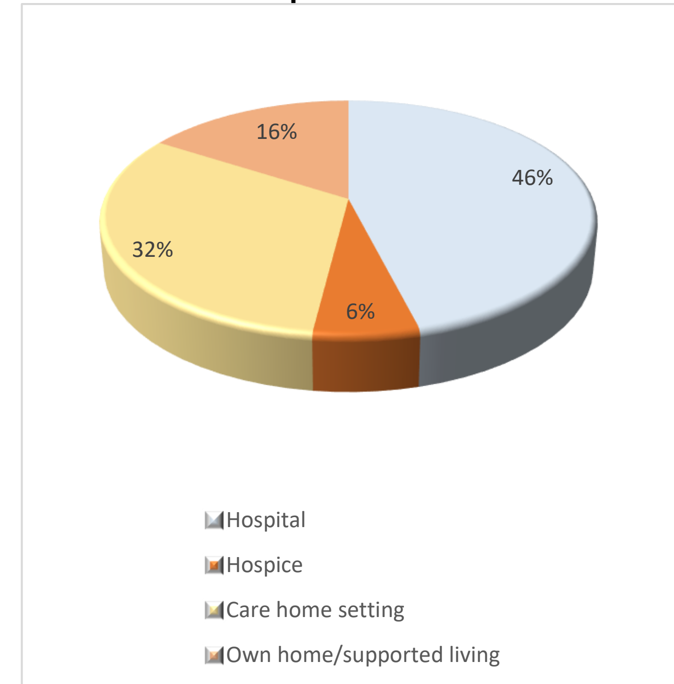
5.7 Place of Death: Completed Reviews 1st April 2023 - 31st March 2024

Place of Death		
N=126		**%**
Hospital	58	46%
Hospice	8	6%
Residential/Nursing home setting	40	32%
Own home/supported living	20	16%

Of the 126 reviews completed during the time period 1st April 2023 - 31st March 2024:

- 58 (46%) individuals died within a hospital care setting, (48% within the 2022/2023 ICB annual report).
- 8 (6%) individuals died within a Hospice care setting; (5% within the 2022/2023 ICB annual report).
- 40 (32%) individuals died within a residential/nursing home setting (of which for the majority of individuals, this would be their usual place of residence), (26% within the 2022/2023 ICB annual report).
- 20 (16%) individuals died within their own home or supported living accommodation, (21% within the 2022/2023 ICB annual report).

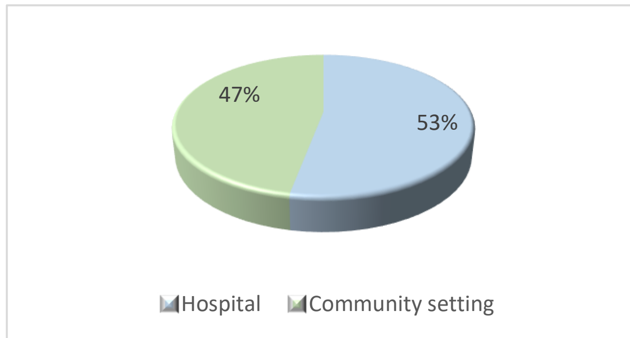
Place of Death – Completed Reviews



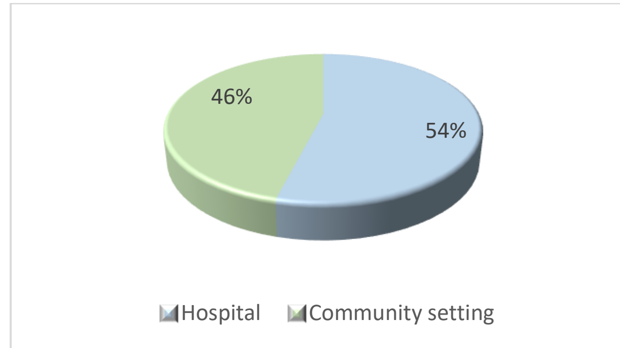
5.7.1 Place of Death: Completed Reviews by Place 1st April 2023 - 31st March 2024

The below charts show place of death from completed reviews within each Place 1st April 2023 - 31st March 2024.

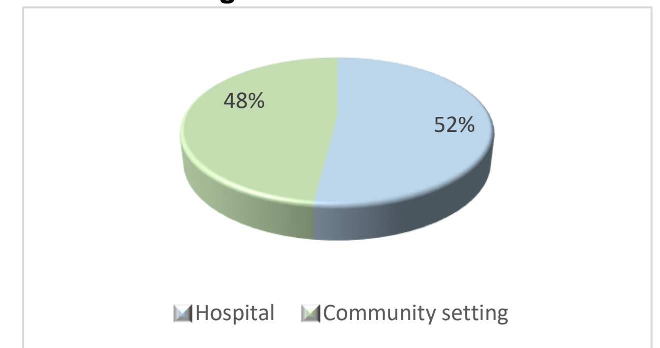
North East Lincolnshire Place



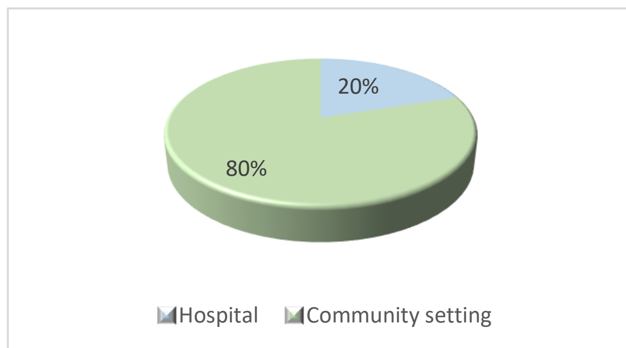
North Lincolnshire Place



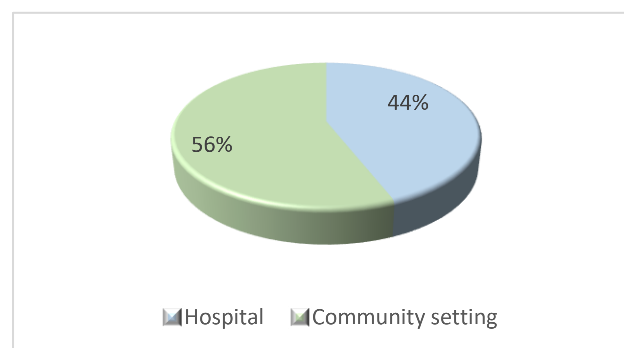
East Riding of Yorkshire Place



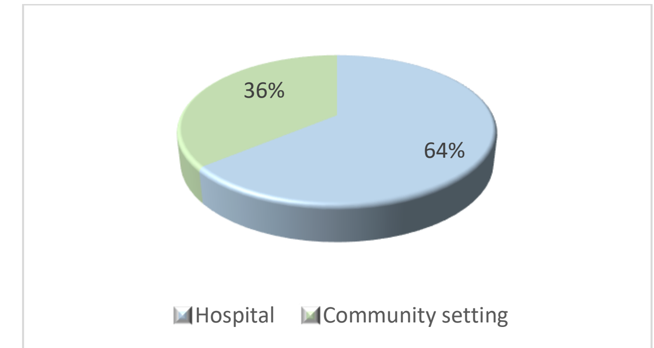
Hull Place



North Yorkshire Place



York Place



To Note: For the purposes of this section, a community setting relates to residential or nursing care home, hospice, own home or supported living accommodation.

Themes and Trends

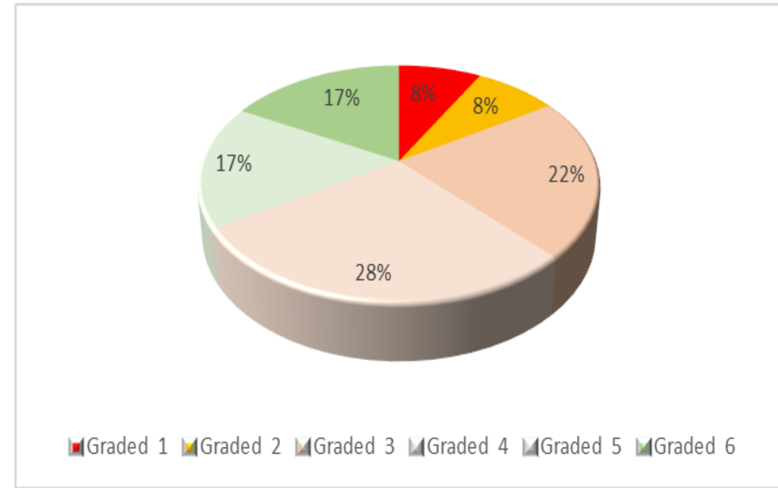
6.0 Grading of Care from Completed Focused Reviews 1st April 2023 - 31st March 2024

Within a focused review, there is a section where the reviewer is asked two questions relating to the care the individual received, and to apportion a grade for that care. The grading is based on a six-point scale as identified within the table below:

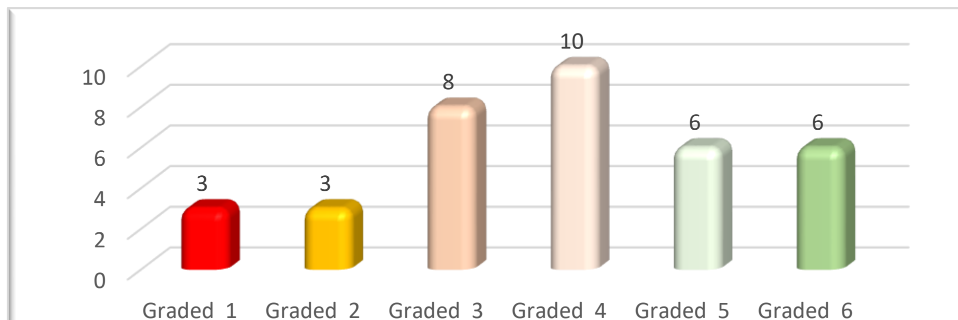
6.1 Quality of Care Person Received Based on Experience

Grade	Grade Overview
1	Care fell short of expected good practice 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
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
4	Satisfactory care (fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing
5	Good care (met expected good practice)
6	Excellent care (exceeded good practice)

Grading of Care as a Percentage



Of the 36 focused reviews completed across the Humber and North Yorkshire Health and Care Partnership, reviewers provided the following grades relating to this question:



Of the completed focused reviews, 61% were identified as a grade of 4 or above with 33% identified as good care or excellent care.

Those reviews where care was graded as 1 or 2, would be subject to investigative processes such as serious incident or safeguarding adult review where learning and actions would be identified, and completion of actions monitored by the appropriate organisation.

Themes and Trends

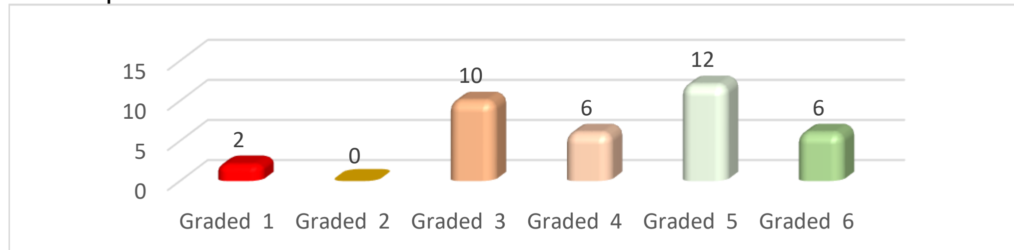
Grading of Care from Completed Focused Reviews 1st April 2023 - 31st March 2024

The second quality question reviewers are asked, relates to how available and effective services were for the person, again with a grade to be apportioned which is also based on a six-point scale.

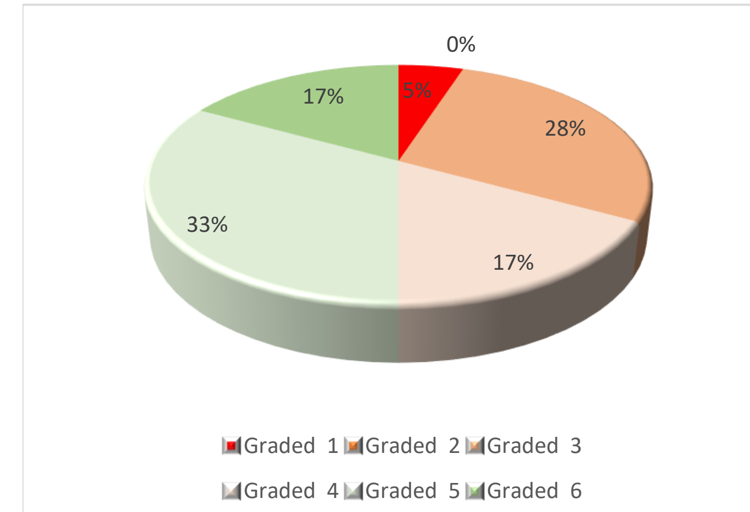
6.2 How Available and Effective Services were for the Person

Grade	Grade Overview
1	Availability and effectiveness of services fell far short of the expected standard, and this contributed to the cause of death.
2	Availability and effectiveness of services 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	Availability and effectiveness of services 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	Availability and effectiveness of services fell short of the expected standard in some areas, but this did not significantly impact on the person's wellbeing.
5	Availability and effectiveness of services was good and met the expected standard.
6	Availability and effectiveness of services was excellent and exceeded the expected standard.

Of the 36 focused reviews completed across the Humber and North Yorkshire Health and Care Partnership, reviewers provided the following grades relating to this question:



Grading as a Percentage



Of the completed focused reviews, 50% were identified as a grade of 5; with 16.6% identified as a grade of 6. As identified previously, those reviews with a grade of 1 would have been subject to serious incident or Safeguarding Adult Review, where learning and actions would be identified, and completion of actions monitored by the appropriate organisation.

Themes and Trends

7.0 Cause of Death: Completed Reviews: 1st April 2023 - 31st March 2024

This section of the report covers the cause of death as recorded on a completed Medical Certificate of Cause of Death (MCCD) for completed reviews and not the perceived cause of death for individuals whose death has not as yet been reviewed.

Within the 126 completed reviews 1st April 2023 - 31st March 2024:

- Diseases of the respiratory system were cited as the most common cause of death within 37% of completed reviews with:
  - ➢ Pneumonia accounting for 17% (increase from the 10% within the 2022/2023 ICB annual report).
  - ➢ Aspiration pneumonia accounting for 14% (increase from the 11% within the 2022/2023 ICB annual report).

- ○ Diseases of the respiratory system were also cited as the most common cause of death (32%) within the 2022/2023 ICB annual report.

- Diseases of the circulatory system were the second most common cause of death recorded within 21% of completed reviews (increase from 14% within the 2022/2023 ICB annual report).
- Cancer was the third most common cause of death recorded within 12% of completed reviews (increase from 6% within the 2022/2023 ICB annual report).

To note: Within the Humber and North Yorkshire ICS, the 3 top causes of death within the total population in 2022 were:

- ▪ Diseases of the circulatory system (26%).
- Cancer (26%).
- Diseases of the respiratory system (11%).

Within the national LeDeR Annual report (2022), the 3 most common reported deaths were:

- ▪ Diseases of the circulatory system: 16.7%.
- ▪ Cancers: 14.6%.
- ▪ Diseases of the respiratory system: 14.5%.

❖ Two of the ICB health outcome priorities for 2024/2025 are cutting cardiovascular disease and reducing harm from cancer.

A recommendation within this report is for a focused review to be undertaken for all deaths notified to the programme from 1st April 2024, where the cause of death relates to diseases of the circulatory system or cancer to align with the ICB priorities.

Other confirmed causes of death from completed reviews included:

- Sepsis 6%; (slight reduction from 7% in the 2022/2023 ICB annual report).
- Dementia and Alzheimer's disease 1% (decrease from 6% in the 2022/2023 ICB annual report).
- Natural causes 5% (remains the same as within the 2022/2023 ICB annual report).
- Epilepsy 5% (slight reduction from 7% in the 2022/2023 ICB annual report).
- Other 11% (due to multiple single numbers of differing causes, these have been identified under the umbrella of 'other' for the purposes of this report) (decrease from 15% in the 2022/2023 ICB annual report).

7.1 Cause of Death: Completed Reviews Only, Humber Places; 1st April 2023 - 31st March 2024

This section of the report covers the cause of death as recorded on a completed Medical Certificate of Cause of Death (MCCD) for completed. reviews from the Humber Places and not the perceived cause of death for individuals whose death has not as yet been reviewed.

Within the 81 completed reviews 1st April 2023 - 31st March 2024:

- Diseases of the respiratory system were cited as the most common cause of death within 35% of completed reviews across the Humber (36% within the 2022/2023 ICB annual report) with:
-
    - Pneumonia accounting for 15% (increase from 9% within the 2022/2023 ICB annual report).
    - Aspiration pneumonia accounting for 16% (increase from 11% within the 2022/2023 ICB annual report).

- Diseases of the circulatory system were the second most common cause of death recorded within 25% of completed reviews (11% within the 2022/2023 ICB annual report).

- Cancer was the third most common cause of death recorded within 10% of completed reviews (9% within the 2022/2023 ICB annual report).

Other confirmed causes of death from the completed reviews included:

- Sepsis 6% (slight reduction from the 7% in the 2022/2023 ICB annual report).
- Dementia and Alzheimer's disease 2% (reduction from the 4.5% within the 2022/2023 ICB annual report).
- Natural causes 5% (reduction from the 9% within the 2022/2023 ICB annual report).
- Epilepsy 4% (slight reduction from the 4.5% reported within the 2022/2023 ICB annual report).
- Other 10% (due to multiple single numbers of differing causes, these have been identified under the umbrella of 'other' for the purposes of this report) (slight increase from the 9% reported within the 2022/2023 ICB annual report).

7.2 Cause of Death: Completed Reviews Only, North Yorkshire Places; 1st April 2023 - 31st March 2024

This section of the report covers the cause of death as recorded on part 1 of a completed Medical Certificate of Cause of Death (MCCD) for completed reviews from the North Yorkshire Places and not the perceived cause of death for individuals whose death has not as yet been reviewed.

Within the 45 completed reviews 1st April 2023 -31st March 2024:

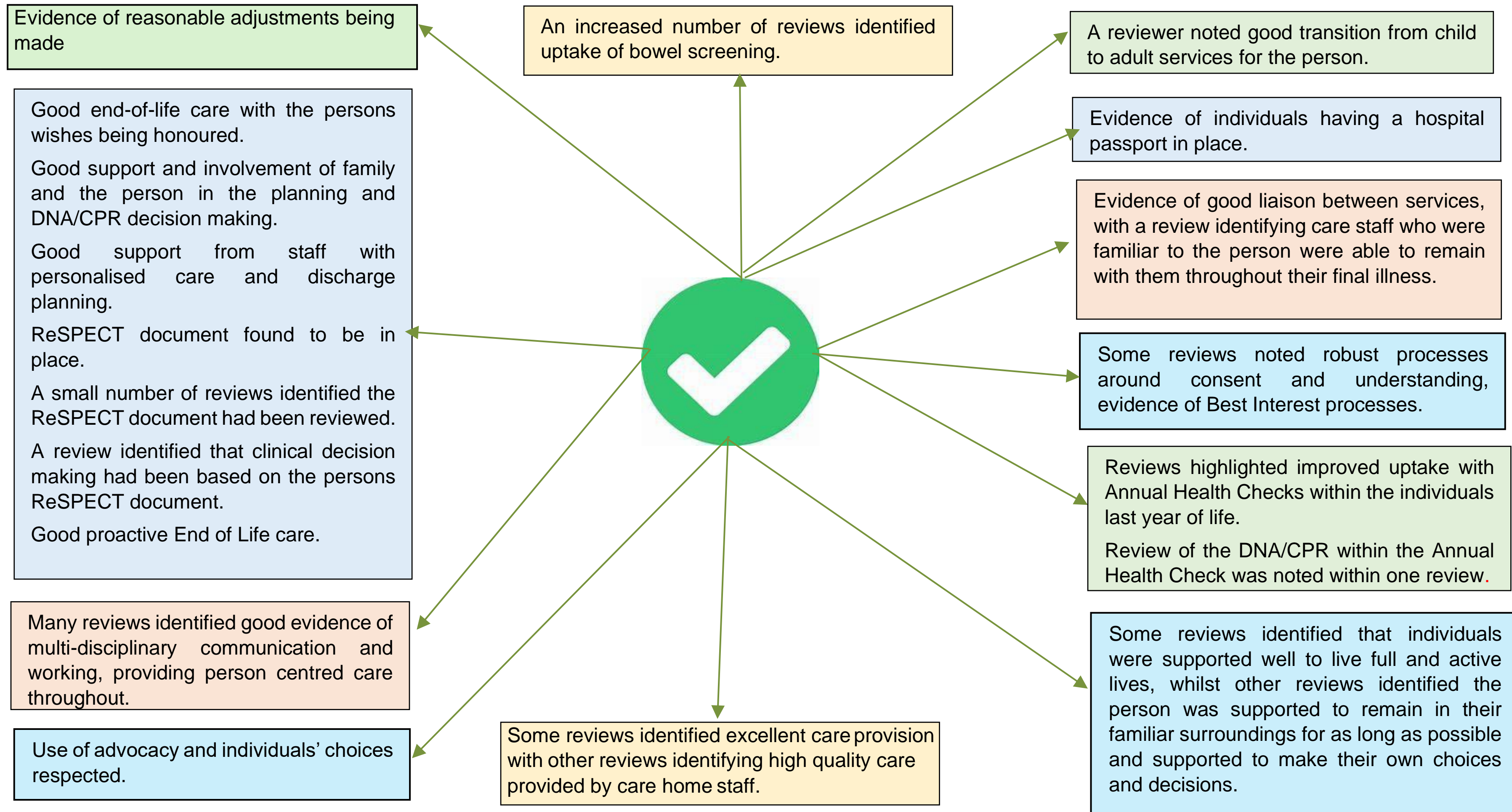
- Diseases of the respiratory system were collectively cited as the most common cause of death within 42% of completed reviews across the North Yorkshire footprint (27% within the 2022/2023 ICB annual report) with:
  - Pneumonia accounting for 22% (15% within the 2022/2023 ICB annual report).
  - Aspiration pneumonia accounting for 11% (10% within the 2022/2023 ICB annual report).
- Cancer was the second most common cause of death recorded within 15% of completed reviews (increase from 5% within the 2022/2023 ICB annual report).
- Diseases of the circulatory system were the third most common cause of death recorded within 13% of completed reviews (decrease from 17% within the 2022/2023 ICB annual report).

Other confirmed causes of death from the completed reviews included:

- Sepsis 7% (same as within the 2022/2023 ICB annual report).
- Epilepsy 4% (reduction from 10% within the 2022/2023 ICB annual report).
- Other 13% (due to multiple single numbers of differing causes, these have been identified under the umbrella of ‘other’ for the purposes of this report) (reduction from 22% within the 2022/2023 ICB annual report).

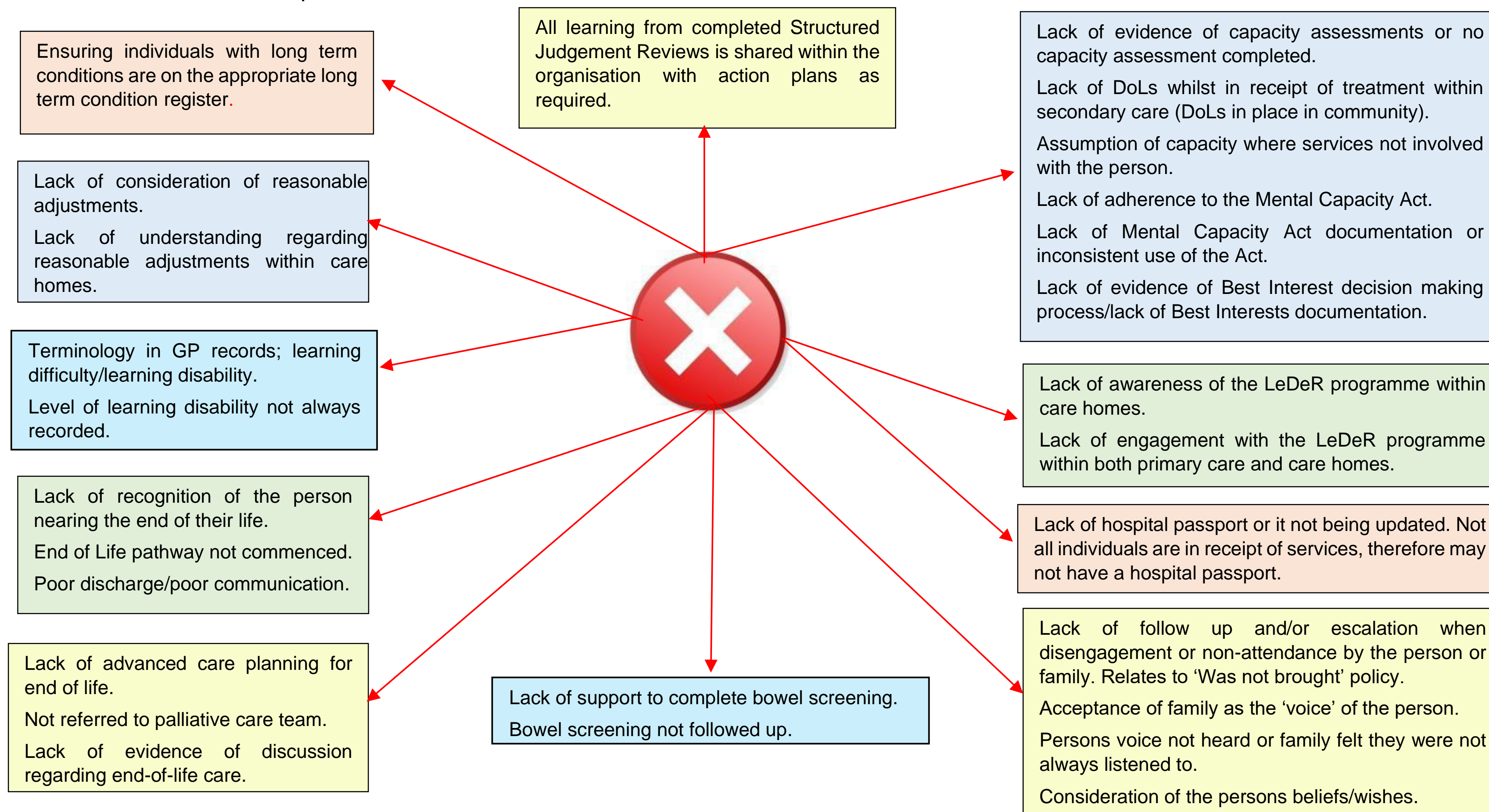
8.0 Identified Good Practice from Completed Reviews 1st April 2023 - 31st March 2024

Below are examples of areas of good practice identified from the 126 reviews completed 1st April 2023 - 31st March 2024 across the Humber and North Yorkshire Health and Care Partnership.



9.0 Identified Learning from Completed Reviews 1st April 2023 - 31st March 2024

Below are examples of the identified learning from the 126 reviews completed 1st April 2023 - 31st March 2024 across the Humber and North Yorkshire Care Partnership.



10.0 Outcomes and Achievements Against the Recommendations within the 2022/2023 Annual Report

10.1 Recommendation: To further Improve the Position across the ICS with Regard to Ensuring Individuals are Invited and Supported to Attend for an Annual Health Check (AHC).

The following is an overview of the work undertaken during 2023/2024 relating to this action by: East Riding Place, City Health Care Partnership (CHCP), Humber NHS Foundation Trust (HFT), North East Lincolnshire Place, North Lincolnshire Place, Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), North Yorkshire and York Transforming Care Partnership (NY&Y TCP), North Yorkshire Place, York Place, Harrogate and District NHS Foundation Trust (H&DFT).

Humber area:

- ERY Place provide monthly reports to all Primary Care Networks (PCNs), with areas which fall below the Place average offered support. Raising awareness of the AHC with care providers through the Specialist Provider forum. Bridlington PCN has achieved 90% completion of AHCs and made progress in increasing register sizes. There will continue to be a focus on this area during the coming year. A pilot project has also been undertaken testing integrated health, social care plans and personal budgets. The AHC and social care review is completed at the same time.
- CHCP Wellbeing Primary Care Liaison Service (WPCLS) have supported Hull PCNs in completion of health checks and also to plan additional resources required for delivery of AHC clinics following an increase within learning disability registers. Provision of support to practices in reducing the number of individuals who 'Do Not Attend' (DNA). Development and distribution of a number of bespoke resources to aid effective communication between patients/carers and professionals alongside development of a pre-screen AHC questionnaire and a Health Action Plan for sharing with patients to improve the quality of the AHC.
- HFT have worked jointly with Primary Care to support Annual Health Checks, undertaking desensitisation and specialist phlebotomy clinics to aid adjustments for individuals. WPCLS work jointly with the Community Learning Disability Team (CLDT) in Hull to support access to AHCs and health action plans, with the specialist Dr undertaking joint AHCs with GPs in Hull for some individuals with profound learning disabilities.
- NEL Place have worked with partners to actively monitor and promote uptake of AHCs. Young people have produced a video for use in schools, colleges, GP screens and websites. There have also been targeted promotions with children's services and work with special schools to increase the number of 14 - 18-year-olds receiving an AHC. Work on a 'buddy scheme has also taken place; a partnership with the CLDT and Foresight to support individuals to complete a pre AHC questionnaire, hospital passport, access to AHCs and provision of information and advice.
- NL Place have validated GP learning disability registers, with work completed with practices to highlight potential patients who could be added. The local authority active lifestyle team has worked in partnership to hold an engagement event and build awareness of the health check for individuals who use council services whilst encouraging families to speak with their GP regarding the Health Check. NL Place local authority also produced two short films (x1 in conjunction with a local drama group for adults with learning disabilities and autism).
- RDaSH have delivered training to GP practices regarding Annual Health Checks and offer support to anyone who GPs identify has having not attended in order for them to attend.

North Yorkshire Area:

- NY&Y TCP provide monthly updates to PCNs in North Yorkshire on their AHC and Health Action Plan (HAP) performance. They are currently in the process of including York PCNs to this workstream. They have developed a Sharepoint site which includes useful resources and Easy Read documents for primary care colleagues in relation to AHCs, with recordings of AHC training sessions which have been delivered available for staff to view. AHCs are also featured within their Living Well newsletter.
  Work is underway to develop a Multi-disciplinary Team (MDT) strategy with primary care, local authorities and CLDT with regard to learning disability register validation. They have developed health and wellbeing workshops (co-developed) which will be co-delivered by self-advocates and families/carers. AHC awareness will form part of these workshops which will take place during the summer.
- NY Place and York Place have developed a Primary Care Community of Practice to create a forum where colleagues can share practice, seek information and guidance alongside other things. Links are also being made with groups and communities from non-white British ethnic backgrounds to understand health inequalities.
- H&DFT children's learning disability nurses have amended their initial assessment document to identify if a young person (aged 14+) receives their AHC. As the young person (on caseload) approaches their 14th birthday, they receive information regarding the AHC (as do their family and carers). The nurses have also provided teaching sessions to 6th form students in a local specialist provision which includes information on AHCs, health passports, records flagging, health promotion and improving health literacy. There are plans for this to be rolled out to other local specialist provision.

- **Year-end position for uptake of Annual Health Checks for each Place:**
  - North Lincolnshire: 73.3%;(under the NHSE trajectory of 75%).
  - North East Lincolnshire: 74.5%; (just under the NHSE trajectory of 75%).
  - Hull Place: 72.9%; (under the NHSE trajectory of 75%).
  - East Riding of Yorkshire Place: 81.4%; (exceeding the NHSE trajectory of 75%).
  - North Yorkshire Place: 81.9%; (exceeding the NHSE trajectory of 75%).
  - York Place:78.3%; (exceeding the NHSE trajectory of 75%).

10.2 Recommendation: For all providers to ensure staff within health and social care receive training in respect of their responsibilities in ensuring Compliance with the Mental Capacity Act (2005), Deprivation of Liberty Safeguard (DoLs) Documentation and the use of Best Interest Meetings with Robust Documentation.

The following is an overview of the work undertaken during 2023/2024 relating to this action by: Northern Lincolnshire and Goole NHS Foundation Trust (NLaG), Hull University Teaching Hospitals Trust (HUTH), Humber Foundation Trust (HFT), North East Lincolnshire Place, York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT)

Humber Area:

- NLaG are in the process of reviewing and revising training for MCA, DoLS and Best Interests to include different levels of training dependent on individual staff roles. The Trust also have two further staff who have completed the Best Interest Assessor training.
- HUTH have required all clinical staff to complete MCA and DoLs training on appointment, with refresher training 3 yearly. The national Oliver McGowan training package is hosted on the Trust training platform, which provides unlimited access and is fully trackable. This is ready to launch once Tier 1 and 2 are available. Currently there is one approved trainer with a further individual identified to complete the training to become an approved facilitator.
- HFT have mandated training across their clinical workforce.
- NEL P provide regular MCA/DoLs training through the local authority with specific sessions delivered by experts in NEL to consider the presumption of capacity, managing care refusals alongside the embedded DoLs and Best Interest Assessor Framework.

North Yorkshire Area:

- Y&SFT have reviewed their Training Needs Analysis (TNA) for staff completing MCA and DoLs training. There has been a formal training overview offer available from April 2023 providing bespoke training packages.
- H&D FT have developed and implemented electronic Best Interest documentation to guide clinicians through the process. This has enabled greater exploration of specific areas where applicable. A DoLs audit was undertaken during quarter 1 2023/2024 which showed areas of good practice and some areas for further development. Actions included review of the MCA training needs analysis to ensure that those completing a DoLs authorisation have received the appropriate level of training.

10.3 Recommendation: Ensuring Individuals with a Learning Disability have Equal Access to Health Screening, Follow Up and Support.

The following is an overview of the work undertaken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Hull Place, North East Lincolnshire Place, Humber NHS Foundation Trust (HFT), Hull University Teaching Hospitals Trust (HUTH), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), North Yorkshire and York Transforming Care Partnership (NY&YTCP).

Humber Area:

- CHCP WPCLS have delivered a number of roadshows to raise awareness to individuals on key health initiatives such as: heart health, mental health awareness, bowel health and healthy relationships. The roadshows were delivered across Hull and included day services and supported living environments. When working with professionals, the WPCLS share different reasonable adjustment methods to aid effective engagement with the client cohort. These have been shared through training sessions, attendance at local events and via the wellbeing newsletter. In addition to this, the service created and distributed a cancer screening guide which included a number of easy read resources, videos, and communication aids to share with patients.
- Hull Place early cancer diagnosis PCN DES has enabled innovative work within primary care; bowel screening, breast screening project which has been highlighted through the cancer alliance.
- NEL Place have screening uptake as part of the learning disability Health Check task and finish group, this will also be part of the Health Action Plan audit planned for 2024/2025. The health and wellbeing team are actively involved in supporting the bowel screening program and are able to offer support to enable the individual to complete the test if required.
- HFT have provided individual work to assist with access to screening programmes including desensitisation/social stories. HUTH have a 'Was not brought Policy' in development with a pilot project well underway to assist in operationalisation of the policy once approved.
- RDaSH have been working with NHS England regarding the bowel screening project for anyone eligible and who has a learning disability. They have seen a good uptake regarding this and provided support to a large number of individuals.

North Yorkshire Area:

- NY&Y TCP have developed health and wellbeing workshops (which are co-developed and will be co-delivered by self-advocates and families/carers), with cancer and cancer screening awareness as part of the workshops which will take place during the summer.

10.4 Recommendation: Sharing Learning from Completed LeDeR Reviews

The following is an overview of the work undertaken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Northern Lincolnshire and Goole NHS Foundation Trust (NLaG), Hull University Teaching Hospitals (HUTH), Humber NHS Foundation Trust (HFT), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), North Yorkshire and York Transforming Care Partnership (NY&YTCP), York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT).

- The Learning from LeDeR newsletter completed by the Humber LAC following every panel meeting is shared with all panel and Steering Group members for distribution across their services, and also across primary care within each Place.

Humber Area:

- CHCP WPCLS utilise training opportunities and events to share key themes from completed LeDeR reviews to professionals and raise awareness to patients. When delivering training to professionals, the service shares key learning themes from reviews and highlight good practice and areas for development. The LeDeR newsletter from each panel meeting is circulated monthly within the organisation.
- NLAG circulate quarterly newsletters across the Trust, and a synopsis is sent to all governance meetings quarterly for discussion within the meeting. A quarterly report is also provided to the Trust Mortality Improvement Group including any actions specific to NLaG.
- HUTH share learning via the mental health, learning disabilities and autism steering group, end of life steering group and with the mortality team lead. Learning is also shared with the CLD service within monthly clinical network meetings. Any learning for identified clinical areas/teams is shared directly with the health/care group leads.
- HFT share learning via their clinical network for learning disability services, safeguarding quarterly meeting which underpins and drives quality improvement programmes for learning disability services.
- RDaSH representative shares the learning from completed reviews internally within the organisation.

North Yorkshire Area:

- NY&Y TCP offer training and development opportunities to staff members based on the learning from completed LeDeR reviews which helps ensure staff are equipped with the knowledge and skills needed to provide high-quality care to individuals with learning disabilities. Learning is also shared with external partners. Active engagement is undertaken with service users and their families to share the learning from completed reviews and seek their feedback on ways to improve services.
- Y&SFT have LeDeR as part of the learning from deaths governance structure and reports are expected monthly to track progress of Structured Judgement Reviews (SJRs) and learning from completed reviews.
- H&DFT have undertaken bespoke training to elderly medicine consultants as a response to a completed review which included specific learning from the case and wider education around themes of aspiration pneumonia and appropriate use of DNACPR.

10.5 Recommendation: Restore2mini Training to be Offered to all Care Home Providers within each Place.

The following is an overview of the work undertaken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Humber Foundation Trust (HFT), North Lincolnshire (NL) Place, North East Lincolnshire (NEL) Place, North Yorkshire and York Places.

- CHCP WPCLS alongside a paediatric consultant in emergency medicine delivered a virtual training session to Hull and East Riding of Yorkshire professionals on supporting the identification of soft signs/identifying deterioration.
- HFT have deteriorating patient training as a mandatory competency for their staff.
- NL Place nursing team have provided three sessions to care home staff during the time period of this report with further training to be planned.
- NEL Place delivered 5 sessions during the time period of this report to care home staff on the deteriorating patient framework with more planned during 2024/2025. There is also a plan in place in relation to how supported living providers may be able to access the training.
- NY&Y Place nursing team have continued to offer training using the Stop and Watch tool to care home providers and is delivered via face to face or virtual platform.

❖ Whilst training has been delivered within all 6 Place areas of the ICB, further work is required to enable this training to be delivered consistently across the ICS and for the training to be the same, so that all staff within the ICS are in receipt of the same training regardless of where they are working.

10.6 Recommendation: Ensuring all individuals have a hospital passport and this is Utilised

The following is an overview of the work taken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Northern Lincolnshire and Goole NHS Foundation Trust (NLaG), Hull University Teaching Hospitals (HUTH), Humber Transforming Care Partnership (Humber TCP), Humber NHS Foundation Trust (HFT), Rotherham, Doncaster and South Humber NHS Foundation Trust,(RDaSH), North Yorkshire and York Transforming Care Partnership (NY&YTCP), York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT).

Humber Area:

- CHCP wellbeing service have distributed over 500 copies of the patient passport, guidance notes and communication boards. It is featured in all training and is promoted at all events. The Passport is incorporated in learning disability Annual Health Check training with an electronic version shared with PCNs. During learning disability awareness week, the team went to day services and care providers in Hull to promote the use of the passport.
- NLAG utilise their electronic system and vulnerability ward rounds to identify patients; those without a passport are encouraged to complete whilst in hospital which is then transferred onto the Trust electronic system. There is also a flag on the system to identify those individuals with a passport.
- HUTH in collaboration with the Humber TCP participated in the development of a hospital passport to support patients with vulnerabilities or who require reasonable adjustments. Implementation of the newly developed passport has commenced with guidance notes for completion also developed. Twice weekly audits are undertaken within the Trust emergency department which includes whether individuals with a learning disability have a hospital passport and that this is being utilised. The learning disability liaison nurse promotes use of patient passports when providing support to this cohort of individuals.
- HFT provide passport proformas with all new assessments in learning disability services with provision of support for completion for clients on caseload.
- RDaSH learning disability team complete a hospital passport for anyone who is on their caseload. They are also distributed within clinics and any events held and also within the VIP bags which have been developed.

North Yorkshire Area:

- NY&Y TCP share information and training opportunities on health passports in the NYY Living Well newsletter. Health passport training opportunities are also featured on the Sharepoint site for primary care colleagues. Encouragement is given for individuals to carry their hospital passport with them at all times and to use it to communicate their medical needs and preferences to healthcare providers.
- Y&SFT offer a passport to all patients referred to the learning disability (and now autism) service. Accessibility via the hospital electronic systems have been improved since March 2024.
- H&DFT continue to promote passports through Trust education and documentation alongside wider strategies across partners in social care and local specialist health services. CLDN continue to provide passports and records flagging form at initial assessment.

10.7 Recommendation: Identification of Learning and Improvements in Relation to End of Life Care

The following is an overview of the work taken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Northern Lincolnshire and Goole NHS Foundation Trust (NLaG), Hull University Teaching Hospitals (HUTH), Humber NHS Foundation Trust (HFT), North Lincolnshire Place (NL Place), North East Lincolnshire Place (NEL Place), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT).

Humber Area:

- CHCP offer a range of end-of-life training modules including initiating conversation and the ReSPECT document. A presentation of the key principles of the national PEoL delivery plan and the ambitions framework was presented to the LeDeR steering group in February 2024 to provide insight into the local mapping work which has been undertaken by provider organisations which serve the population of Hull and East Riding of Yorkshire; outlining key actions required to try and level up the services provided against the key ambitions.
- NLAG vulnerabilities lead attends the end-of-life operational group to ensure the voice of patients with learning disability/autism is heard. The end-of-life and vulnerabilities team meet quarterly to discuss any projects for collaborative working.
- HUTH share the learning from LeDeR at the Trust end-of-life steering group. End of life care is reviewed as part of the structured judgement review undertaken for patients with a learning disability/autism who pass away in hospital. The learning disability liaison nurse regularly shares reports, easy read information and best practice documentation relating to end of life for individuals with a learning disability at relevant committee meetings and steering groups.
- HFT lead for end-of-life facilitates a new special interest group within learning disability services.
- NL Place and NEL Place have learning disability and autism included as specific areas within the Northern PEoL work plan to ensure support through the strategic network. Easy read ReSPECT guidance has been shared during 2023/2024 and was part of the ReSPECT working group to support good end of life planning. During 2023/2024 the learning disability task and finish group cascaded best practice information across primary care, to ensure PEoL was part of the Annual Health Check programme.
- RDaSH have a planned conference which will look at the physical health and life journey of individuals with a learning disability from transition to adult services, AHCs, communication, dementia and end of life care.

North Yorkshire Area:

- Y&SFT have had a pilot project with one east coast care provider for easy read advanced care planning. This is also on the Trust autism work plan to roll out a pilot project for autistic patients.
- H&DFT secured £2.6million social finance HELPSS (Harrogate End of Life Planning and Support Service) project which is looking to improve and increase identification of patients that are in their last year of life, improve access to advance care planning and clinical decision making around treatment interventions through development of a dedicated advance care planning team. To also provide 24/7 telemedicine access for patients identified in their last year of life or less, families and professionals in any setting. This is due to launch summer 2024. A collaborative project with Marie Curie and HDFT Hospital and community charity to relaunch and develop provision of end-of-life volunteers to support patients in the hospital setting in their last days/hours of life. The aim is to improve the experience of care in the hospital setting for patients and their families. This is due to commence in the spring of 2024.

10.8 Recommendation: Continue to Raise Awareness of the LeDeR Programme

The following is an overview of the work taken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Hull University Teaching Hospitals (HUTH), Humber NHS Foundation Trust (HFT), North Lincolnshire Place (NL Place), North East Lincolnshire Place (NEL Place), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), Orth Yorkshire and York Transforming Care Partnership (H&NY TCP), York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT), North Yorkshire and York Place.

Humber Area:

- CHCP WPCLS, delivered two training sessions during 2023 to primary care. They also supported a city-wide protected time for learning event in Hull and delivered a presentation to practice staff with a key focus around local and national LeDeR findings/themes.
- HUTH safeguarding team and learning disability liaison nurse has worked in collaboration with the mortality lead and medical examiners within the Trust to support review of records to assist Structured Judgement and LeDeR reviews. The Trust have an intranet page on learning disability for staff guidance and LeDeR as well as providing presentations at internal meetings.
- HFT share the LeDeR newsletter across the organisation including creating links with mental health services to raise awareness around notifications for people who are autistic. Learning disability clinicians can inform and support bereaved families to engage with the LeDeR process if they wish.
- NL Place LAC for the LeDeR programme developed and shared briefing papers regarding the LeDeR programme for both primary care and care home and domiciliary providers.
- NEL Place have LeDeR as a standing agenda item on the multi-agency learning disability Place group. LeDeR themes have also been shared through the local supported living, care home provider calls and primary care protected learning event for awareness.
- RDaSH raise awareness of LeDeR within all training which is delivered to care providers and other professionals.

North Yorkshire Area:

- NY&Y TCP have featured the main messages from the national LeDeR annual report in their Living Well newsletter.
- Y&SFT have shared a one-minute guide via their communications team in internal Trust publications. Monthly reporting to the internal learning from deaths meeting to cascade newsletters from local authority and ICB LeDeR forums.
- H&DFT provided a presentation on findings of the LeDeR annual report with their learning disability link workers. They also provided a bespoke training session around LeDeR to clinicians in elderly medicine. Awareness of the LeDeR programme has been raised with the Trust medical examiners with a particular focus on identifying autistic patients.
- NY&Y Place LAC is working on the production of a short video to raise awareness of LeDeR, Once completed, this will be shared across all ICS providers and added to the ICB website. The video will be translated into one other language initially.

10.9 Recommendation: Other Areas of Work Undertaken Pertinent to LeDeR

The following is an overview of the work taken during 2023/2024 relating to this action by: City Health Care Partnership (CHCP), Northern Lincolnshire and Goole NHS Foundation Trust (NLaG), Hull University teaching Hospitals (HUTH), Humber Transforming Care Partnership (HTCP), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), Humber NHS Foundation Trust (HFT), East Riding Place, North Yorkshire and York TCP (NY&Y TCP), York and Scarborough NHS Foundation Trust (Y&SFT), Harrogate and District NHS Foundation Trust (H&DFT).

Humber Area:

- CHCP WPCLS have delivered 20 accessible and interactive roadshows across community extra care sites in Hull. The AIS and WPCLS established and delivered a "Getting Started with Makaton" face to face training to internal staff within CHCP. The PCLS have continued to be a "Fast Follower" for the national NHSE reasonable adjustment flag project which has included supporting the national team in the creation of the national e-learning package. The service has also supported raising awareness of the project through delivering presentation at key stakeholder events. The WPCLS supported Hull GP practices with the national autism annual health check pilot, which included the service creating and sharing an autism annual health check guide with the national team.
- NLaG have undertaken round 5 of the learning disability improvement standards audit. Updating of flagging on systems to enable better identification of vulnerable patients and easier data collection particularly around readmissions and roll out of the mandatory flagging on reasonable adjustments. The Trust are members of the Northern Lincolnshire health and wellbeing group. The vulnerabilities team have fund raised in order to purchase a portable sensory device for Diana Princess of Wales Hospital Grimsby. In addition, with monies from the Humber TCP single use sensory equipment for use in the emergency department have been purchased. The Trust are working across the ICB with regard to health inequalities particularly in relation to prioritising patients with a learning disability on waiting lists. They have also undertaken an audit into the use of restrictive practice in patients with a learning disability. Work is also progressing into the implementation of the Oliver McGowan training.
- HUTH have developed a virtual ward for learning disability and safeguarding within their electronic nursing records. Once recorded, an electronic flag for learning disabilities remains in place and pulls through for any future episodes of care within the Trust. The learning disability liaison nurse is developing a 'Learning Disability Assessment' which should be undertaken upon admission to highlight support requirements and need for reasonable adjustments. The Trust are also developing 'Diamond Standard Pathways' relevant to emergency and planned admissions as well as outpatient attendances, alongside the introduction of 'learning disability magnets' on patient headboards to increase awareness of an individual's diagnosis of a learning disability and requirement for reasonable adjustments. Introduction of learning disability and autism champions across the Trust and currently supporting the development of 'Prioritisation of Patients' with a learning disability' project to reduce health inequalities in this cohort of patients.
- Humber TCP held a STOMP/STAMP conference in North Lincolnshire and due to the success, plans are now underway to hold further conferences across the ICB.
  RDaSH have secured funding for additional VIP bags. In collaboration with the ICB, visits were undertaken to a number a GP practices within NL with the aim being to see what a visit to the practice was like for adults with a learning disability. The findings have been fed back to practices.

- HFT have a new learning disability engagement lead, involving people with a learning disability and their families in service delivery. They also have an Advanced Clinical Practitioner trainee in their learning disability service and are in the process of implementing the Oliver McGowan training.
- ERY Place are exploring reduction/better management of pneumonia within their learning disability population with easy read information regarding the pneumonia vaccine. Theya re also looking at causes of aspiration pneumonia.

North Yorkshire Area:

- NY &Y TCP have commissioned an autism liaison service in York hospital, which delivers the same principles as the learning disability liaison service. They have also Implemented quality improvement measures (via HOST commissioner arrangements) with monitoring systems to track outcomes and identify areas for improvement in the care provided to individuals with learning disabilities/autism.
- Y&S FT have invested in the recruitment of a substantive complex needs specialist nurse (Autism). This service is planned for launch this year and is already supporting patients with autism access Trust services.
- H&DFT have contributed to amendments to the regional (WYAAT) access policy to prioritise patients with learning disabilities. This has been further expanded to include patients with learning disabilities on P1 waiting lists in line with the HNY project group. A learning disabilities dashboard has been developed to support monitoring of a range of learning disability specific information. A learning disability outpatient pathway has been developed to offer guidance to clinicians and promote/support the provision of reasonable adjustments. Trust learning disability nurses have been working in collaboration with Inclusion North and other partners to develop a series of workshops to help reduce inequalities in health for people with a learning disability/autism. The Trust have also developed a Friends and Family Test tool for use by children and young people with complex special educational needs and disability (SEND) and non-verbal due to autism or learning disability to ensure their voices are heard as part of the patient feedback process. This project received the Health Innovation Award at the NHSE National SEND Awards. The Initial triage process for Pre assessment has been updated. Accessible Information Standard Guidance has been developed and supports staff to create information in different formats such as easy read.

11.0 Overview of the LeDeR Steering Group from the Chair

The below is an overview of the work undertaken by the ICB LeDeR Steering Group during 2023/2024.

Over the past year, the Humber LeDeR Steering Group has continued to meet on a bi-monthly basis.

- In July 2023, the Steering Group evolved to become an ICB wide steering group as we welcomed colleagues from across York and North Yorkshire Places in joining us.

- The previous year has also seen us transition to working with a new provider who is now undertaking all of our LeDeR reviews across the ICB. The relationship we have with the new provider has enabled us to strengthen our systems and processes to ensure learning from our LeDeR reviews is identified and taken forward.

- We have had opportunity to showcase our local work within an NHS England Listening event where we were commended for our 'Learning Lessons Newsletter' and the positive Annual Health Check work undertaken within one of our Place areas.

- Whilst we recognise there is still work to do across our system to reduce the health inequalities for people with a diagnosis of a learning disability and/or autism, we are aware that overall people within our Place areas receive good care. To this end during 2024/2025, the Steering Group will be undertaking scheduled deep dive activity into specific pathways of care to identify opportunities for service improvement across our system, along with reviews of thematic learning which will enable us to work as system partners to strengthen the opportunities for reasonable adjustments; thus, improving access to and experience of care. Focus for deep dives will be in relation to:
    - Aspiration pneumonia.
    - Pneumonia.
    - Healthy Lifestyles.

  Alongside these areas of work, a 'Task and Finish' Group has emerged from the Steering Group to look at a consistent approach for Health Passports across the ICS. This piece of work is being led by our Northern Lincolnshire and Goole NHS Foundation Trust (NLaG) representative.

- I would like close by offering my personal thanks to all who have been involved in the LeDeR Steering group over the past year and in particular, thank my two Local Area Contact colleagues (LACs) for their ongoing commitment and dedication to the work of LeDeR.

12.0 Key Themes from Reviews Completed 1st April 2023 - 31st March 2024

Of the 126 reviews completed 1st April 2023 - 31st March 2024, reviewers did not identify any learning within 32.5%. The following are the main key themes identified and are the same as identified in preceding annual reports:

Annual Health Checks:
This area has remained a priority within each Place of the ICB. Of the completed reviews, 11% identified learning relating to Annual Health Checks with the main themes being:

- The individual was not on the GP learning disability register.
- No record of completion of the Annual Health Check.
- An Annual Health Check had not been completed in the year preceding the persons death.
- The standard of the completed Annual Health Check.

This area of work will continue to be a priority for 2024/2025.

Mental Capacity:
Completed reviews continue to identify appropriate use of the Mental Capacity Act and Best Interest Decision making, however, it has been highlighted within 16% of reviews completed during the timeframe above, that further work continues to be required relating to:

- Documentation of mental capacity assessment.
- Assumption of capacity.
- Best Interest processes.
- Lack of DoLs documentation.
- Lack of consistent use of the Mental Capacity Act.

This will continue to be a focused area of work during 2024/2025.

End of Life Care:
It is to be acknowledged that many reviews have identified good end of life care and planning, however 18% of completed reviews identified further work continues to be required regarding:

- Recognition that someone is nearing the end of their life.
- Earlier end of life discussions and advanced care planning.
- Review of the ReSPECT/DNA/CPR document either annually or when a person's condition changes.
- Commencement of end-of-life pathways.
- Consideration of the individuals wishes.

This will continue to be monitored within completed reviews during 2024/2025.

Access and Support with Uptake to Screening:
Whilst this has not been a major key them within completed reviews, with many reviews identifying uptake of bowel screening, there have been some reviews which have identified that bowel screening has not been completed.
To ensure this is not an issue across the ICS and that individuals are being supported for all screening, this will be a focus for all completed reviews during 2024/2025 with the findings feeding into the Steering Group.

13.0 Recommendations for Actions to be Taken Forward for 2024/2025

From the findings and learning from the 126 reviews completed 1st April 2023 – 31st March 2024, the following recommendations are put forward as areas of work to be undertaken across the Humber and North Yorkshire Integrated Care System for 2024/2025:

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.

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.

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.

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

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.

Work to continue to fully understand the position across the ICS regarding our non-white British population and where possible individuals within this cohort who have a learning disability in order to ensure no individual who sadly passes away is missed from having their death reviewed.

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.

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.

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.