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 2022 to 31st March 2023

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

11th May 2023

Content **Page**

Within the past year, we have sadly lost one of our colleagues, Mr Gary Stark.

Gary was a much respected and active member of the Humber LeDeR Steering Group. He was a passionate advocate in promoting the rights of people with a learning disability to ensure equity and equality of access to services.

As the Local Area Contacts for the LeDeR Programme within the Humber, and with the kind permission of Gary's family, we would like to dedicate this year's Annual report to him.

He will not be forgotten, and we will forever be grateful for the opportunity to have known Gary and worked with him towards improving patient experience and local services.

Executive Summary

On July 1st 2022, Integrated Care Systems (ICS) with an Integrated Care Board (ICB) were legally established replacing Clinical Commissioning Groups (CCGs).

This report, is the second Learning from lives and deaths; people with a learning disability and autistic people (LeDeR) (previously known as the Learning Disabilities Mortality Review Programme) annual report written on the new Integrated Care System (ICS) footprint, known as NHS Humber and North Yorkshire Health and Care Partnership, and has been written by NHS North Lincolnshire Health and Care Partnership (previously NLCCG) on behalf of the following Partnerships (previously CCGs):

- NHS North Lincolnshire Health and Care Partnership (NL H&CP).
- NHS North East Lincolnshire Health and Care Partnership (NEL H&CP).
- NHS East Riding of Yorkshire Health and Care Partnership (ERY H&CP).
- NHS Hull Heath and Care Partnership (Hull H&CP).
- NHS North Yorkshire Health and Care Partnership (NY H&CP).
- NHS York Health and Care Partnership (Y H&CP).

To note:

- NHS York Health and Care Partnership was previously known as NHS Vale of York CCG under the previous Clinical Commissioning Groups footprint. Following the change to the Integrated Care Board (ICB) on 1st July 2022, the boundaries for NHS North Yorkshire and NHS Vale of York changed and they became NHS North Yorkshire Health and Care Partnership and NHS York Health and Care Partnership. This has led to a number of towns and villages previously within NHS Vale of York now sitting within NHS North Yorkshire.

- This Report includes the period 1st April 2022 – 30th June 2022 when Clinical Commissioning Groups were still in existence. For ease throughout the report, each individual Partnership area will be known as their respective Place area:
  - NHS North Lincolnshire Health and Care Partnership (NL Place).
  - NHS North East Lincolnshire Health and Care Partnership (NEL Place).
  - NHS East Riding of Yorkshire Health and Care Partnership (ERY Place).
  - NHS Hull Heath and Care Partnership (Hull Place).
  - NHS North Yorkshire Health and Care Partnership (NY Place).
  - NHS York Health and Care Partnership (Y Place).

All of the six Places within the Humber and North Yorkshire Health and Care Partnership have robust systems and processes for the management of the learning disability mortality reviews.

- The Humber Places: NEL, NL, ERY and Hull, continue to work collaboratively in identifying actions from learning alongside positive practice from completed reviews through their joint Governance panel meeting, with NY Place undertaking the same process on behalf of York Place.

- Collaborative working across the six Places commenced during 2021, to develop robust processes in order to share learning and good practice, with further work continuing during 2023/2024 to further enhance and strengthen these processes.

A total of 119 deaths were sadly notified to the LeDeR programme from across the six Places within the Humber and North Yorkshire Health and Care Partnership from 1st April 2022 - 31st March 2023.

- 60% of the people whose death was notified to the programme were male; this is slightly higher than that of the national picture as identified within the National LeDeR report 2021, of 56%. For the Humber area, this was 56% and for North Yorkshire this was 64%.
- 100% of the people whose death was notified to the programme were identified as being white British, this is the same as reported within the ICS LeDeR annual report of 2021/2022 and higher than that of the national picture of 91% as identified within the national LeDeR report, 2021.
- 45.5% of people whose death was notified to the programme died within a hospital setting, this is lower than the 55% as reported within the ICS annual LeDeR report 2021/2022 and lower than the national picture of 61% as identified within the national LeDeR report 2021.

During the time-period of this report; 1st April 2022 - 31st March 2023, 85 LeDeR reviews were completed across the six Places. It is to be noted that a number of these reviews have been completed outside of the required NHS England timeframe of six months from the date of notification and relate to people who died between 2020 – 2022.

The most common confirmed cause of death identified within the reviews completed from 1st April 2022 – 31st March 2023, was respiratory issues (32%), with pneumonia accounting for 10% and aspiration pneumonia accounting for 11%. Respiratory issues were also cited as the most common cause of death within the 2021/2022 report within 27% of completed reviews.
Cardiac issues were the second most common cause of death recorded within 14% of completed reviews. COVID – 19 was cited as the cause of death within 7% of completed reviews (this includes those deaths recorded as COVID-19 pneumonia).

The main key learning from the reviews completed 1st April 2022 - 31st March 2023 remain as identified within the 2021 – 2022 report, namely:

- Ensuring all individuals aged 14 years and over receive an invitation for an Annual Health Check. Whilst progress continues to be positive within this area, this work remains a priority within all Places across the Humber and North Yorkshire health and Care Partnership.
- Whilst a number of reviews identified appropriate use of the Mental Capacity Act and Best Interest Decision making, it is clear for other reviews that all providers need to ensure health and social care staff have an understanding in the use of the Mental Capacity Act, Deprivation of Liberty Safeguards (DoLs), Capacity Assessments and Best interests, including completion of robust documentation.
- Access to health screening does not appear to have been identified as a key theme within reviews completed during the timeframe of this report, however, this area remains a key focus regarding individuals with a learning disability having equal access to health screening, follow up and support when they are deemed to have ‘not attended’ or declined to partake in screening.

- It is acknowledged that many reviews have identified good end of life care planning however, areas of focus from completed reviews continue to be based around ensuring early recognition and decision-making regarding end-of-life planning and completion of the ReSPECT document within both hospital and community settings, allowing good end of life conversation, early planning with the individual and their family and those who care for them.

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 32 of this report.

The NHS England LeDeR Learning from lives and deaths – People with a learning disability and autistic people Annual Report 2021 can be accessed at: www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf .

1.0 Introduction and Background

The Learning from lives and deaths – 'People with a learning disability and autistic people' (LeDeR), formerly known as the Learning Disabilities Mortality Review programme, 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 which came into effect in 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 Serious Incident Review process 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 will be the primary review process for a child with a learning disability. The LeDeR Programme and CDR Programme are currently working together nationally to align the two programmes more closely.

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 and Quality for Hull and East Riding Health and Care Partnerships. The Local Area Contacts (LACs) within the respective Place areas locally, allocate the review to a reviewer and undertake the quality assurance process. During 2022/2023, the Place areas have continued to work closely together in respect of the LeDeR 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 LeDeR from across the Humber and North Yorkshire Health and Care Partnership footprint.

LeDeR Panels

Due to the geographical area of the Humber and North Yorkshire Health and Care Partnership, there are two LeDeR panel meetings for sharing of the learning from initial reviews and for discussion and approval of the completed focused reviews. Both panels have membership from system partners within the localities and have identical Terms of Reference. The learning and good practice from the reviews is shared within a combined LeDeR learning newsletter which is completed each month following the review panels. However, further work is required to ensure this sharing of information is consistent and how the learning from the Steering Groups is shared across the ICB footprint. This will be an area of focus during 2023/2024.

LeDeR Steering Groups

The LeDeR Steering Groups provide oversight, support and governance for the local delivery of the LeDeR programme, with membership from across the respective Transforming Care Partnership footprints. The learning from the reviews is shared with the respective LeDeR Steering Groups within each locality for monitoring of the required actions, whilst also feeding into the respective Transforming Care Partnerships.

3.0 Deaths of Individuals with Learning Disabilities in our Local Area 1st April 2022 – 31st March 2023

Sadly, a total of 119 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 2022 - 31st March 2023. The impact of the COVID-19 pandemic has continued to be felt nationally during the timeframe of this report.

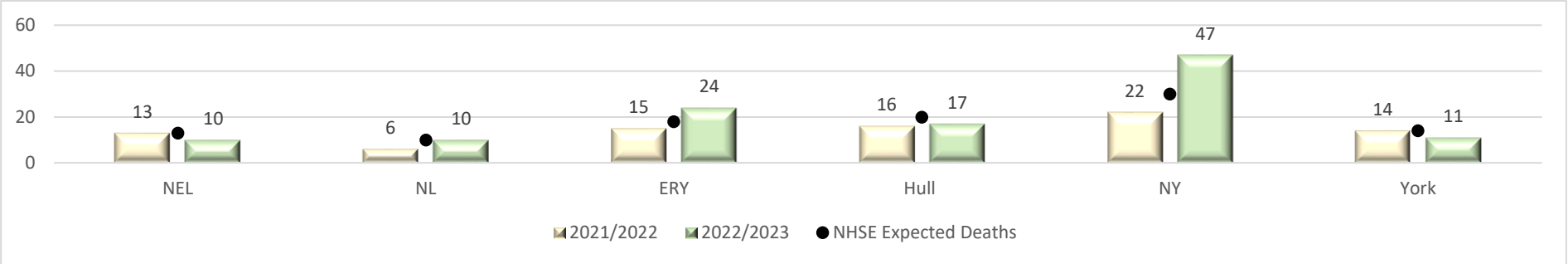
Figure 1 below identifies the number of deaths reported by each of the Places within the Humber and North Yorkshire Health and Care Partnership, with a comparator to the number of deaths reported 1st April 2021 - 31st March 2022.

The black circle within each area relates to the NHS England number of expected deaths per year per Place (NEL:13 deaths per annum, NL:10 deaths per annum, ERY:18 deaths per annum, Hull:20 deaths per annum, NY: 30 deaths per annum, York:14 deaths per annum).

To note:

- Any increase in the number of notifications for North Yorkshire may be due in part to the changes to the boundaries within North Yorkshire and York.
- There have been no notifications within the Humber and North Yorkshire Partnership of individuals with a confirmed diagnosis of autism only.

Figure 1: Number of Deaths Reported 1st April 2022 - 31st March 2023 with a Comparator to Deaths Reported 1st April 2021 – 31st March 2022



4.0 Overview of Completed Reviews 1st April 2022 – 31st March 2023

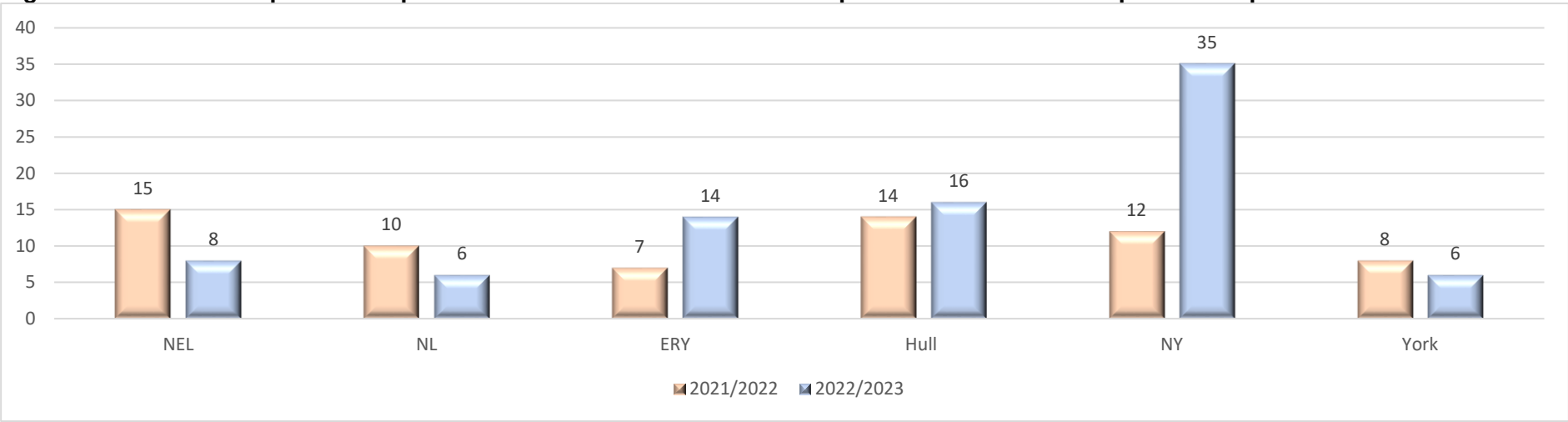
In June 2021, changes to the programme and a move to a new web platform saw a change in process for completion of reviews. All deaths notified to the programme, receive an initial review, which consists of the allocated reviewer speaking to; family, carers, and professionals involved in the persons' 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) feel 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.

Between 1st April 2022 – 31st March 2023, 85 initial LeDeR reviews were completed across the six Places. These reviews were from notifications submitted to the programme between 2020 – 2022.

Figure 2 below, identifies the number of reviews completed by each Place 1st April 2022 – 31st March 2023, with a comparator of the number completed 1st April 2021 – 31st March 2022.

Figure 2: Reviews Completed 1st April 2022 - 31st March 2023 with a Comparator to Reviews Completed 1st April 2021 – 31st March 2022



To Note:

- Deaths notified to the programme after 1st October 2022 would not be required to be completed within the timeframe of this report. Any reviews which meet this criterion will be included within the 2023/2024 Annual LeDeR Report.

Of these completed reviews, 28 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 the review within the required timeframe related to:

- Lack of reviewers to allocate the review to.
- Reviewer capacity to complete the review within timeframe.
- Initial review completed within timeframe; however, this review indicated a focused review was required leading to delay in the completion of the focused review.
- The individuals death being subject to a statutory investigation such as coroner, Child Death Review (CDR), safeguarding or serious incident investigation.

Figure 3 below identifies the number of reviews completed within timeframe by each Place 1st April 2022 - 31st March 2023, with figure 4 showing the breakdown of completed reviews by year of notification to the programme.

Figure 3: Reviews Completed within Timeframe 1st April 2022 - 31st March 2023 with a Comparator to Reviews Completed Outside of Timeframe 1st April 2022 – 31st March 2023

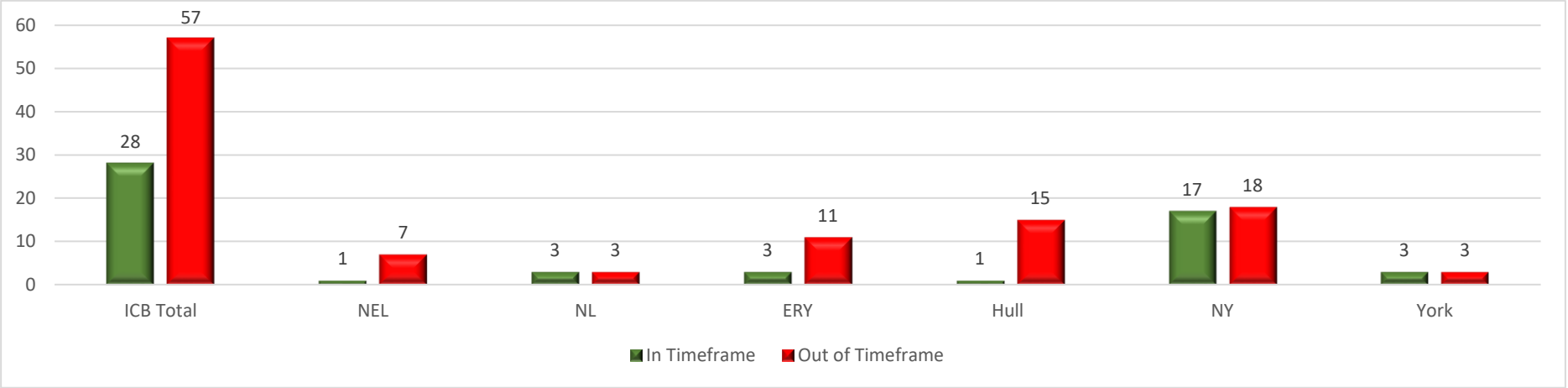
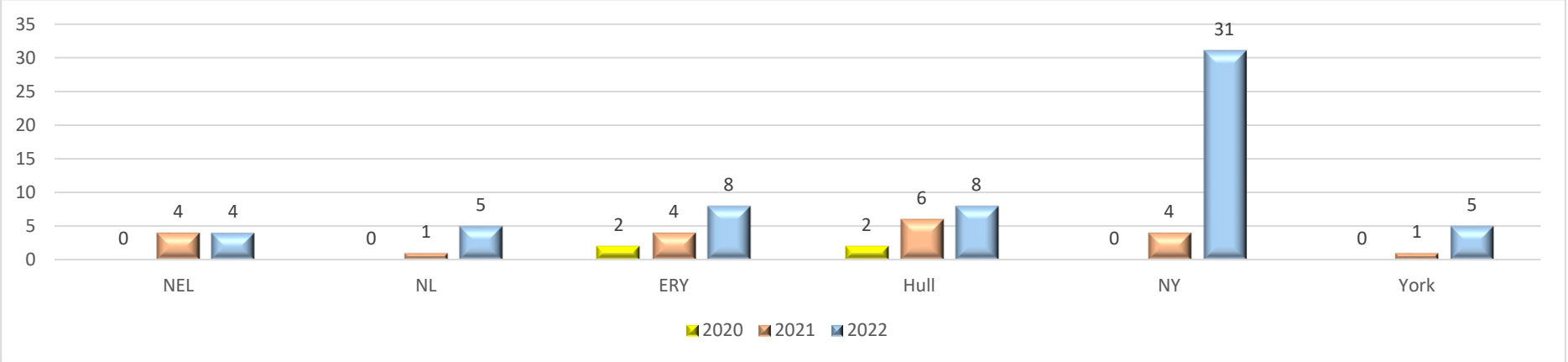


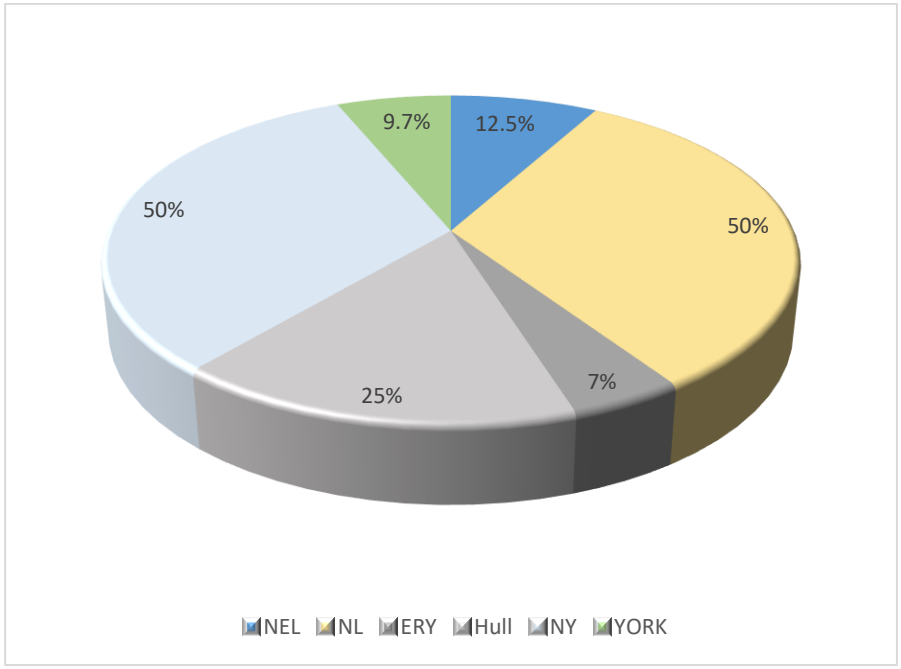
Figure 4: Reviews Completed by each Place During 2022 – 2023 from Year of Notification



Of the 85 initial reviews completed, 14 (16.4%) were identified as requiring a focused review to be completed (a more in depth look at the individuals life and death).

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 2022 - 31st March 2023.

Figure 5: Focused Reviews Completed by Place 1st April 2022 – 31st March 2023



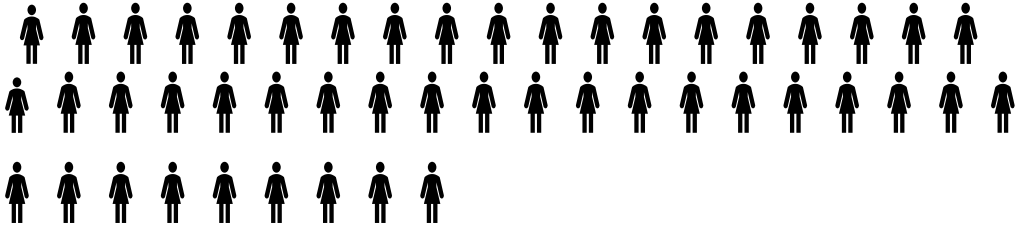
5.0 Themes and Trends

5.1 Gender of Individuals from Reported Deaths 1st April 2022 – 31st March 2023

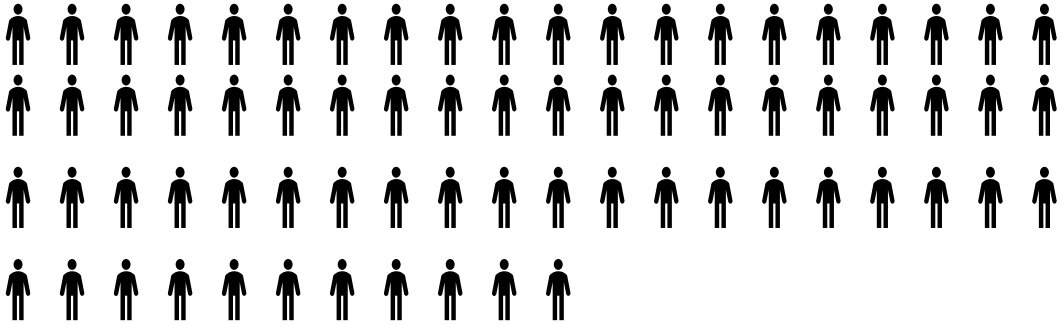
	Gender	
	Female	**Male**
N = 119	48	71
%	**40%**	**60%**

Of the 119 deaths sadly reported by the six Places 1st April 2022 - 31st March 2023:

- The individual's gender was reported within the notification in all deaths.
- 48 of the individuals identified as female (40%).

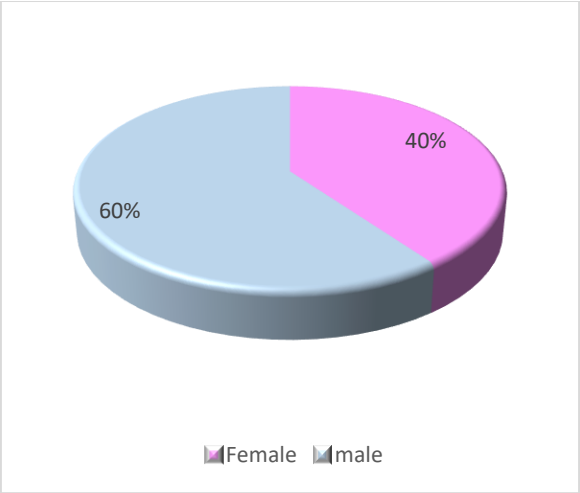


- 71 of the individuals identified as male (60%).



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

Gender Comparison



Within the Learning from lives and deaths – People with a learning disability and autistic people Annual Report 2021 (https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf), which covered deaths notified to the programme January 2021 – December 2021, the reported genders were:

- 56% identified as male.
- 42% identified as female.
- 1% identified as other.

5.1.2 Gender of Individuals from Reported Deaths Humber and North Yorkshire Places 1st April 2022 – 31st March 2023

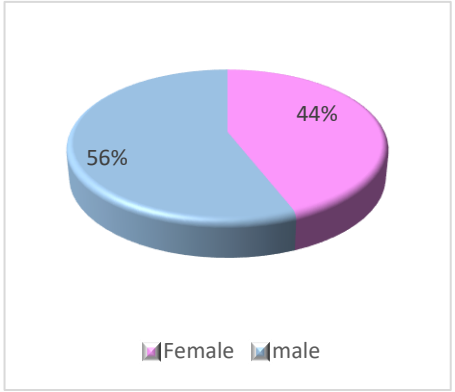
Humber Places

	Gender	
	Female	**Male**
N = 61	27	34
%	**44%**	**56%**

Of the 61 deaths reported by the four Places within the Humber:

- 27 of the individuals identified as female (44%).

- 34 of the individuals identified as male (56%).



The gender comparison of individuals whose deaths were notified within the Humber 1st April 2022 – 31st March 2023, was the same for males and slightly higher for females to that of the national picture (as reported within the National LeDeR Annual report 2021).

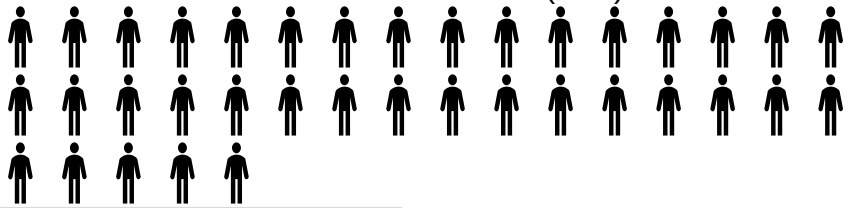
North Yorkshire Places

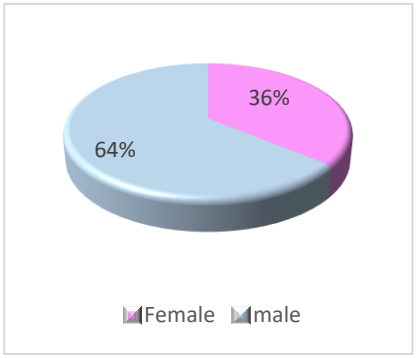
	Gender	
	Female	**Male**
N = 58	21	37
%	**36%**	**64%**

Of the 58 deaths reported by the two Places within North Yorkshire:

- 21 of the individuals identified as female (36%).

- 37 of the individuals identified as male (64%).



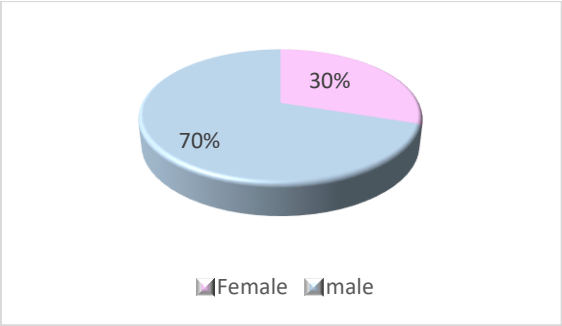


The gender comparison of individuals whose deaths were notified within North Yorkshire 1st April 2022 – 31st March 2023, was higher for males and lower for females to that of the national picture (as reported within the National LeDeR Annual report 2021).

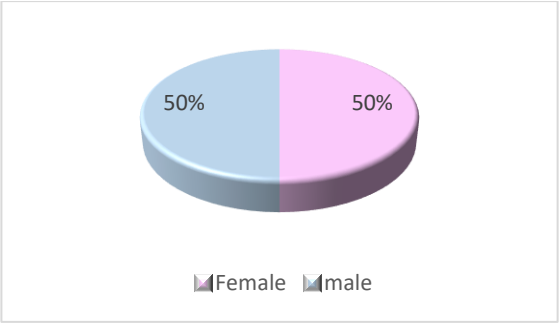
5.1.3 Gender of Individuals from Reported Deaths by Individual Place 1st April 2022 – 31st March 2023

The below charts show the gender comparison within each Place for reported deaths from 1st April 2022 – 31st March 2023.

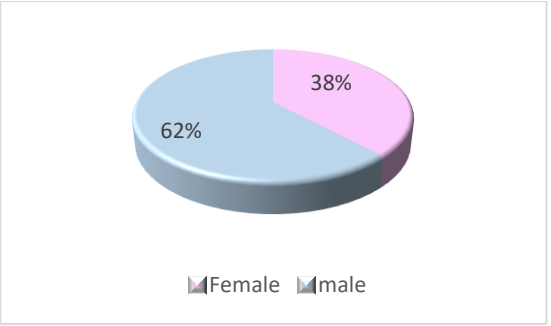
North East Lincolnshire Place



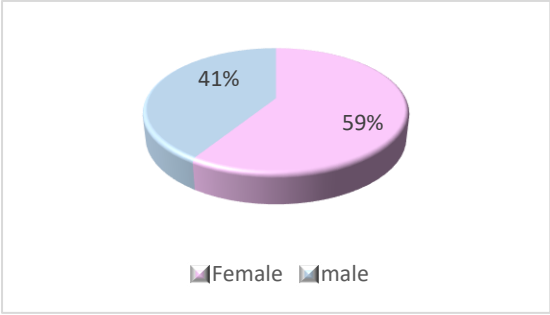
North Lincolnshire Place



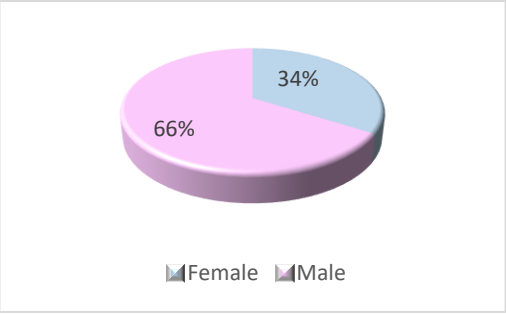
East Riding of Yorkshire Place



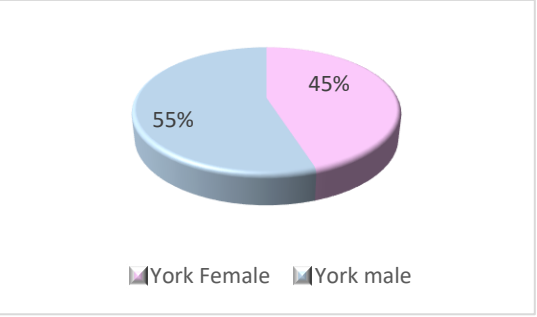
Hull Place



North Yorkshire Place



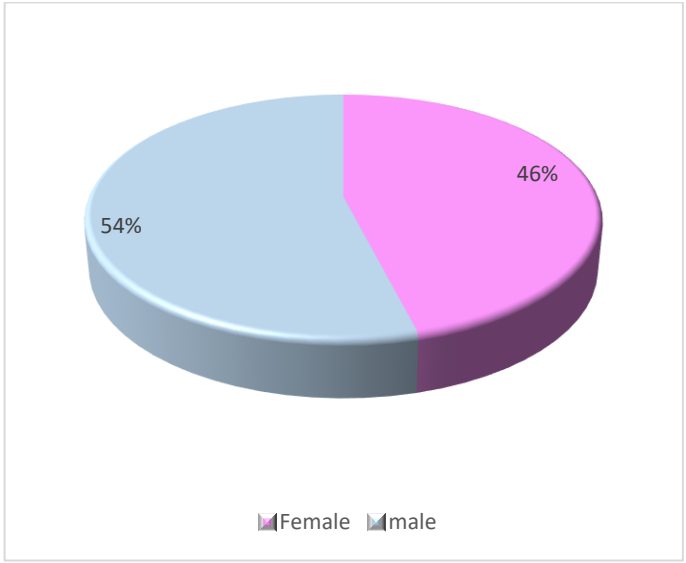
York Place



5.2 Gender of Individuals from Completed Reviews 1st April 2022 – 31st March 2023

	Gender	
	Female	**Male**
N = 85	39	46
%	**46%**	**54%**

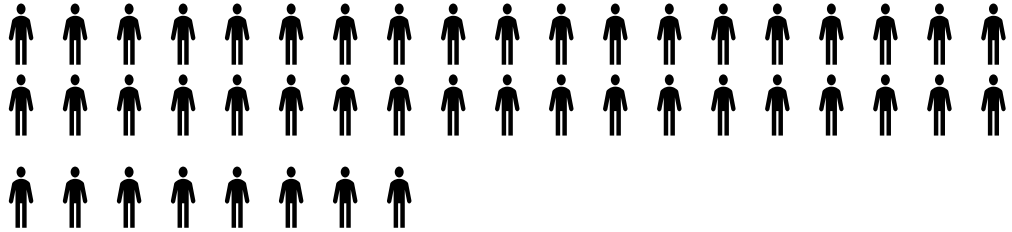
Gender Comparison



Of the 85 reviews completed by the six Places 1st April 2022 - 31st March 2023:

- 39 of the individuals identified as female (46%).

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



5.2.1 Gender of Individuals from Completed Reviews Humber and North Yorkshire Places 1st April 2022 – 31st March 2023

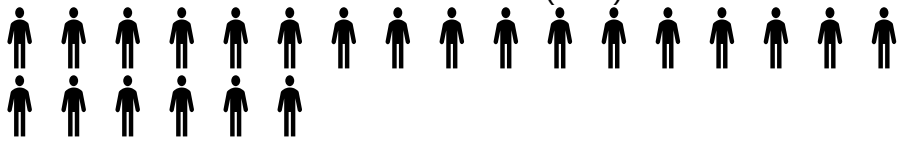
Humber Places

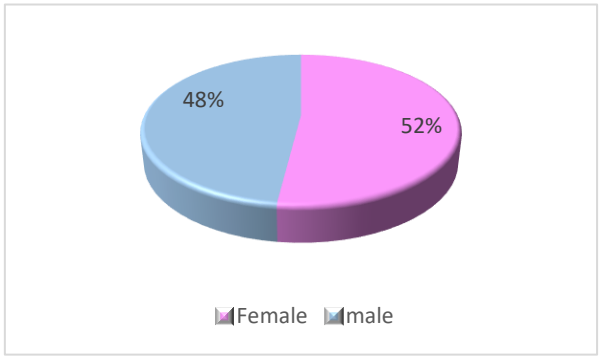
	Gender	
	Female	**Male**
N = 44	23	21
%	**52%**	**48%**

Of the 44 reviews completed by the four Places within the Humber:

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

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





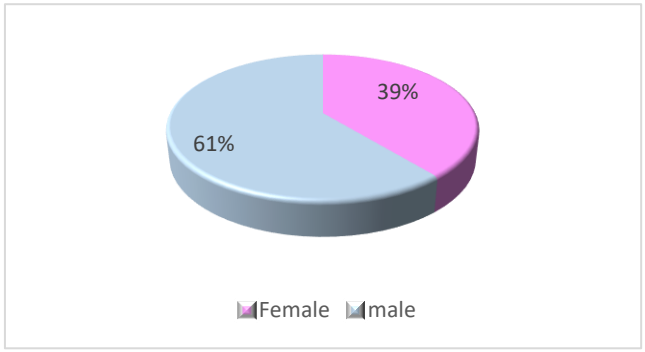
North Yorkshire Places

	Gender	
	Female	**Male**
N = 41	16	25
%	**39%**	**61%**

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

- 16 of the individuals identified as female (39%).

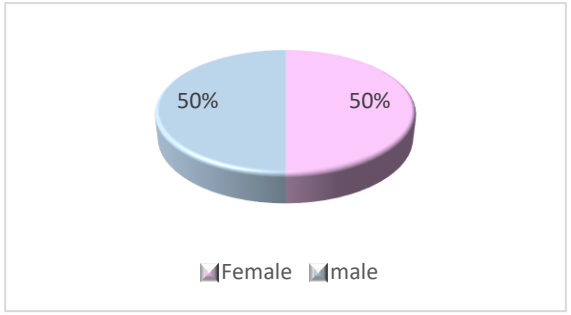
- 25 of the individuals identified as male (61%).



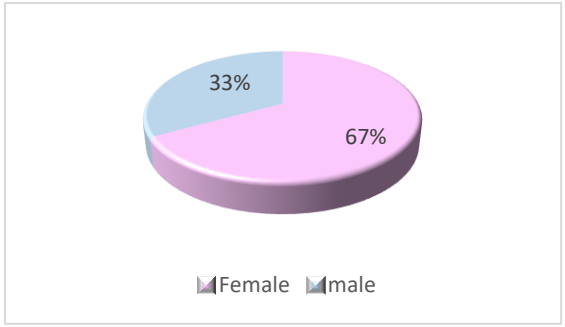
5.2.2 Gender of Individuals from Completed Reviews by Individual Place 1st April 2022 – 31st March 2023

The below charts show the gender comparison within each Place for completed reviews 1st April 2022 – 31st March 2023.

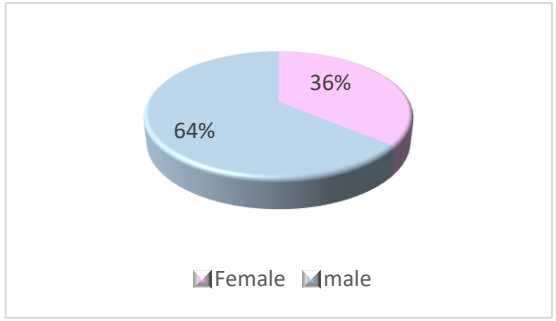
North East Lincolnshire Place



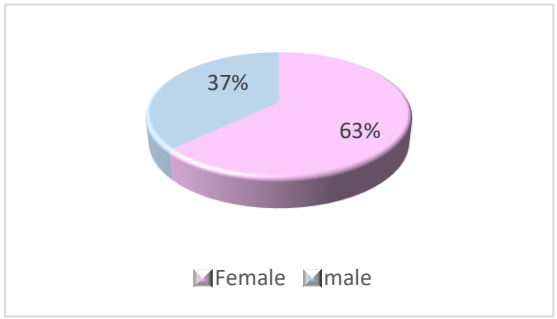
North Lincolnshire Place



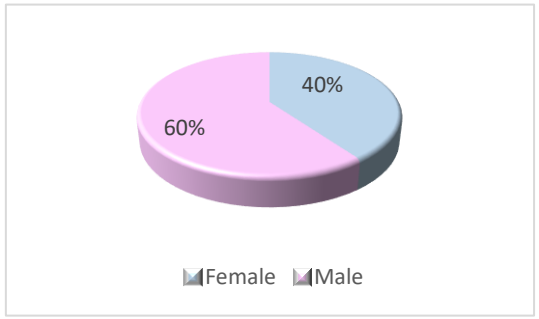
East Riding of Yorkshire Place



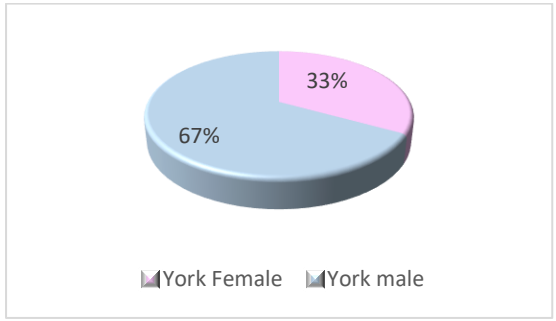
Hull Place



North Yorkshire Place



York Place



Themes and Trends

5.3 Ethnicity of Individuals from Reported Deaths 1st April 2022 – 31st March 2023

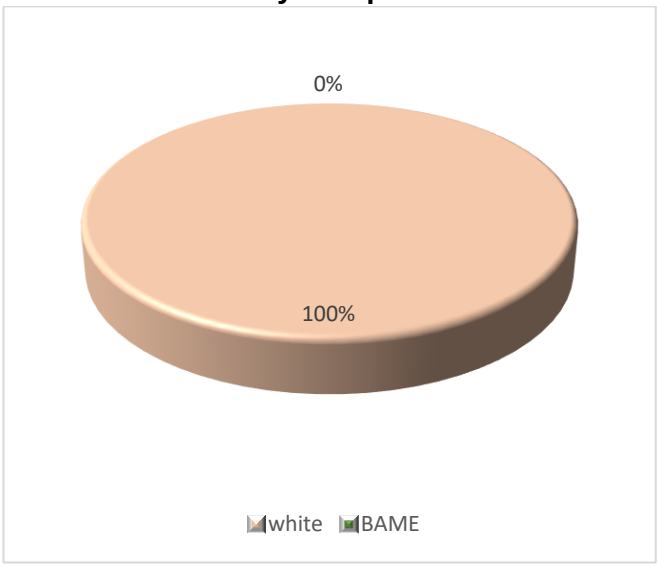
	Ethnicity	
	White	**BAME**
N = 119	119	0
%	**100%**	**0%**

- The ethnicity of the individual was reported within all 119 deaths notified to the programme 1st April 2022 – 31st March 2023.
- Of the 119 deaths reported, 100% of individuals were denoted as being of white British ethnicity, (this is the same as reported within the 2021/2022 Humber and North Yorkshire annual report).
- The population of the Humber and North Yorkshire, of which the six Place boundaries are within, is approximately 86% white (Census 2011), similar to that of the general population (85%) as identified within the LeDeR National Report 2021.
- The ethnicity comparison of individuals whose deaths were notified within the Humber and North Yorkshire Health and Care Partnership is much higher than that of the national picture which was noted within the 2021 Annual report to be 91%. York Place Local Authority colleagues have undertaken a review of their data regarding non-white British service users who have sadly passed away with data comparison against LeDeR notifications. This review has provided assurance in relation to there being no missed notifications to the LeDeR programme for this cohort of individuals. This piece of work is to be replicated within North Yorkshire Place.

- Recommendation is for this piece of work to also be completed within the Humber Places for the Humber and North Yorkshire Health and Care Partnership to be assured that no individuals have been missed from the LeDeR programme.

To note:
Of the 85 reviews completed 1st April 2022 – 31st March 2023, none of the individuals were of a non-white British background.

Ethnicity Comparison



Themes and Trends

5.4 Age of Individuals at the time of Death: Reported Deaths 1st April 2022 - 31st March 2023

Of the 119 individuals whose deaths were reported 1st April 2022-31st March 2023:

- The age range was 16-90 years (05-95 years in 2021-2022 report).
- The mean average age of death was 60.1 years (60.4 years in 2021-2022 report).
- The median age of death was 62.5 years (62 years in 2021-2022 report).

In relation to those individuals who were female:

- The age range was 21-90 years (17-95 in 2021/2022 report).
- The mean average age of death was 63.2 years (73 in 2021/2022 report).
- The median age of death was 62.5 years (60.5 in 2021/2022 report).

In relation to those individuals who were male:

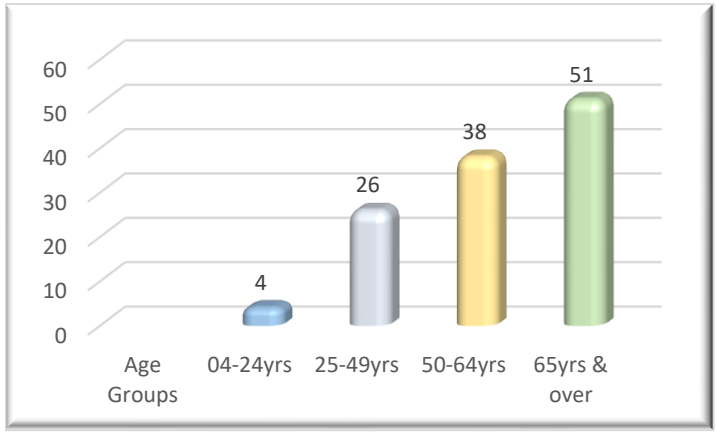
- The age range was 16-87 years (5-86 years in 2021/2022 report).
- The mean average age of death was 58.7 years (62.8 in 2021/2022 report).
- The median age of death was 62 years (64.5 in 2021/2022 report).

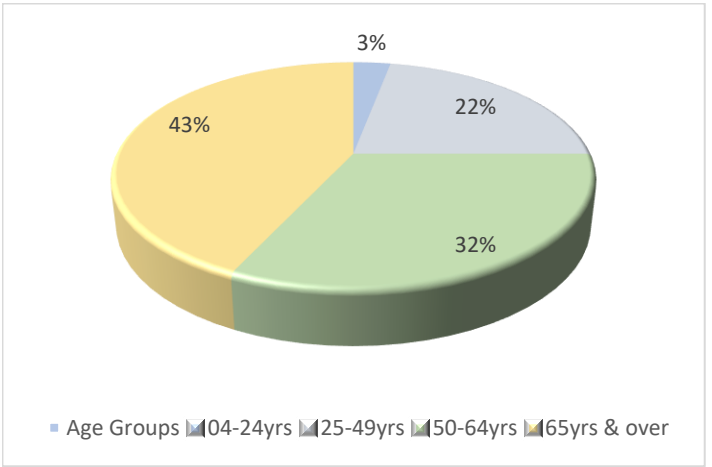
The median age at the time of death for individuals with a learning disability across the 6 Places, was around the same as identified within the 2021-2022 Humber and North Yorkshire Health and Care Partnership annual report and as a comparator to the national picture was:

- Slightly higher than the national picture of 61 years for deaths reported during 2021 (as identified within the national report).
- Slightly higher than the national picture of 60 years for females for deaths reported during 2021 (as identified within the national report).
- Slightly higher than the national picture of 61 years for males for deaths reported during 2021 (as identified within the national report).

The median age at death in the general population was 86 years for females and 83 years for males in 2016-2018 (most current data available).

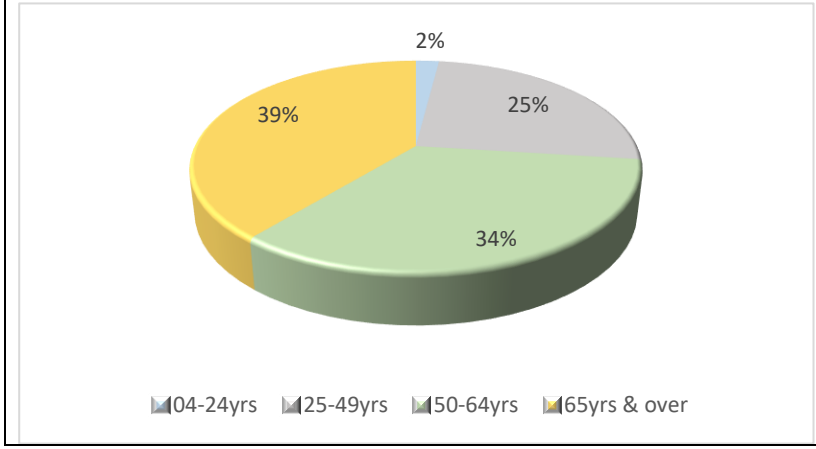
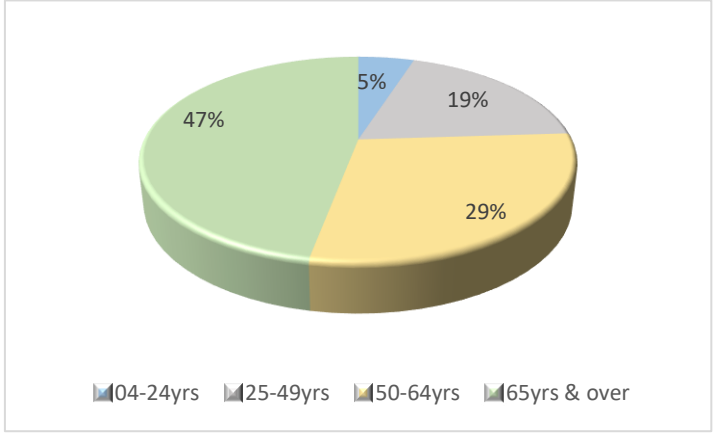
Age at Death - Reported Deaths





Themes and Trends

5.4.1 Age of Individuals at the time of Death: Reported Deaths, Humber and North Yorkshire Places 1st April 2022-31st March 2023

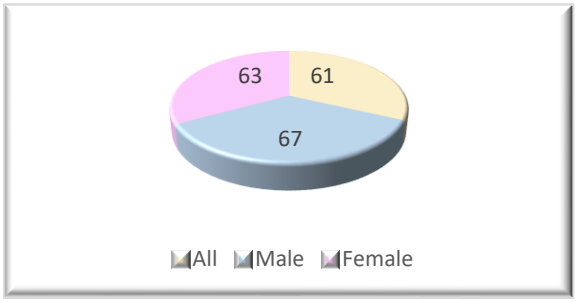
Humber Places	North Yorkshire Places
Of the 61 individuals whose deaths were reported within the Humber Places 1st April 2022 -31st March 2023: ➢ The age range was 23-90 years. ➢ The mean average age of death was 61.5 years. ➢ The median age of death was 62 years. **In relation to those individuals who were female:** ➢ The age range was 34-90 years. ➢ The mean average age of death was 64 years. ➢ The median age of death was 62 years. **In relation to those individuals who were male:** ➢ The age range was 23-87 years. ➢ The mean average age of death was 59.6 years. ➢ The median age of death was 62 years. Chart below shows the ages ranges as percentages due to small numbers within some cohorts.  	Of the 58 individuals whose deaths were reported within North Yorkshire Places 1st April 2022 -31st March 2023: ➢ The age range was 16-86 years. ➢ The mean average age of death was 59.4 years. ➢ The median age of death was 61.5 years. **In relation to those individuals who were female:** ➢ The age range was 21-81 years. ➢ The mean average age of death was 62.2 years. ➢ The median age of death was 65 years. **In relation to those individuals who were male:** ➢ The age range was 16-86 years. ➢ The mean average age of death was 58 years. ➢ The median age of death was 62 years. Chart below shows the ages ranges as percentages due to small numbers within some cohorts. 

Themes and Trends

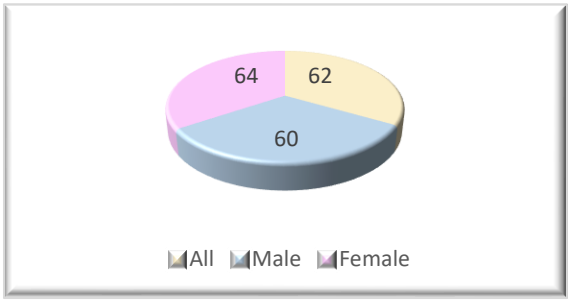
5.4.2 Median Age of Individuals at the time of Death: Reported Deaths at Individual Place 1st April 2022 - 31st March 2023

The below charts show the median age of individuals at the time of death for reported deaths within each Place 1st April 2022 – 31st March 2023.

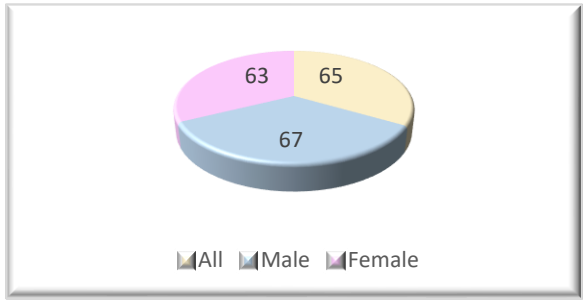
North East Lincolnshire Place



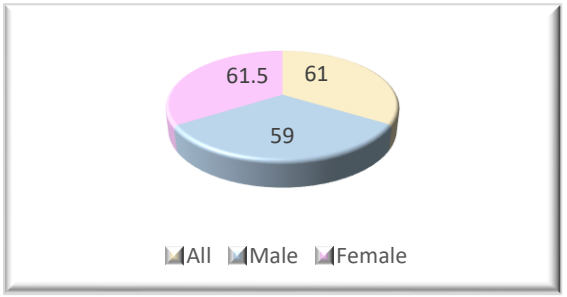
North Lincolnshire Place



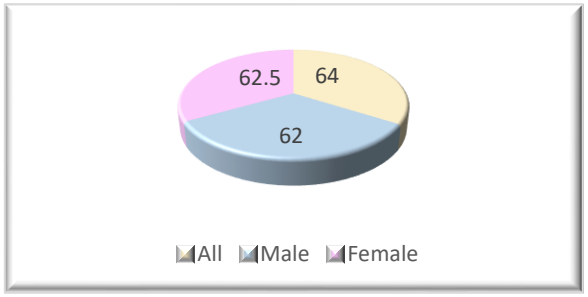
East Riding of Yorkshire Place



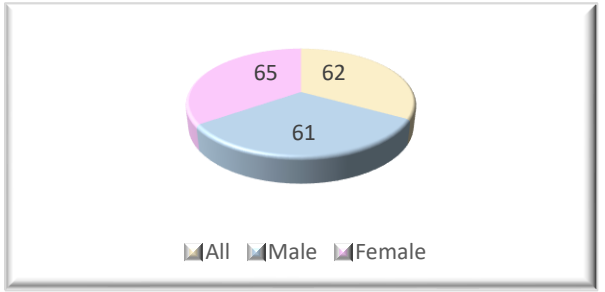
Hull Place



North Yorkshire Place



York Place



Themes and Trends

5.5 Age of Individuals at time of Death: Completed Reviews 1st April 2022 - 31st March 2023

For the 85 completed reviews during the time period 1st April 2022 - 31st March 2023:

- The age range was 11-90 years.
- The mean average age of death was 57 years.
- The median age of death was 61 years.

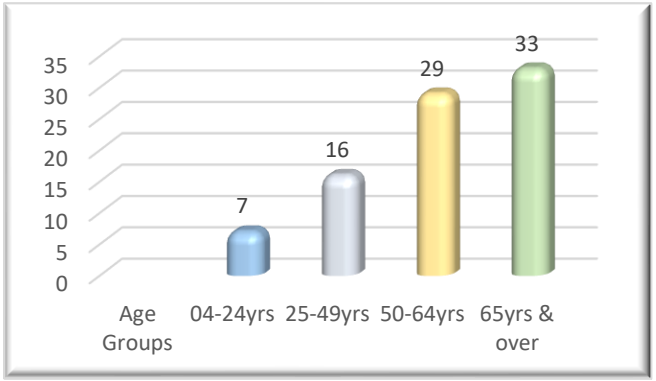
In relation to those individuals who were female:

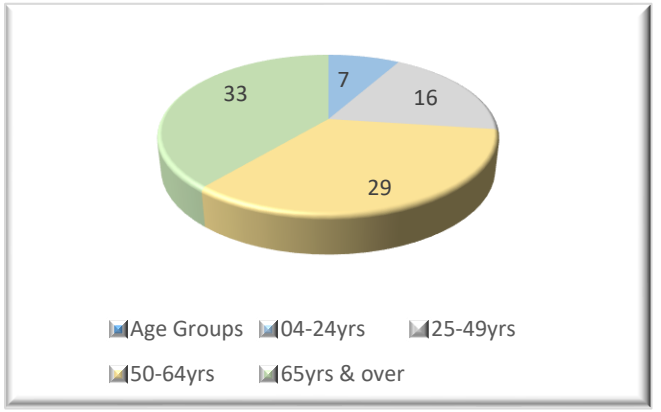
- The age range was 21 -90 years.
- The mean average age of death was 63.2 years.
- The median age of death was 62.5 years.

In relation to those individuals who were male

- The age range was 18-82 years.
- The mean average age of death was 56.7 years.
- The median age of death was 60.5 years.

Age at Death – Completed Reviews





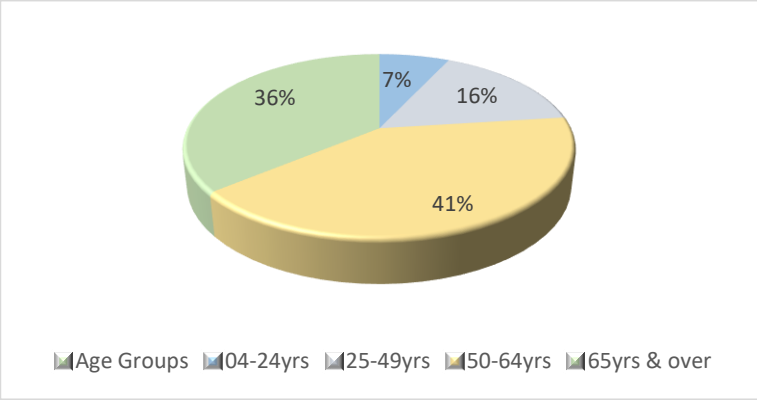
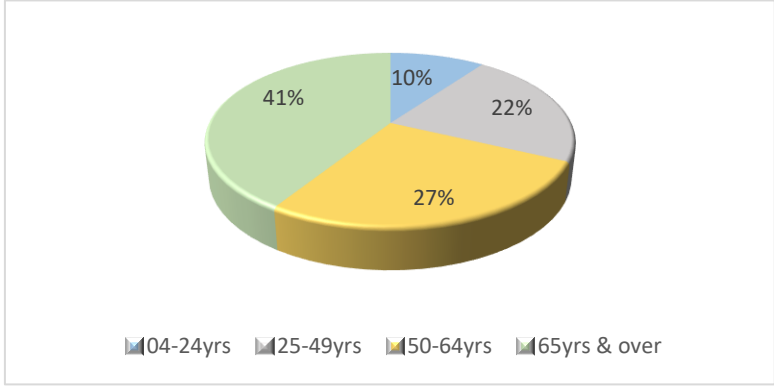
The average life expectancy in England 2018-2020 (latest data available) was: 83.1 years for females and 79.3 years for males: www.ons.gov.uk/peoplepopulationandandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom2018to2020

The average life expectancy in the Yorkshire and Humber region in England 2018-2020 (latest data available) was 82 years for females and 79 years for males: www.ons.gov.uk

To note:
The deaths of children up to the age of 18 years follow a separate statutory review process overseen by the Child Death Overview Panels within each respective Place where an assigned LeDeR reviewer is invited to attend the meeting.

Themes and Trends

5.5.1 Age of Individuals at time of Death: Completed Reviews, Humber and North Yorkshire Places 1st April 2022 – 31st March 2023

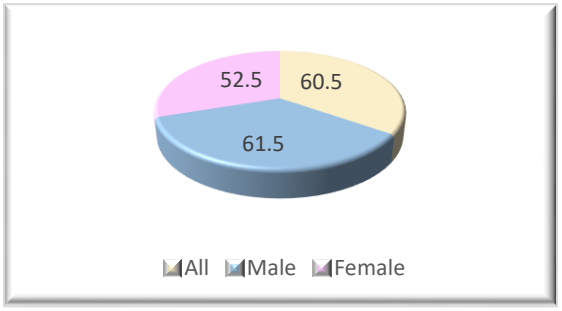
Humber Places	North Yorkshire Places
Of the 44 reviews completed in the Places within the Humber 1st April 2022 -31st March 2023: ➢ The age range was 11-90 years. ➢ The mean average age of death was 59.7 years. ➢ The median age of death was 61.5 years. **In relation to those individuals who were female:** ➢ The age range was 11-90 years. ➢ The mean average age of death was 59.1 years. ➢ The median age of death was 62 years. **In relation to those individuals who were male:** ➢ The age range was 18-82 years. ➢ The mean average age of death was 60.2 years. ➢ The median age of death was 61 years. Chart below shows the ages ranges as percentages due to small numbers within some cohorts. 	Of the 41 reviews completed in the North Yorkshire Places 1st April 2022 -31st March 2023: ➢ The age range was 12-80 years. ➢ The mean average age of death was 54.1 years. ➢ The median age of death was 59 years. **In relation to those individuals who were female:** ➢ The age range was 21-81 years. ➢ The mean average age of death was 62.2 years. ➢ The median age of death was 65 years. **In relation to those individuals who were male:** ➢ The age range was 16-86 years. ➢ The mean average age of death was 58 years. ➢ The median age of death was 62 years. Chart below shows the ages ranges as percentages due to small numbers within some cohorts. 

Themes and Trends

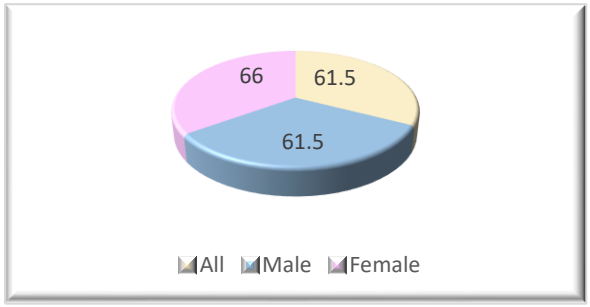
5.5.2 Median Age of Individuals at the time of Death: Completed Reviews, Individual Places 1st April 2022 - 31st March 2023

The below charts show the median age of individuals at the time of death for completed reviews within each Place 1st April 2022 – 31st March 2023.

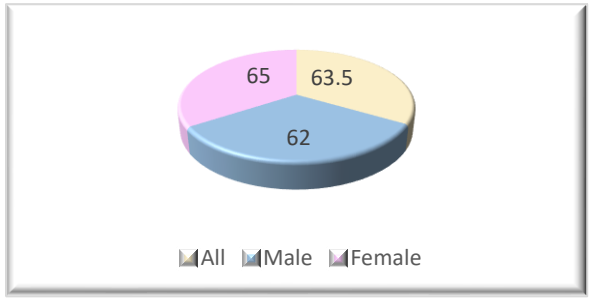
North East Lincolnshire Place



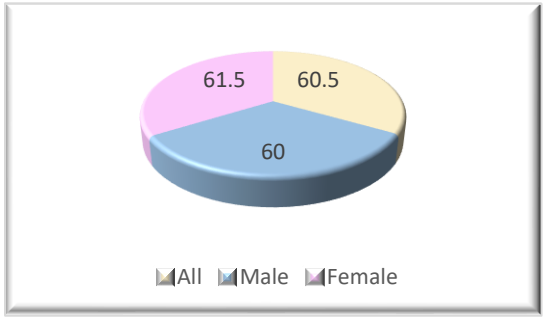
North Lincolnshire Place



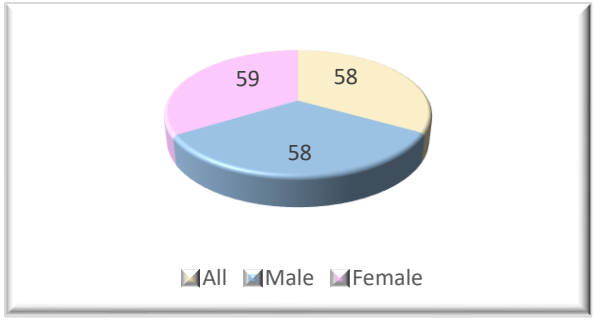
East Riding of Yorkshire Place



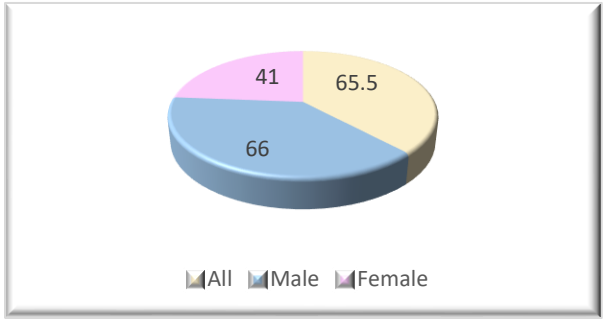
Hull Place



North Yorkshire Place



York Place



Themes and Trends

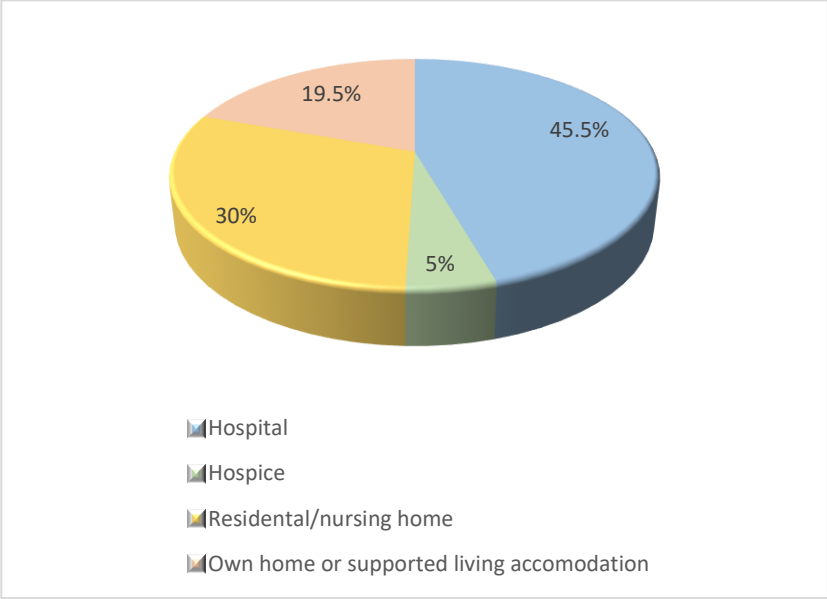
5.6 Place of Death: Reported Deaths 1st April 2022 – 31st March 2023

Place of Death		
	N=119	%
Hospital	54	45.5%
Hospice	6	5%
Residential/Nursing home setting	36	30%
Own home/supported living	23	19.5%

Of the 119 deaths sadly reported during the time period 1st April 2022 - 31st March 2023:

- 54 (45.5%) individuals died within a hospital care setting, (reduction from the 2021/2022 Humber and North Yorkshire annual report of 55%).
- 6 (5%) individuals died within a Hospice care setting; (slight increase from the 2021/2022 Humber and North Yorkshire annual report of 4%).
- 36 (30%) individuals died within a residential/nursing home setting (of which for the majority of individuals, this would be their usual place of residence), (increase from the 2021/2022 Humber and North Yorkshire annual report of 19%).
- 23 (19.5%) individuals died within their own home or supported living accommodation, (slight reduction from the 2021/2022 Humber and North Yorkshire annual report of 21%).

Place of Death - Reported Deaths



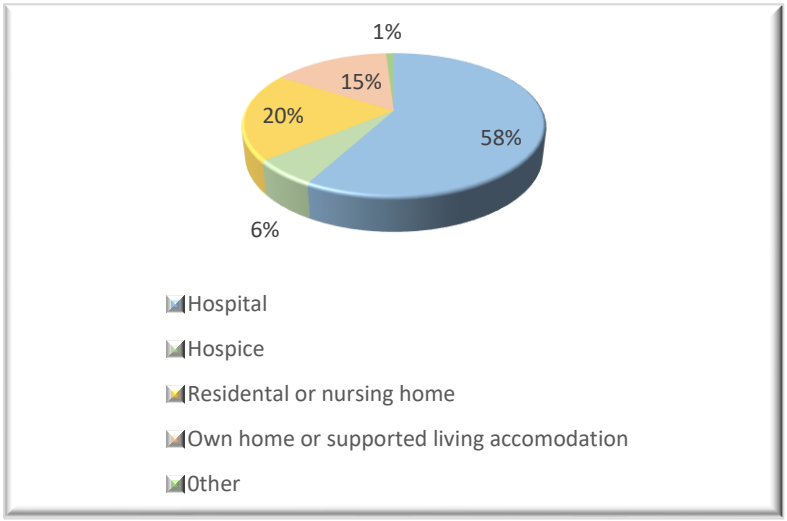
- The reported place of death as hospital for individuals whose death was reported 1st April 2022 – 31st March 2023, is lower at 45.5% than reported within the Humber and North Yorkshire 2021-2022 LeDeR Annual report of 55%, and also lower than the 61% reported within the LeDeR National report for deaths which occurred during 2021.

Themes and Trends

5.7 Place of Death: Completed Reviews 1st April 2022 - 31st March 2023

Place of Death		
	N=85	%
Hospital	41	48%
Hospice	4	5%
Residential/Nursing home setting	22	26%
Own home/supported living	18	21%

Place of Death – Completed Reviews



Of the 85 reviews completed during the time period 1st April 2022 -31st March 2023:

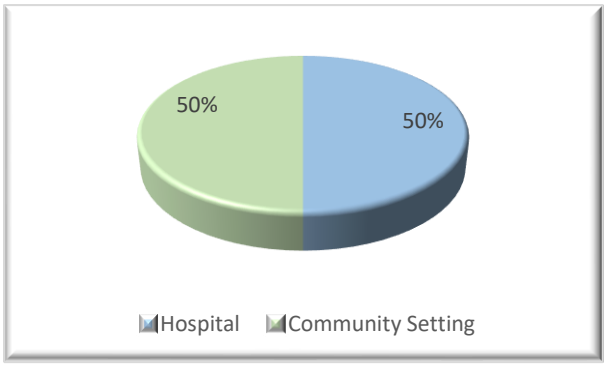
- 41 (48%) individuals died within a hospital care setting, (a reduction from the 2021/2022 Humber and North Yorkshire annual report of 58%).
- 4 (5%) individuals died within a hospice care setting, (slight decrease from the 2021/2022 Humber and North Yorkshire annual report of 6%).
- 22 (26%) individuals died within a residential or nursing home setting (of which for the majority of individuals, this would be their usual place of residence), (increase from the 2021/2022 Humber and North Yorkshire annual report of 20%).
- 18 (21%) individuals died within their own home or supported living accommodation, (an increase from the 2021/2022 Humber and North Yorkshire annual report of 15%).

- The reported place of death as hospital for individuals within the completed reviews 1st April 2022 – 31st March 2023, is lower at 48%% than reported within the Humber and North Yorkshire 2021/2022 LeDeR Annual report of 58%, and also lower than the 61% reported within the LeDeR National report for deaths which occurred during 2021.

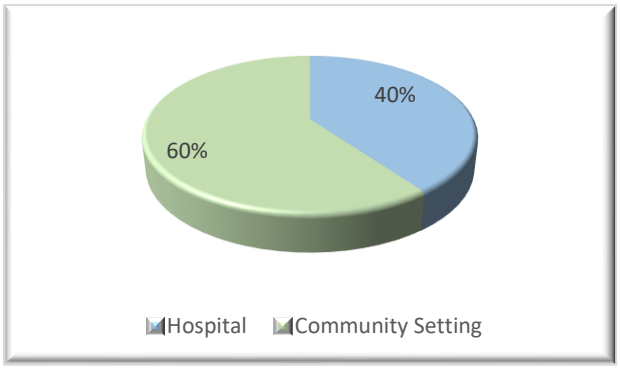
5.7.1 Place of Death: Completed Reviews by Place 1st April 2022 - 31st March 2023

The below charts show the place of death for individuals from completed reviews within each individual Place 1st April 2022 – 31st March 2023.

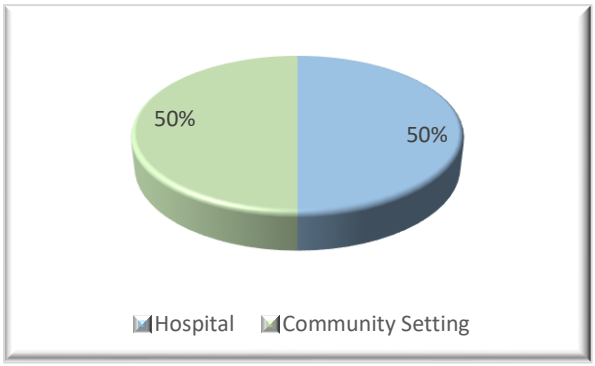
North East Lincolnshire Place



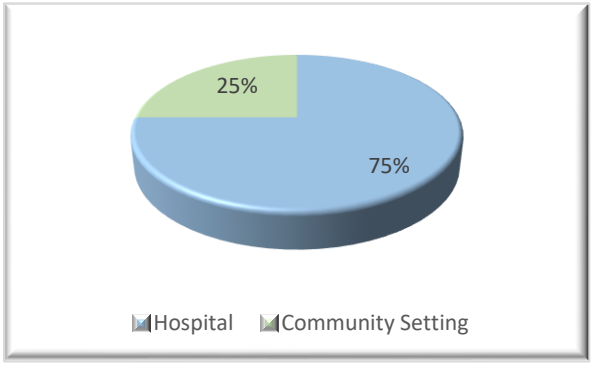
North Lincolnshire Place



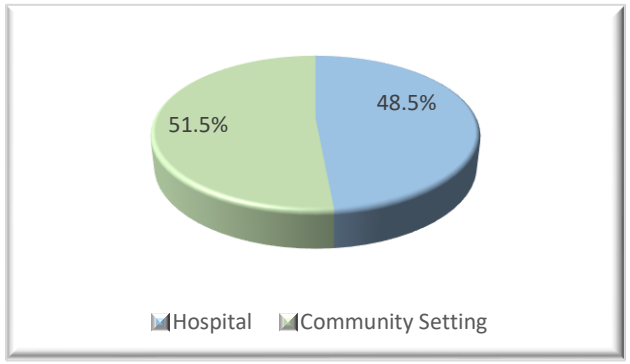
East Riding of Yorkshire Place



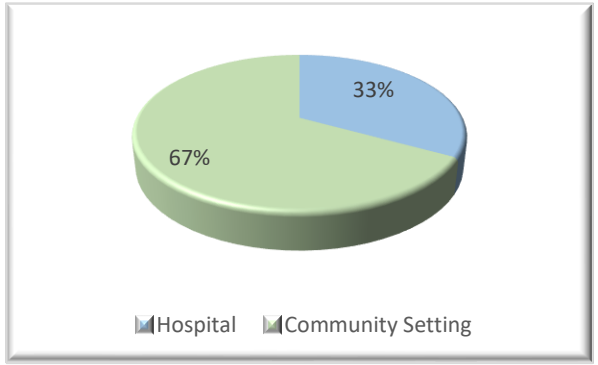
Hull Place



North Yorkshire Place



York Place



To Note: For the purposes of this section, a community setting relates to residential or nursing care homes, hospice, own home or supported living accommodation. A larger proportion of individuals with a learning disability within the Hull area appear to die within a hospital setting, however, the reason for this is not clear from the completed reviews.

Themes and Trends

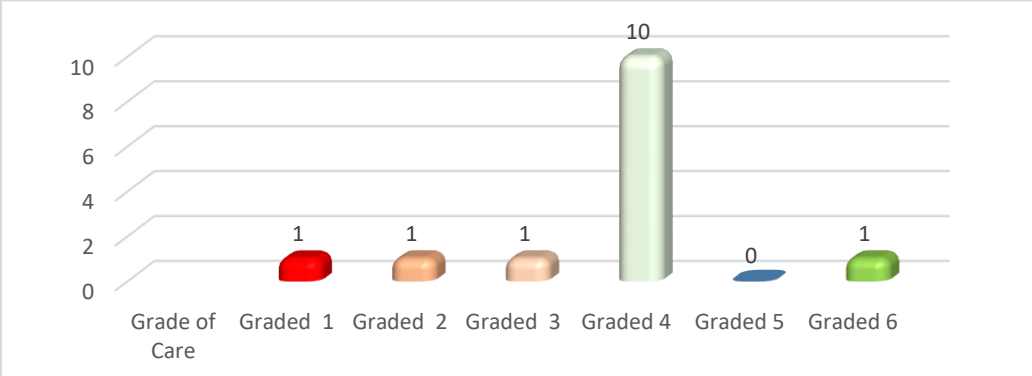
6.0 Grading of Care from Completed Focused Reviews 1st April 2022 - 31st March 2023

Reviews completed prior to June 2021, had several questions relating to the quality of care an individual received as part of the review. These questions are no longer part of the initial review process, however, there remains a section within the focused review where the reviewer is asked two questions relating to the grading of care the individual received. The grading is based on a six-point scale.

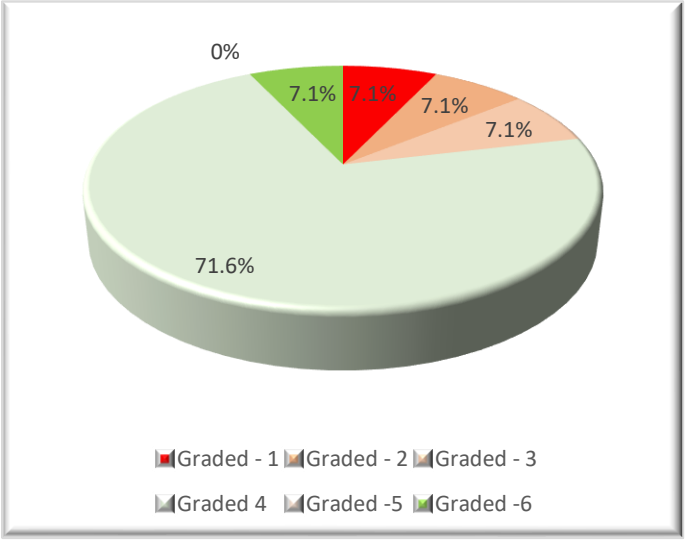
6.1 Quality of Care Person Received Based on Experience

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)

Of the 14 focused reviews completed across the Humber and North Yorkshire Partnership, reviewers provided the following grades relating to this question:



Grading of Care as a Percentage



Of the completed focused reviews, 71.6% were identified as a grade of 4; Satisfactory care (fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing for the quality of care the person received based on experience as identified by the reviewers.

Due to the small number of focused reviews undertaken, it is difficult to define any particular themes or trends.

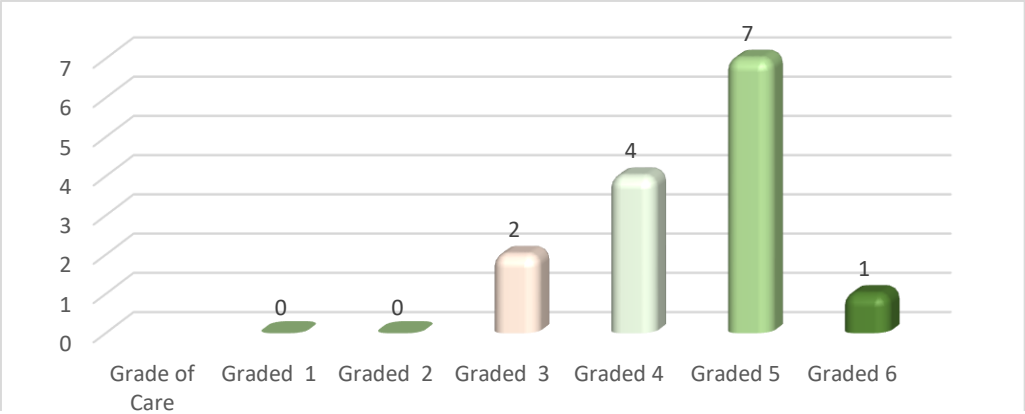
Grading of Care from Completed Focused Reviews 1st April 2022 - 31st March 2023

The second quality question reviewers are asked to grade relates to how available and effective services were for the person. This grading is also based on a six-point scale.

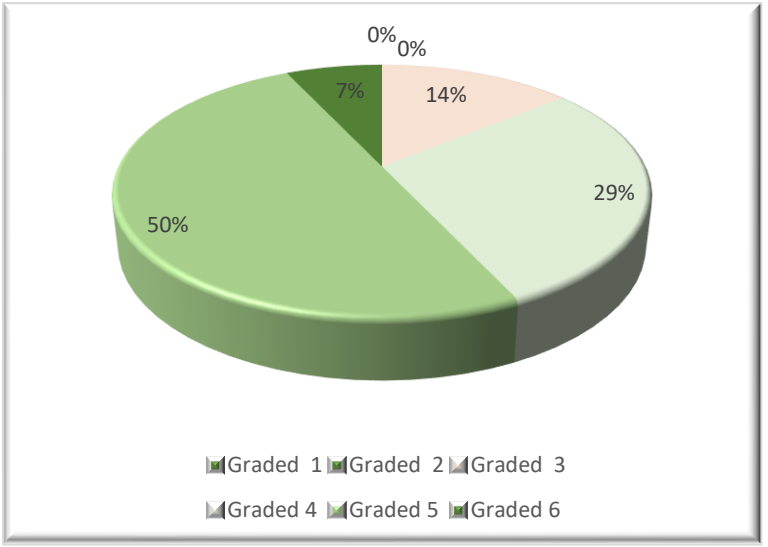
6.2 How Available and Effective Services were for the Person

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 14 focused reviews completed across the Humber and North Yorkshire 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; Availability and effectiveness of services was good and met the expected standard for the quality of care relating to availability and effectiveness of services as identified by the reviewers. Due to the small number of focused reviews undertaken, it is difficult to define any particular themes or trends.

For this standard within the national LeDeR report the majority of reviews fell between grades 3 and 5.

Themes and Trends

7.0 Cause of Death: Completed Reviews Only; 1st April 2022 – 31st March 2023

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 85 completed reviews 1st April 2022 - 31st March 2023:

- Respiratory issues were collectively cited as the most common cause of death within 32% of the completed reviews across the ICB with:
  - Pneumonia accounting for 10%.
  - Aspiration pneumonia accounting for 11%.

Respiratory issues were also cited as the most common cause of death within the 2021/2022 report within 27% of completed reviews.

- Cardiac issues (circulatory) were the second most common cause of death recorded within 14% of completed reviews. This is a slight increase from the 2021/2022 report which identified 12%
- COVID – 19 was cited as the cause of death within 7% of completed reviews (this includes those deaths recorded as COVID-19 pneumonia).

COVID-19 was recorded as the most common cause of death in the 2021 national LeDeR report followed by diseases of the circulatory system followed by diseases of the respiratory system: www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf

Other confirmed causes of death from the completed reviews included:

- Sepsis 7%; similar to the 2021/2022 report.
- Dementia and Alzheimer's disease 6% (slight increase from the 2021/2022 report of 4.5%).
- Natural causes 5%; similar to the 2021/2022 report.
- Cancer 6%. Cancer was reported as the most common cause of death within the 2021/2022 report at 16%.
- Epilepsy 7%.
- Other 15% (due to multiple single numbers of differing causes, these have been identified under the umbrella of 'other' for the purposes of this report).

- The individual's learning disability was not found to be recorded as the cause of death within any of the reviews completed.

7.1 Cause of Death: Completed Reviews Only, Humber Places; 1st April 2022 – 31st March 2023

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 44 completed reviews 1st April 2022-31st March 2023:

- Respiratory issues were collectively cited as the most common cause of death within 36% of the completed reviews across the Humber with:
  - Pneumonia accounting for 9%.
  - Aspiration pneumonia accounting for 11%.
- Cardiac issues were the second most common cause of death recorded within 11% of completed reviews.
- COVID – 19 was cited as the cause of death within 9% of completed reviews (this includes those deaths recorded as COVID-19 pneumonia).

Other confirmed causes of death from the completed reviews included:

- Sepsis 7%.
- Dementia and Alzheimer's disease 4.5%.
- Natural causes 9%.
- Cancer 9%.
- Epilepsy 4.5%.
- Other 9% (due to multiple single numbers of differing causes, these have been identified under the umbrella of 'other' for the purposes of this report).

7.2 Cause of Death: Completed Reviews Only, North Yorkshire Places; 1st April 2022 – 31st March 2023

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 North Yorkshire Places and not the perceived cause of death for individuals whose death has not as yet been reviewed.

Within the 41 completed reviews 1st April 2022-31st March 2023:

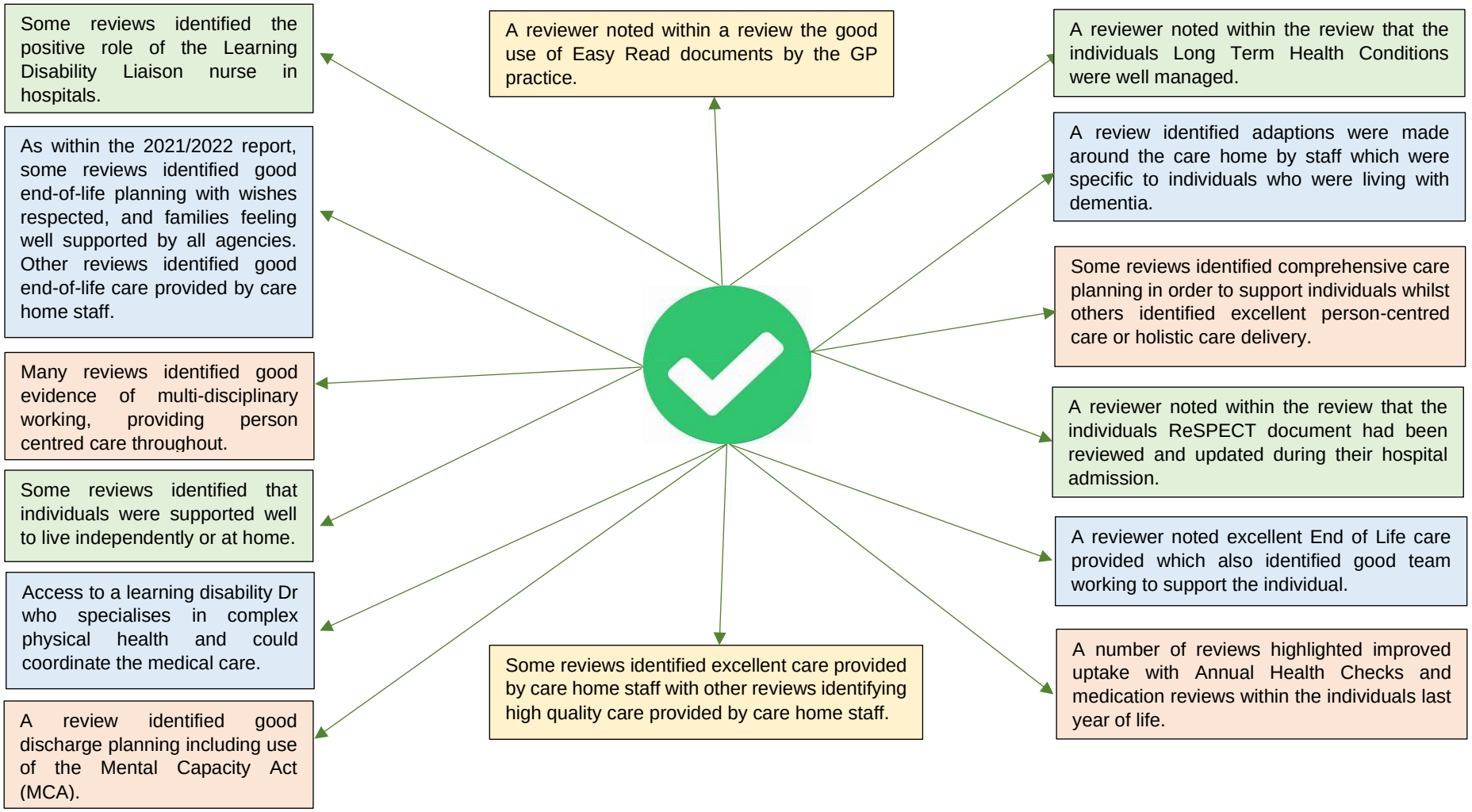
- Respiratory issues were collectively cited as the most common cause of death within 27% of the completed reviews across Yorkshire footprint with:
  - Pneumonia accounting for 15%.
  - Aspiration pneumonia accounting for 10%.
- Cardiac issues were the second most common cause of death recorded within 17% of completed reviews.
- COVID – 19 was cited as the cause of death within 5% of completed reviews (this includes those deaths recorded as COVID-19 pneumonia).

Other confirmed causes of death from the completed reviews included:

- Sepsis 7%.
- Dementia and Alzheimer's disease 7%.
- Cancer 5%.
- Epilepsy 10%.
- Other 22% (due to multiple single numbers of differing causes, these have been identified under the umbrella of 'other' for the purposes of this report).

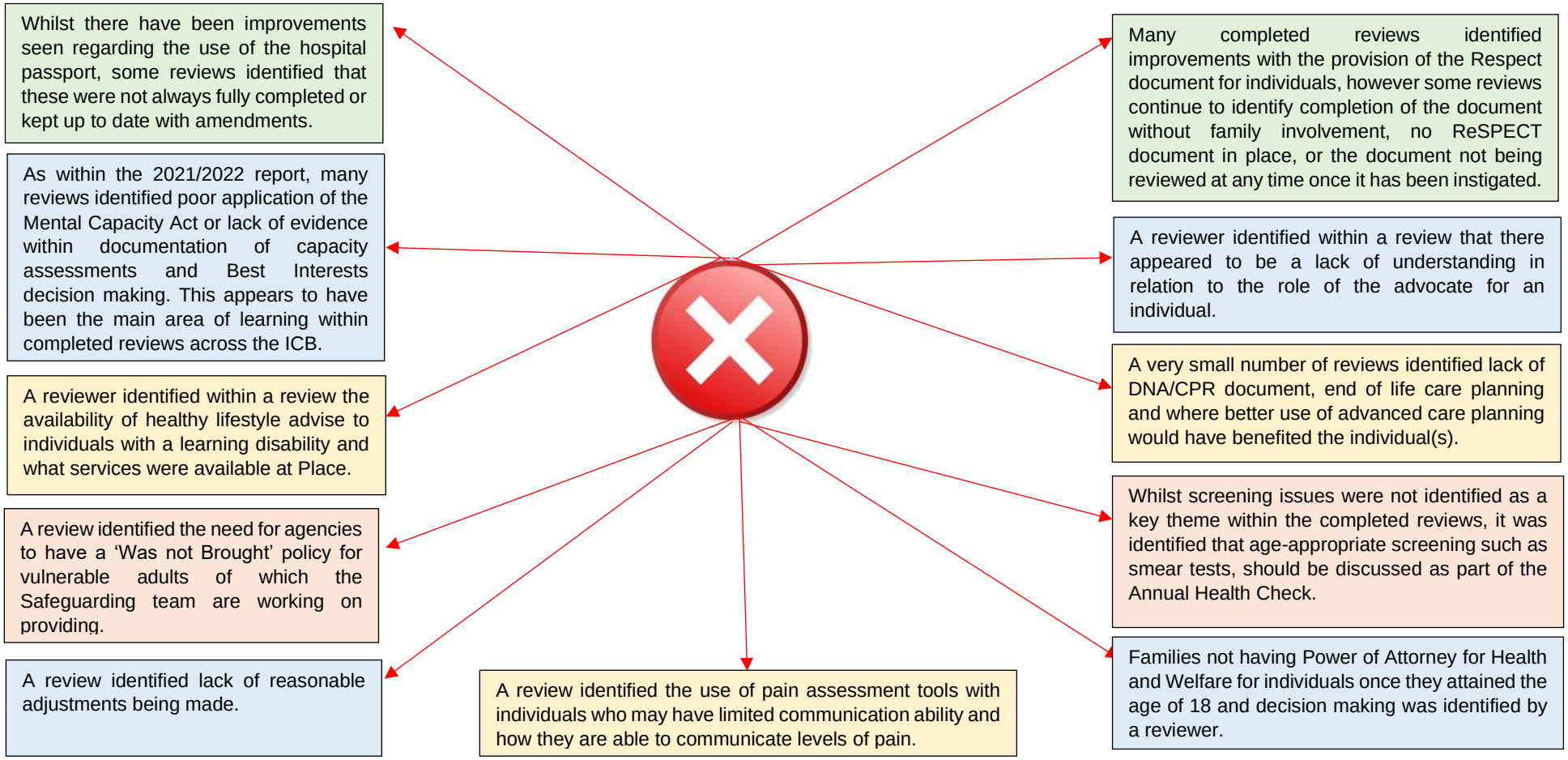
8.0 Identified Good Practice from Completed Reviews 1st April 2022 – 31st March 2023

Below are examples of areas of good practice identified from the 85 reviews completed 1st April 2022 – 31st March 2023 across the Humber and North Yorkshire Care Partnership.



9.0 Identified Learning from Completed Reviews 1st April 2022 – 31st March 2023

Below are examples of the identified learning from the 85 reviews completed 1st April 2022 – 31st March 2023 across the Humber and North Yorkshire Care Partnership.



10.0 Outcomes and Achievements

10.1 Humber and North Yorkshire Health and Care Partnership

There have been many positive initiatives undertaken to improve the experience and services delivered to service users within each Place across the Humber and North Yorkshire Health and Care Partnership, below are just a few examples of these.

- All six Places within the Humber and North Yorkshire Health and Care Partnership have participated in the Improving Access to Bowel Screening Project which is aimed at improving the uptake of this screening programme.
- Both North East Lincolnshire and North Lincolnshire Places have been part of a stopping over medication of people with a learning disability, autism, or both with psychotropic medicines (STOMP) project. The project aims to improve the management of individuals with a learning disability, autism or both, who are taking psychotropic medication in line with the national STOMP agenda.
- All Places have been working with system partners in improving the uptake of the Annual Health Check for all individuals aged 14 and over through various ways such as:
  - Supporting practices to move to birthdate recall.
  - Refresher training, visits, and information sessions at Primary Care learning time events.
  - Working with special schools at Place in promoting the Annual Health Check to young people approaching their 14th birthday and explaining the benefits of the review and the subsequent wellbeing plan.
  - A range of easy read documents to support the Annual Health Check have been developed and shared across the Humber Partnership for use.
  - Targeted training has been provided within NEL for primary care sites with lower uptake for the health check which has seen a positive improvement.

- The Humber and North Yorkshire Health and Care Partnership ended the financial year with 80.3% uptake for Annual Health Checks against the trajectory of 75%, with each Place individually exceeding the trajectory as identified below:
  - NEL Place – 81.5%.
  - ERY Place – 79.4%.
  - NY Place – 82.8%
  - NL Place – 76%.
  - Hull Place – 77.5%.
  - York Place – 82.8%

- Discussions have taken place with University colleagues to deliver training to students on both nursing and social work courses. Support for this has been provided by experts by experience. It is anticipated this will be further developed during 2023/2024.
- Raising the profile of the LeDeR programme has been undertaken across the Health and Care Partnership where opportunities have arisen; this will continue during 2023 and into 2024.

- Commencing in January 2023, awareness on learning disability, autism and MCA/DoLs training sessions have been provided for care home and primary care staff across Hull and East Riding.
- Hull Place are participating in a national pilot for offering and undertaking autism annual health checks.
- Cancer alliance have attended the Humber Steering Group to discuss how they engage with people with a learning disability and autism regarding screening and easy read information.
- Hull Place are in the final year of a pilot to develop a new model of care delivery for improving the health outcomes and quality of life of individuals with a profound and multiple learning disability. The positive work of this pilot has been seen within completed LeDeR reviews since the commencement of the project in May 2021.
- The Quality Assurance and Improvement Team at York Place have been working with care providers with a focus placed on improving recognition (softer signs and NEWS2), response and communication. The aim is to reduce avoidable harm, enhance clinical outcomes and improve the experience of deteriorating residents. The training has provided a positive impact in care homes and domiciliary care who have implemented the tools into their practice. The training develops staff skills and knowledge in recognising deterioration and how to respond to change. Training also includes communication skills and how to use the SBAR (Situation, Background, Assessment and Recommendations) tool to help staff relay accurate, relevant and timely information to other health and care services including GPs and district nurses. Care staff are supported to use the tools and embed this change in to practice.

10.2 Transforming Care Partnerships (TCP) 1st April 2022 – 31st March 2023

Both the Humber Transforming Care Partnership (TCP) and the North Yorkshire and York Transforming Care Partnership (TCP) have had work streams during the financial year 1st April 2022-31st March 2023. These workstreams have focused on improving the lives of people who have a learning disability or autism. Below is a brief overview from both TCP areas.

Humber Transforming Care Partnership

- A health check exemplar project undertaken in Bridlington has now been completed. This project has:
  - Seen a growth in the learning disability register sizes.
  - Developed co-produced easy read resources.
  - Built a sensory friendly waiting area.
  - Developed pathways which remove barriers to health checks and follow up treatment.

The project also delivered a series of themed wellbeing events. It is anticipated that the learning from the project can be used more widely. The TCP are currently awaiting the outcome of the evaluation study to understand the difference the project has made for local people with a learning disability and autistic people.

- Further health and wellbeing initiatives are being developed to support people with a learning disability, autistic people and their carers to access good quality health care.
- Individuals with lived experience have been speaking to students on the Learning Disability nursing courses within Hull University regarding about the barriers they face in accessing health care, and helping students understand how reasonable adjustments can be made to improve their experience.
- Partaking in a national pilot for autistic health checks as one of the aims of the NHS long term plan. One thousand autistic people in the Hull area have been offered a health check (similar to the health check offered to people with a learning disability). It is expected the learning from this pilot will be used by NHS England national team to implement health checks for all autistic people who are aged 14 and over.

North Yorkshire and York Transforming Care Partnership

- Co-production continues to develop a Learning Disability and Autism website as a central point for patients, professionals, carers and families. The TCP are working closely with Inclusion North, carers and families, experts by experience and Healthwatch in the development of the website.
- Plans are underway for delivery of some health roadshows during 2023/2024. Topics such as cancer will be included as part of these roadshows.
- The TCP have met with the Primary Care Networks and General Practitioners regarding improving follow up for missed Annual Health Checks, improving the overall completion of the Annual Health Check and to spotlight on areas such as completion during long term admission to hospital. A meeting has also taken place with paediatricians to explore the possibility of a prompt to GP's/practices when an individual attains the age of 14 to ensure they are included onto the Annual Health Check register call list.

10.3 Humber LeDeR and North Yorkshire LeDeR Steering Groups 1st April 2022 – 31st March 2023

In line with the NHS England LeDeR Policy the two LeDeR Steering Groups within the Humber and North Yorkshire Health and Care Partnership have continued to strengthen. The Steering Groups provide oversight, support and governance for the local delivery of the LeDeR programme. Below is a brief overview from both Steering Groups.

Humber Steering Group

- The Humber LeDeR Steering Group has continued to meet throughout 2022/23. Membership has been revised and strengthened to ensure representation from across the Humber footprint and now includes colleagues who have a lived experience of Autism and those who are working with people with a diagnosis of Autism.
- Learning from the Humber LeDeR reviews is shared within the Steering Group. Work is in progress to connect areas of learning and service improvement with the existing communities of practice. Task and finish groups will be developed to take learning forward. People with lived experience and/or their carers will be key members of these groups to ensure services are tailored and responsive to the needs of people with a diagnosis of a Learning Disability and/or Autism.

North Yorkshire Steering Group

- Following identification within completed reviews of staff groups not being fully aware of the LeDeR programme, information has been shared with care home and domiciliary care providers across York and the North Yorkshire footprint.
- Plans continue to arrange training and awareness sessions with universities, coroner and palliative care.
- Content and quality of Annual Health Checks has been identified as not always of a high or accurate standard or linked to specific measures to address particular health needs. Plans are in place for monitoring within LeDeR reviews of evidence of health action plans over the remainder of this financial year. Examples identified will be shared for learning.
- Local authority within York Place have reviewed their data relating to the deaths of non-white British service users. This has then been compared to the notifications from within York Place to the LeDeR programme which has provided assurance that there have been no missed notifications. This piece of work will be completed across North Yorkshire Place also.

10.5 Providers within the Humber Area 1st April 2022 – 31st March 2023

As active members of both the Humber LeDeR Panel meeting and the Humber Steering Group, the below identifies some examples of work undertaken by the following care providers within the Humber:

- **Northern Lincolnshire and Goole NHS Foundation Trust (NLaG).**
- **Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH).**
- **Humber NHS Foundation Trust.**
- **Hull University Teaching Hospitals NHS Trust (HUTH).**
- **City Health Care Partnership Community Interest Company (CHCP).**

- HUTH secured funding from Health Education England for a clinical educator for learning disability and dementia..
- NLaG are working with local partners to review and raise awareness in the provision of reasonable adjustments for individuals.
- Humber have developed nurse led phlebotomy, which supports individuals where other attempts to obtain blood tests have been tried. It aims to look at least restrictive approaches, desensitisation, and appropriate supportive care.
- The community learning disability team from RDaSH were out and about within North Lincolnshire on the health bus talking to people about STOMP, with communication boards, sensory items and information on medications.
- CHCP supported the development of a reporting system to identify individuals who had not received an Annual Health Check, and also supported practices in identifying and delivering reasonable adjustments to ensure individuals were able to access their health check.
- Both HUTH and NLaG required clinical staff to complete Mental Capacity Act and Deprivation of Liberty's training. This has a focus on mental capacity assessment and how this informs consent or best interest decision making.
- NLaG have developed 'flagging' within the patient administration system (PAS) to identify individuals who may require support at outpatient appointments. This will enable the Trust to send accessible appointment letters and be proactive in the provision of reasonable adjustments particularly in relation to outpatient appointments.
- Humber have restructured their learning disability epilepsy service to provide a blended model of clinics including regular telephone, video and face to face. They have continued provision of home visits when needed and ad hoc telephone support.
- RDASH utilised the health bus to attend care homes and day activities to discuss constipation for there "dying for a poo event". Here we spoke about constipation and the signs and symptoms to people with an LD and their care givers. We gave out healthy bowel information and what a healthy poo should look like.
- CHCP developed the hospital passport in collaboration with patients/carers and system partners, which has been implemented across the Humber. Guidance and communication boards have been created and shared across the TCP area.
- HUTH have developed a mental health, learning disability and autism strategy, with an implementation plan.
- NLaG have continued with specific ward rounds (at least twice weekly) to ensure vulnerable patients are appropriately identified and their needs are being met.

- Humber undertake complex health clinics with the learning disability speciality doctor which aims to get better outcomes for
- people in conjunction with primary, acute and other community health services in Hull.
- RDASH are partaking in a pilot with NHSE to support individuals with a learning disability to complete their bowel screening, understand the importance of this and share information around the screening process.
- CHCP provided virtual training covering annual health checks, cancer screening, reasonable adjustments, learning disability and autism awareness and severe mental illness awareness to primary care staff across Hull and East Riding of Yorkshire.
- HUTH have developed electronic care plans for patients with learning disabilities and included learning disability and autism as part of the electronic assessment tool.
- NLaG have a carers strategy in place. The Trust are working with carers/partners to identify carers and improve their experience whilst in hospital with their loved one.
- Humber continue their nurse prescriber led STOMP clinics, specifically looking at not over prescribing medications with a focus on positive behaviour support and active support.
- CHCP are partaking in the autism specific annual health check pilot within Hull. A health check template and register search report have been created, alongside training and guidance/resources which have been shared with identified practices as part of the pilot. Feedback to date has been positive.
- 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 is pulled through to future episodes of care allowing for swift identification on admission to enable support and reasonable adjustments to be provided.
- Changing places facility within NLaG in progress with an anticipated completion date of mid-April 2023.

10.6 Providers within the North Yorkshire Area 1st April 2022 – 31st March 2023

As active members of both the North Yorkshire and York LeDeR Panel meeting and the North Yorkshire and York Steering Group, the below identifies some examples of work undertaken by the following care providers within North Yorkshire:

- **York and Scarborough NHS Foundation Trust (Y&SFT).**
- **Tees, Esk and Wear Valley NHS Foundation Trust (TEWV).**
- **Harrogate and District NHS Foundation Trust (H&DFT).**

- York and Scarborough learning disability service has just 2000 individuals alerted on their hospital electronic system, with the team working closely with GP practices to add to this data and work cohesively with their community partners.
- York and Scarborough have completed a scoping exercise in relation to the autism service. They have also secured funding for 2023/2024 to develop the service.
- Harrogate and District Trust have an electronic form in place for Mental Capacity, with targeted training having been completed.
- A sensory room is being built and embedded within the new Scarborough hospital. Work has taken place regarding the fund raising alongside patients and community partners in order to provide equipment for the new facility.
- York and Scarborough hospital have developed Mental Capacity Act (MCA) leads within the wider safeguarding team.
- The Trust are continuing to work with community partners and patients to develop accessible documentation and easy read advance care plans.
- A working feedback group has now been established for autism liaison development with autistic patients.
- South Tees hospital have developed and easy read hospital pack.
- South Tees Trust have added a blue diamond logo to their electronic patient record system which enable staff to identify any patient who has a learning disability.
- The Trust have appointed a Mental Capacity Act (MCA) and Deprivation of Liberty Lead (DoLs).
- The Trust have introduced a new hospital passport and are in the process of developing an app.
- Following the findings of a DNACPR audit approximately 3 years ago which looked at reasons for DNA/CPR (ie; learning disability to not be a reason for DNA/CPR), and the decision making process, Harrogate and District Trust completed targeted training with staff. A re-audit was completed this year which identified much improved results.
- During learning disability week, Harrogate and District Trust explored how pain tools were used and documented with the learning disability team working with ward staff to review how clinical judgement is used alongside a pain tool score, as an option for assessment and to improve documentation.
- The clinical advisor role within Harrogate and District Trust has been extended for six months, with the post holder supporting the learning disability team.

11.0 Key Themes and Recommendations for Improvement from Reviews Completed 1st April 2022 – 31st March 2023

The following are the main key themes for improvement, identified from the learning from completed reviews 1st April 2022-31st March 2023

Annual Health Checks:
Whilst all Place areas surpassed the 75% trajectory set by NHSE of individuals aged 14 years and over to receive their Annual Health Check, this area remains a priority with continued work required to ensure all individuals are offered an Annual Health Check and for the completed to be of a high standard with a Health action plan also completed.

Mental Capacity:
Whilst some reviews have identified appropriate use of the Mental Capacity Act and Best Interest Decision making, it is clear from other reviews completed during the timeframe above, that further work continues to be required relating to:

- Mental Capacity Compliance.
- Documentation of mental capacity assessment.
- Documentation of Best Interest Decision making.

End of Life Care:
It is to be acknowledged that many reviews have identified good end of life care and planning. Areas of focus from completed reviews continue to be based around:

- Recognition and earlier decision making which may avoid individuals being transferred to hospital within their last days of life.
- Earlier consideration of completion of the ReSPECT document allowing good end of life conversation and early planning with the individual, their family and those who care for them.
- Education and training in respect of end of life care and the ReSPECT document.

Access and Uptake to Screening:
Whilst this does not appear to have been identified as a key theme within the completed reviews during the timeframe above, this area remains a key focus with regard to individuals being supported to attend for age-appropriate screening, ensuring support relating to:

- Uptake of routine bowel screening and follow up where not undertaken.
- Provision of reasonable adjustments to support individuals to uptake the screening offered.

Cause of Death:

- For individuals whose identified cause of death within the Humber and North Yorkshire Health and Care Partnership during 2023/2024 is epilepsy or ischaemic heart disease to be subject to a focused review.

Availability and Uptake of Hospital Passports:
Embedding of the hospital passport across all areas to be monitored throughout 2023/2024.

Early Recognition of the Deteriorating Patient:
For RESTORE2mini training to be offered to all care home providers within each Place area, including the use of softer signs to recognise deterioration.

12.0 Recommendations and Actions to be taken forward for 2023/2024

From the findings and learning from the 85 reviews completed 1st April 2022 – 31st March 2023, the following recommendations have been made as areas of work to be undertaken across the Humber and North Yorkshire Health and Care Partnership for the remainder of 2023 and into 2024:

- For the Steering Groups to review membership and ensure representation from the collaboratives and to ensure the recommendations from reviews are shared and reflected in transformation work streams across the Humber and North Yorkshire Health and Care Partnership to further improve the lives of individuals with a learning disability living within our areas.
- During Quarter 1 2023/2024, the chairs of the Steering Groups to work towards merging and becoming a Humber and North Yorkshire Health and Care Partnership Steering Group by the end of Quarter 2 2023/2024.
- For deaths notified to the LeDeR programme where the cause of death is identified to be epilepsy or ischaemic heart disease, for these deaths to be undertaken as focused reviews to identify learning which may influence changes to pathways, in addition to those required as meeting the criteria as set by NHS England.
- During Quarter 1 2023/2024, the chairs of the governance panel meetings to work towards merging and becoming a Humber and North Yorkshire Health and Care Partnership Governance Panel by the end of Quarter 1 2023/2024.
- RESTORE2mini training to be offered to all care home providers within each Place area, including the use of softer signs to recognise deterioration.
- Continue to build on the work undertaken during 2021/2022 to further improve the position across the ICS with regard to ensuring individuals (over the age of 14 years) are invited and supported to attend for an Annual Health Check, whilst ensuring the completed assessment is robust and meets the needs of the individual.
- 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.
- To continue to build on the progress made in ensuring individuals with a learning disability have equal access to health screening, follow up and support when they are deemed to have ‘not attended’ or not partaken in screening (such as bowel screening).
- Continue to raise awareness of the LeDeR Programme within all health and social care partners to ensure all individuals with a learning disability or autism who sadly die within the Humber and North Yorkshire Health and Care Partnership area have their death reviewed through notification to the programme.
- To strengthen current processes for sharing learning and good practice identified from completed reviews across the Humber and North Yorkshire Health and Care Partnership ICS footprint by ensuring the LeDeR newsletter is shared widely following each panel meeting.
- Continue to identify learning and improvements in relation to End of Life care, in particular relating to early recognition and decision making with regard to end of life planning and completion of the ReSPECT document within both hospital and community settings. To recognise good end of life planning from completed reviews which has enabled good end of life conversation, early planning with the individual and their family

and those who care for them. Provide feedback to the appropriate End of Life workstreams from learning from completed LeDeR reviews pertinent to these areas.