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

Annual Report

1st April 2021 to 31st March 2022

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Head of Nursing - NLCCG (on behalf of the 6 CCGs within the Humber and North Yorkshire Health and Care Partnership)
10th May 2022

Content **Page**

Executive Summary

This is the fourth Learning Disabilities Mortality Review (LeDeR) Programme Annual Report from NHS Clinical Commissioning Groups (CCGs). This report is the first LeDeR Annual Report written on the new Integrated Care System (ICS) footprint and has been written by NHS North Lincolnshire CCG (NLCCG) on behalf of the following CCG's:

- NHS North Lincolnshire Clinical Commissioning Group (NLCCG).
- NHS North East Lincolnshire Clinical Commissioning Group (NELCCG).
- NHS East Riding of Yorkshire Clinical Commissioning Group (ERYCCG).
- NHS Hull Clinical Commissioning Group (Hull CCG).
- NHS North Yorkshire Clinical Commissioning Group (NYCCG).
- NHS Vale of York Clinical Commissioning Group (VoYCCG).

All six CCGs within the Humber and North Yorkshire Health and Care Partnership have robust systems and processes in place for the management of the learning disability mortality reviews:

- The 4 CCGs within the Humber area (NLCCG, NELCCG, ERYCCG and Hull CCG), continue to work collaboratively to identify actions from learning alongside positive practice for all completed reviews through a joint Governance panel meeting for all completed reviews chaired by NHS NLCCG, with NHS NYCCG undertaking the same process on behalf of NHS VoYCCG.
- Collaborative working across the six CCGs commenced during 2021, to develop robust processes in order to share learning and good practice from completed reviews. This will be enhanced through the distribution of a developed Learning Lessons Newsletter, completed monthly, incorporating the learning and good practice from reviews across all six CCGs within that month. Whilst the newsletter has been in place within the Humber area for several months now, the reviews completed within NYCCG and VoYCCG have been added from 1st April 2022. Further work is required to ensure the newsletter is shared widely across the Humber and North Yorkshire Health and Care Partnership during the remainder of 2022. This will further enhance the identified learning and early identification of shared themes and trends for focussed work across the ICS area throughout the remainder of 2022 and into 2023.

A total of 86 deaths were sadly notified to the LeDeR programme from across the six CCGs from 1st April 2021 - 31st March 2022.

- 51% of the people whose death was notified to the programme were male, (lower than that of the national picture as identified within the National LeDeR report 2021, which covered the deaths notified to the programme between 1st January 2018 - 31st December 2020) of 57%.
- 100% of the people whose death was notified to the programme were white British, which is higher than that of the national picture of 89% in 2020, as identified within the National LeDeR report, 2021. It is identified that there may be under reporting from across our BAME communities, which will be a key area of focus during 2022/2023.
- 55% of people whose death was notified to the programme died within a hospital setting, this is slightly lower than that of the national picture of 60%, and lower than reported within the 2020/2021 Annual Reports (63% reported for the Humber CCG area and 60% reported for North

Yorkshire and Vale of York CCG area). A larger proportion of individuals with a learning disability within the North Yorkshire area appear to die within a community setting. Review of this differentiation will be a consideration for this year to identify any learning and the opportunity to share across the system. It is also unclear as what impact the on-going COVID-19 pandemic has had locally in relation to this figure.

During the time-period of this report; 1st April 2021-31st March 2022, 66 LeDeR reviews were completed across the six CCGs. It is to be noted that some of the reviews have been completed outside of the required NHS England timeframe of six months and will therefore relate to people who have died during 2020.

The most common confirmed cause of death identified within the reviews completed from 1st April 2021 – 31st March 2022, was cancer (16%) with pneumonia (12%) and COVID -19 (12%) as the second most common causes. However, collectively, respiratory issues were cited as the most common cause of death within part 1 of the Medical Certificate Cause of Death (MCCD).

- The main key learning from the reviews has highlighted several areas which will be taken forward as areas requiring improvement throughout 2022 /2023:
  - Further improvement in the uptake of Annual Health Checks to meet the NHSE trajectory of at least 75% of eligible individuals (over the age of 14 years) receiving this valuable annual check.
  - Continued work is required with regard to health and social care staff; in the understanding and use of the Mental Capacity Act, Deprivation of Liberty Safeguards (DoLs), Capacity Assessments and Best interests, including completion of robust documentation.
  - Continued work 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).
  - Further improvements in relation to End of Life care, ensuring early recognition and decision making with regard to 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 which can be seen within page 20 of this report.

The Bristol 2020 National Annual LeDeR Report can be accessed at: https://leder.nhs.uk/resources/annual-reports

1.0 Introduction and Background

The Learning Disabilities Mortality Review (LeDeR) 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 of preventable health conditions, and up to 30 years earlier than the remainder of the population.
Individuals with a learning disability, their families and carers, have been central to the development and delivery of the programme nationally.

On 23rd 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: https://www.england.nhs.uk/learning-disabilites/improving-health/mortality-review/

The name for the programme also changed to 'Learning from Life and Death Reviews – people with a learning disability and autistic people'. However, it will continue 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, As we move forward into Integrated Care Systems (ICS's), (from 1st July 2022), NHS England regional teams will hold ICS's to account for the delivery of the actions identified from completed reviews with quarterly reports required on progress made.

The changes brought about by the policy have seen:

- The LeDeR programme transfer from the University of Bristol web-based system to a new web-based platform from 1st June 2021.
- Local Area Contacts (LACs) and reviewers required to complete mandated training in order to access the system and complete LeDeR reviews. This training is now an annual requirement for all involved in delivery of the programme.
- A change to the review process (as identified in section 4 below).
- Changes required to the LeDeR workforce with effect from 1st April 2022, to ensure reviewers are independent of provider organisations with reviewers working in teams to ensure no reviewer works alone and all reviewers having the time they require to complete reviews with the support to undertake them.

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 would be 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 Director of Nursing and Quality within each of the six CCGs have the Executive lead for the LeDeR programme. The Local Area Contacts (LACs) within the respective CCGs, locally allocate the review to a reviewer and undertake the quality assurance process. During 2021/2022, the CCGs have continued to work more closely together in respect of the LeDeR process:

- Development of a Humber and North Yorkshire Health and Care Partnership three-year LeDeR strategy.
- Quarterly returns as required by NHSE of the learning and progress against actions is completed and returned as one and not individual CCGs.
- Further collaborative working will continue for the remainder of 2022/23.

LeDeR Panels

Due to the geographical area of North Yorkshire and the Humber, there are two LeDeR panel meetings for sharing of the learning from initial reviews and for discussion and approval of the completed focussed 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 now being shared within a combined LeDeR learning newsletter which is completed each month following the review panels. The learning from the reviews is shared with the respective LeDeR Steering Groups within each locality for monitoring of the required actions.

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 footprint.

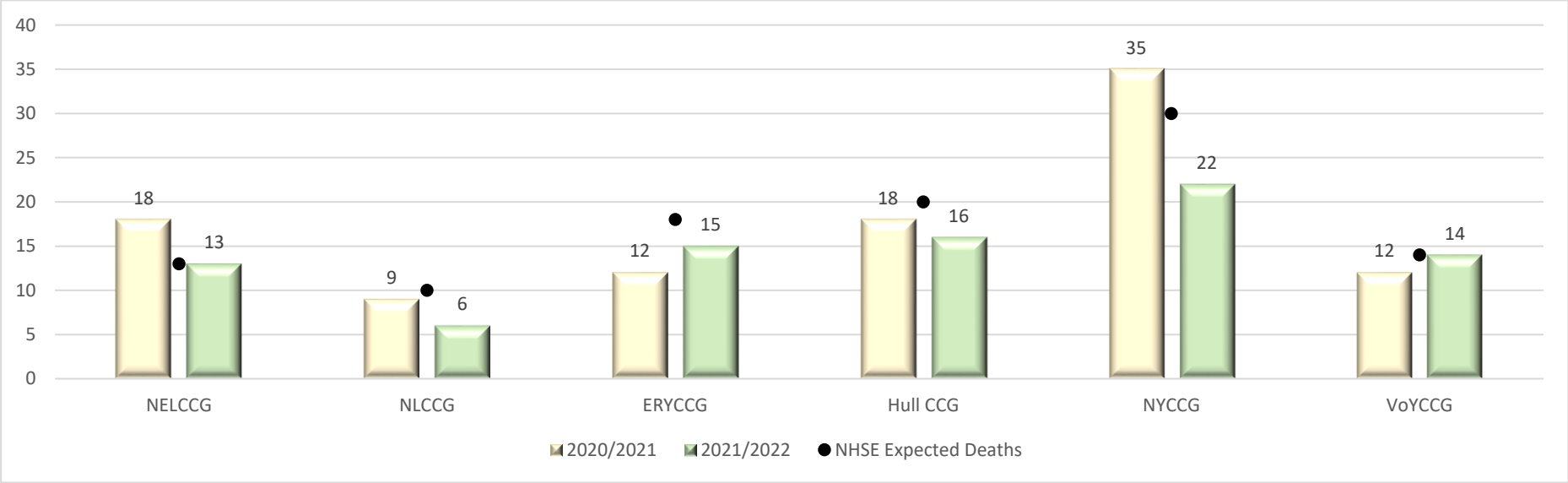
3.0 Deaths of Individuals with Learning Disabilities in our Local Area 1st April 2021 – 31st March 2022

Sadly, a total of 86 deaths of individuals with a learning disability were reported across the six CCGs within the Humber and North Yorkshire Health and Care Partnership during the time-period 1st April 2021 - 31st March 2022. The impact of the COVID-19 pandemic has continued to be felt during the timeframe of this report. Locally, of the 86 reported deaths into the LeDeR programme, 2 deaths have been attributed to COVID-19, with 3 further deaths possibly attributed to COVID-19, however this has not been confirmed as yet, as the reviews have not been completed for these individuals.

Figure 1 below identifies the number of deaths reported by each CCG, 1st April 2021-31st March 2022, with a comparator to the number of deaths reported 1st April 2020 - 31st March 2021. The black circle within each CCG area relates to the NHS England number of expected deaths per year per CCG (NELCCG: 13 deaths per annum, NLCCG: 10 deaths per annum, ERYCCG: 18 deaths per annum, Hull CCG: 20 deaths per annum, NYCCG: 30 deaths per annum, VoY CCG: 14 deaths per annum).

Figure 1.

Number of Deaths Reported 1st April 2021 - 31st March 2022 with a Comparator to Deaths Reported 1st April 2020 – 31st March 2021



To Note:

- NLCCG had a total of 8 deaths reported during the timeframe above, however, 2 cases were identified as 'not being in scope' as the individuals did not have a formal diagnosis of a learning disability or a formal diagnosis of autism, therefore excluded from the programme.

4.0 Overview of Completed Reviews 1st April 2021 – 31st March 2022

With the changes to the LeDeR programme which took effect from 1st June 2021, there was a new process for completion of the reviews.
All notifications of a person's death into the LeDeR programme receives an initial review. The allocated reviewer will speak to the persons family or someone who new them well, talk to the GP or review the GP records and speak to at least one other individual involved in the persons' care. Where a more detailed review is required, a focussed review follows, which is a more in-depth review of the persons health and social care. Focussed reviews are undertaken in the following situations:

- Where a person is from a Black, Asian or Minority Ethnic (BAME) background, due to the significant under reporting and increased health inequalities within these communities.
- Where in the professional judgement of the reviewer or LAC, there is significant learning likely from undertaking a focussed review. Where there are concerns in relation to the quality of care provided to the person by one or more providers, or where there is a lack of integrated or co-ordinated care.
- Where a family member requests a focussed review.
- All reviews of individuals with autism and no learning disability are currently subject to a focussed review.

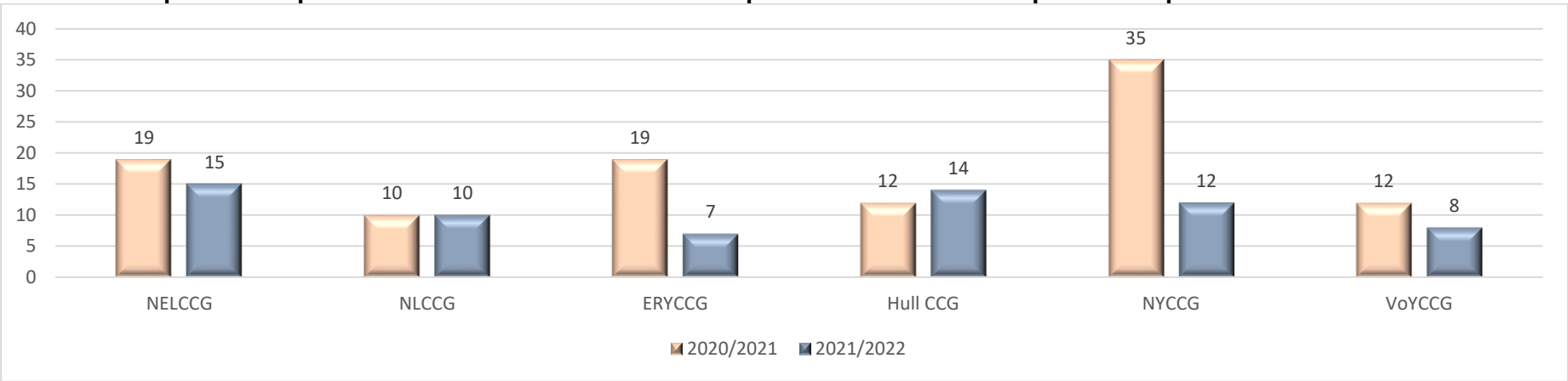
Reviewers no longer make recommendations for the review they complete. The reviewer identifies area of learning along with areas of good practice which are then shared/discussed at the local governance LeDeR panel meeting.

Between 1st April 2021 – 31st March 2022, 66 LeDeR reviews were completed across the six CCGs.
The number of available reviewers has had some impact on CCG abilities to assign reviews. NHS England provided support to all CCGs for reviews which had been notified to the new platform between 1st March 2022 and 1st June 2022 by commissioning completion of these reviews along with further support for additional reviews (not included within this cohort) to be added to further aid timely completion of reviews within the system.

Of the 66 reviews completed, 36 were completed within the required timeframe (completion within six months of the notification date). Of the completed reviews, one met the criteria of a focussed review.

Figure 3 below identifies the number of reviews completed by each CCG 1st April 2021 – 31st March 2022, with a comparator of the number completed 1st April 2020 – 31st March 2021, with figure 4 showing the number of reviews completed within timeframe by CCG 1st April 2021-31st March 2022.

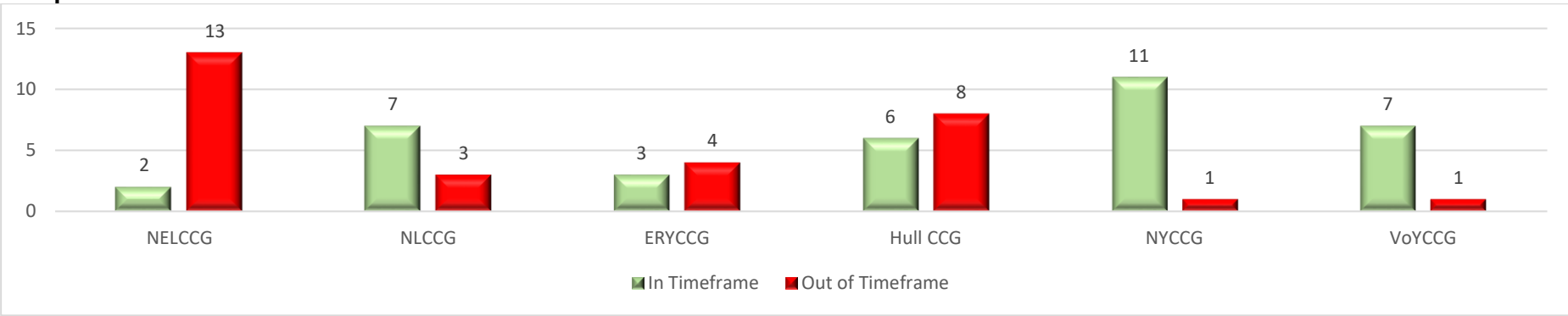
Figure 3.
Reviews Completed 1st April 2021 - 31st March 2022 with a Comparator to Reviews Completed 1st April 2020 – 31st March 2021



To Note:

- Deaths notified to the programme after 1st October 2021 would not be required to be completed and approved within the timeframe of this report. Any reviews which meet this criterion will be included within the 2022/2023 Annual LeDeR Report.

Figure 4.
Reviews Completed within Timeframe 1st April 2021 - 31st March 2022 with a Comparator to Reviews Completed Outside of Timeframe 1st April 2021 – 31st March 2022

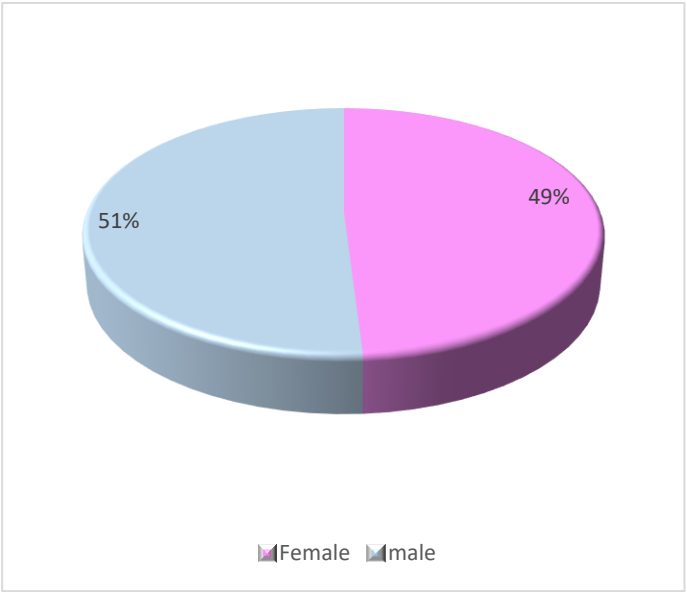


5.0 Themes and Trends

5.1 Gender of Individuals from Reported Deaths 1st April 2021 – 31st March 2022

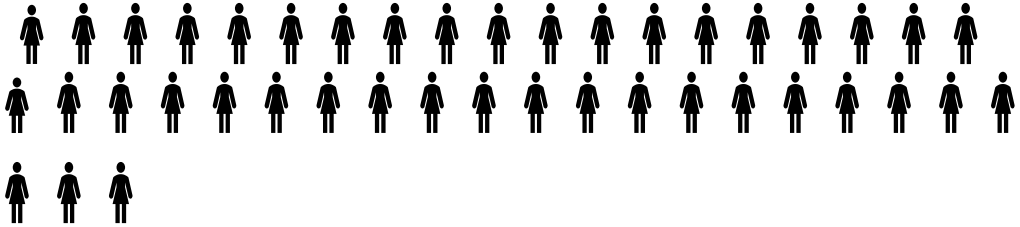
	Gender	
	Female	**Male**
N = 86	42	44
%	**49%**	**51%**

Gender Comparison

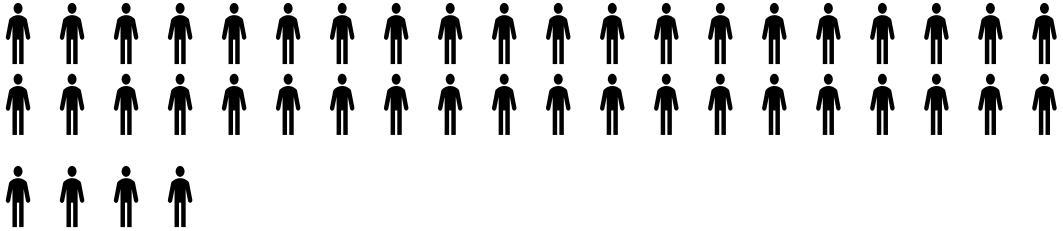


Of the 86 deaths sadly reported by the six CCG's 1st April 2021 - 31st March 2022:

- The individual's gender was reported within the notification in all deaths notified to the programme 1st April 2021 – 31st March 2022.
- 42 of the individuals were female (49%).



- 44 of the individuals were male (51%).



The gender comparison of individuals whose deaths were notified within the Humber and North Yorkshire Health and Care Partnership 1st April 2021 – 31st March 2022, was lower for males and higher for females to that of the national picture.

Within the Learning Disabilities Mortality Review Programme Annual Report 2020 (published 2021), covering deaths notified to the programme 1st January 2018–31st December 2020, the reported genders were:

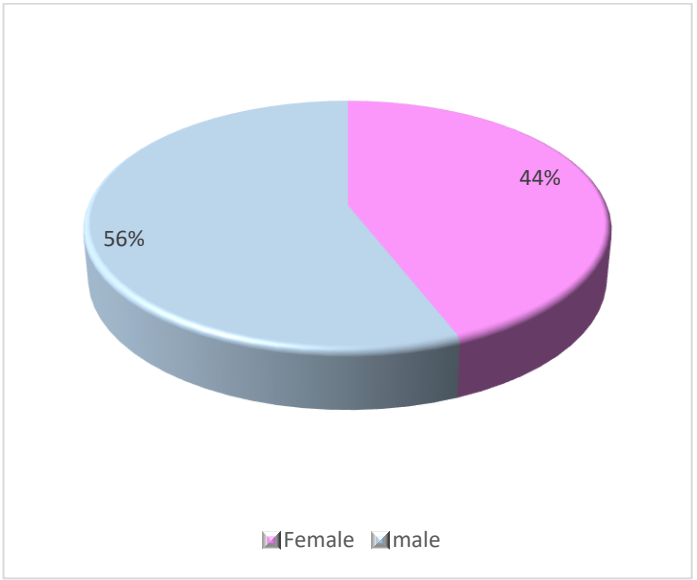
- 57% male.
- 43% female.

Information obtained from page 20 of the National Report which can be accessed at: https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

5.1.1 Gender of Individuals from Completed Reviews 1st April 2021 – 31st March 2022

	Gender	
	Female	**Male**
N = 66	29	37
%	**44%**	**56%**

Gender Comparison



Of the 66 reviews completed 1st April 2021 - 31st March 2022:

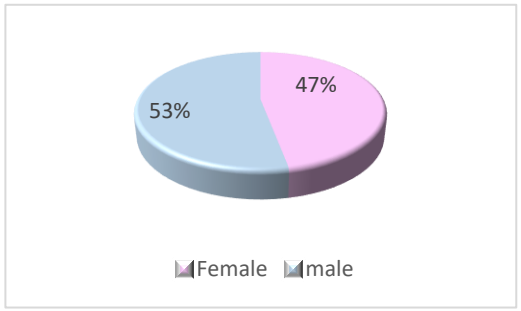
- 29 of the individuals were female (44%).

- 37 of the individuals were male (56%).

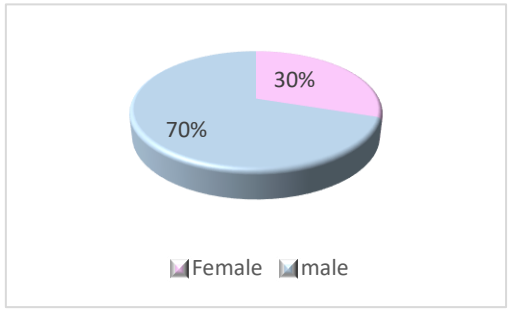
5.1.2 Gender of Individuals from Completed Reviews by CCG 1st April 2021 – 31st March 2022

The information below shows the gender comparison of the completed reviews by CCG.

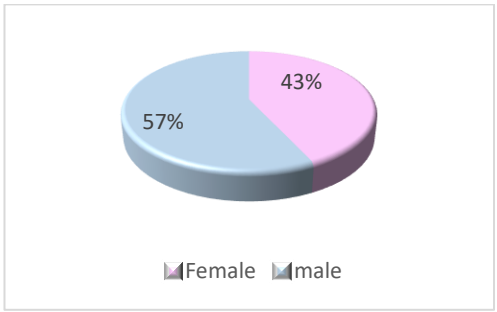
NELCCG



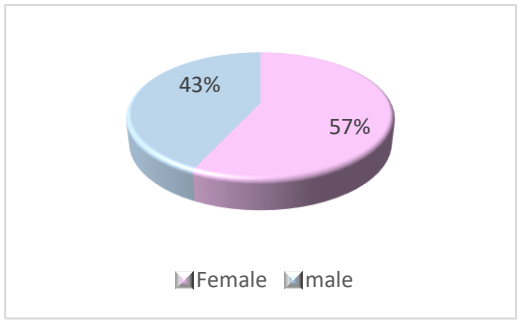
NLCCG



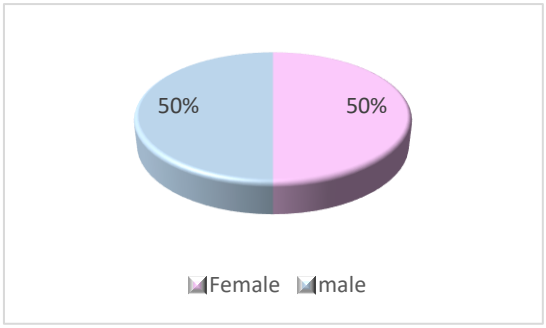
ERYCCG



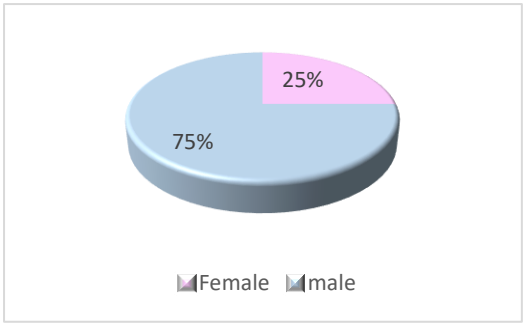
Hull CCG



NYCCG



VoYCCG

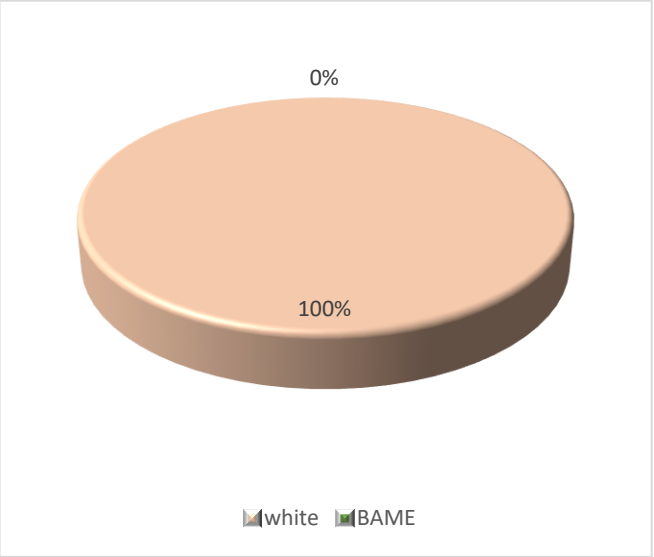


Themes and Trends

5.2 Ethnicity of Individuals from Reported Deaths 1st April 2021 – 31st March 2022

	Ethnicity	
	White	**BAME**
N = 86	86	0
%	**100%**	**0%**

Ethnicity Comparison



- The ethnicity of the individual was reported within all 86 deaths notified to the programme 1st April 2021 – 31st March 2022.
- Of the 86 deaths reported, 100% of individuals were recorded as being of white British ethnicity.
- The population of North Yorkshire and the Humber of which the six CCGs boundaries are within, is approximately 86% white (Census 2011).
- 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. It is identified there may be under reporting from across our BAME communities which will be a key area of focus during 2022/2023.
- Recommendation to also ensure GP registers are up to date for individuals with a learning disability/autism to ensure identification of these individuals within our community.

To note:
Of the 66 reviews completed 1st April 2021 – 31st March 2022, none of the individuals were of a BAME background.

Within the Learning Disabilities Mortality Review Programme Annual Report 2020 (published 2021), covering deaths notified to the programme 1st January 2018 – 31st December 2020, the reported ethnicity ratio was:

- 90% white British in 2019.
- 89% white British in 2020.

Information obtained from page 21 of the National Report which can be accessed at: https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

Themes and Trends

5.3 Age of Individuals at the time of Death: Reported Deaths 1st April 2021 - 31st March 2022

Of the 86 individuals whose deaths were reported 1st April 2021 -31st March 2022:

- The age range was 5-95 years.
- The mean average age of death was 60.4 years.
- The median age of death was 62.5 years.

In relation to those individuals who were female:

- The age range was 17-95 years.
- The mean average age of death was 73 years.
- The median age of death was 60.5 years.

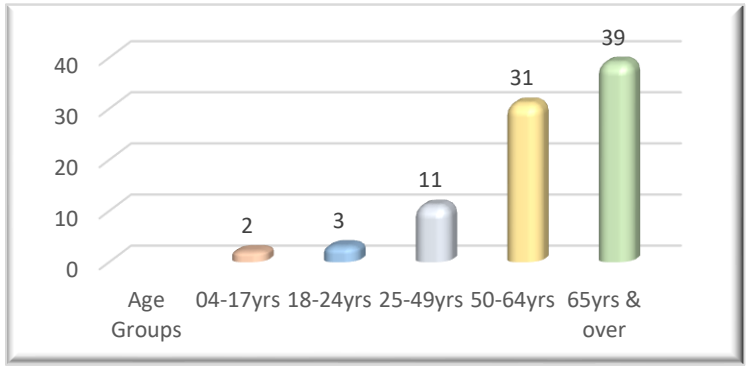
In relation to those individuals who were male:

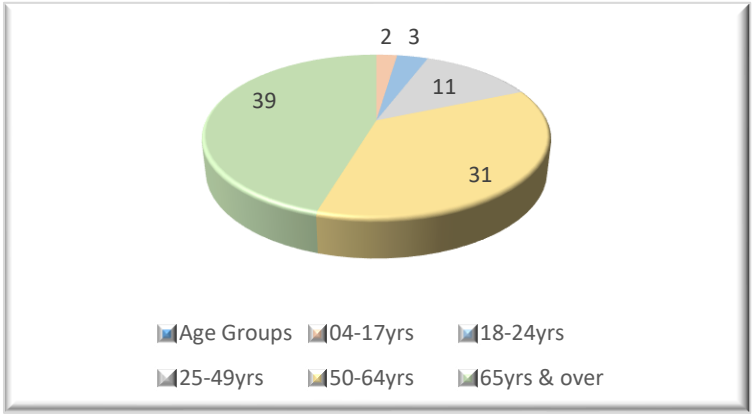
- The age range was 5-86 years.
- The mean average age of death was 62.8 years.
- The median age of death was 64.5 years.

- The median age at the time of death for individuals with a learning disability across the 6 CCGs within the Humber and North Yorkshire Health and Care Partnership as a comparator to the national picture was:
  - Lower for females (60.5 years against the national figure of 66 years).
  - Around the same for men (64.5 years against the national figure of 65 years).

To note:
The deaths of children up to the age of 18 years are reviewed through the Child Death Review Process (CDR), with an assigned LeDeR reviewer invited to attend the meeting.

Age at Death - Reported Deaths





Within the Learning Disabilities Mortality Review Programme Annual Report 2020 (published 2021), covering deaths notified to the programme 1st January 2018 – 31st December 2020:

- The median age at the time of death was 61 years.
- The median age at time of death for males was 65 years.
- The median age at time of death for females was 66 years.

Information obtained from page 21 of the National Report: accessed at:
https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

Themes and Trends

5.3.1 Age of Individuals at time of Death: Completed Reviews 1st April 2021 -31st March 2022

For the 66 completed reviews during the time period 1st April 2021 -31st March 2022:

- The age range was 9-95 years.
- The mean average age of death was 59.7 years.
- The median age of death was 61 years.

In relation to those individuals who were female:

- The age range was 23 -95 years.
- The mean average age of death was 59.4 years.
- The median age of death was 60 years.

In relation to those individuals who were male

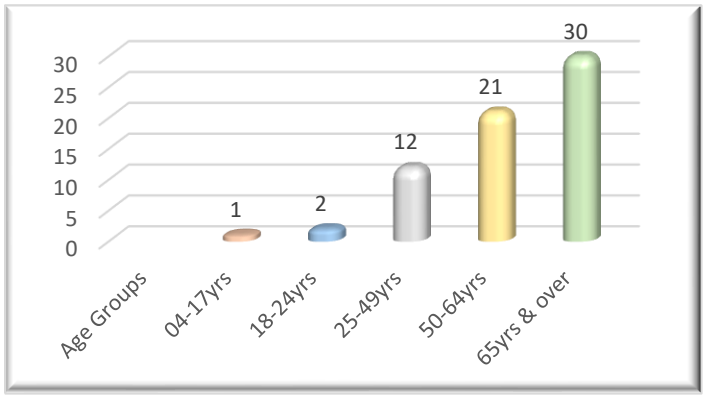
- The age range was 9-86 years.
- The mean average age of death was 60 years.
- The median age of death was 64 years.

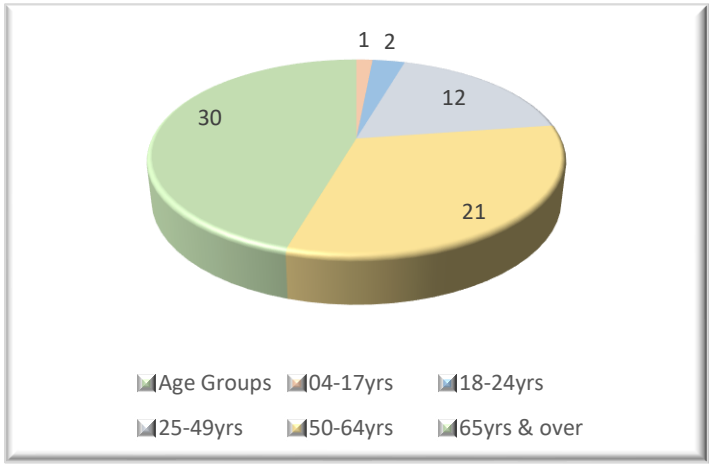
- The average life expectancy in England 2018-2020 (latest data available) was 83.1 years for females and 79.3 years for males. Information from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2018to2020 [accessed 11th May 2022]

- 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. Information from: https://www.ons.gov.uk [accessed 11th May 2022]

To note: One of the reviews was completed through the Child Death Review process.

Age at Death – Completed Reviews



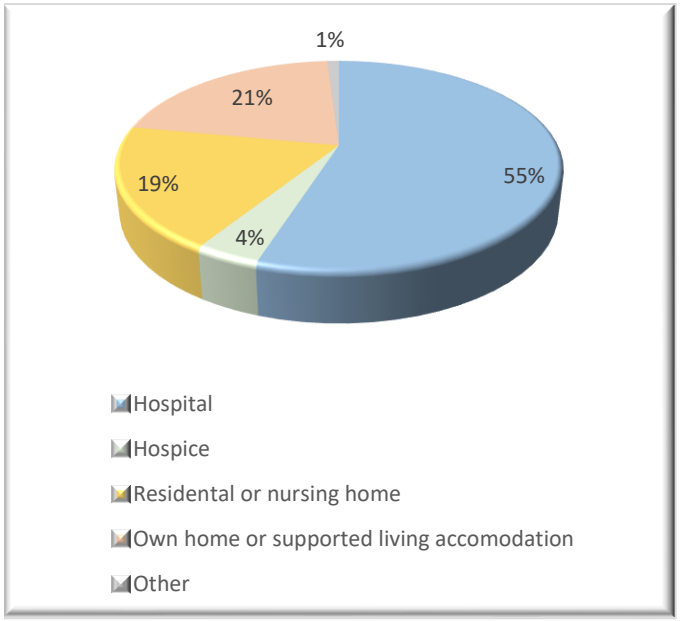


Themes and Trends

5.4 Place of Death: Reported Deaths 1st April 2021 – 31st March 2022

Place of Death		
	N=86	%
Hospital	47	55%
Hospice	4	4%
Residential/Nursing home setting	16	19%
Own home/supported living	18	21%
Other	1	1%

Place of Death - Reported Deaths



Of the 86 deaths sadly reported during the time period 1st April 2021 -31st March 2022:

- 47 individuals died within a hospital care setting (55%).
- 4 individuals died within a Hospice care setting (4%).
- 16 individuals died within a residential or nursing home setting (of which for a proportion of individuals, this would be their usual place of residence) (19%).
- 18 individuals died within their own home or supported living accommodation (21%).
- 1 individual died within other settings. To maintain confidentiality, for the purposes of this report, place of death is not disclosed.

- The reported place of death as hospital for individuals whose death was reported 1st April 2021 - 31st March 2022, is slightly lower at 55% to that of the national picture at 60% and lower than reported within the 2020/2021 Annual Reports (63% reported for the Humber CCG's area and 60% reported for North Yorkshire and Vale of York CCGs. It remains unclear as to what impact the on-going COVID -19 pandemic has had locally in relation to this figure.

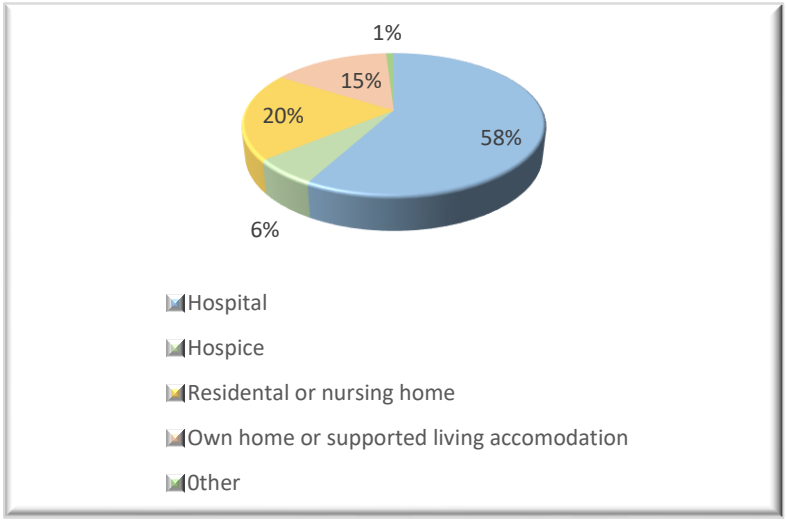
Within the Learning Disabilities Mortality Review Programme Annual Report 2020 (published 2021), covering deaths notified to the programme 1st January 2018 – 31st December 2020, the proportion of deaths in hospital for individuals with a learning disability remained stable at approximately 60% each year with 46% for the general population. Information obtained from page 41 of the National Report which can be accessed at: https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

Themes and Trends

5.4.1 Place of Death: Completed Reviews 1st April 2021 - 31st March 2022

Place of Death		
	N=66	%
Hospital	38	58%
Hospice	4	6%
Residential/Nursing home setting	13	20%
Own home/supported living	10	15%
Other	1	1%

Place of Death – Completed Reviews



Of the 66 reviews completed during the time period 1st April 2021 -31st March 2022:

- 38 individuals died within a hospital care setting (58%).
- 4 individuals died within a hospice care setting (6%)
- 13 individuals died within a residential or nursing home setting (of which for a proportion of individuals, this would be their usual place of residence) (20%).
- 10 individuals died within their own home or supported living accommodation (15%).
- 1 individual died within other settings. To maintain confidentiality, for the purposes of this report, place of death is not disclosed.

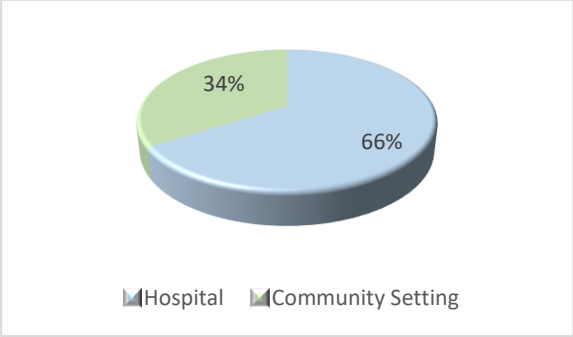
- The reported place of death as hospital for individuals whose death was reviewed 1st April 2021 - 31st March 2022, is very slightly lower at 58% to that of the national picture of 60%. The impact of the on-going COVID-19 pandemic on the place of death is not clear.

Themes and Trends

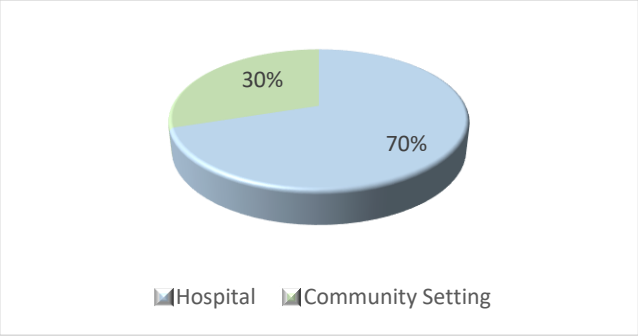
5.4.2 Place of Death: Completed Reviews by CCG 1st April 2021 - 31st March 2022

The information below shows the place of death of the completed reviews by CCG.

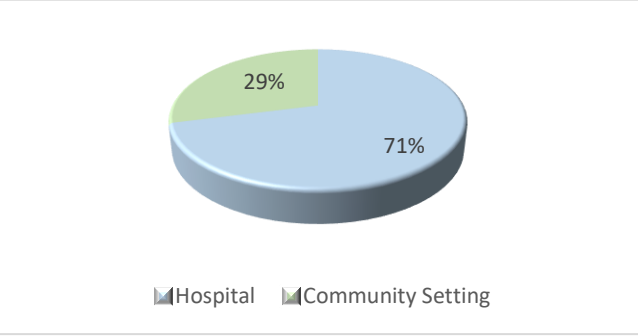
NELCCG



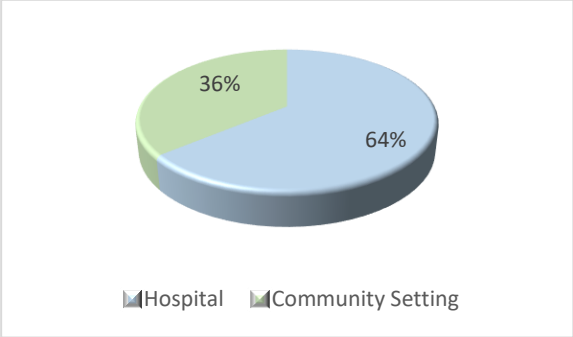
NLCCG



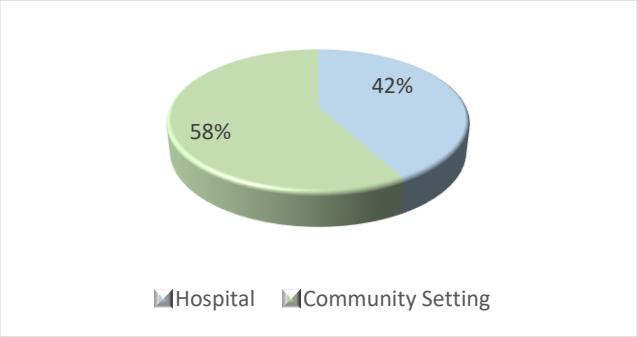
ERYCCG



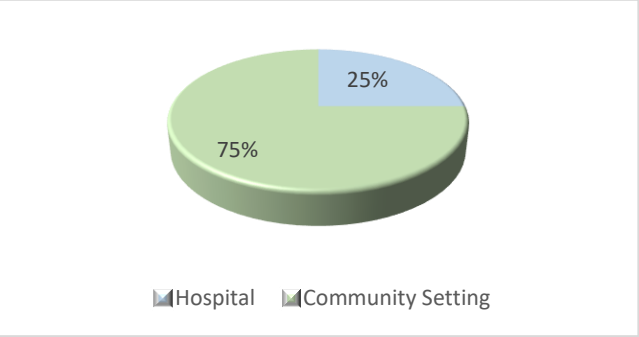
Hull CCG



NYCCG



VoYCCG



A larger proportion of individuals with a learning disability within the North Yorkshire area appear to die within a community setting. For the purposes of this section, a community setting relates to residential or nursing care homes, hospice, own home or supported living accommodation. Review of this differentiation will be a consideration for this year to identify any learning and the opportunity to share good practice across the system.

Themes and Trends

5.5 Cause of Death: Completed Reviews Only; 1st April 2021 – 31st March 2022

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 66 completed reviews 1st April 2021-31st March 2022:

- The most common recorded cause of death was Cancer (16%).

The second most common recorded causes of death from the completed reviews were:

- Pneumonia (12%).
- COVID -19 (12%) (this includes those deaths recorded as COVID-19 pneumonia).

However, collectively, respiratory issues (27%) were cited as the most common cause of death within part 1 of the Medical Certificate Cause of Death (MCCD), with aspiration pneumonia accounting for 4.5%.

COVID-19 (23) was recorded as the most common cause of death during 2020 within the Learning Disabilities Mortality Review Programme Annual Report 2020 (published 2021), with bacterial pneumonia (19%) and pneumonia (11%) as the second and third most common causes.

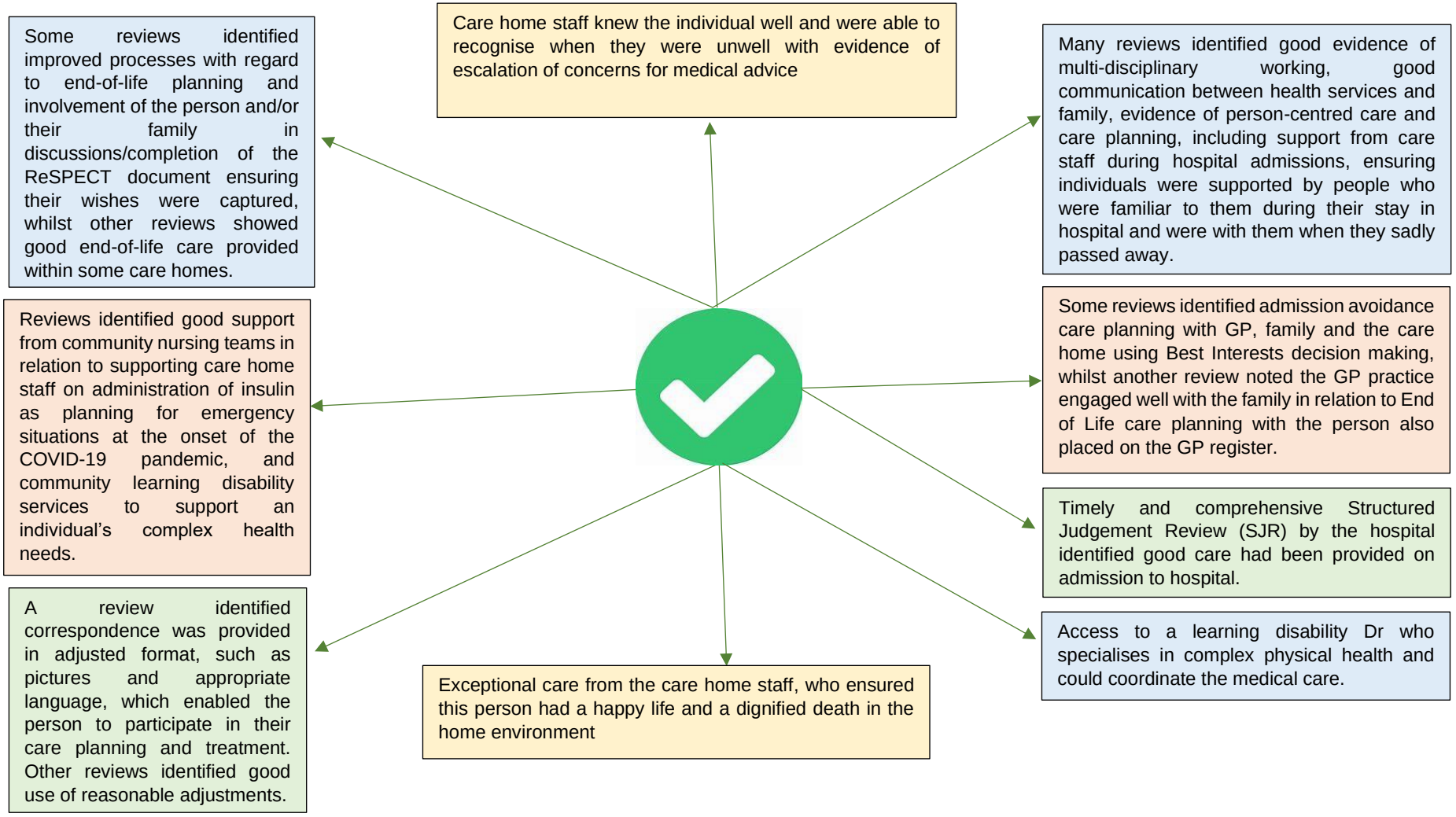
Other confirmed causes of death from the completed reviews included:

- Sepsis (7.5%).
- Dementia and Alzheimer's disease (4.5%).
- Natural causes (4.5%).
- Cardiac Issues (12%) (due to multiple different cardiac causes, these have been identified under the umbrella of 'cardiac' for the purposes of this report).
- Organ Failure (4.5%).
- Other (10.6%): (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.

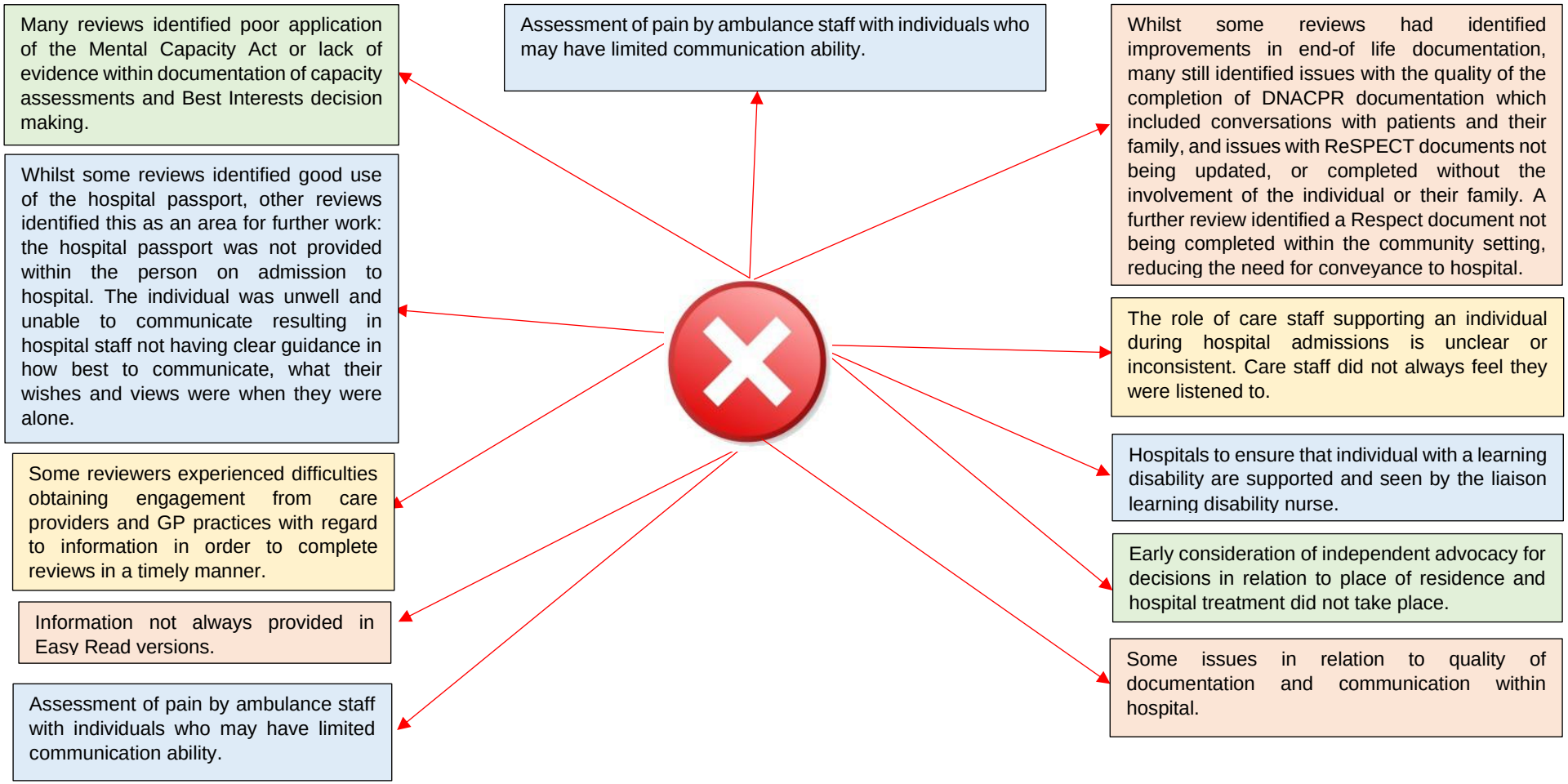
6.0 Identified Best Practice from Completed Reviews 1st April 2021 – 31st March 2022

Below are examples of areas of good practice identified from the 66 reviews completed 1st April 2021 – 31st March 2022 across the six CCG's:



7.0 Identified Learning from Completed Reviews 1st April 2021 – 31st March 2022

Below are examples of identified learning from the 66 reviews completed 1st April 2021 – 31st March 2022 across the six CCG's:



8.0 Outcomes and Achievements

There have been many examples of positive initiatives undertaken to improve the experience and services delivered to service users across the Humber and North Yorkshire Health and Care Partnership.

8.1 Annual Health Checks: 1st April 2021 – 31st March 2022

Despite the on-going COVID -19 pandemic, all CCG's have seen an improvement in compliance against individuals aged 14 and over with a learning disability being offered an Annual Health Check. The Humber Transforming Care Partnership, set a local trajectory of 67% for completion of Annual Health Checks, with the national trajectory remaining at 75% (the symbol* within the below indicates the local trajectory). Whilst the improvements are noted, further work is required within most areas to build on these improvements and ensure all individuals are offered and receive their Annual Health Check. Below are the achievements and some of the work which has been undertaken to improve uptake by CCG.

NLCCG achieved 71.68% completion of Annual Health Checks against the local trajectory of 67%* (national trajectory 75%). Practices across North Lincolnshire worked collaboratively with the community learning disability team (CTLD) from RDaSH to reach this. Learning disability registers held by GP's were validated to ensure no one was missed, with individuals who had not engaged with the programme, being identified for future work in order to support them to attend for this appointment. It is acknowledged further worked is required to improve on this position during 2022/2023.

NELCCG are currently developing a baseline of what the minimum Annual Health Check should cover to ensure all primary care teams are working to the standard.

ERYCCG achieved 68% completion of Annual health Checks against the local trajectory of 67%* (national trajectory of 75%).

Hull CCG achieved 73% completion of Annual Health Checks against the local trajectory of 67%* (national trajectory 75%). The commissioned Wellbeing Service have provided support to GP practices in relation to the Annual Health Check through various means including workshops for individuals with a learning disability, their families and care staff and support with completion of the health check booklets.

NLCCG are developing a workplan in conjunction with the CTLD team to support GP practices to spread delivery of the Annual Health Check throughout the year whilst increasing the number completed. Focus during Quarter 1 of 2022/2023 will be in ensuring individuals who have not received a check at all to receive during this timeframe.

NELCCG achieved 55.1% completion of Annual Health Checks against the local trajectory of 67%* (national trajectory 75%). It is noted that further work is required during 2022/2023 to improve on this position with variation across GP practices, alongside clarity of reporting.

NYCCG achieved 69.9% completion of Annual Health Checks against the national trajectory of 75%. The CCG has an Annual Health Check champion within the CCG, with an action plan to increase uptake.

VoYCCG achieved 81.8% completion of Annual Health Checks against the national trajectory of 75%.

Outcomes and Achievements

8.2 Other Areas of Work Undertaken by CCG's: 1st April 2021 – 31st March 2022

Identified below are some of the other areas of work undertaken by the CCG's: 1st April 2021 – 31st March 2022.

NLCCG: Development of the required 3-year LeDeR strategy on behalf of the six CCGs across the Humber and North Yorkshire Health and Care Partnership. The strategy is based on the learning from the 2021/2022 LeDeR Annual reports from both areas.

NYCCG have developed an accessible leaflet in relation to DNACPR.

NLCCG is participating in the national bowel screening programme to support individuals with a learning disability to participate in this important screening programme. Currently, 12/19 GP practices are engaged with the project with more expected to follow. Patients who are eligible for screening are identified, with the coordination hub sending a screening kit and instructions to the patient, whilst flagging with the CTLD team who can then offer appropriate support.

ERYCCG has a workstream looking at standardising the learning disability health passport and the interface with digital solutions.

Hull CCG are in the final year of the pilot project of a Specialist Doctor post which commenced in May 2021. The purpose of the role was 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 (PMLD) living in Hull. The positive work of this pilot has been seen within some of the completed LeDeR reviews completed during 2021/2022.

NELCCG have updated their Mental Capacity Act and Deprivation of Liberty Policy, alongside a requirement for levels of MCA training for all staff. A Best Interests Assessor learning event has also been delivered with a further 5 individuals trained to become Best Interest Assessors.

ERYCCG have produced a short video raising awareness of the LeDeR process, featuring a LeDeR reviewer, a parent of a young person who has sadly passed away and the Specialist Doctor for learning disability. This was shared across the Humber area.

NYCCG are partaking in the national bowel screening programme to support individuals with a learning disability with screening.

Hull CCG are currently developing a 'what happens at Best Interests Meeting' patient information leaflet which will be shared more widely once completed.

Outcomes and Achievements

8.2 Other Areas of Work Undertaken by CCG's: 1st April 2021 – 31st March 2022

NELCCG: Forensic outreach service is operating a local 'spoke' service delivered by the community provider within NEL (Care plus Group) in partnership with Humber Foundation Trust.

Hull CCG are partaking in the national bowel screening programme to support individuals with a learning disability with screening, with 19 of the 32 practices currently signed up to the project.

NYCCG have delivered training in relation to LeDeR to GP practices. The training has incorporated the learning and key themes from completed reviews. The training has further been adapted for delivery to community care providers and charities through the virtual platform project ECHO.

NLCCG will be producing Easy Read End of Life information across Northern Lincolnshire during 2022/2023.

NLCCG: developed the LeDeR learning newsletter which is completed following each panel meeting with the identified learning and good practice from each completed LeDeR review. Further work will be undertaken during 2022/2023 to incorporate the learning from the reviews completed across all six CCGs and shared widely across health and social care colleagues.

NY CCG have identified a BAME lead who has commenced work with GP practices and hospitals to explore ethnicity and diversity needs across the region.

ERYCCG has a workstream looking at standardising the learning disability health passport and the interface with digital solutions.

Outcomes and Achievements

8.3 Work Undertaken by the Humber Transforming Care Partnership and North Yorkshire and York Transforming Care Partnership 1st April 2021 – 31st March 2022

Both Transforming Care Partnerships (TCP) have developed several work streams during the financial year 1st April 2021-31st March 2022, which have focussed on improving the lives of people who have a learning disability or autism. Below is some of the work and plans for further development from across both TCP areas:

Humber TCP: Successful in a bid to host an exemplar site for Annual Health Checks within the Bridlington Primary Care Network. Aim of the project is to increase the number of people who access an Annual Health Check by providing a volunteer who will support the individual to prepare and attend, helping them understand any action plans which are developed. There will be a sensory friendly pod where the Annual Health Check will be completed. Through this work, the Primary Care Network has also identified and added more individuals to the GP Learning Disability Registers.

Yorkshire TCP: A project to develop a service to provide a safe space for individuals with a learning disability and/or autism has progressed well. This will aim to prevent admission where possible.

Humber TCP: Reasonable adjustments flag pilot underway in Hull, people who need reasonable adjustments to access care and support only need to tell one service. The project will also raise awareness for requirements to make reasonable adjustments, and what they might be.

A sleep support service has been commissioned across the Humber area. Families with children and young people who have a neurodiverse condition can access support and equipment to help with improving sleep. Training is being offered for schools to develop an in-house sleep champion, health and social care staff can access sleep awareness training, and they can also become accredited sleep practitioners.

Humber TCP: Have held several interactive online learning events. This has provided opportunity to share the work in relation to coproduction and housing for people with a learning disability or autism, whilst providing attendees the opportunity to tell the TCP what would help them. Plans are to continue running these events throughout 2022/2023.

Yorkshire TCP: Alongside the local authority, the TCP is investing in a housing needs assessment and local market developed to develop capacity and competency needed to discharge people from hospital. 25 new properties are to be commissioned before March 2024.

Humber TCP: A dynamic support register for adults and children has been developed to ensure all health and social care partners can communicate effectively and have the most up to date information about people with a learning disability or autism who are at risk of becoming unwell due to their mental or physical health. The register enables services to act quickly if areas of concern are seen.

Humber TCP: Preparing to launch autism training modules, aimed at primary care staff, this will be available for anyone through the TCP website. The training has been developed with autistic people, who provide insight into their experiences of accessing healthcare, and describe how their experience can be improved through reasonable adjustments. There will also be a coproduced course on neurodiversity awareness for health and social care staff. The "what to expect" series of animated videos will help people to understand what to expect at an autism assessment and what will happen when transitioning from children's to adults' services.

Outcomes and Achievements

8.4 Humber LeDeR Steering Group and North Yorkshire and Vale of York LeDeR Steering Group 1st April 2021 – 31st March 2022

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 some of the work and plans for further development from across both Steering Groups:

The Humber Steering Group has continued to strengthen its membership from across the Humber footprint. Membership now includes self-advocates who are supported to attend the meeting by the Engagement Lead for the Transforming Care Partnership. Meeting information is provided in easy read format to ensure inclusivity and participation.

Following the addition of individuals with autism into the LeDeR programme, membership of the Humber Steering Group now includes colleagues from an independent charity who work with people with autism.

Discussions are underway with the nursing and social work faculties at Hull University, for Humber Steering group members and self-advocates to support student learning by raising awareness of the LeDeR programme. It is hoped this offer can be expanded to General Practice trainees and trainees at the Hull York Medical School.

The North Yorkshire and York Steering Group have welcomed an expert by experience to the group. Learning will be shared from key task force groups that he sits on across the county

Training has been shared at the North Yorkshire and York Steering Group including cancer screening uptake and strategy, Annual Health Checks and DNACPR best practice.

The North Yorkshire and York Steering Group has continued to strengthen its membership from across the North Yorkshire footprint. The group is an established pathway for exchange of information with the North Yorkshire and York TCP Board, and the North Yorkshire Mental Health and Learning Disability Partnership Board.

Community practice webinars with a focus on DNACPR have been held across North Yorkshire and Vale of York CCG areas.

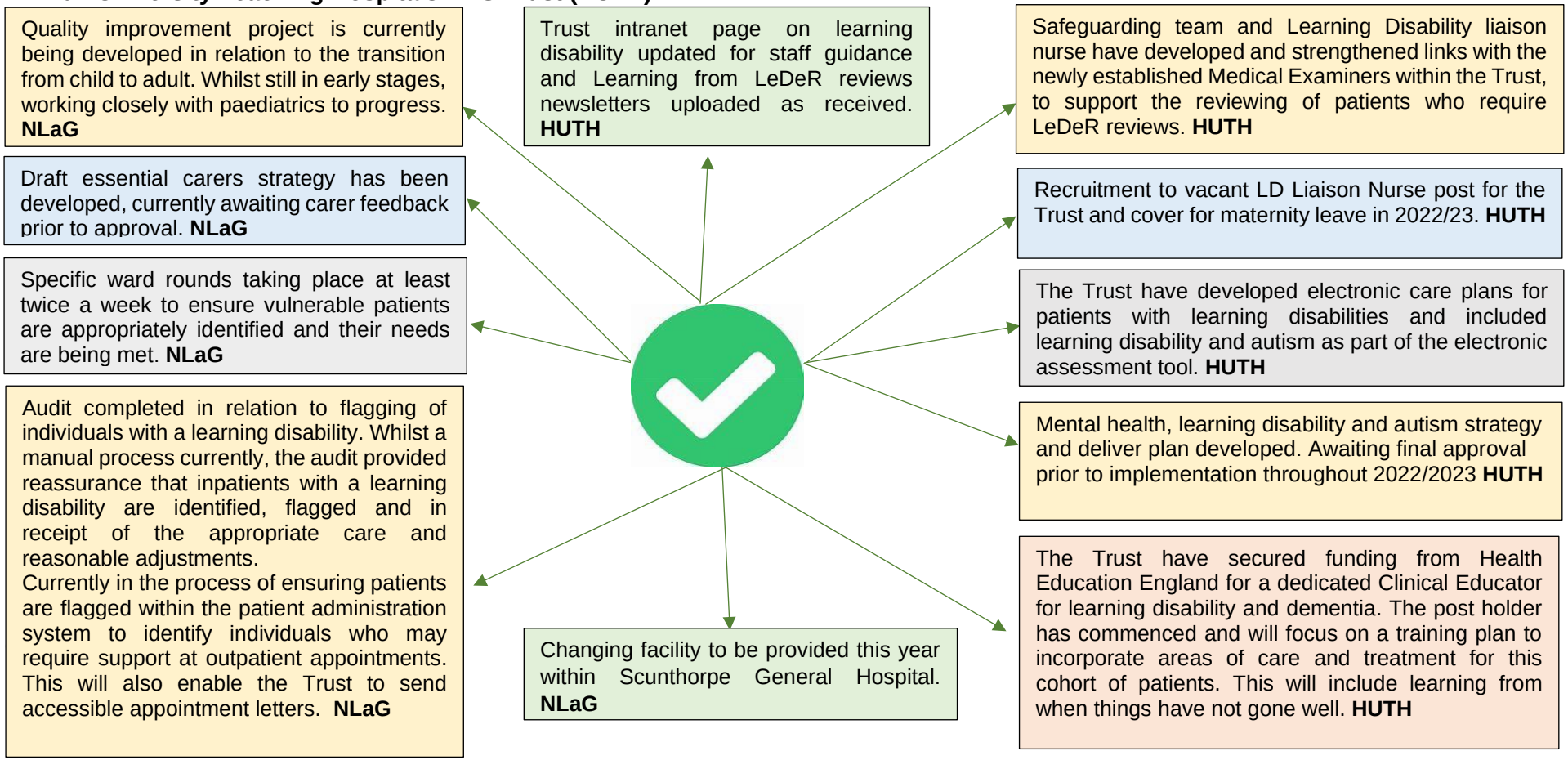
The Humber Steering Group are looking to hold two learning events across the Humber area during 2022/2023 to raise the profile of LeDeR and the work being undertaken. Discussion to take place at the next meeting to set up a working group and project plan to take this forward.

Outcomes and Achievements

8.5 Work Undertaken by Providers within the Humber and North Yorkshire Health and Care Partnership Footprint 1st April 2021 – 31st March 2022

Identified below are some of the areas of work undertaken by the following care providers within the Humber and North Yorkshire Health and Care Partnership from 1st April 2021 -31st March 2022:

- **Northern Lincolnshire and Goole NHS Foundation Trust (NLaG).**
- **Hull University Teaching Hospitals NHS Trust (HUTH).**



Outcomes and Achievements

8.5 Work Undertaken by Providers within the Humber and North Yorkshire Health and Care Partnership 1st April 2021 – 31st March 2022

Identified below are some of the areas of work undertaken by the following care providers within the Humber and North Yorkshire Health and Care Partnership 1st April 2021 -31st March 2022:

- **Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH).**
- **Humber NHS Foundation Trust (Humber).**

Weekly Stopping Over Medication Of People (STOMP) clinics commenced August 2021 in North Lincolnshire, run by a psychiatrist and a community learning disability nurse. These clinics look at all areas for individuals with a learning disability: physical health, behaviour, environment and mental health. Four weeks after each reduction, the individuals is invited for a further appointment to ensure they are managing on the reduced doses of medication. Good progress has been seen by the clinics. Education has been required for individuals, families and care providers. **RDaSH**

In June 2022, the CTLD team in North Lincolnshire will be hosting a health campaign on the health bus 'Dying for a poo'. The aim of the day is to educate individuals with a learning disability, their families and care providers on constipation. Information will be provided in Easy Read, and it is hoped visual aids will also be available. **RDaSH**

Implementation of the 'Follow my Lead' training and accreditation programme; a communication package co-produced with the PMLD group. Providers can access training, workbooks and be audited to gain accreditation. Designed to improve communication and quality of life for individuals with PMLD. **Humber**

Complex health clinics with the LD speciality doctor looking to get better outcomes for people in conjunction with primary, acute and other community health services (Hull) and linking with the dynamic support risk register held by the TCP. **Humber**

In June 2022, the CTLD team in North Lincolnshire will be hosting a health campaign on the health bus 'Dying for a poo'. The aim of the day is to educate individuals with a learning disability, their families and care providers on constipation. Information will be provided in Easy Read, and it is hoped visual aids will also be available. **RDaSH**

In May 2022, the CTLD team in North Lincolnshire will commence physical health clinics for all individuals under the care of psychiatry. Individuals will be invited to attend for a full physical health assessment which will include blood tests and ECG following NICE guidelines. It is hoped that this offer will be able to be extended to all individuals open to the CTLD team in all pathways. **RDASH**

Delivery of COVID-19 and other vaccinations in environments which are ideal for individuals where it is not possible for them to attend a vaccine centre. **Humber**

The Trust continue to be involved in co-produced training and learning for families and carers, undergraduate students, and other health professionals. **Humber**

Commencement of nurse prescriber led STOMP clinics, specifically looking at not over prescribing medications with a focus on positive behaviour support and active support. **Humber**

Outcomes and Achievements

8.5 Work Undertaken by Providers within the Humber and North Yorkshire Health and Care Partnership 1st April 2021 – 31st March 2022

Identified below are some of the areas of work undertaken by the following care providers within the Humber and North Yorkshire Health and Care Partnership from 1st April 2021 -31st March 2022:

- **City Health Care Partnership Community Interest Company (CHCP) Hull.**
- **Harrogate and District NHS Foundation Trust (H&DFT).**
- **York and Scarborough NHS Foundation Trust (Y&SFT).**
- **Tees, Esk and Wear Valley NHS Foundation Trust (TEWV).**

Recruitment of a clinical advisor with a joint role in the learning disabilities and adult safeguarding teams. This role has the capacity to visit patients in a timely manner and build relationships with both patients and staff. They are also mentored in managing a small caseload of patients with a learning disability, whilst ensuring specialist support is available to staff and patients in the absence of the learning disability nurse. **H&DFT**

TEWV have devised the 'My Future Wishes' document in relation to End of Life planning.

Learning disability training is now included within mandatory training at South Tees hospital. They are also in the process of developing a hospital pack for individuals who may be admitted to the emergency department. **TEWV**

Work undertaken to raise awareness in the provision of reasonable adjustments for individuals. During Learning Disability week there was a focus on the 'Stop, Think, Adjust' campaign, which included the use of videos shared via the Trust's communication and social media sites. A tool was devised to support staff to explore the changes that could be made to their areas of practice to improve accessibility. **H&DFT**

York and Scarborough hospitals have completed work to ensure all individuals on their register have a hospital passport. **Y&SFT**

Learning disability training is now included within mandatory training at South Tees hospital. They are also in the process of developing a hospital pack for individuals who may be admitted to the emergency department. **TEWV**

CHCP disseminates the LeDeR panel newsletter via their marketing team, to cascade the positive practice and areas of improvement identified following completed local LeDeR reviews.

CHCP have continued to support the LeDeR programme during 2021/2022, through designated staff as LeDeR reviewers, staff who are active members of both the Humber LeDeR Panel meetings and Humber Steering Group. Reviewers were also engaged with the testing of the new web-based system prior to its induction providing reviewer feedback on the system.

CHCP's wellbeing team have previously supported GP practices by providing advice regarding accessibility issues, training and developing resources., however being aware of the significant COVID-19 impact on primary care, the team offered GP practices to actively manage and deliver the Annual Health Check on their behalf through Mutual Aid Agreement. Two nurses accessed the electronic healthcare register and identified individuals eligible for their health check and made direct telephone contact with them to invite them to attend as well as explaining the importance of having a check.

9.0 Key Themes and Recommendations for Improvement from Reviews Completed 1st April 2021 – 31st March 2022

The following are the main key themes for improvement, identified from the learning from completed reviews 1st April 2021-31st March 2022 across the six CCG's within the Humber and North Yorkshire Health Care Partnership:

Annual Health Checks:
Whilst it is positive to see the progress made across the CCGs in relation to individuals having receive their Annual Health Check, further work is required to attain the trajectory set by NHSE of 75% of individuals aged 14 years and over to receive their Annual Health Check and for the check to be of a high standard.

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 is required and in particular relating to:

- Mental Capacity Compliance.
- Documentation of mental capacity assessment.
- Documentation of Best Interest Decision making.
- Family as decision makers once an individual is over the age of 18 years.
- Compliance with Deprivation of Liberty Safeguards (DoLs).

Learning Disability Specialist Nurses:
A small number of reviews identified availability of the learning disability nurse within the hospital area for all individuals with a learning disability as an area for improvement to enhance the care provided to individuals whilst in hospital.

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 within the community setting 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 of work from previous completed reviews with regard to individuals being supported to attend for age-appropriate screening with the main areas of focus/improvement continuing to be:

- Uptake of routine bowel screening including available support and follow up where not undertaken.
- Ensuring all individuals with a learning disability have access to attend for screening or reasonable adjustments are made in order to support them to uptake the screening offered.

Availability and Uptake of Hospital Passports:
Some reviews continue to identify availability of hospital passports for individuals as an area requiring further work and ensuring they are kept up to date.

10.0 Recommendations and Actions to be taken forward for 2022/2023

From the findings and learning identified within the 66 reviews completed 1st April 2021 – 31st March 2022, 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 2022 and into 2023:

- To further develop both Steering Groups to ensure implementation of the actions and recommendations identified by the LeDeR Panels to inform local development and changes to services provided across the Humber and North Yorkshire Health and Care Partnership.

- Continue to build links between both Steering Groups and Transforming Care Partnerships to ensure all learning and 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.

- Continue the improved position 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 in line with the required NHS England trajectory. To have a focus during Quarter 1 and Quarter 2 on ensuring those individuals who have not as yet received an Annual Health Check to be identified as a priority.

- Education and training for all health and social care staff 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 build robust processes for sharing learning and good practice identified from completed reviews across the Humber and North Yorkshire Health and Care Partnership.

- Further improvements in relation to End of Life care, ensuring early recognition and decision making with regard to 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.

- To review and action the possible under reporting to the LeDeR programme of deaths which occur within our BAME communities across the Humber and North Yorkshire Health and Care Partnership. To also ensure all GP registers are up to date for individuals with a learning disability/autism to ensure identification of these individuals within our communities.

- To undertake a review of the difference in place of death across the Humber and North Yorkshire Health and Care Partnership to identify any best practice which can be shared across the system.