NHS North Lincolnshire Clinical Commissioning Group
NHS North East Lincolnshire Clinical Commissioning Group
NHS East Riding of Yorkshire Clinical Commissioning Group
NHS Hull Clinical Commissioning Group

Learning Disabilities Mortality Review Programme Annual Report
1st April 2020 to 31st March 2021.

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Head of Nursing - NLCCG (on behalf of the 4 Humber CCG's)
May 14th 2021

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Executive Summary

This is the third Learning Disabilities Mortality Review (LeDeR) Programme Annual Report from NHS Clinical Commissioning Groups (CCG'S) and the first joint Humber CCG's Annual Report. This report 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).

All four of the CCG's within the Humber area have robust systems and processes in place for the management of Learning Disability Mortality reviews:

- The Local Area Contacts (LAC's) from NL and NEL CCG's continue to work collaboratively to quality assure and approve each completed review within Northern Lincolnshire.
- Hull and ERY CCG have a joint assurance panel to quality assure and approve each completed review within the areas covered by both CCG's.
- Collaborative working is currently underway for the current assurance panel to move to a Humber assurance panel covering all reviews completed across all four CCG's. This will further enhance the identified learning and early identification of shared themes and trends for focussed improvement work across the Humber area.

The Humber area sadly saw 55 deaths reported to the LeDeR Programme (1st April 2020 – 31st March 2021), with 62% of the individuals being male – this is slightly higher than the national average of 58% (National Annual LeDeR Report 2019).

During the time-period of this report (1st April 2020 - 31st March 2021), 60 LeDeR reviews were completed. Of these reviews, 87% of individuals were identified as having received care which was graded as 'Satisfactory' or above, with 60% of these individuals identified as receiving care that met or exceeded good practice compared to 56% nationally.

The most common confirmed cause of death identified within the completed reviews was Aspiration Pneumonia (17%) closely followed by Pneumonia (13%). This is in line with the national picture and equated to 30% of the overall causes of death identified within completed reviews.

- The main key learning from the reviews has highlighted several areas which will be taken forward as areas requiring improvement throughout the remainder of 2021 and into 2022:

- Continued improvement in the uptake of Annual Health Checks to ensure at least 75% of those eligible (over the age of 14 years) receive this valuable annual check.

- Further work is required around use and understanding of the Mental Capacity Act, Deprivation of Liberty Safeguards (DoLs), Capacity Assessments and Best interests, including completion of robust documentation.

- Continued improvement 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). This is also in line with national findings.

- Work is required to be undertaken with regard to Aspiration Pneumonia and Pneumonia as primary causes of death in individuals with a learning disability and the potential for some of these deaths to be preventable.

It is to be noted that whilst the above areas have been identified as areas of work to improve the lives of individuals with a learning disability, reviewers also identified and highlighted areas of good practice which can be seen on pages 18-19 of this report.

The Bristol 2019 National Annual LeDeR Report can be accessed at: https://www.bristol.ac.uk/sps/leder/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). LeDeR is a non-statutory process set up to contribute to improvements in the quality of health and social care for individuals with learning disabilities in England. LeDeR involves reviewing the deaths of all individuals over the age of 4 years with a learning disability to identify any potentially avoidable factors which may have contributed to the person's death.

The programme has a focus on the learning that can be gained from reviewing the care and treatment provided to an individual with learning disabilities throughout their life, and the circumstances in which the individual sadly dies.

The purpose of the LeDeR programme nationally and locally is to:

- Stop individuals who have a learning disability from dying to soon.
- To help improve health and care services locally for individuals with learning disabilities.

1.1 Links with other Review Processes

Where appropriate, the LeDeR review process links with other investigations/reviews such as:

- Safeguarding Practice Reviews (SPR's).
- Safeguarding Adult Reviews (SAR's).
- Safeguarding Adult Enquiries (Section 42 Care Act).
- Domestic Homicide Reviews (DHR's).
- Serious Incident Reviews.
- Coroners' investigations.
- Child Death Reviews.

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.

2.0 Governance Arrangements

The Executive lead for LeDeR within the CCG's are the Directors of Nursing and Quality, with each CCG having a Local Area Contact (LAC), who locally allocate the review to a reviewer and organise the quality checking process. During 2020/2021, the CCG's have been working more closely together and in respect of the LeDeR process:

- Hull and North Lincolnshire (NL) Clinical Commissioning Groups (CCG's) have a shared LAC (since February 2021).
- Hull and East Riding of Yorkshire (ERY) CCG's have a shared approval panel for completed reviews.
- NL and North East Lincolnshire (NEL) CCG's have a shared approval process (since 2019).

- The previous Hull and ERY CCG's LeDeR Steering Group is now a Humber Steering Group with representation from all four CCG's.

The LeDeR annual report is received and approved through the differing governance structures of each of the Humber CCG's.

Following the publication of the NHS England LeDeR Policy; Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021(published 23rd March 2021), further work will be undertaken during 2021 to ensure the four CCG's collectively meet the requirements within the policy. The two immediate pieces of work which are required to be completed by June 2021 are:

- CCG's to develop a three year LeDeR Strategy; this will be undertaken collectively across the four CCG's.
- Further development of the Hull and ERY approval panel for completed reviews to ensure a Humber wide approach with the panel representing the four CCG's to ensure a collaborative approach to both the assurance process of reviews and identification of the collective learning within the Humber.

The learning from the LeDeR annual report is shared with the Humber Steering Group and the Transforming Care Partnership as well as more widely with the Safeguarding Boards of each locality. Each CCG is responsible for receiving the recommendations and delivering local actions to ensure these are fulfilled.

Further review and development of the current Humber Steering Group in line with the requirements of the policy will also take place during 2021/2022.

3.0 Deaths of Individuals with Learning Disabilities in our Local Area 1st April 2020 – 31st March 2021

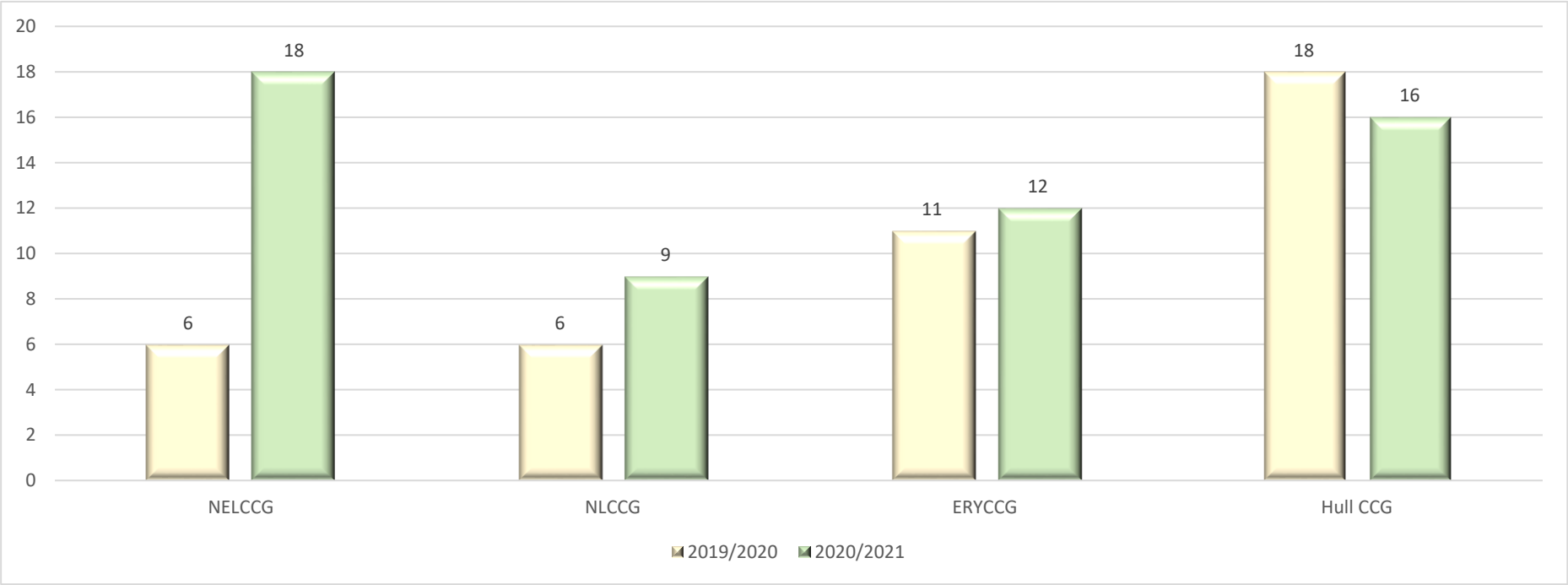
Sadly, a total of 55 deaths of individuals with a Learning Disability were reported across the four CCG's within the Humber area during the time-period 1st April 2020 - 31st March 2021. The impact of the Covid-19 pandemic has seen 8 of the reported deaths of individuals who died during the time-period above, sadly attributed to Covid-19.

Whilst this is a noted increase in the number of deaths reported, this may be due to an increased awareness of the LeDeR programme primarily amongst Care Home, Domiciliary Care Providers and Primary Care colleagues for reporting to the programme.

Figure 1 below identifies the number of deaths reported by each CCG 1st April 2020 – 31st March 2021, with a comparator to 1st April 2019 – 31st March 2020.

Figure 1.

Number of Deaths Reported 1st April 2020 - 31st March 2021 with a Comparator to Deaths Reported 1st April 2019 – 31st March 2020



4.0 Overview of Completed Reviews 1st April 2020 – 31st March 2021

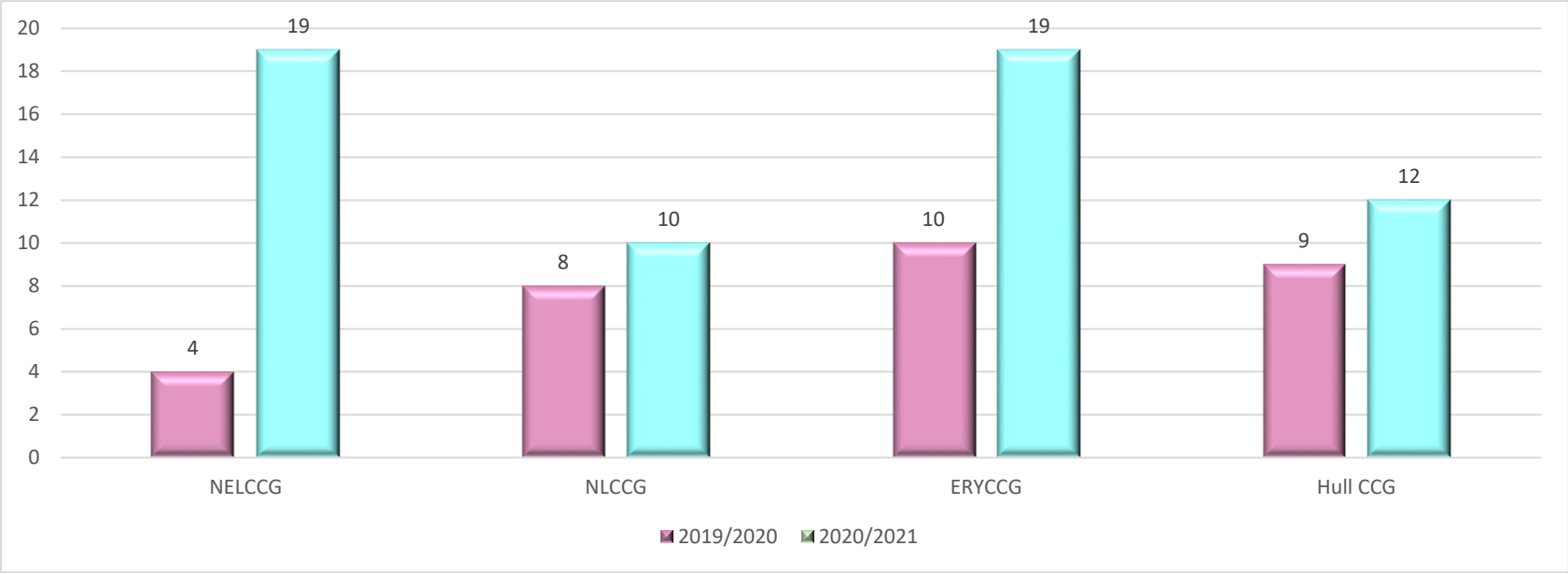
Between 1st April 2020 – 31st March 2021, 60 LeDeR reviews were completed across the four CCG's.
Whilst the Covid-19 pandemic has had an impact on the CCG's abilities to assign reviews, and the reviewers abilities to complete reviews due to a variety of reasons such as:

- Staff re-deployment;
- Requirement to access records remotely and seek family engagement remotely due to the National lockdown;

the four CCG's were able to increase the number of reviews completed from 31 for the time period 1st April 2019 - 31st March 2020.

Figure 2 below identifies the number of reviews completed by each CCG April 1st 2020 – March 31st 2021, with a comparator of the number completed by each CCG April 1st 2019 – March 31st 2020.

Figure 2.
Reviews Completed 1st April 2020 - 31st March 2021 with a Comparator to Reviews Completed 1st April 2019 – 31st March 2020



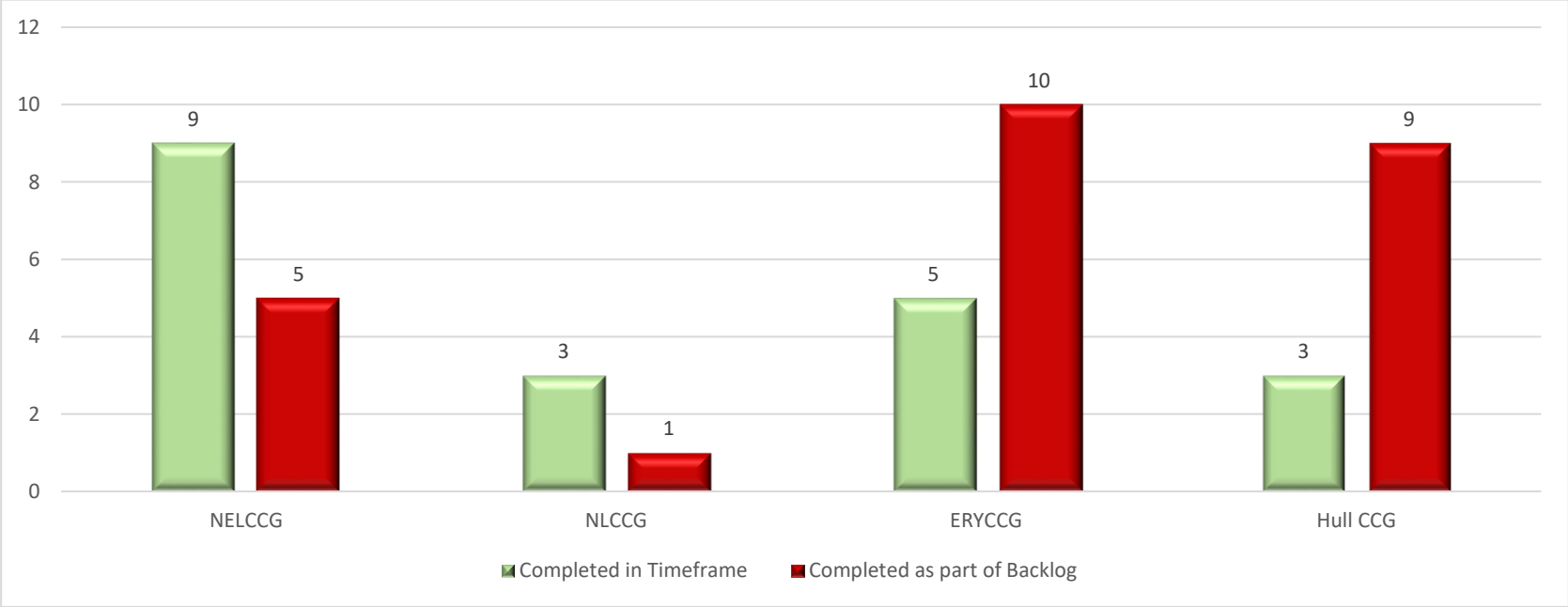
To note; any death notified after the 1st October 2020 would not require the review to be completed and approved within this financial year's annual report. Any reviews which meet this criteria will be included within the 2021/2022 annual report.

The main impact of the Covid-19 pandemic on completion of reviews, has been in meeting the required standard for reviews to be allocated to a reviewer within three months and completed within six months following the date of notification of an individual's death to the LeDeR programme.

Of the 60 reviews completed 1st April 2020 – 31st March 2021, 20 were completed within the required timeframe and 25 were part of a 'backlog' of reviews which were overdue the 6 month timescale for completion. The 'backlog' reviews had a requirement to be completed by 31st December 2020 of which all the CCG's met.

Figure 3 below identifies the number of reviews completed in timeframe and the number of reviews within the backlog by CCG April 1st 2020 – March 31st 2021.

Figure 3.
Reviews Completed in Timeframe and Reviews within the Backlog by CCG 1st April 2020 - 31st March 2021



To note; any death notified after the 1st October 2020 would not require the review to be completed and approved within this financial year's annual report. Any reviews which meet this criteria will be included within the 2021/2022 annual report.

5.0 Themes and Trends

5.1 Gender of Individuals from Reported Deaths 1st April 2020 – 31st March 2021

	Gender	
	Female	**Male**
N = 55	21	34
%	**38%**	**62%**

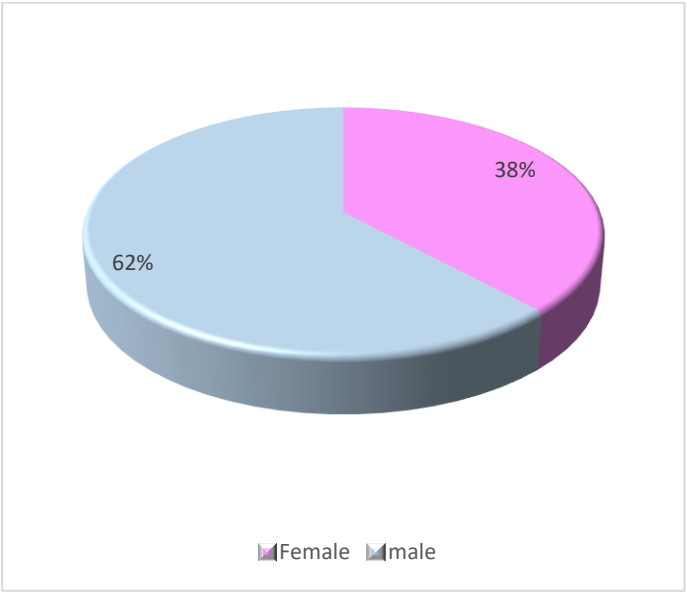
Of the 55 deaths sadly reported by the four CCG's 1st April 2020 - 31st March 2021:

- The individual's gender was reported within the notification in all deaths notified to the programme.
- 21 individuals were female (38%).

- 34 of the individuals were male (62%).

- The gender comparison of individuals whose deaths were notified within the Humber area 1st April 2020 – 31st March 2021, was not dissimilar to that of the national picture.

Gender Comparison



Within the Learning Disabilities Mortality Review Programme Annual Report 2019 (published in 2020), which covered deaths notified to the programme between 1st July 2016 – 31st December 2019, the reported genders were:

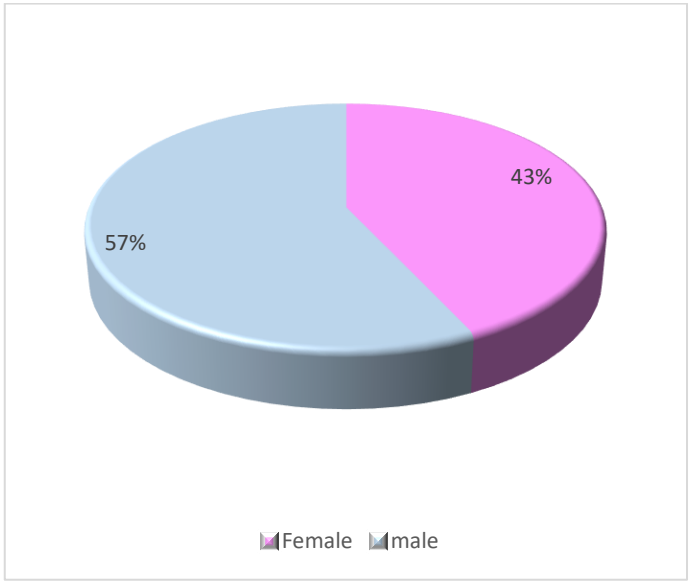
- 58% male.
- 42% female.

Information obtained from page 21 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 2020 – 31st March 2021

	Gender	
	Female	**Male**
N = 60	26	34
%	**43%**	**57%**

Gender Comparison



Of the 60 reviews completed 1st April 2020 - 31st March 2021:

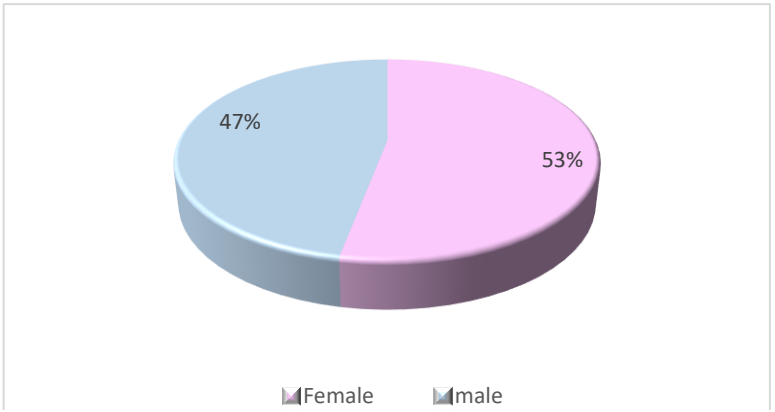
- 26 of the individuals were female (43%).

- 34 of the individuals were male (57%).

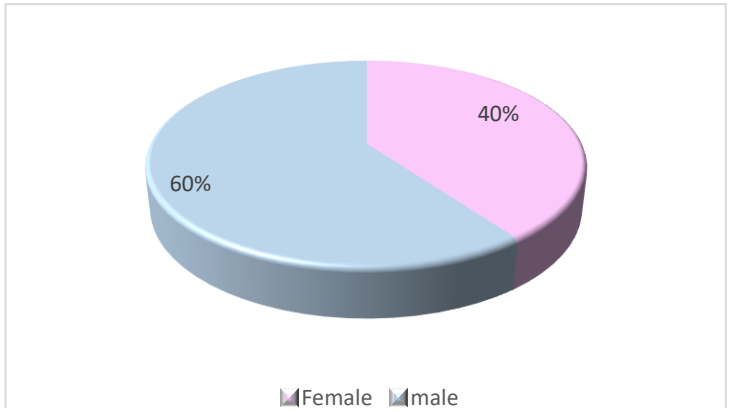
5.1.2 Gender of Individuals from Completed Reviews by CCG 1st April 2020 – 31st March 2021

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

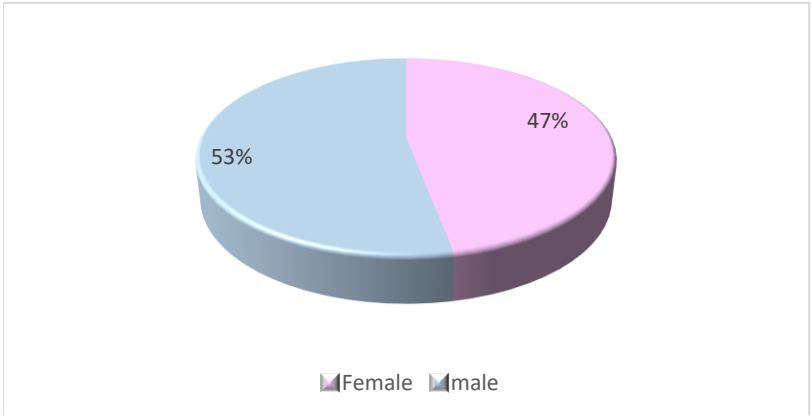
NELCCG



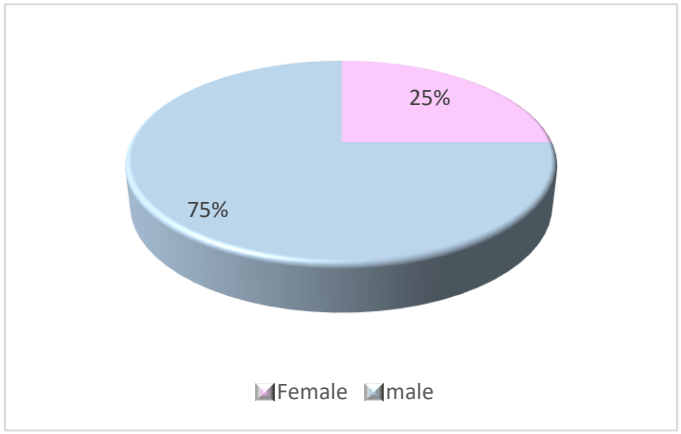
NLCCG



ERYCCG



Hull CCG

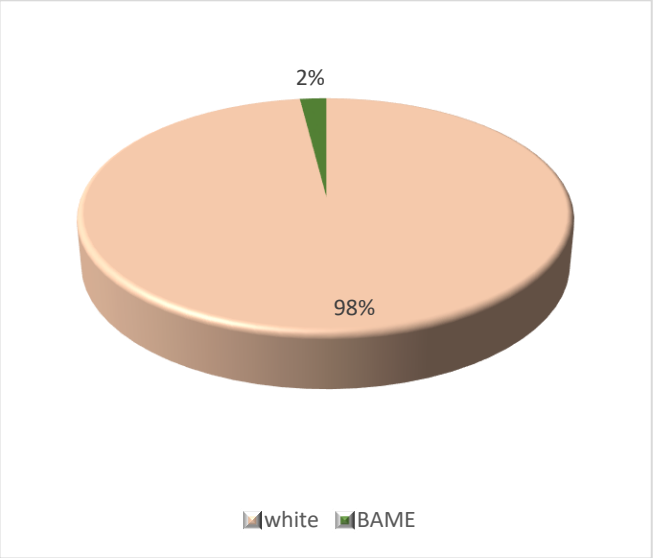


Themes and Trends

5.2 Ethnicity of Individuals from Reported Deaths 1st April 2020 – 31st March 2021

	Ethnicity	
	White	**BAME**
N = 55	54	1
%	**98%**	**2%**

Ethnicity Comparison



- The ethnicity of the individual was reported within all 55 deaths notified to the programme 1st April 2020 – 31st March 2021.
- Of the 55 deaths reported, 98% of individuals were recorded as being of white British ethnicity.
- There was one death reported of an individual from Black, Asian and Minority Ethnic (BAME) groups.

- The population of Yorkshire and the Humber of which the four CCG's boundaries are within, is approximately 86% white (Census 2011).
- The ethnicity comparison of individuals whose deaths were notified within the Humber area was higher than that of the national picture.

To note:

Of the 60 reviews completed 1st April 2020 – 31st March 2021, none of the individuals were of BAME background.

Within the Learning Disabilities Mortality Review Programme Annual Report 2019 (published in 2020), which covered deaths notified to the programme between 1st July 2016 – 31st December 2019, the reported ethnicity ratio was:

- 90% white British.
- 10% BAME groups.

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 2020 - 31st March 2021)

Of the 55 individuals whose deaths were reported 1st April 2020 - 31st March 2021:

- The age range was 9-86 years.
- The mean average age of death was 58.4 years.
- The median age of death was 61 years.

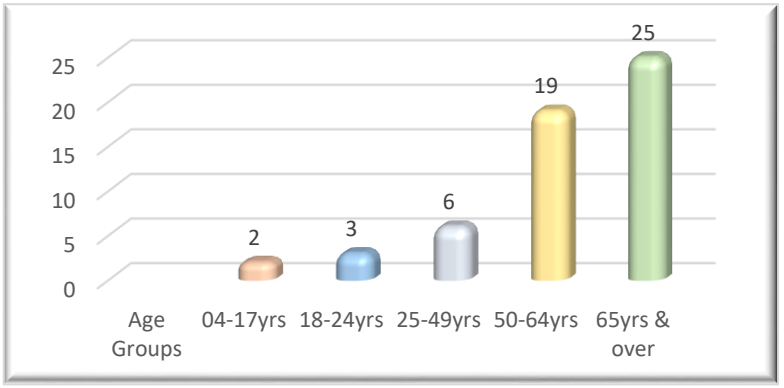
In relation to those individuals who were female:

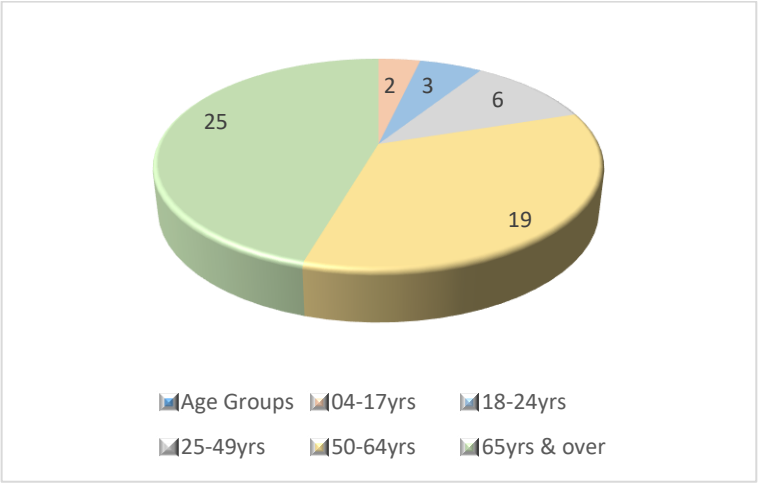
- The age range was 11-85 years.
- The mean average age of death was 59.4 years.
- The median age of death was 65 years.

In relation to those individuals who were male:

- The age range was 9-86 years.
- The mean average age of death was 57.5 years.
- The median age of death was 61 years.

Age at Death - Reported Deaths





- The median age at the time of death for individuals with a Learning Disability across the four CCG's within the Humber area as a comparator to the national picture was:
  - Higher for females (65 years against the national figure of 59 years).
  - The same for males (61 years).

- The median age at the time of death for individuals reported within the Learning Disabilities Mortality Review Programme Annual Report 2019 (published in 2020) was 60 years.
- The median age at time of death for males was 61 (age 4 – 98 years).
- The median age at time of death for females was 59 years (age 4-104 years).

Information obtained from page 29 of the National Report which can be accessed at: https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

5.3.1 Age of Individuals at the time of Death (completed reviews 1st April 2020 - 31st March 2021)

For the 60 completed reviews during the time period 1st April 2020 -31st March 2021:

- The age range was 9-86 years.
- The mean average age of death was 56.8 years.
- The median age of death was 60 years.

In relation to those individuals who were female:

- The age range was 22-79 years.
- The mean average age of death was 58.3 years.
- The median age of death was 59.5 years.

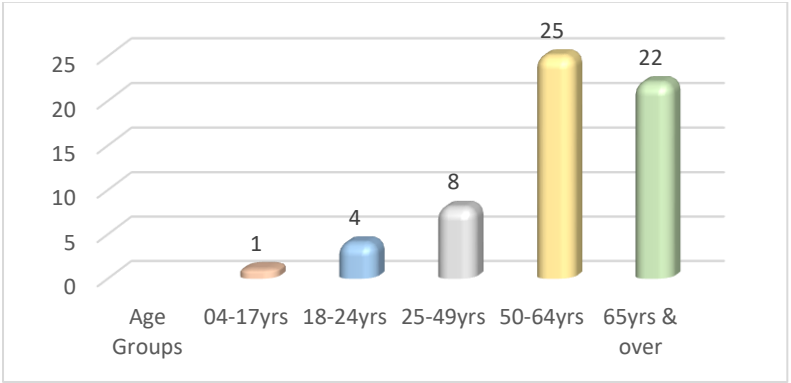
In relation to those individuals who were male:

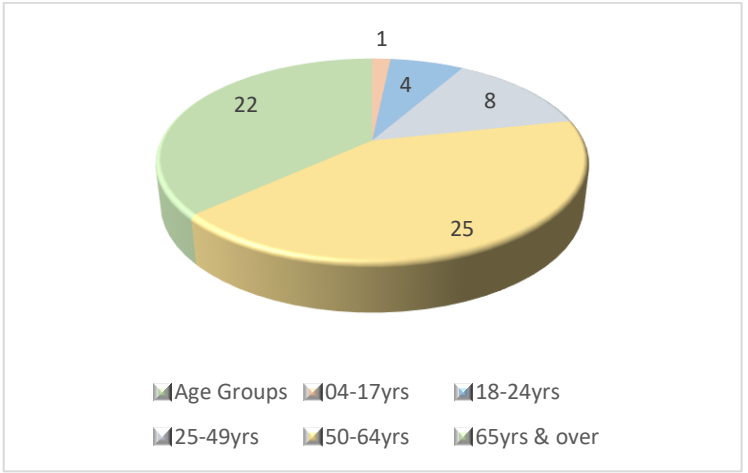
- The age range was 9-86 years.
- The mean average age of death was 56.8 years.
- The median age of death was 60.5 years.

- The average life expectancy in 2019 within Yorkshire and the Humber of which the four CCG's boundaries are within is:
  - 82 years for females.
  - 79 years for males.

There was 1 review completed through the Child Death Overview Process.

Age at Death – Completed Reviews





Within the general population in England in 2019, life expectancy was:

- 83 years for females.
- 80 years for males.

www.healthdata.org [accessed 30th April 2021]

Themes and Trends

5.4 Place of Death - Reported Deaths 1st April 2020 – 31st March 2021

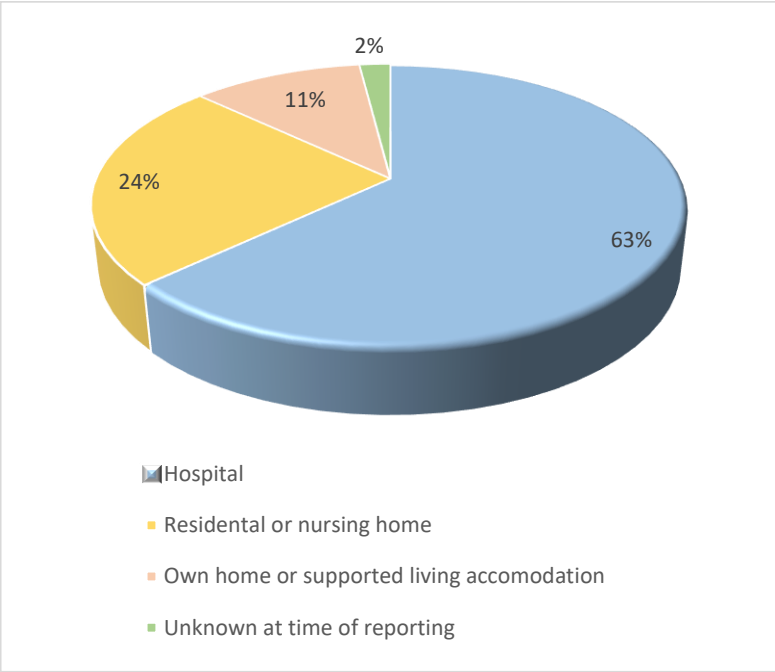
Place of Death		
	N=55	%
Hospital	35	63%
Residential/Nursing home setting	13	24%
Own home/supported living	6	11%
Not known at time of reporting	1	2%

Of the 55 deaths sadly reported during the time period 1st April 2020 - 31st March 2021:

- 35 individuals died within a hospital care setting (63%).
- 13 individuals died within a residential or nursing home setting (of which a proportion would be their usual place of residence) (24%).
- 6 individuals died within their own home or supported living accommodation (11%).
- 1 reported death did not have the individual's place of death documented within the initial notification. Due to this review not yet being completed, it is not possible to confirm the place of death for the purposes of this report.

- The reported place of death as hospital for those individuals whose death was reported 1st April 2020 - 31st March 2021, is slightly higher at 63% to that of the national picture at 60% (data from 2019).
  It is unclear as to whether the Covid-19 pandemic has had an impact locally on the place of death for those deaths reported during the timeframe of this report.

Place of Death - Reported Deaths



Within the Learning Disabilities Mortality Review Programme Annual Report 2019 (published in 2020), the proportion of deaths in hospital for individuals with a learning disability is 60% with 46% for the general population.

Information obtained from page 32 of the National Report which can be accessed at: https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

5.4.1 Place of Death - Completed Reviews 1st April 2020 - 31st March 2021

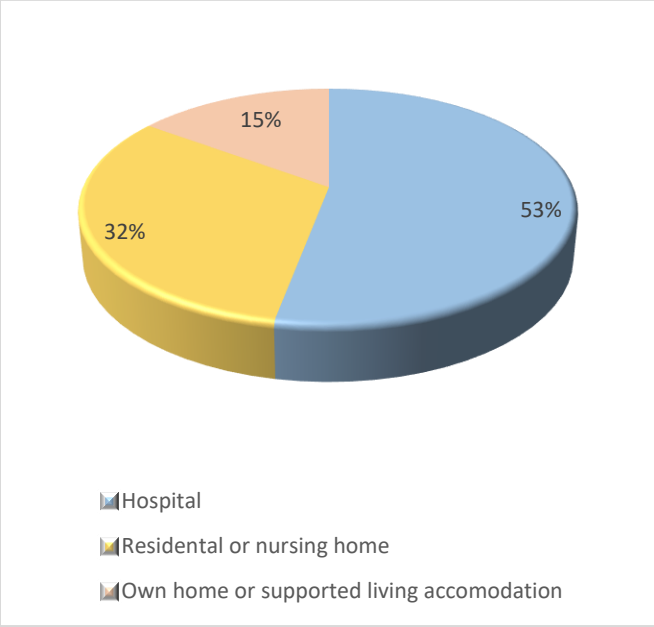
Place of Death		
	N=60	%
Hospital	32	53%
Residential/Nursing home setting	19	32%
Own home/supported living	9	15%

Of the 60 reviews completed during the time period 1st April 2020 -31st March 2021:

- 32 individuals died within a hospital care setting (53%).
- 19 individuals died within a residential or nursing home setting (of which a proportion would be their usual place of residence) (32%).
- 9 individuals died within their own home or supported living accommodation (15%).

- The reported place of death as hospital for those individuals whose death was reviewed 1st April 2020 - 31st March 2021, is lower at 53% to that of the national picture of 60%.

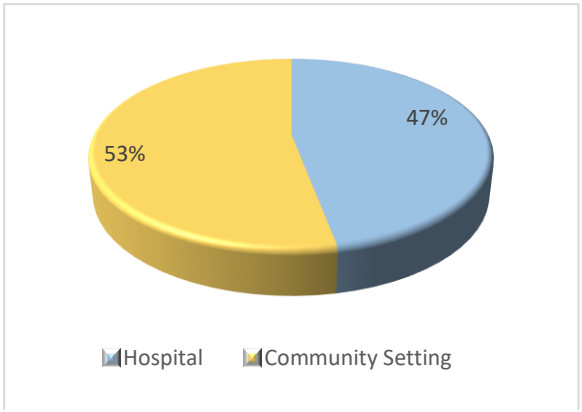
Place of Death – Completed Reviews



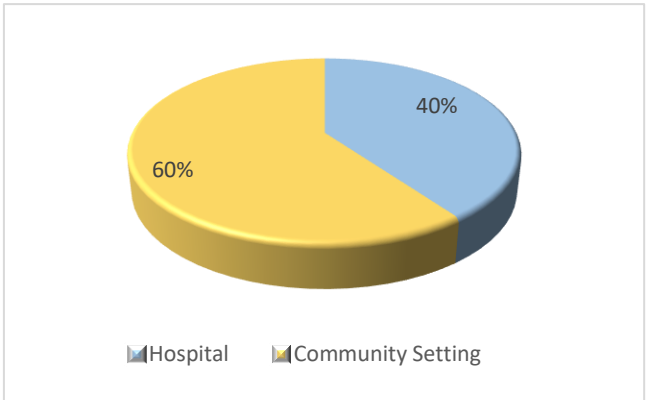
5.4.2 Place of Death - Completed Reviews by CCG 1st April 2020 - 31st March 2021

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

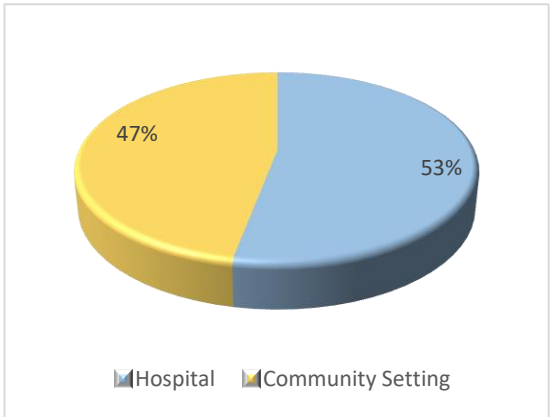
NEL CCG



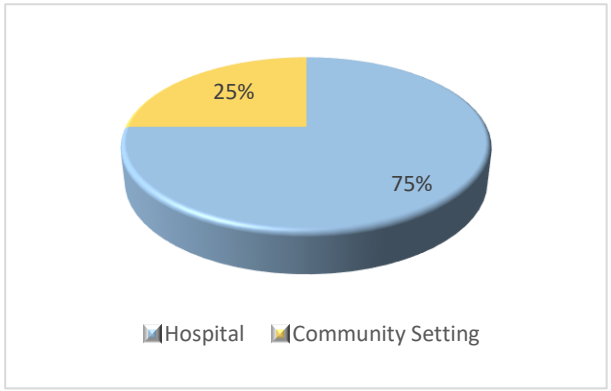
NLCCG



ERY CCG



Hull CCG



A larger proportion of individuals with a learning disability within Northern Lincolnshire appear to die within a community setting. For the purposes of this section, a community setting relates to Residential or Nursing Care Home, own home or supported living environment.

Themes and Trends

5.5 Cause of Death – Completed Reviews Only; 1st April 2020 – 31st March 2021

This section of the report covers only the cause of death from completed reviews and not the perceived cause of death for individuals whose death has not as yet been reviewed.

In line with the National picture, the most common cause of death of individuals with a learning disability within three of the four CCG's, and the second most common cause of death within the fourth CCG was aspiration pneumonia (17%) closely followed by pneumonia (13%). These causes equated to 30% of the total causes of death identified within the reviews completed. The percentage per CCG was identified as:

- NELCCG – 16%.
- NLCCG – 50%.
- ERY CCG – 21%.
- Hull CCG – 50%.

Other confirmed causes of death from the completed reviews included:

- Cancer.
- Dementia and Alzheimer's disease.
- Sepsis.
- Cardiac issues (multiple different cardiac causes have been identified under the umbrella of 'cardiac' for the purposes of this report).
- Covid-19.
- Other- (multiple small numbers of differing causes have been identified under the umbrella of 'other' for the purposes of this report).

- Within an extremely small minority number, the individual's learning disability was reported as the cause of death.

The Learning Disabilities Mortality Review Programme Annual Report 2019 (published 2020), reported the following as the most frequent cause of death for individuals with a learning disability:

- Bacterial pneumonia (24%).
- Aspiration pneumonia (16%).
- Down's syndrome (11%).
- Dementia/Alzheimer's disease (9%).
- Sepsis (7%).
- Epilepsy (6%).

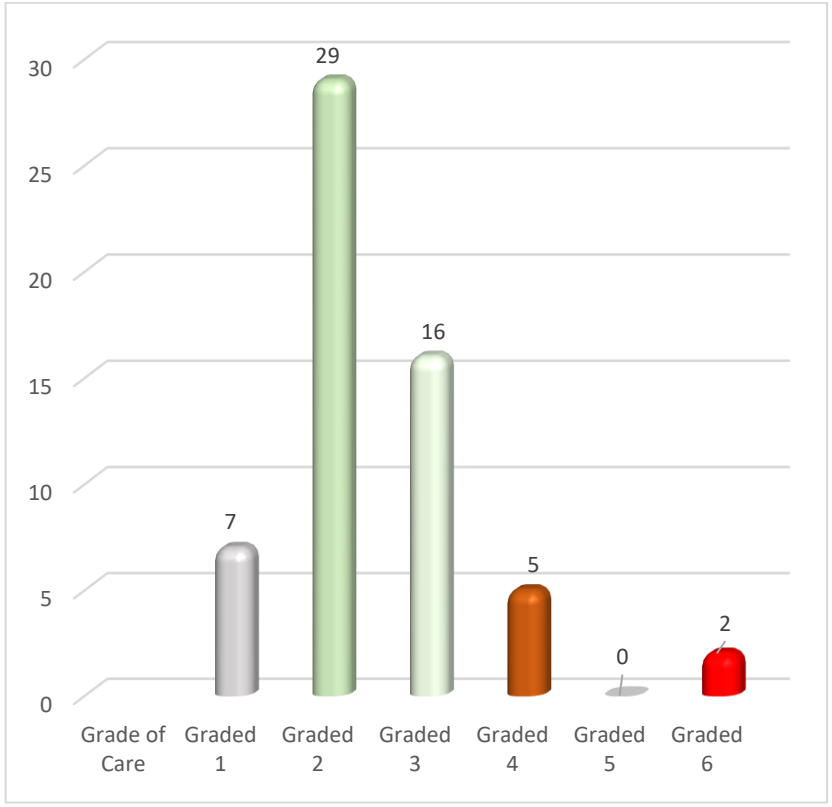
Themes and Trends

5.6 Grading of Care - Completed Reviews 1st April 2020 – 31st March 2021

On consideration of the available evidence and completion of the review, the reviewer provides an overall assessment of the quality of care afforded to the individual from the following grading criteria:

Overall Assessment of Quality of Care	
Grade	**Grading Criteria**
1.	This was excellent care (it exceeded expected good practice).
2.	This was good care (it met expected good practice).
3.	This was satisfactory care (it fell short of expected good practice in some areas but did not significantly impact on the person's well-being).
4.	Care fell short of expected good practice and this did impact on the person's well-being but did not contribute to the cause of death.
5.	Care fell short of expected good practice and this significantly impacted on the person's well-being and/or had the potential to contribute to the cause of death.
6.	Care fell far short of expected good practice and this contributed to the cause of death.

Grading of Care - Reviewed Cases



Grading of Care – Completed Reviews 1st April 2020 – 31st March 2021

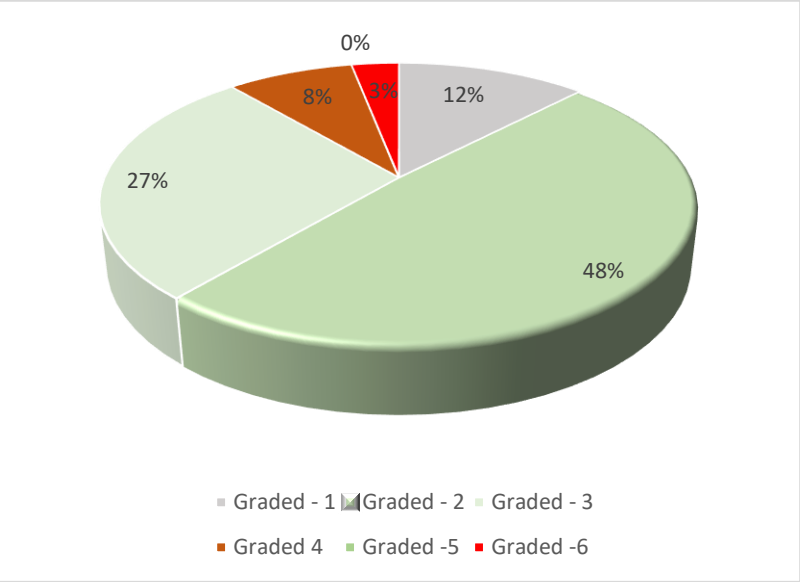
Of the 60 LeDeR reviews completed 1st April 2020 - 31st March 2021, the following grading's of care were applied:

- 7 cases graded as 1 (12%).
- 29 cases graded as 2 (48%).
- 16 cases graded as 3 (27%).
- 5 cases graded as 4 (8%).
- 0 cases graded as 5 (0%).
- 2 cases graded as 6 (3%).

Of the cases reviewed across the four CCG's:

- 87% of individuals had their care graded as satisfactory or greater.
- Of this 87%, 60% of individuals had the care they received graded as; met or exceeded good practice - this is slightly above the nationally reported 56%.
- Four of the cases reviewed were subject to multi-agency review. A multi-agency review is undertaken where it is felt (following the initial review) that further learning could be obtained by including the views of a wider range of people and agencies who were involved in supporting the individual who has died. A more in-depth analysis is carried out on the circumstances leading up to the individual's death.

Grading of Care of Reviewed Cases as a %



Within the Learning Disabilities Mortality Review Programme Annual Report 2019 (published in 2020):

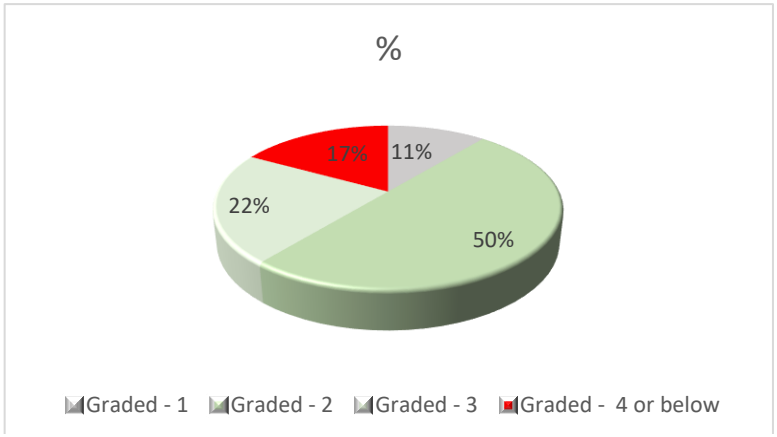
- 56% of individuals were reported to have received care which met or exceeded good practice (care graded as 1 or 2).

Information obtained from page 50 of the National Report which can be accessed at:
https://www.bristol.ac.uk/sps/leder/resources/annual-reports/

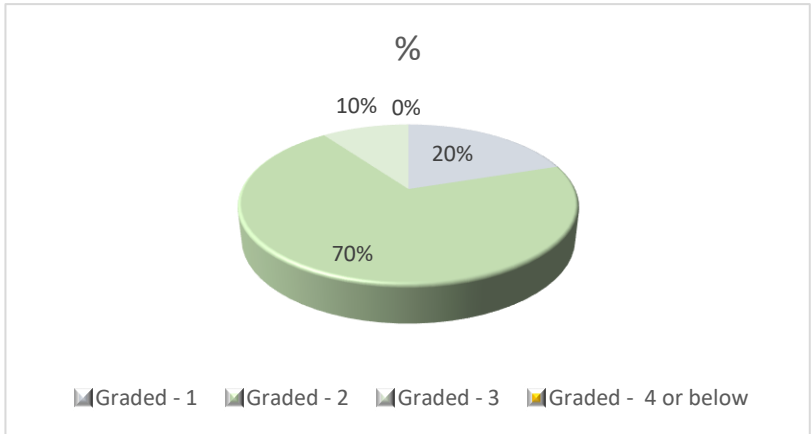
5.6.1 Grading of Care – Completed Reviews by CCG 1st April 2020 - 31st March 2021

The information below shows the grading of care as identified from completed reviews by CCG.

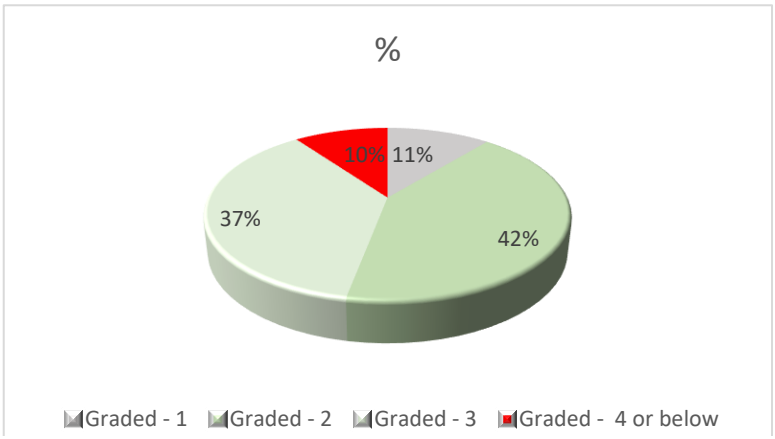
NELCCG



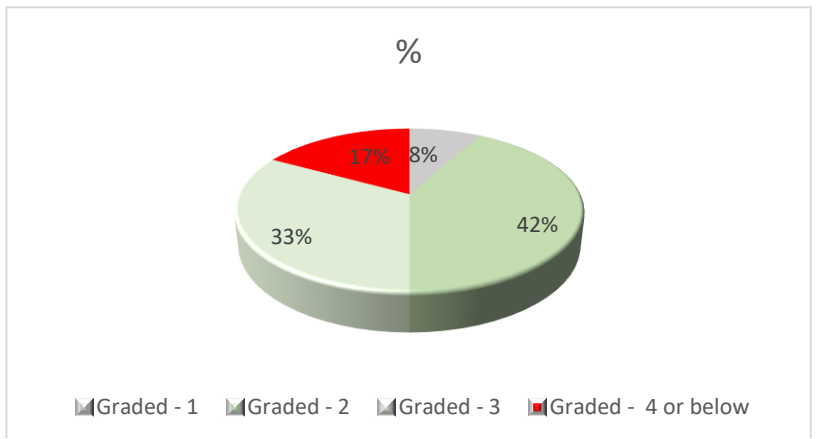
NLCCG



ERYCCG

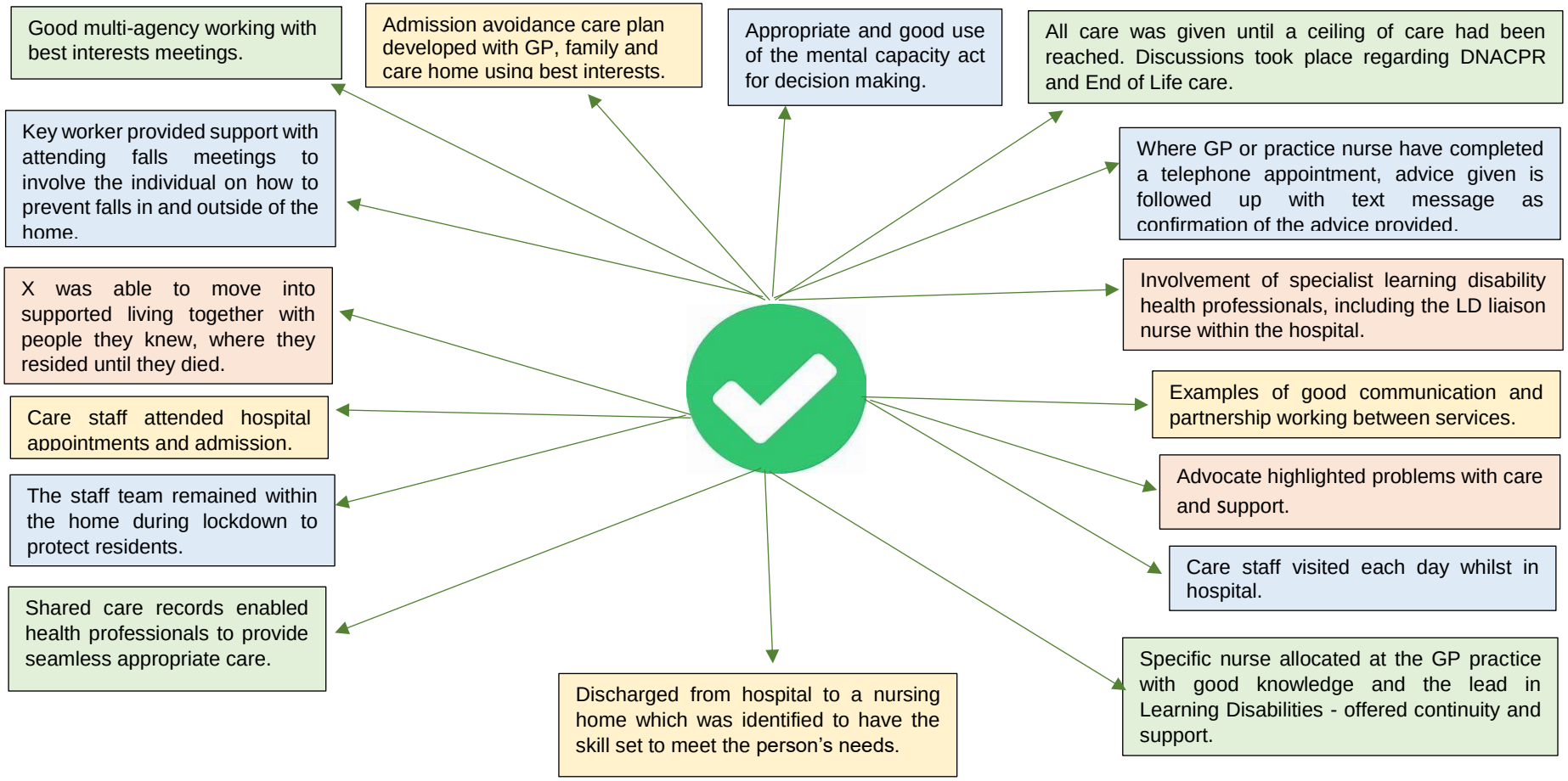


Hull CCG

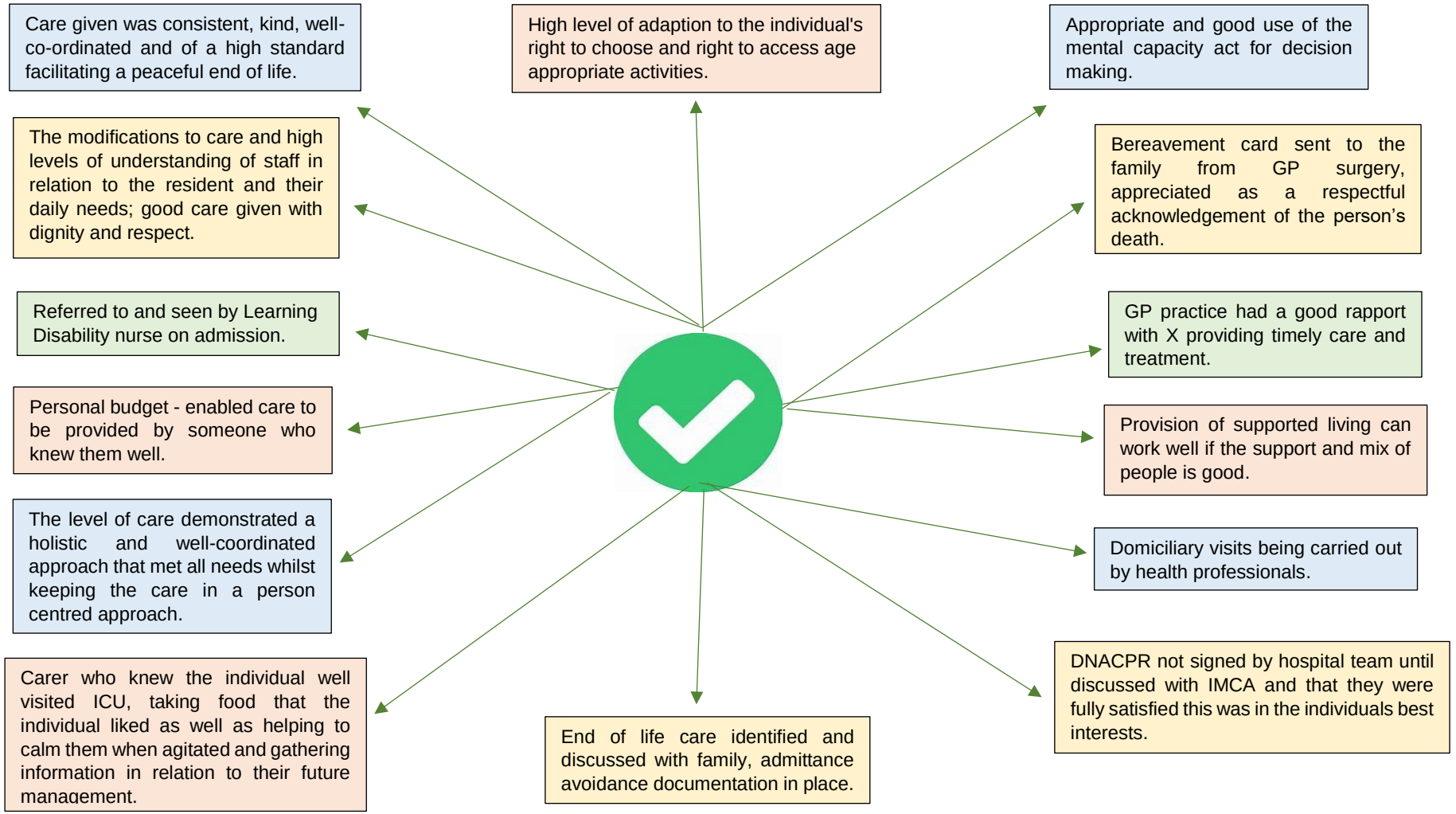


6.0 Identified Best Practice from Completed Reviews April 1st 2020 – March 31st 2021

Below are some examples of areas of good practice identified from the 60 reviews completed 1st April 2020 – 31st March 2021.

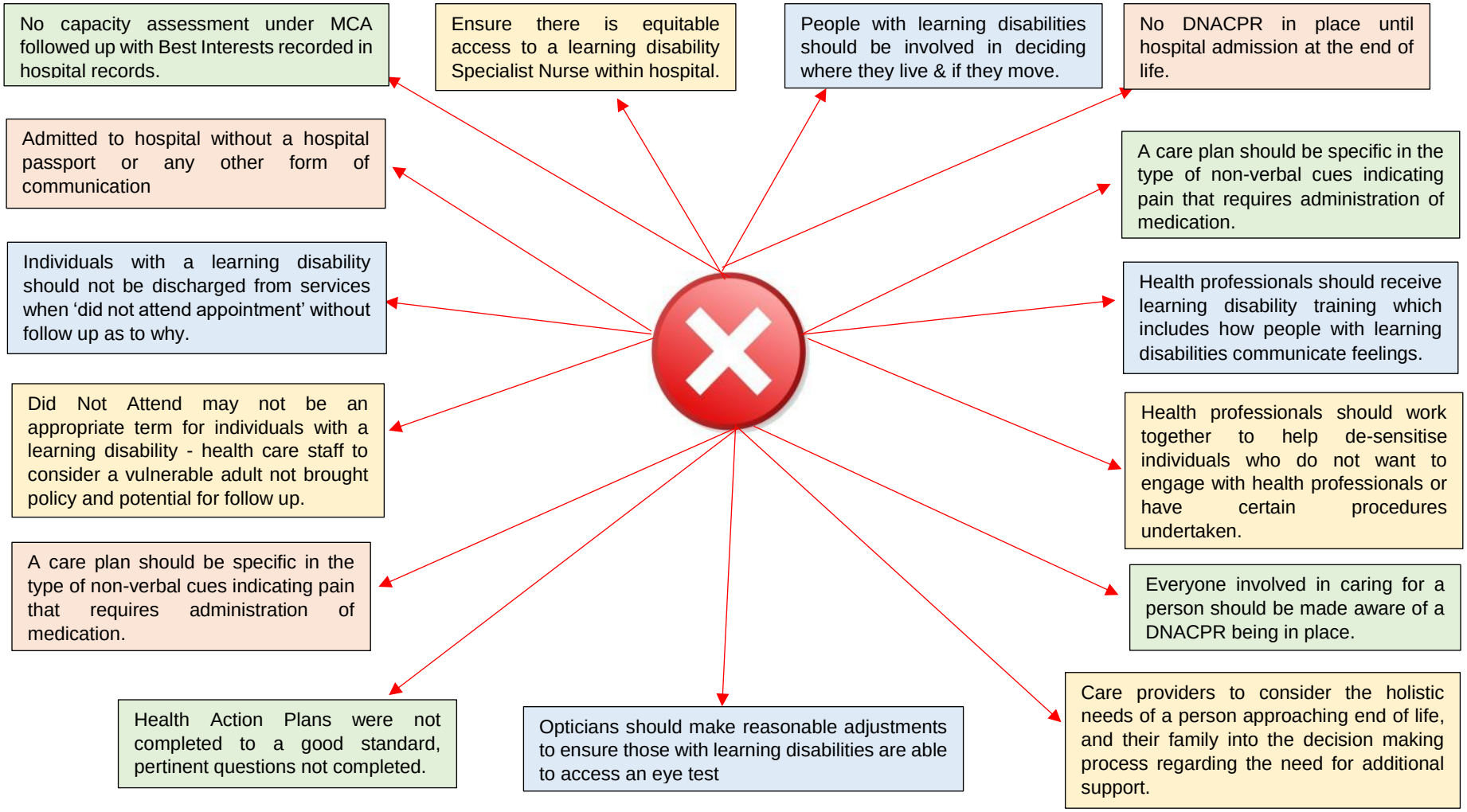


Identified Best Practice from Completed Reviews (2) April 1st 2020 – March 31st 2021

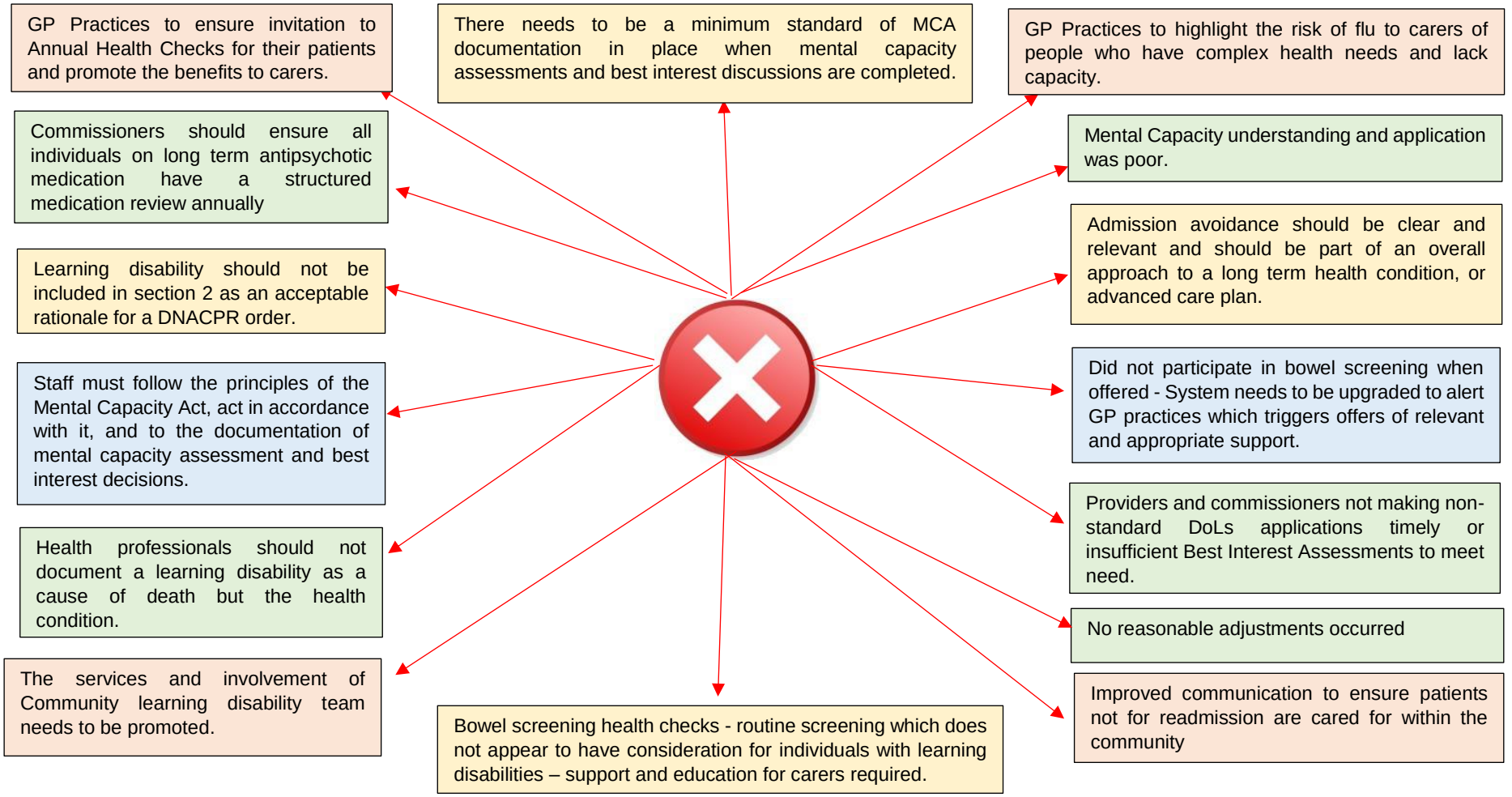


7.0 Identified Learning from Completed Reviews 1st April 2020 – 31st March 2021

Below are some of the examples of identified learning from the 60 reviews completed 1st April 2020 – 31st March 2021.



Identified Learning from Completed Reviews (2) 1st April 2020 – 31st March 2021

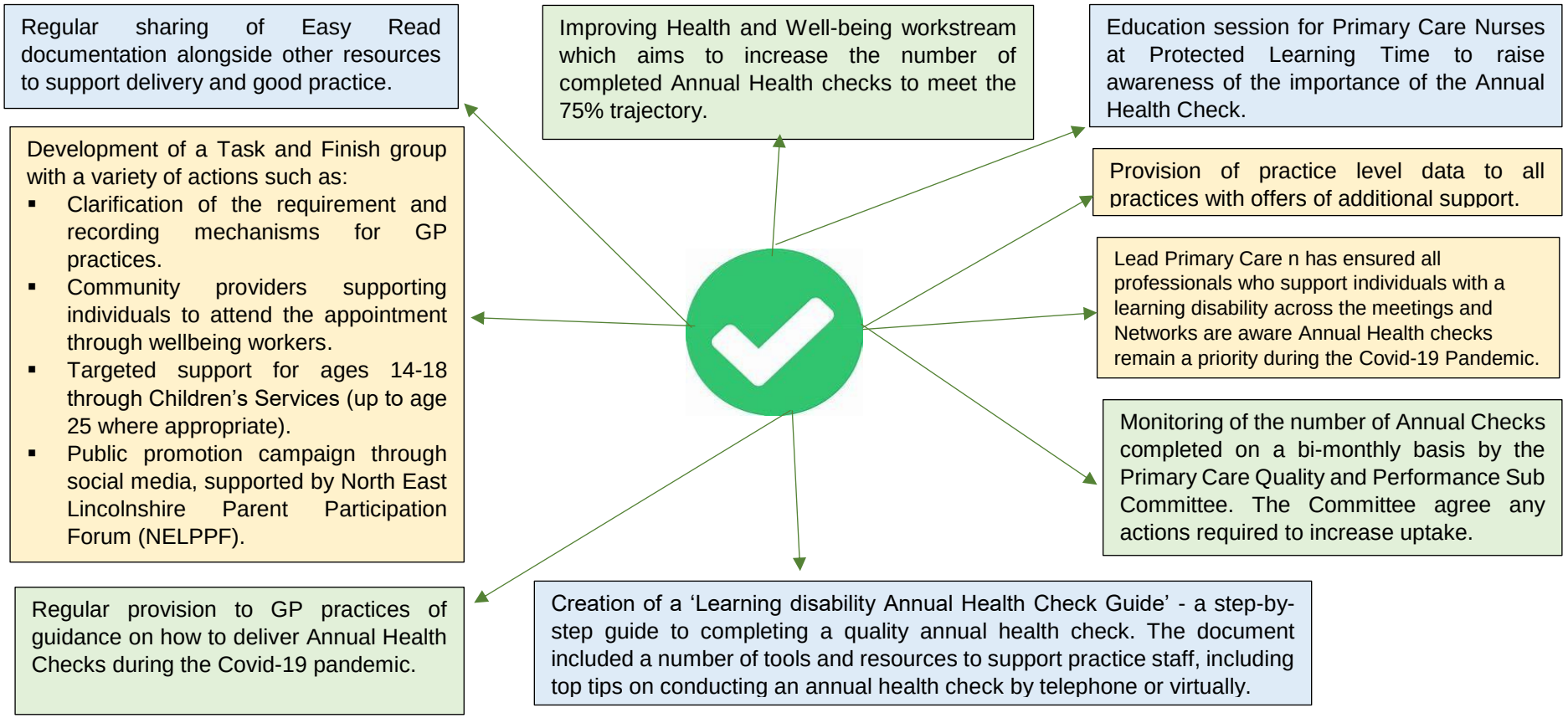


8.0 Outcomes and Achievements

There have been many examples of positive initiatives undertaken to improve the experience and services delivered to service users across the Humber area:

8.1 Annual Health Checks 1st April 2020 – 31st March 2021

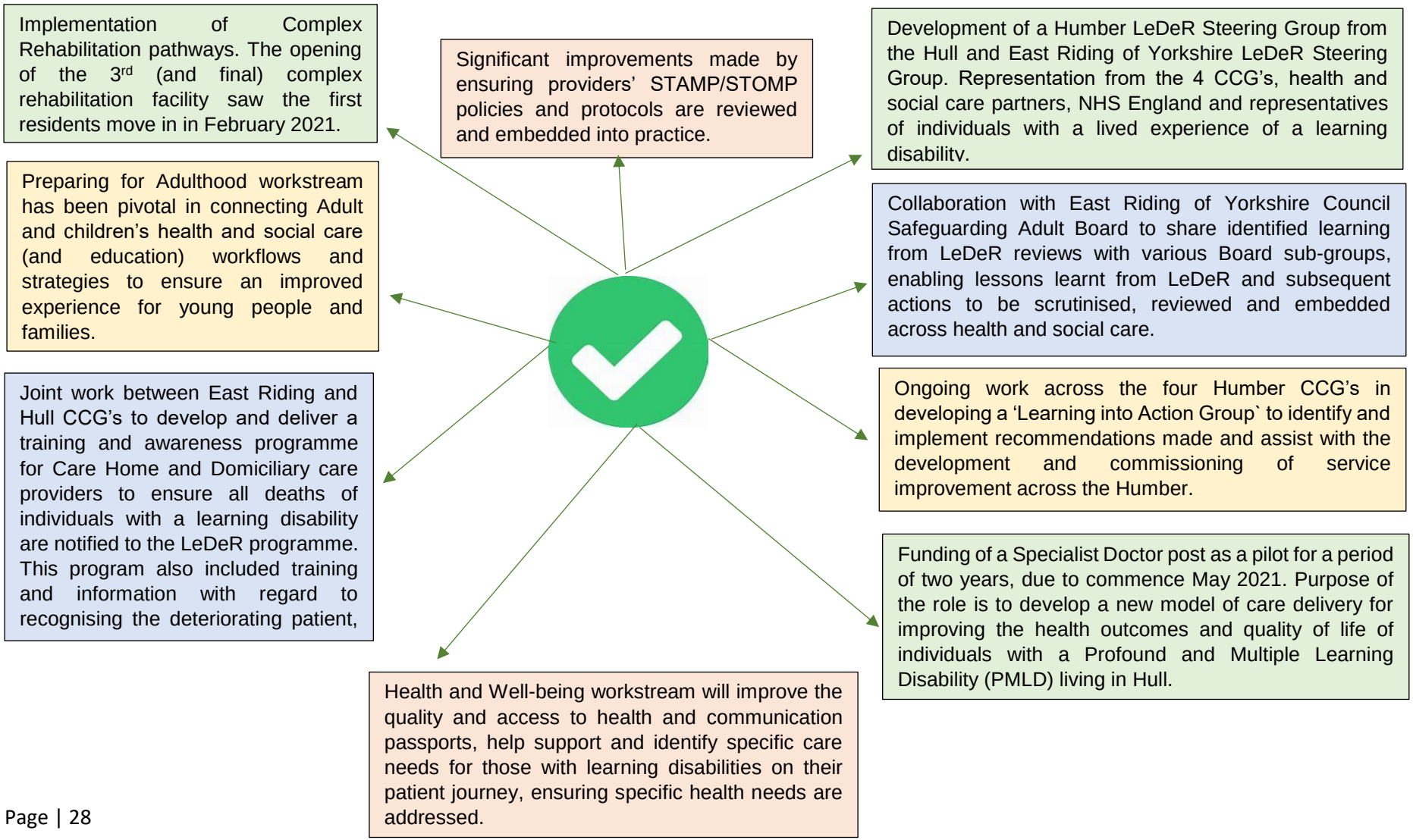
Despite the Covid 19 Pandemic, local data suggests that all CCG's have seen an improvement in compliance against individuals aged 14 and over with a learning disability being offered an Annual Health Check. Despite these improvements, further work is required to continue building on the good progress to ensure all individuals are offered and receive their Annual Health Check. Below are some examples of the work which has been undertaken to improve uptake.



Outcomes and Achievements

8.2 Other Areas of Work Undertaken by CCG's, 1st April 2020 – 31st March 2021

Identified below are some of the other areas of work undertaken by the CCG's 1st April 2020 – 31st March 2021.



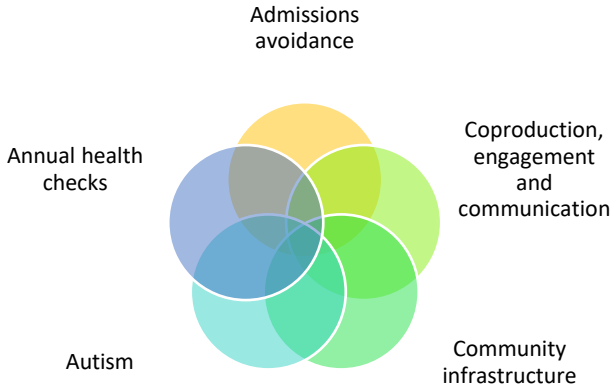
Outcomes and Achievements

8.3 Work Undertaken by the Humber Transforming Care Partnership (TCP) April 1st 2020 – March 31st 2021

Over the past year the Humber Transforming Care Partnership (TCP) has been developing and evolving, with a new Transforming Care team, providing dedicated programme management and fostering a greater focus on partnership working. Below is some of the work undertaken and plans for further development:

Development of a 3 year plan, which includes several new work streams. These work streams will support the partnership to meet their trajectories for:

- Reducing inpatient admissions.
- Increasing uptake of Annual Health checks.
- Supporting individuals to live better lives in the community and to live well for longer.



The co-production, engagement, and communications work stream will work across the TCP area to develop two-way communications between the partnership and communities it serves. This will include regular co-production workshops, support and coaching for people with lived experience to attend TCP meetings, and production of a regular newsletter.

Work will take place to understand and develop pathways and services for individuals with neurodiverse conditions, including autism. This work will be complemented by development of a training package for people living with autism, as well as the health and social care professionals who may support them.

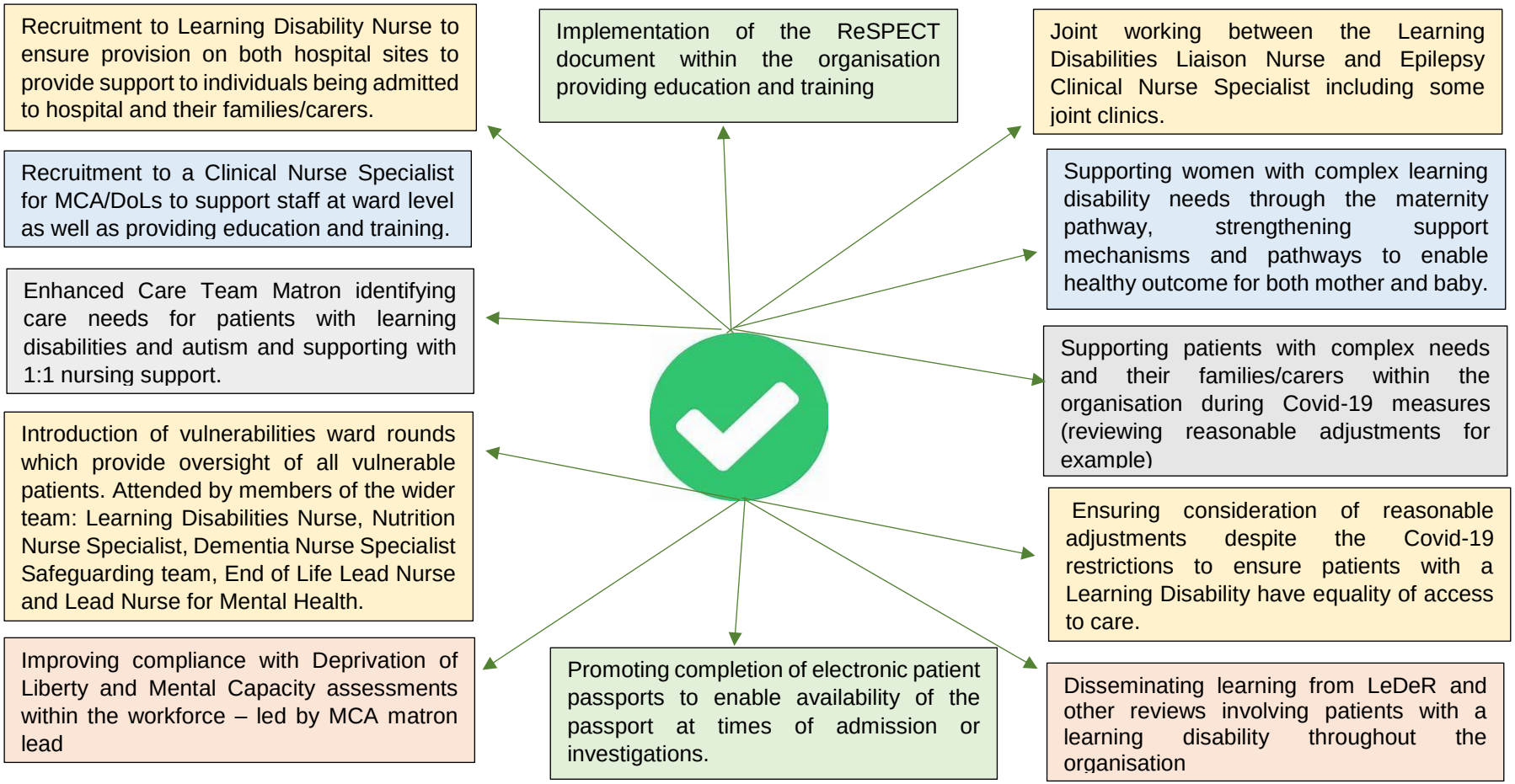
Whilst the TCP has a long way to go, it is now much clearer in what it must do. There is strong leadership, a clear vision and a willingness across the partnership to work alongside our communities to improve lives.

Outcomes and Achievements

8.4 Work Undertaken by Secondary Care Trusts within the Humber Area April 1st 2020 – March 31st 2021

Identified below are some examples of areas of work undertaken by the two Acute Care Providers within the Humber area 1st April 2020 – 31st March 2021:

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

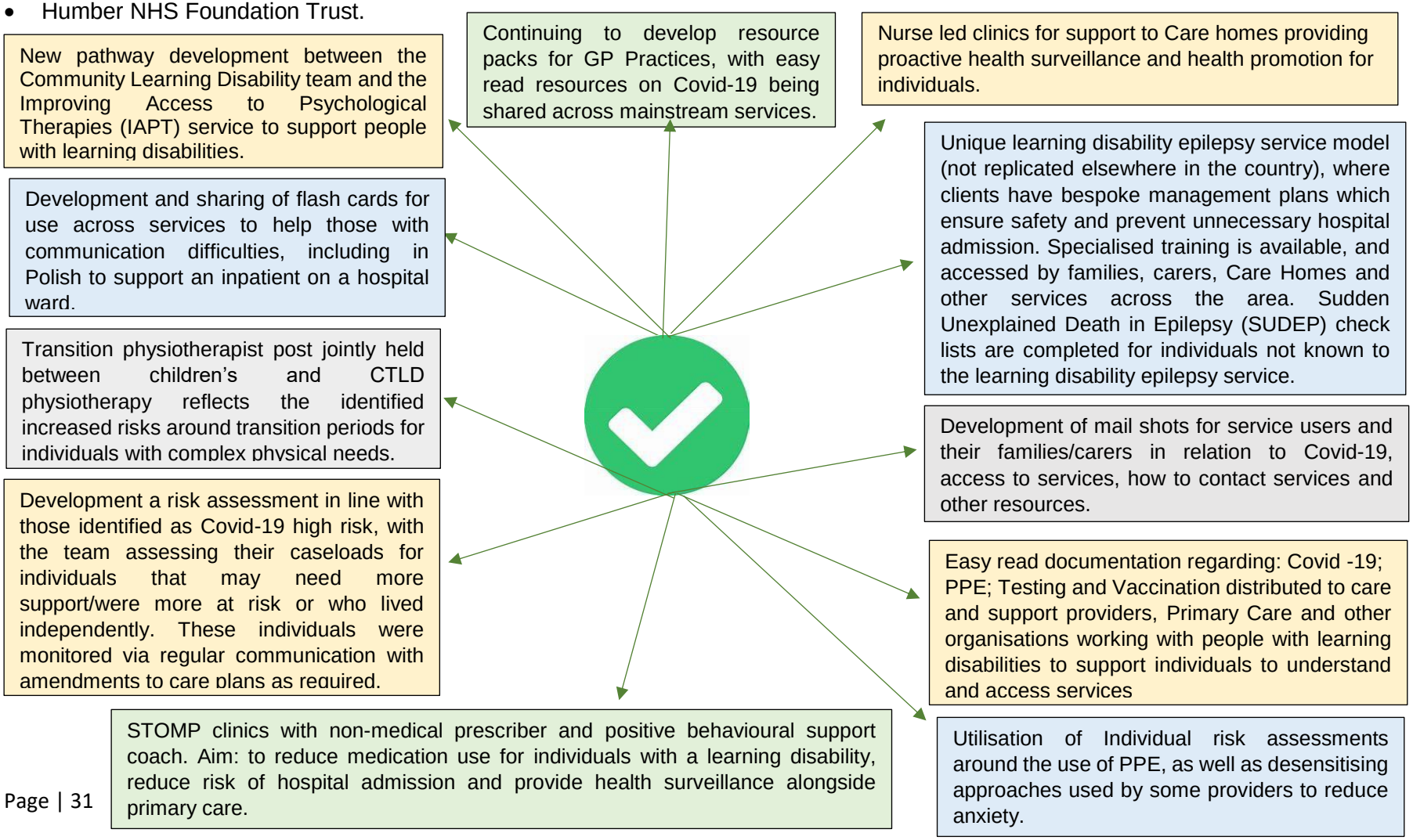


Outcomes and Achievements

8.5 Work Undertaken by Mental Health Trusts within the Humber Area April 1st 2020 – March 31st 2021

Identified below are some examples of areas of work undertaken by the following Mental Health Care Providers within the Humber area 1st April 2020 – 31st March 2021:

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



Outcomes and Achievements

8.6 Work Undertaken by Wellbeing Service of City Healthcare Partnership April 1st 2020 – March 31st 2021

Identified below are examples of areas of work undertaken by the Wellbeing Service of City Healthcare Partnership 1st April 2020 - 31st March 2021:

Development of bespoke resources in response to Covid 19 and the national lockdown such as:

- Makaton videos for individuals in care homes to understand lockdown.
- Social stories to help children and individuals with communication difficulties understand Covid 19.
- An easy read time capsule, and variety of accessible activities to reduce boredom and frustration during lockdown.
- Bespoke communication boards to support video conferences and health consultations.
- Bespoke communication boards to support emergency staff assessing patients.
- Communication boards in relation to: handwashing, Covid -19 symptoms, self-isolation and managing good and bad days.
- GP pack, which included communication boards, communication fans, pain scales and easy read resources.

Development and sharing of an 'LD audit tool' to support GP practices in achieving the Learning Disability Quality Incentive 2020. The audit enabled the team to identify any areas that required support from the service.

Development and sharing of an 'LD audit tool' to support GP practices in achieving the Learning Disability Quality Incentive 2020. The audit enabled the team to identify any areas that required support from the service.

Provision of support to the mass vaccination centre in relation to accessibility and provision of reasonable adjustments for individuals with a learning disability.

Creation of accessible resources for use around the vaccination centres to aid understanding of the vaccination process.

Liaison with Community Learning Disability team and GP practices to provided support in relation to Mental Capacity and Best Interest Decisions. Review of electronic templates used by practices, prompts and guidance offered in relation to what to include when assessing mental capacity and completing Best Interest documentation.

Learning Disability awareness training delivered remotely over a 6 week period to Care home staff. Topics identified as local priorities through completed reviews:

- Learning Disability Awareness & Health inequalities.
- Annual Health Checks.
- LeDeR and specific health issue of constipation and Epilepsy.
- Communication and Accessible Information Standard (AIS).
- Diagnostic over shadowing and signs/symptoms.
- Spot light on specific health issues – epilepsy.

Establishment of a learning disability champion network.

9.0 Key Themes and Recommendations for Improvement from Reviews Completed 1st April 2020 – 31st March 2021

The following are the main key themes for improvement, identified from the learning from completed reviews 1st April 2020-31st March 2021.

Annual Health Checks:
Whilst all CCG's have identified an improved end of year position with regard to the uptake of Annual Health Checks for all individuals aged 14 years and over, continued improvements are required in order to reach the required NHSE trajectory of 75 % of eligible individuals.
Also it has been noted within some of the completed reviews that further work is required in relation to the quality of completion of the documentation and ensuring annual medication reviews are also completed.

End of Life Care:
Whilst many reviews have identified good end of life care, others identified:

- Recognition and earlier decision making may avoid individuals being transferred to hospital within their last days of life.
- Further work required to ensure learning disability is not included as an acceptable rationale for a DNACPR order.
- Further work required to ensure learning disability is not documented as a cause of death.

Mental Capacity Act Compliance:
Many reviews identified learning in relation to:

- Mental Capacity Compliance.
- Awareness across Health and Social Care in relation to the documentation of Best Interests.
- Compliance with Deprivation of Liberty Safeguards (DoLs).

Access and Uptake to Screening:
Whilst many reviews identified an improved picture in relation to individuals being supported to attend for age appropriate screening, this continues to be identified as an area for improvement in line with national findings. Main areas to improve:

- Uptake of routine bowel screening including available support and follow up where not undertaken.
- Use of terminology when individuals with a learning disability do not attend for appointments or do not return test kits.
- 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.

Learning Disability Specialist Nurses:
Some reviews identified the utilisation of Learning Disability Nurses within the community setting and availability of Learning Disability Nurses within hospitals as an area for improvement to enhance the care provided to individuals within both settings.

Availability and Uptake of Hospital Passports:
Some reviews identified availability of hospital passports for individuals as an area requiring further work.

10.0 Recommendations and Actions from Completed Reviews

From the findings and learning from the 60 reviews completed 1st April 2020 – 31st March 2021, the following recommendations have been identified as areas of focussed work to be undertaken across the Humber area for the remainder of 2021 and into 2022:

- Reduction in the number of individuals with a learning disability who die from aspiration pneumonia through education and training to reduce an individual's risk of aspiration, therefore reducing the risk of aspiration pneumonia.

- Reduction in the number of individuals with a learning disability who die from pneumonia.

- Continued improvement to ensure all 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.

- Raising awareness through 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).

- To further build on the End of Life work already underway across the Humber to ensure recognition and timely decision making to avoid individuals being transferred to hospital within their last days of life.

- Undertake further work in ensuring learning disability is not included as an acceptable rationale for DNACPR order, or documented as a cause of death.

- Continue to build on the current relationship between the Humber LeDeR Steering Group and the Humber Transforming Care Partnership (TCP) Board to work collaboratively on improving services and care pathways for individuals with learning disabilities living within the Humber area.

- Increase engagement with Primary Care General practice with regard to the LeDeR programme and promote the importance of having a nurse lead for learning disabilities within each practice or Primary Care Network (PCN) (as a minimum).

- To continue to strengthen the collaborative working already in place across the Humber to identify and share learning from LeDeR reviews, whilst making changes to enhance the lives of those individuals within the Humber area living with a learning disability.

11.0 Priorities and Next Steps for 2021/2022

2021/2022 will see continued collaborative working across the four CCG's within the Humber, to further improve the lives of individuals with learning disabilities, remove health inequalities to reduce the number of individuals with a learning disability dying early.
In addition to the recommendations identified within section 10.0 of this report, the CCG's will:

- Develop a three year LeDeR Strategy, informed by recommendations identified within this report.
- Further develop the Humber Steering Group to implement the actions and recommendations made from the LeDeR review panel to inform local development and changes to services provided across the Humber.
- Ensure expert by experience individuals are part of the membership of both the LeDeR review panel and the Humber Steering Group.
- Continue to build links between the Humber Steering Group and TCP to ensure learning and recommendations from reviews are reflected in transformation work streams across the Humber.
- Consider formal recognition of the need for family support following the death of a loved one and the role of care providers in provision of this support.
- Continue to raise awareness of the LeDeR Programme within all Health and Social Care Partners to ensure all individuals with a learning disability who sadly die within the Humber area have their death reviewed through notification to the programme. This will also be pertinent with the inclusion of autism into the programme from the autumn of 2021.
- Ensure robust processes are in place for sharing the learning and good practice identified from completed reviews across the Humber and wider partners.
- Consider targeted campaigns with regard to national learning throughout the coming year.
- Ensure compliance with the NHSE LeDeR policy.